The Key Worker

Resources for Early Childhood Intervention Professionals

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FOREWORD

Parenting a young child with developmental disabilities can be very challenging, especially in the early stages. Parents have to make sense of a new and complex world of disability and health issues, and learn to negotiate a new world of services, professionals and appointments. They have to do this while dealing with their own feelings of sadness, and working out how their own needs, and those of their family, can be met. All of this can be emotionally and physically stressful.

The more health or development problems a child has, the more services they receive and the more professionals they have to deal with. And the more services and professionals there are, the less likely it is that the overall service they receive will be well-coordinated or family-centered. Managing these competing demands is a particular source of stress for many families.

What can Early Childhood Intervention (ECI) services do to help? One of the great ethical precepts for human services is 'Do no harm'. This is based on the recognition that, despite the best intentions, even services that set out to be helpful can inadvertently make things worse for families. ECI services are no exception. We can make things worse in a number of ways – by failing to listen or respond to parental concerns, by not giving them information about relevant services, or by overloading the family with appointments and information as well as competing demands upon their time and understanding.

This is where the Key Worker role is so important. An issue repeatedly highlighted in the research literature is the need for effective coordination of services for families of children with special care needs. Numerous research studies have reported that parents want a single point of contact with services and an effective, trusted person to support them to get what they need.

Why do we need a resource guide on the Key Worker role? One reason is that few if any ECI professionals will have received any training in this role in their undergraduate courses. Another reason is that the Key Worker role is not a simple one - developing Key Worker skills is not done overnight, but requires years of practice. It also demands a high level of trust between members of the Early Childhood Intervention Services (ECIS) team.

Although parenting a young child with disabilities can be challenging, it can also be very rewarding. Many families report that, although they would not have wished the experience on themselves, having a child with a developmental disability has actually made them stronger. Of course, this does not happen overnight. The Key Worker role is one of the ways that ECI services can provide support that will help families become stronger. The Key Worker is in a unique position to build parental competencies and confidence – to put them back in control of their lives. Once the child starts school, no such support exists. So ECI services need to equip parents for the long journey ahead.

Noah's Ark has a well deserved reputation for developing resources to support best practice in its services. It is to be commended on the production of this resource. It addresses a key aspect of contemporary practice in a practical manner, and should provide ECI agencies and teams with the ideas and examples they need to make the Key Worker role a central feature of their support for families.

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"Early Childhood Intervention Services need to equip parents for the long journey ahead."

Dr. Tim Moore (2012)

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WHAT IS THIS RESOURCE ABOUT AND WHO IS IT FOR?

In 2003, Noah's Ark Inc. - a non-government, not-for-profit provider of Early Childhood Intervention Services (ECIS) in Victoria began to change how it works with the families of children with a disability or developmental delay. It gradually moved from a centre-based group therapy model to one which is home and community based. At the heart of this change was a desire to work with families and children in an everyday setting.

Staff found that going to families' homes led to a range of discussions and situations not found in structured group settings. Parents were more open about their feelings and began talking about all of the issues in their lives – finances, relationships and housing. Some staff were uncomfortable about the conversations they found themselves in, and some felt they were losing sight of the child under the pressure of family need. There was a clear requirement for structure, boundaries, clarity, professional development and support for staff taking on this role.

This resource was developed to support Early Childhood Intervention (ECI) professionals to reflect on the relationships they develop with families, particularly as they visit families at home. In the shift to visiting families at home, one staff member is appointed to work closely with the family, developing a primary relationship. They become known as the Key Worker. They are a person to whom the family can turn to for assistance. The Key Worker can help a family understand their child's situation, cut through the jargon, navigate services and make sense of new information.

Diagnosis of a developmental delay or disability can lead to a period of turmoil for families, and having a positive and supportive relationship with an ECI professional can make a significant difference. When parents and carers are supported, resourced and motivated they are better able to meet their family's needs, including a child's additional needs, both in the present and in preparing for the future.

WHAT IS A KEY WORKER?

The 'Key Worker' model involves one ECI professional becoming the primary point of contact for a family adapting to having a child with a disability or developmental delay. The process of families adapting is multi-layered and ongoing. A key component of this role is using family-centred and strengths-based approaches which support families to be in control of their situation. The role focuses on five key areas that have been identified as important for families:
- emotional support from family, friends, and professionals
- information and advice which enables them to navigate services, understand professional terminology and access resources
- opportunities to identify and address their needs in parenting a child with a disability
- support and developing skills in advocating for the needs of their child and family
- support in service coordination.

This resource is intended primarily for ECI professionals, but may also be useful to any professional working with families in family support; disability services; or community health. For each of the five areas of support, the resource provides an overview of current literature, linking it to the real-life experience of many families; plus tip sheets and tools which may be used for professional development and supervision, together with lists of additional reading. Families who have a child with a developmental delay or disability, or anyone involved with these families, may also find the resource useful.

THE KEY WORKER AS PART OF A BROADER ROLE

Assisting families adapting to having a child with a disability is only one part of the ECI role. The other major focus is on supporting a child's development. One of the strengths of ECI in Victoria is that there are teams that bring together professionals from a range of backgrounds, including therapists, teachers, psychologists and social workers. Noah's Ark has combined the Key Worker approach with a transdisciplinary approach. The transdisciplinary approach involves one member of a team working with the family on developing approaches to supporting the child's learning opportunities, incorporating suggestions from other team members. Other teams work in a multidisciplinary way, with a number of members of the team from different disciplines each working with the family.

THE 'TRANSDISCIPLINARY KEY WORKER' MODEL

 The 'Transdisciplinary Key Worker' model extends the role of the ECI professional to become both the primary contact for the family and the main person working with the family on extending the child's learning opportunities. A key component of the transdisciplinary role is that one staff member integrates information and advice from their team and presents it to the family, rather than staff from different disciplines meeting with the family independently. The use of family-centred and strengths-based approaches remains central to the role. The Transdisciplinary Key Worker role focuses, in addition to those components of the Key Worker model, on families having:

- holistic Family Services Support plans.
- integrated approaches for promoting their child's development as part of daily life or routines.
- close working relationships between staff in children's services who work with the child and one ECI professional who knows the child and family well.
- the opportunity to call in other professional disciplines when required.

This approach only works when there is sufficient investment in supporting and maintaining the quality of relationships and communication between team members to ensure transdisciplinary practice. There is a service benefit, as well as a family benefit, in only one staff member visiting the family, leading to less intrusions in the family home.

While a transdisciplinary approach does frame some of the discussions, this resource focuses on the Key Worker components of the role. We will do further work on the transdisciplinary components in the future.

WHY IS THE KEY WORKER'S RELATIONSHIP WITH FAMILIES IMPORTANT?

"...children's first and most enduring educators are their families. Families provide the caring relationships, the models, the opportunities and the experiences shaping children's learning and development." The Victorian Early Years Learning and Development Framework (2009)

Children learn through exploration and practice, and they learn most from those with whom they have the deepest relationships and those with whom they spend the most time – their families and carers. Recognition of this has changed the face of ECI over recent years. The implication, of course, is that if ECI is to support and optimise the development of children with additional needs, it must do so through strong and positive relationships with their family.

Families of a child with additional needs have a particular need for support, often experiencing stresses that can undermine their ability to meet their child's needs. Families vary widely in the skills and resources they possess. Some adapt quickly to their child's needs and assume responsibility for coordinating services. For others, diagnosis of a developmental delay or disability adds yet another layer to what is already a difficult and complex situation. Each Key Worker has to be ready to negotiate her or his role individually with each family and to renegotiate it as the child's situation and the family's needs change. It is vital that service providers understand each child's family, their culture, values and what they see as important, because what they see as important will influence and inform their actions. Without this understanding, which grows from discussions with the family, it is unlikely that a Key Worker and family will work well together. A family's culture shapes parents' roles, the things they worry about, relationships across family and friendship networks, how child development is understood and what having a child with a disability means. This resource supports Key Workers to embrace the diversity of families and their individualised needs.

Most families will not have access to a person like a Key Worker beyond the preschool years, and an experienced Key Worker will recognise that she or he has only a small window of opportunity to build the family's skills, knowledge and confidence to manage more and more independently into the future.

OTHER RESOURCES

Details on other resources can be found at www.ecii.org.au.

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EMOTIONAL
SUPPORT

"Don't just do something,
stand there and pay attention."

Pawl & St John (1998)

Emotional Support

THE FAMILY - THE BEGINNING OF THE DANCE

"Forming partnerships with the myriad of professionals who have entered my life via Micah is like learning to dance. At first my professional partners and I often do not glide gracefully across the floor. Our movements feel stiff, awkward and out of sync. We sometimes seem to be listening to different music with conflicting beats and rhythms. Our toes – our feelings – get stepped on as we try to manoeuvre around unspoken worries." (Janice Fialka, parent 2001)

When a Key Worker meets a family, it is the start of a relationship that may go for on for several years. It is a relationship that will involve a degree of intimacy given the likelihood of visits to the family home and discussion around issues "as personal and value laden as child rearing." (Hanson & Lynch 2010)

"Most relationships evolve gradually over time. In this unique parent-professional partnership dance, we are often forced into instant closeness, bringing us nose-to-nose with strangers long before there is a foundation of trust to cushion the strong feelings. I'm struck by the fact that we parents sometimes cry in front of people whose last names we don't know. Our unexpected display of our feelings of sadness, rage, or frustration sometimes make it hard to return to your office. We are not sure what you think of us and our strong emotions." (Janice Fialka, parent 2001)

The relationship that forms between a family and a Key Worker is a dynamic one, "characterised by mutual acceptance, respect, trust, commitment, openness and shared responsibility" (Brotherson et al 2009). Each party brings to the relationship hopes, beliefs, experiences, attitudes and feelings.

Let us look first at what each party may bring to the "partnership dance".

FAMILIES

By the time a family meets the Key Worker they will have already experienced a considerable amount in relation to their child with additional needs. They will have spent varying lengths of time waiting for an early intervention service. They will have at least had significant concerns about their child's development and many may have also received a diagnosis.

> "At the beginning, finding out that there were problems was very difficult as it was a bit of a shock. I think I was in denial. You just sort of go into shock and then grief." (Megan, parent - The Key Worker DVD 2010)

All families need emotional support and usually receive this through their informal networks of extended family and friends. The emotional needs of a family who have a child with a disability can be exacerbated by the additional stressors they may experience. Guralnick (2005) proposes that these stressors can include:

- The need for information on the disability and likely developmental patterns, and to inform decision-making regarding specialists, and intervention programs and activities.

> "Before the Key Worker comes in you just don't know what you're meant to be doing. All this autism thing and first of all you don't really understand what all these people are talking about." (Sue-Anne, parent - The Key Worker DVD 2010)

- Interpersonal and emotional distress – for example, grief, isolation, stigma, the impact of child's behaviour.

> "In the beginning I was having all these horrible thoughts that people would pick on him and he would have a tormented life." (Helen, parent - Ochiltree & Forster 2010)

- Resource needs – the child may require extra resources and the family's income may be reduced because the child's need for care, multiple appointments with healthcare professionals, and lack of child care can affect parents' ability to work (Sloper & Beresford 2006).

> "A freshly graduated social worker met this mother at her home eager to take her to select her son's first brand new wheelchair. The mother hardly shared the social worker's enthusiasm. To the mother this was the shattering of another dream. She wanted to be selecting a tricycle for her son, not a wheelchair." (Janice Fialka, parent 2001)

- Threats to confidence – the cumulative impact of all these stressors can undermine parents' confidence in their ability to meet their child's needs.

> "I was worried it was something I was doing or not doing." (Sue-Anne, parent - The Key Worker DVD 2010)

For some parents the emotional impact of their child's disability is just one of many challenges they face. The family might have other issues that would have existed whether or not they had a child with a disability – for example, poverty, drug and alcohol abuse, legal matters, mental health issues or domestic violence. Regardless of the degree and range of these complexities, having a child with a disability can have an additional impact in a range of areas. Australian Social Trends (2008), a compilation of Australian Bureau of Statistics data from 2003, provides some information on families with a child with a disability in Australia:

- 33% of parents who were primary carers for their child with a disability reported that their caring role had placed strains on their relationship with their spouse or partner.
- 52% reported they were losing touch or lacking time together with other immediate family members.
- 26% reported they were losing touch with their friends.
- 29% of lone parents who had a child with severe/profound disability were in the workforce compared to 52% of lone parents who did not have a child with a disability.
- 47% of families with a child with a severe/profound disability lived in rental accommodation compared to 28% of other families.
- 18% of primary caring parents had been diagnosed with a stress-related illness.
- While families with a child with a disability had a variety of "experiences and circumstances," they were more likely to have "lower socioeconomic status, labour force participation and income than other families with young children".

Sloper and Beresford (2006) point out that "it is within these constrained financial circumstances that families have to meet the costs associated with bringing up a disabled child, which are estimated to be three times that of bringing up a non-disabled child". Parents with children with disabilities "have higher levels of stress and lower levels of well-being" than parents of children without disabilities. Some of the factors that can influence these 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 styles".

THE KEY WORKER

An experienced Key Worker entering into a relationship with a family comes with the knowledge, and sometimes anxiety, that providing emotional support is often part of their role in that relationship. The provision of emotional support can be very challenging for many Early Childhood Intervention (ECI) professionals. Research conducted by Brady et al (2004), as discussed in McWilliam (2010), looked at "types and patterns" of discussion on home-visits. They found that the category of professional verbal behaviour that was displayed least (less than 1%) was "accepts feelings", which they defined as "accepts or clarifies the feelings of family members in a non-threatening manner, without judgement or evaluation of feelings". The study observed that when families did express their feelings, the ECI professionals had a tendency to offer solutions to "fix" the problem rather than respond to the parents' emotions.

The range of families that an ECI professional works with is likely to be diverse, varying in cultural and linguistic background, religious beliefs, socioeconomic circumstances, views on child-rearing and disability; the size and make-up of the family, gender roles – the list is endless. The basis for establishing an effective partnership with any family is respect for their background and perspectives. As ECI professionals build close relationships with families and may work with the same family for several years, it is vital that they develop an understanding of diversity. "Building relationships with some families can be more challenging than others" (Hanson & Lynch 2010).

Bringing emotions out in the open can be a "frightening proposition" for both the parent and the professional, according to McWilliam (2010). Professionals may avoid dealing with the emotions of the families they work with because they don't see it as being part of their role, they "lack confidence in their ability to say the right thing or they fear that they may say the wrong thing and make things worse. So they say nothing". McWilliam goes on to warn that the family-professional relationship will "remain incomplete unless this level of intimacy can be attained".

In a study that explores the dynamics of emotional support between the home-visiting ECI professional and the parent, Brotherson et al (2009) found that families with complex needs can at times trigger "emotional discomfort" in ECI professionals. In some instances this came from feeling "inadequate to meet the often overwhelming issues facing the family" and feeling that the situation called for skills "beyond their training" and/or their knowledge of other services that could assist the family. For others, the discomfort arose from being in an environment and situation far from the professional's own personal experiences; some felt "unsafe" in the house or the neighbourhood or just uncomfortable being in a home they saw as "smelly" and "dirty".

While some professionals in Brotherson et al's study appeared to "distance themselves" from families with complex needs, others indicated they "felt deeply the challenges being experienced by both the children and the families on their caseload" and had trouble switching off at the end of the day. There was also discussion about setting boundaries with families, and there were dilemmas over issues such as whether or not professionals should hand out their mobile phone number to families. Some of the ECI professionals also expressed concern about whether the broader service system would be adequate to meet the needs of the more complex families.

HOW DOES THIS AFFECT THE RELATIONSHIP BETWEEN FAMILY AND KEY WORKER?

From a family's perspective, there may be barriers to forming a relationship with the Key Worker. In some cultures, the concept of an equal partnership with a professional does not sit well and the family may feel uncomfortable with the relationship. They may even see the ECI professional as incompetent or uninterested if the professional does not fulfill the teaching or instructional role the family is expecting (Hanson & Lynch 2010). Some fathers may feel more able to talk to male rather than female support workers, but there may be few male workers available (Social Care Institute for Excellence 2005).

The gap between the life circumstances, experiences and views of the family and the ECI professional can sometimes be wide, creating challenges in building the parent-professional partnership. Hanson and Lynch (2010) provide the example of a middle class, university-educated ECI professional who has been raised "to believe she has control of her life", and who may experience some challenges in empathising with a mother who is "uneducated, impoverished, and feels powerless to change her life circumstances". Indeed, Hanson and Lynch suggest that "for those who have not lived in poverty, its impact on daily life and aspirations is impossible to imagine"; and the wider this gap, the more likely it is that the ECI professional will feel "ineffectual or in more extreme circumstances even at odds or repulsed by a family". The gap can also be a barrier from the parents' perspective. "When they find themselves amid a team of highly trained professionals some family members might not feel they have the knowledge or understanding to participate as equal partners and might be embarrassed by their lack of education or social experience." This can also work the other way round: some ECI professionals can be intimidated by parents who are "highly educated professionals" (Hanson & Lynch 2010).

In their study, Brotherson et al (2009) found that hope and urgency were emotional needs shared by many parents of children with disabilities and their ECI worker. This was about having hope for the child and a sense of urgency to make a difference for the child's development. Parents who felt this urgency often viewed the ECI worker "as a source of hope and concrete strategies for their child". When parents and ECI professionals were matched in these feelings, the professionals found working with the family more emotionally satisfying. When parents did not share this sense of urgency, the ECI professional was often left feeling "frustrated by a lack of follow through and a perceived lack of engagement on the part of the parents".

Professionals can at times increase the stress experienced by parents by "making too many demands on their time" (Centre for Community Child Health 2009). Brotherson et al (2009) caution against professionals carrying the sense of "shared urgency" too far: "Professionals should be cautious about pushing their own sense of urgency, born of their strong commitment and belief in the power of early intervention, too far onto the all-too-willing shoulders of parents whose emotions already centre so strongly around making progress for their child."

Both parents and professionals need to pace themselves to avoid burn-out and to take the time to "allow the child to simply be a child." Professionals need to find a way to "achieve a balance and slow down to avoid exhaustion and appreciate the strengths of the children and families with whom they are working" (Brotherson et al 2009).

Brotherson et al's study suggested that the more significant the family's emotional needs, the higher the likelihood of a significant mismatch with the professional, as the family needs triggered the professionals' "feelings of inadequacy, frustration or sadness". Some of the professionals in the study said they did not feel adequately prepared to work with families and "found it easier to revert to child focussed intervention". The emotions experienced by the professionals indicated a sense of "overload" which had an impact on professionals' ability to address families' needs.

WHY IS RESPONDING IMPORTANT?

1. Families who are supported are better able to support their child.

- Family is the principle context in which children develop (Kelly et al 2005) and the well-being of the family has important consequences for the well-being of the child. It is therefore important for ECI to look at what is stressing and/or supporting the family system.

- Under Guralnick's (2005) Developmental Systems model, a key focus of Early Intervention is on reducing family stressors to soften their impact, leaving the family more able to interact positively with and create positive experiences for their child, and take care of the child's health and safety needs.

- The Success Works (2009) report on the Key Worker talks about emotional support being provided with the hope that it will help the parents "feel calmer and more able to make their own decisions and follow through on strategies".

- If a plan is not implemented, it cannot succeed (Hanson & Lynch 2010), and if plans are to be implemented, they need to fit with a family's priorities, beliefs, values, goals and resources.

2. ECI professionals can help families to build strong and supportive networks.

- Families have the greatest opportunities to have a direct impact on the child's development. While ECI professionals have few opportunities for direct impact, they have considerable opportunity for indirect impact by providing the family with the support and information they need (Jung 2010).

- The ECI model of practice has been changing gradually from one that is clinical and centre-based, to a more transdisciplinary and home-visiting service model. With this shift, "the responsibility to meet emotional needs has increasingly fallen onto the shoulders of the home visitor" (Brotherson et al 2009).

- If the ECI professional does not form a relationship with the adults in a child's life, he or she is "rendered relatively ineffectual", and failure to respond to a parent's real and sometimes strong emotions can have a very detrimental effect on that partnership (McWilliam 2010).

- It is equally important to look at the emotional needs of the Key Worker, as a professional's unmet emotional needs can be a barrier to responding appropriately to a family's emotional needs. "Burn-out" is a risk for professionals, and this can lead them to "avoid addressing emotional issues or to become callous to them" (Brotherson et al 2009).

- Key Workers need also to look beyond their own relationships with families, to help each family to identify and use other more natural and sustainable sources of support. Emotional support through informal networks can be more helpful than formal supports. Crockenberg (1988) described the various benefits of social support for parents:
  - The number of stressful events can be reduced by providing "instrumental support" such as babysitting, financial assistance or parenting advice.
  - The impact of stressful events can be lessened by emotional support from people in the social network.

- Social supports can help parents actively to develop better coping strategies – for example, helping them to improve their child-rearing skills.
- Crockenberg (1988) also draws on the work of Crittenden (1985), which proposes that emotional support can have a positive effect on a parent's self-worth "as a person deserving of care and capable of caring for someone else". This can then enhance parents' capacity and propensity to nurture their child.

- Cochran and Niegro (1995) recommended that ECI should include network change as a possible outcome and that measures of network-related consequences should be a part of any overall assessment strategy. In their review of the literature on social support in families of children with disabilities, Dunst et al (1997) suggested that greater support from a person's social network is associated with:
  - More effective personal functioning of the parent
  - More positive perceptions of the child's behaviour
  - Better family functioning
  - More positive parenting behaviour
  - More positive and less negative child affect.
- There is an increasing push for ECI services to show that their programs have had positive outcomes for families as well as children, as evidenced in the Early Childhood Intervention Australia (Victoria Chapter) Outcome Statements (2005) and the Family Outcomes Survey (Early Childhood Outcomes Centre 2005). "Regardless of whether it is considered a means – supporting the parent to achieve child outcomes – or an end in itself, the need to provide emotional supports to families remains a critical component of Early Intervention" (Brotherson et al 2009).

HOW DO YOU RESPOND?

- "Emotional support in ECI consists of behaviours and attitudes such as being positive about children and parents, being responsive, showing interest in the whole family, being friendly and being sensitive" (McWilliam et al 1998).
- "Sometimes all the parents want is someone who will listen to, accept and validate their feelings" (McWilliam 2010).
- Emotional support can be provided by ECI professionals through "listening and responding to the family, being positive and strengths-based, and through general warmth and friendliness" (Jung 2010).
- Emotional support means addressing parents' emotional needs in ways that acknowledge (but do 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 quoted in Centre for Community Child Health 2009).
- The Success Works (2009) report on the Key Worker describes emotional support as "supporting parents to feel positive about what they achieved and are doing in support of their child" and "encouraging parents to understand and feel good about their child's strengths and abilities". The Key Worker's role in emotional support also includes building rapport/relationships with the family, suggesting practical strategies, and referral to relevant service providers, but it does not extend to counselling, respite, and crisis intervention.
- Hanson and Lynch (2010) advise that "the intimacy of this form of service delivery cannot be overestimated. Working with issues as personal and value laden as child-rearing requires families to place a high degree of trust in ECI professionals who must in turn adopt the strictest codes of both ethical and respectful behaviour."

Developing a real partnership with parents requires respect, genuineness, empathy, humility, quiet enthusiasm, and personal integrity – these are the qualities of a "helper" (Davis et al 2002). Active listening involves attending, questioning, encouraging, paraphrasing, summarising and recognition. The internet offers any number of instructions on how to achieve this – for example, "sit up straight or lean forward slightly to show your attentiveness with body language"(Flexible Learning Toolboxes). Instructions can include some useful tips, e.g. "avoid letting the speaker know how you handled a similar situation. Unless they specifically ask for advice, assume they just need to talk it out". "Nodding, smiling, showing looks of concern, having eye contact, avoiding constant note taking and so forth let the parent know that what he or she is saying is important to the provider" (Kelly et al 2005). However, it is easy to imagine someone carefully following such instructions and still being very stiff and awkward with a family. The qualities of the "helper" are required to pull it off.

In 2009, Early Childhood Intervention Australia – Victorian Chapter, commissioned a report by Workwell Consulting on the core competencies required of an ECI professional – that is, "the skills, knowledge, values and belief sets" of capable ECI professionals (ECIA Vic 2009). One of the six areas covered is engaging others, which includes the ability to develop rapport, initiate and maintain discussion in sensitive situations, use active listening skills and be empathic. Emotionally supportive relationships with families are highlighted throughout, with a focus on elements already discussed above: developing family strengths, fostering a relationship with the child, a collaborative approach, empowering others, and the

ECI professional's ability actively to seek feedback and reflect on both his or her own practice and that of the team members. These are qualities and abilities that ECI service managers will look for when employing new ECI professionals. It is important also to continue to develop these qualities and abilities in existing staff.

"We only have one person, and that person is very competent and experienced. It's not a hassle. I kind of feel that even on a bad day I could still manage with that person coming out because of the nature of the person that they are." (Parent - Moore & Larkin 2005)

P.J. McWilliam's chapter on "Talking to Families" in Robin McWilliams' book, *Working with Families of Young Children with Special Needs (2010)*, is a practical guide with many suggestions on how to build emotionally supportive partnerships with families. For example:

- Create opportunities for informal conversation.
- Acknowledge and recognise the strengths of both the child and the parent.
- Seek the parents' opinions and ideas.
- Seek to understand the family and see the child through their eyes.
- Show that you care about the whole family.
- Acknowledge and respond to their feelings.

McWilliam (2010) also encourages the ECI professional to respond to the emotions in a message before responding to the literal content. "Solutions come later but first we must validate their feelings." She reassures the professional that "just because you acknowledge their feelings doesn't mean you are responsible for resolving their worries, fears, anger or sadness they may express."

Self-reflection is vital if ECI professionals are to build their capacity to provide emotional support to families. Kelly et al (2005) prompt ECI professionals "to pay attention to their own uncomfortable feelings," as these feelings can provide "clues about the success or failure" of their attempts to engage the family. Professionals need to "respond empathically and to pause and listen" if a parent expresses emotions such as "shame, anger, doubt or fear", they must avoid thinking that they can make these feelings go away or "fix the problem" that triggered the feelings. Simply "accepting and listening are powerful tools" in building a relationship with a family, as is validating the importance, for both parent and child, of the issues raised.

Cross-cultural competence will help ECI professionals to form a healthy partnership with parents from different cultural backgrounds. Hanson and Lynch (2010) suggest ways to develop this:

- Consider each element of difference in comparison to your own personal experience and belief system, as "our own beliefs, biases and behaviours are so ingrained that we often fail to recognise that they simply represent our own worldview, not the way all people view the world."
- Reflect on your own values. If, for example you place "high value on punctuality, self-determination and achievement, it may be more challenging to work with a family who miss or are late for appointments, who have difficulty making decisions and who do not follow through on the services that are available."
- Consider what your biases might be – the thoughts you don't necessarily share with others, the jokes you find amusing, and the backgrounds of the

friends, colleagues and mentors you choose to spend time with. "Biases that exist are not easily compartmentalised. They influence one's work."

- Learn more about others' cultural and socio-cultural perspectives.
- Apply your self-awareness and the information learned about other cultures to your practice. If you suspect personal bias is influencing your work with a family, discuss it with your team.

"In family-centered intervention, one important issue is to support families' different ways to manage stress" (Yleven & Granlund (2009). Folkman et al (1997) found that three types of coping were "related to the occurence and maintenance of positive affect: positive reappraisal; goal-directed problem-focussed coping; and infusing ordinary events with positive meaning".

Informal supports are more helpful for families than formal supports (Jung 2010). Families need to rely first on those supports that spring from their own social and community network, with formal services filling gaps in a way that complements rather than replaces these informal supports (Dunst 2000). Social support is one of the most effective ways to reduce the effects of family stressors (Kelly et al 2005), and social support together with coping strategies are the two most important ways to relieve stress for caregivers (Pearlin et al 1990). Emotional support from friends and family can protect parents from stressors (Kelly et al 2005).

A family's network of support can be set out visually as an Eco-Map (Jung 2010) (Eco-Mapping is also relevant in Identifying and Addressing Needs, Section 3). This tool, developed by social worker Ann Hartman in 1975, maps all the systems involved in a family's life, ranging from friends and family to social networks and formal support services. Developed by the family and professional together, an Eco-Map can show both the range and strength of the supports and connections a family has. Developing the map can also strengthen the relationship between professional and family, as it enables a "more natural feeling, casual conversation" (Jung 2010) rather than the "often sterile feeling of traditional questionnaire style intake paperwork". The map is a picture in which "the people in and connections of a family are literally visible, allowing them to see their family in a new way" (Jung 2010). Importantly, the map enables any interventions to be designed around the supports already available to a family. If a map is created when the professional first starts working with a family, there is the opportunity to conduct the exercise again down the track to see any development in the support network.

Brotherson et al (2009) discuss several strategies to encourage practitioners to become more emotionally responsive to families. These centre on reflective practice - looking at the relationships you have with families and how your values affect those relationships, putting yourself "in a family's shoes". The authors also discuss the need for ECI professionals to re-energise and "address physical and emotional fatigue." Ways to do this include finding "joy and energy in our work to combat fatigue", "vigorous dancing and drumming" (McConnell 2008), "use of humour in the workplace" (Kimata 2004; Nelzek & Derks 2001), journaling (Kremenitzer 2005), and meditation.

Fialka (2001) sees "a huge need to promote a work environment that values and practices reflective practice and self-care". The field of ECI "is worn out by the unreasonable demands placed upon the professionals" and under such pressure, the areas most likely to suffer first are "time allotted for meaningful and ongoing reflective practice and consultation". Fialka (2001) believes that it is not possible to carry out the role of ECI professional "well and compassionately if we do not engage in regular opportunities to think about our work and its impact on each of us professionally and personally".

> **"The key to addressing family emotional needs through partnerships in home visitor based programs is to enable and empower home visitors in their own emotional strength by equipping them with the skills to address both their emotional needs as well as family emotional needs."** **(Brotherson et al 2009)**

WHAT DOES IT LOOK LIKE WHEN WE HAVE RESPONDED?

> **"Addressing emotional needs of families is a critical component of enabling and empowering families to become effective partners in meeting their children's needs." (Brotherson et al 2009)**

The ultimate goal of providing emotional support to families is to enable them to withstand or overcome stressors that may limit their ability to have good quality interactions with their children, create positive experiences for them,

and ensure their health and safety (Guralnick 2005). The goal is to empower families to make the most of their child's everyday learning opportunities (Dunst 2006).

"Parents gave up trying to fix the child and focussed on what their child could do and in supporting them to be happy." (The Key Worker DVD 2010)

While having a child with a disability can subject families to extra stressors, there can also be some strong positives. All families are different and there is evidence that some of these families "do more than adjust or adapt to the challenges, but ultimately transcend them, emerging stronger for the experience" (Bayat et al 2007 quoted in Centre for Community Child Health 2010, p23). King et al (2006) found that "raising a child with a disability can be a life-changing experience that spurs families to examine their belief systems. Parents can come to gain a sense of coherence and control through changes in their world views, values and priorities that involve different ways of thinking about their child, their parenting role, and the role of the family. Although parents may grapple with lost dreams, over time positive adaptations can occur in the form of changed world views concerning life and disability, and an appreciation of the positive contributions made by children to family members and society as a whole. Parents' experiences indicate the importance of hope and of seeing possibilities that lie ahead."

"For me it made me have to look at different ways of thinking about things so that I could stay positive." (Megan, parent - The Key Worker DVD 2010)

"I think I look at everything different now." (Sue-Anne, parent - The Key Worker DVD 2010)

SUMMARY

"You as professionals have the opportunity to allow us our feelings, even to invite us to 'fall apart' once in awhile in the presence of someone who understands and cares. Your compassion and non-judgemental attitude can be a gift that decreases our sense of isolation, softens our stress, and decreases the number of times we unintentionally step on toes!" (Janice Fialka, parent 2001)

The relationship an ECI professional develops with families is key to effective early childhood intervention, and the ability to provide emotional support can be crucial in that relationship. While all families require emotional support from time to time, usually from family and friends, families with a child with a disability can experience a range of additional stressors which can exacerbate this need. The intimacy of the relationship with the home-visiting ECI professional – sometimes working with the same family for several years – can mean at times that the responsibility for providing emotional support can fall to the professional.

The relationship between ECI professional and parent is dynamic, and it is important to look at the emotional needs of both. If the ECI professional has unmet emotional needs, or emotional needs that are a mismatch for those of the family, or has experienced emotional burn-out, then his or her capacity to address the emotional needs of parents will be heavily compromised.

ECI professionals work with families of seemingly infinite diversity. The greater the gap between the experiences and circumstances of the professional and the parent, the greater the challenges to developing a relationship in which emotional support can be given and received. The gap may create discomfort in both the ECI professional and the parent, and this may undermine the partnership.

The capacity to provide emotional support depends on a combination of traits, skills, attitudes, beliefs and behaviours, some which will be sought by ECI service managers in recruiting new staff. Some can be taught and practised, such as active listening, while attitudes and beliefs can be addressed through the development of a culture of reflective practice and self-care.

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Emotional Support

WHAT IS THE PRACTICE?

All families need emotional support from time to time, and most receive it from friends and relatives. Families who have a child with a disability or developmental delay may experience additional stressors and isolation. A Key Worker is someone to whom a family can turn to discuss their situation and how they are feeling.

WHAT DOES THE PRACTICE LOOK LIKE?

Listening respectfully to families and accepting and validating their feelings is the core of emotional support. Being positive about children and parents, and being warm and friendly, and sensitive and responsive to their needs creates the basis for a positive relationship, and a reliable and consistent relationship is, in and of itself, emotionally supportive. Supporting parents to recognise their own and their child's strengths, and what they have all achieved, can help them build emotional resilience. Connecting families to their own support network is also important. If Key Workers are to be able to provide this support, they must also attend to their own emotional needs.

HOW DO YOU DO THE PRACTICE?

There are three main ways Key Workers can assist families with emotional support:

- **Key Worker – family relationship** – Key Workers can build strong and close relationships with a family through discussing the family's personal issues, such as child-rearing, in the family home. The relationship needs to be founded on trust, honesty and respect. Key Workers need to be sensitive to sociocultural diversity and see the child through the eyes of the family. Focussing on child and family strengths and being empathic and responding to feelings, rather than jumping in with solutions, are important foundations for an emotionally supportive relationship.

- **Family support network** – Key Workers have a time-limited involvement with a family, and their relationship should be in addition to the family's network of support, rather than a replacement. Identifying the strengths of a family's informal network and helping them to build on this – through conversation with the family, undertaking an Eco-Mapping exercise, involving extended family or friends in home visits, linking the family with support groups, providing information about community groups or making referrals to counselling – can ensure that a family is well supported into the future.

- **Key Worker's emotional needs** – The dynamic relationship between a family and Key Worker can draw on Key Workers' emotional resources. If they are to have the emotional strength and energy to sustain these sometimes demanding relationships, they need to ensure that they regularly reflect on their own needs, beliefs, values and perspectives. Supervision can be helpful, to discuss boundaries, difficult situations and emotional discomfort. Reflective practice, team support, and use of humour in the workplace are important to staff in re-energising and creating a culture of self-care.

HOW DO YOU KNOW THE PRACTICE WORKED?

- Parents have someone to talk to when they need it.
- Parents have someone to rely on for help when they need it.
- Families and Key Workers have strong, respectful and empathic relationships.
- Key Workers are emotionally strong and energised.
- ECI teams have a culture of self-care and reflective practice.

THE KEY WORKER – FAMILY RELATIONSHIP

Bronwyn has three children under the age of seven. The eldest, Edward, has additional needs and has been allocated a Key Worker called Jacinta. Bronwyn and her husband Roger had been struggling without help for a long time while Edward sat on a waiting list. She had some anxiety about meeting Jacinta the first time – *What if I don't like her? What if she thinks I've been doing a bad job of meeting Edward's needs? Where should I begin to tell my story?* When Jacinta arrived she was warm and friendly and seemed relaxed and unhurried. She spoke to each of the children as well as Bronwyn and Roger, and was positive with all – *That's great lego-building Edward! What a cute baby!* When Bronwyn talked about some of the challenges she and Roger had been experiencing, Jacinta listened carefully and empathised with them – *It sounds like things have been difficult but that you've worked together well as a team.* Jacinta gave the family some written information about her role and made another time to come back to discuss the family's goals. Bronwyn and Roger were reassured – they sensed that Jacinta was someone who would listen to them and respond to their family's needs.

THE NETWORK

Pietro is raising his son Antonio alone as his wife died during child birth. Antonio incurred a brain injury during the birth and there have been a lot of medical professionals involved since that time. Antonio's Key Worker, William, did an Eco-Mapping exercise with Pietro one day as there was a complicated network of people around Pietro and Antonio but William was unclear about who was doing what and what was working well and not so well for the family. The Eco-Map showed that Pietro and Antonio did have a lot of people in their lives. It also revealed that Pietro did not receive the support he craved from his parents and his sister as they lacked confidence to care for Antonio for even a short time and were uncomfortable discussing his disability. After discussion with William, Pietro invited his parents and his sister to the next home visit so that they too could build their skills and confidence with Antonio. Over time they began to babysit, allowing Pietro some time to see his old friends and join a community group that was working together to build an inclusive playground. By the time Antonio moved onto school, Pietro's informal support network was broad, strong and both practically and emotionally supportive.

THE KEY WORKER

Karen has been a Key Worker for four years. She has always enjoyed her work, although there have always been some families she enjoyed working with more than others. She is feeling more and more frustration with each visit to one family who are Somali refugees. Their child's development does not seem to be a priority, and their strong religious views make her feel uncomfortable. Karen was beginning to feel that she was not providing a good service for this family, and this was having an impact on how she felt about her job. After talking with her supervisor, Karen spent some time by herself reflecting on her own views about child rearing and religion. She went to an information session on Somali refugees and consulted with her team mates, some of whom shared similar experiences and had different perspectives and insights. This support, reflection and learning gave Karen a renewed energy and interest in her work.

Emotional Support

REFLECTION & DEVELOPMENT - Early Childhood Intervention Practitioner Competencies

The majority of competencies below are taken directly from *Early Childhood Intervention Practitioner Competencies* (ECIA Vic 2009) available at www.eciavic.org.au. The competencies in *italics* have been added and content has been reordered and recategorised. Please read through and assess yourself against these statements by selecting a level on the scale below.

Once you have assessed yourself please look at which items you have marked yourself relatively high and relatively low. Use this as a basis for reflection and goal setting on the final page. Goals may centre on developing your skills or knowledge in particular areas or they may centre on how you might share your skills and knowledge with your team. Please then use the completed form as a tool for discussion in your next supervision session.

This Is New To Me	Beginning To Learn This	Reasonable Knowledge & Skills	Good Knowledge & Skills, Sometimes Challenged	Very High Knowledge, Confident Teaching Others
1	2	3	4	5

Competency	1	2	3	4	5
KNOWLEDGE OF FAMILIES					
Recognise features of family systems.					
Define family as it relates to the child and his/her circumstances and identify the role of the child within that family.					
Appreciate a child's role as part of a family unit and the different relationships and interactions between carers – child – sibling and extended families.					
Demonstrate an understanding of loss, grief and adaption and the processes by which families respond to their children's disabilities and health challenges.					
State ways in which specific circumstances affect family dynamics.					
RELATIONSHIP BUILDING					
1. Communication					
Use a family's language and symbols in one's communication with the family.					
Positively reframe another person's reported experiences when required.					
Sensitively present information which may be difficult for families to acknowledge and/or accept.					
Build rapport by acknowledging and/or matching another person's verbal language patterns, body language and emotional state.					
Initiate and maintain dialogue especially in sensitive situations.					
Elicit information from another person using questioning and clarifying.					
Check understanding through repeating, rephrasing, paraphrasing and summarising.					
Empathise by stating another person's experiences, feelings, priorities and intentions.					

This Is New To Me	Beginning To Learn This	Reasonable Knowledge & Skills	Good Knowledge & Skills, Sometimes Challenged	Very High Knowledge, Confident Teaching Others				
1	2	3	4	5				
Competency				1	2	3	4	5
2. Strengths-Based Practice								
Enable families to develop their strengths.								
Empower families to identify and build strengths.								
Reinforce and build confidence in carers that they possess good knowledge of their child.								
Empower and enable others while managing realistic expectations.								
Provide a positive but realistic acknowledgement of the child and their family.								
Provide positive feedback to reward effort and encourage enjoyment.								
3. Family-Centred Practice								
Work in partnership with families to ensure their needs are addressed.								
Promote and support family members' participation within planned interventions.								
Frame and solve problems collaboratively.								
4. Network/Capacity Building								
Identify useful and accessible generic support networks and community resources.								
Assist families to identify, enlarge and call on their informal networks of support.								
Assist families to identify and build upon the strengths in their formal and informal network of support.								
5. Embracing Diversity								
Recognise that each family is unique, and approach each family without assumption or judgement.								
Gauge a family's readiness, realism and rate of change expectation.								
Recognise the other person's current situation.								
Display sensitivity and respect for sociocultural and family diversity.								
6. Boundaries								
Adhere to the ethical guidelines/code of conduct specified by own agency and relevant professional bodies/associations.								
Be clear about and respect the professional boundaries of the relationship.								

SELF-CARE/REFLECTIVE PRACTICE

|	1	2	3	4	5
Actively seek feedback.					
Identify and state personal and professional growth areas.					
Reflect on own and team member's practice.					
Engage in self-reflection to better understand own values, motivations and behaviours.					
Make time with team to consciously and critically reflect on practice.					
Constructively challenge other's thoughts and actions to enable practice improvements.					
Seek out and participate in professional development opportunities.					
Using feedback, reflective practice and professional development, propose enhancements to own behaviours.					

Reflection on my strengths and areas for development

Goals for Learning, Development or Mentoring

1.

2.

3.
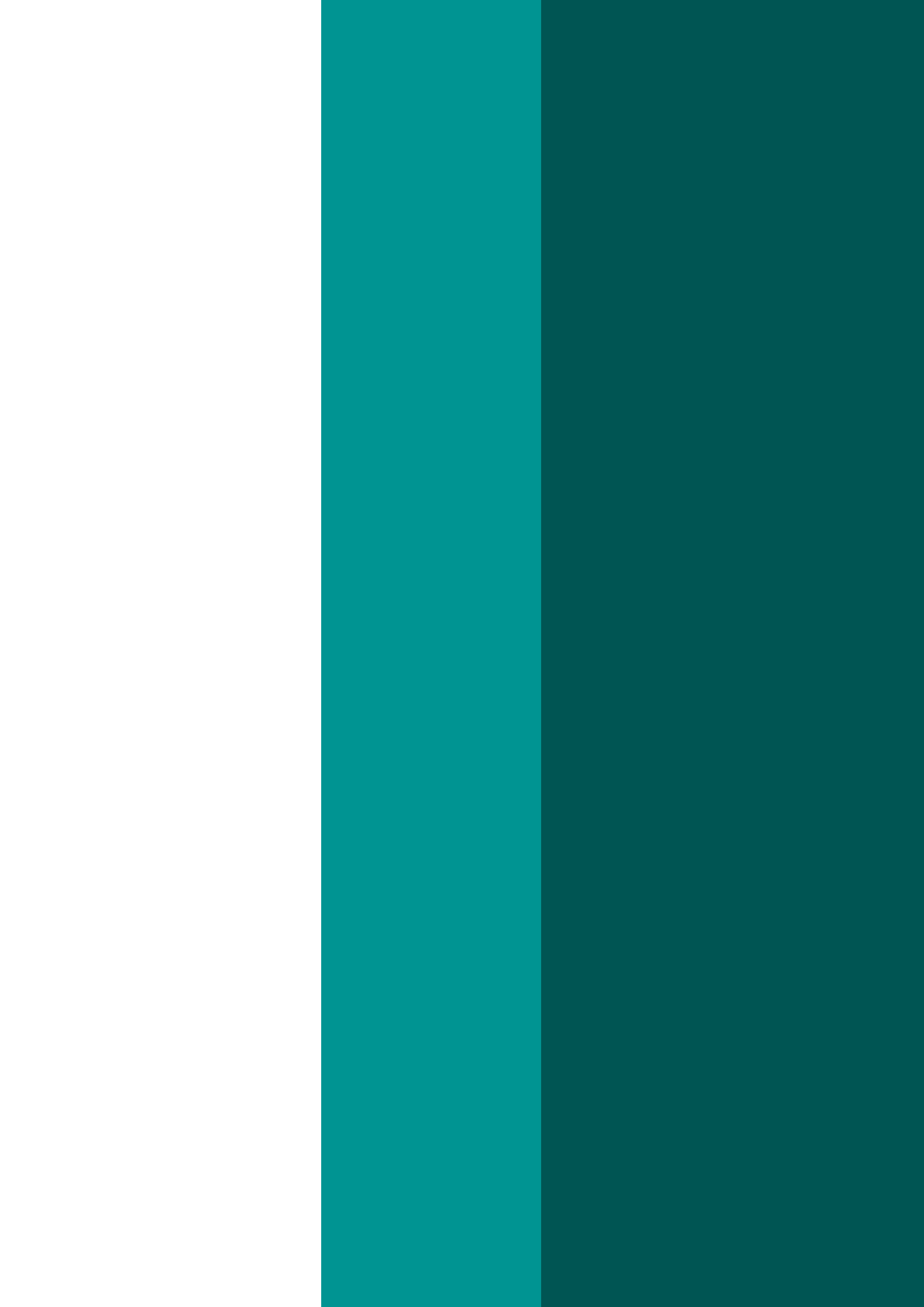
02

INFORMATION AND ADVICE

"Knowledge is Power."

Sir Francis Bacon (1597)

Information + Advice

THE FAMILY

When people first become parents, they are thrown into a new world where the knowledge and skills they have accumulated in their life can seem of little value and they are thirsting for the answers to questions they had never imagined before: How do I know what she is crying about? Will I be causing him long-term damage if I give him a dummy to suck? Cloth or disposable? How can I claim back child care expenses? Am I being a good parent? The list goes on. Many of these questions can be answered by friends or family. Sometimes more advice is offered than is welcome (Gowen et al 1993).

When a child has a disability or developmental delay, questioning can go into overdrive, while sources of information and advice can be elusive. Friends and family may no longer have the answers and the emotional impact of the concerns about the child's development can also make these discussions less easy than they might be.

> **"When you discover that something is wrong it does impact the family dynamic and your extended family because they're dealing with it too, so that's really hard." (Megan, parent - The Key Worker DVD 2010)**

When a Key Worker first meets a family, the family has already been dealing for some time with their concerns about their child's development or the impact of the child's diagnosis on the family. Their need for information, their sense of all they don't know, may have already begun to erode their confidence as parents (Guralnick 2005).

> **"...for years you don't know what you are doing, you haven't had the right information, you're grasping at straws."(Parent - Mitchell & Sloper 2000)**

> **"On a daily basis I'd go off to work and Jack was tagged with different things from day to day and it would make it harder on the family unit when I'd come home and Rochelle had been told this and that from varying people, so it just made it difficult for the family to function with the extra stresses in life." (Brad, parent - The Key Worker DVD 2010)**

WHY IS RESPONDING IMPORTANT?

1. Responding can help to reduce stress and empower parents.

Parents need knowledge and skills to promote their child's development, make good decisions, and access the resources they need, and responding can help them to develop these.

Empowerment is one of the primary goals of ECI services (Dunst et al 1988). According to Dunst (2007), the "responsibility for child rearing rests within the family" and the role of the ECI professional is to work with the family in a way that supports and strengthens the parents to "carry out child-rearing responsibilities effectively and efficiently". Providing families with the information they need to promote their child's development, make decisions and access the resources they need is therefore a central plank in the Key Worker's role.

> **"I should know what to do for my child."**
> **(Parent - Moore and Larkin 2005)**

Guralnick's (2005) Developmental Systems Model lists information needs first in the list of stressors that may have an impact on family patterns of interaction. Information received about the child's diagnosis and prognosis can have an effect on the quality of parent-child interactions. Parents will be required to make decisions about services, specialists and interventions. Families can be overwhelmed, and those "who experience frustration and failure may experience a loss of control and feelings of inadequacy" (Guralnick 2005, p153). As a result, ECI professionals are often encouraged to interact with families in ways that are supportive and empowering, and to assist families in identifying and using informal supports (Dunst 2000, cited in Bailey & Powell 2005).

> **"I just felt, have I made the right decision and what should I be doing, where else should I be going and what was the best thing for him, have I done enough, have I done too much?" (Parent - Moore and Larkin 2005)**

Mitchell and Sloper (2000) refer to the large amount of research showing that parents of children with disabilities experience higher stress levels than parents of children without disabilities (Quine & Pahl 1991, Sloper & Turner 1993, Wallander & Varni 1998). The Australian Bureau of Statistics report on *Australian Social Trends* (2008) reports that 18% of parents of children with a disability have been diagnosed with a stress-related illness.

Additionally, research (cited in Mitchell & Sloper 2000) has shown that feeling well informed about a source of stress contributes to feeling a sense of control (Weitz 1991), which is related to an increased ability to cope with stressful events (Janis 1983). Information is required if people are to access support and resources that can widen their strategies for coping.

2. Information is families' first and strongest need.

Bailey and Powell (2005) looked at 11 studies from 1992 to 2002 which had used the Family Needs Survey (Bailey & Simeonsson 1988) with a diverse range of families (1,368 families) from across the world. In each of the 11 studies, the need for information was rated considerably higher than any other need, with 52% of respondents saying they definitely wanted assistance in this domain compared to an average of 28% indicating a desire for assistance in other areas.

> **"I had a lot of questions that needed answers. I needed information and guidance in terms of goal setting. I wanted someone to say it was going to be OK. I wanted to learn." (Parent - Moore and Larkin 2005)**

3. Information is central to achieving family outcomes.

The U.S. federal government has funded the Early Childhood Outcomes Center (Bailey et al 2005) to promote the development and implementation of child and family outcomes for infants, toddlers and pre-schoolers with disabilities. The Center has developed three outcomes for children and five for families, and these outcomes form the basis of the Family Outcome Survey that has been used in Noah's Ark since 2008 as an outcome measure.

Information and advice to the family is core to each of the five family outcomes:
- Families understand their child's strengths, abilities and special needs.
- Families know their rights and advocate effectively for their children.
- Families help their children develop and learn.
- Families have support systems.
- Families are to gain access to desired services, programs, and activities in their community.

HOW DO YOU RESPOND?

Type of information and advice

> **"I wanted to know what could we do, what could we buy, what equipment does he need to climb and do all these things." Parent - Moore and Larkin 2005)**

According to Jung (2010), family members usually want information in four areas:
- their child's disability
- services that are available
- general child development
- strategies to use with their child.

Mitchell and Sloper (2000) identify the most important content areas as:
- financial issues
- disability information
- child care and respite
- leisure activities
- support groups
- knowing your rights and how to complain
- sources of support for the whole family including siblings
- housing options and adaptions
- help in dealing with emotional problems and behaviours.

Success Works (2009) discusses the boundaries of the Key Worker role and sees the following as being within those boundaries:
- empowering the family to support the development of their child
- passing on knowledge and research on child development
- suggesting practical strategies to support the child's development
- providing information about relevant parent education programs and referral to parent-to-parent support
- being informed about current practice, resources (e.g. new funding, new programs).

The following are listed as outside the Key Worker's role:
- legal advice
- financial support or financial counselling
- family planning
- medical advice
- genetic counselling
- sexual assault or family violence counselling or support
- drug or alcohol counselling or support.

It would, however, be the Key Worker's responsibility to let the family know where they could get advice on these issues.

Delivery of information and advice

Family-centred practice has families actively at the centre of decision-making, and proactively involves families in acting on these decisions. Research has shown numerous benefits for families, including an increased sense of empowerment and well-being, feeling competent and confident as parents, and having a more positive view of their child's behaviour (Dunst & Trivette 1996). Using family-centred practice, Key Workers assist families to make choices by helping them to identify and focus on priorities, "evaluate options and make informed decisions", while promoting "active family participation" using the family's strengths and building new skills to achieve their goals (Wilson & Dunst 2005).

> **"There shouldn't be any assumptions made about the ability of the family to cope or not to cope...because everybody who is placed in the situation of suddenly having a disabled child needs help or needs some space to get back on their feet and face the problems." (Parent - Mitchell & Sloper 2000)**

While people should be viewed as "experts on their own lives and situations" (McCashen 2005) and parents can be viewed as experts on their own children, individuals vary in their ability and confidence to take action and make decisions. Key Workers must be mindful of where families are on this "empowerment continuum" (McCashen 2005, p120) and reflect on whether the way in which they are providing advice is helping families to build their capacity to make informed decisions and take action on them. In a traditional model of early childhood intervention, professionals used their expertise to solve problems for families, having determined what needed to be "fixed" from their professional point of view. In a family-centred model, the practice around providing information and advice to families needs to reflect the goal of **capacity building**. Deal & McCashen (1998) provide some reminders for reflection:

We can	*We can't*
• Be respectful	• Know what is best for others
• Make options available	• Make choices for others
• Offer another view	• Impose our views
• Be encouraging	• Make people do what we want
• Change our beliefs	• Impose our beliefs on others
• Encourage change	• Control processes or outcomes

Mitchell and Sloper (2000) researched the information needs of families with a child with a disability or chronic illness, looking at what types of information families would like to receive and how they would like to receive it. This resulted in the publication, *User-friendly information for families with disabled children: A guide to good practice*. They found that parents proposed similar criteria for good quality information regardless of their child's illness or disability. The criteria fell into four main areas:

- how information is presented
- the content of information
- the way information is delivered and
- how information is organised.

Parents felt that information needed to be:

- accessible
- easy to read
- non-threatening
- jargon-free
- clear
- visually attractive
- indexed
- utilising headings, bold fonts and drawings
- provided in a variety of formats including leaflets and booklets, verbal advice and guidance and the internet.

Most parents in the study preferred to be informed and guided verbally, and given written material to read later at their own pace. With written information, parents wanted it to state clearly where they could go for further information.

"You need them to tell you but when you go away quite often you've forgotten everything they've said, so if it's written down on a piece of paper as well, exactly what they've said to you, then you can go back and when you've got five minutes to spare you can read it and then you remember it." (Parent - Mitchell & Sloper 2000)

Study participants wanted to know that information was up-to-date and accurate, and wanted it at key times in their lives such as diagnosis and transition to school. The depth of information required varied widely, depending on factors such as parental time and expectations, personal confidence and years spent as a carer.

"Our Key Worker gave us a lot of hard copy information at the start and I'm not the kind of person who reads anything. I think she worked that out pretty quickly and now she just tells us about services as the need for them arises." (Megan, parent - The Key Worker DVD 2010)

Delivery of information needs to be for all families regardless of class, ethnicity or disability (Mitchell & Sloper 2000). Information needs to be "culturally relevant and respectful of family diversity" (Centre for Community Child Health 2009).

A strong theme that emerged was that parents see "personal contact and guidance from information givers" as a high priority. The information giver was given a range of names, including Key Worker. Parents wanted this person to:

- guide them through the maze of information available
- get to know their family and thus be able to tailor information to their individual family needs
- have an approachable and understanding manner
- listen respectfully to them
- have good communication skills underpinned by appropriate training
- have a comprehensive knowledge of local services.

"If you had one person you knew you might be more confident." (Parent - Mitchell & Sloper 2000)

"It needs to be one person as far as possible who … could be parachuted into the family – right from the beginning to be introduced to the family and to get to know the family, to have time to sit down with them and absorb the culture of that family. And then they are in the best position then to make some kind of decision on what way the information should be given to that family, how much information. It would be some kind of key worker or facilitator." (Parent - Mitchell & Sloper 2000)

Parents valued "continuity of personnel and the opportunity to build a relationship with their information provider". This would enable the Key Worker to target relevant information "as and when needed in a more relaxed and personal manner". Parents wanted the information to cut across boundaries of professional disciplines so that it was more holistic and comprehensive.

Key Workers are not the only source of information, nor are they a source of information that will continue to be available once the child goes to school. Encouraging parents to build their informal network of support is important, to ensure that the family has access to not only the emotional, social and practical support they may need but also to a broader range of information and advice.

"I actually found out some information from parents within the group...we got taken away to a cafe for a little chat and we suddenly started getting all the information that I didn't know already, so that was good." (Parent - Moore and Larkin 2005)

WHAT DOES IT LOOK LIKE WHEN WE HAVE RESPONDED?

Success Works (2009) listed the positive effects of information and advice for parents as:

- increased ability to support their child's development
- improved links to the community
- better understanding of their child
- better understanding of the services that are available
- better knowledge of the resources they have available to them
- empowering parents to work effectively with their children using their own abilities and resources
- development of parents' existing skills and strengths
- more positive approach to their child's development.

"I think we're a lot better at it now and we're better at trying to learn the signals that he is stressed...We've learnt different strategies that will help him." (Sue-Anne, parent - The Key Worker DVD 2010)

IN SUMMARY

"I've had lots of questions along the way and I think she's taken the time to listen to me and help me with those questions." (Parent - Moore and Larkin 2005)

Information and advice to families is central to all the work done in ECI. It assists families in promoting their child's development, making informed decisions and accessing

the resources they need. Areas that families want to know about include their child's disability, services available, general child development, and strategies to use with their child. Families prefer this information to be provided by a person who knows the whole family – someone who can guide them through the maze of information available and tailor the information to suit their individual needs, providing information that is accurate, appropriate and accessible at time when they need it. They like to be guided verbally and given written materials to read at their own pace.

Information and advice should be provided in a way that is empowering for families – that gives them the knowledge they need to enhance their confidence as parents, to understand and respond to the needs of their child and to access the services and resources they need. Information and advice can reduce some of the stress that families may be experiencing. It can help them see their child's strengths, know their rights, build their skills in aiding their child to develop and learn, build their network of supports, and gain access to services, programs and activities in the community.

Respectful relationships and good communication underpin quality service delivery in this area. Parents value the continuity of the relationship with the "information giver" or Key Worker, and they prefer holistic information that cuts across discipline boundaries.

To improve the delivery of information and advice, it could be beneficial to review written materials used by individuals, teams and service-wide, and to look at how information and advice is provided verbally to families, ensuring that this is consistent with the evidence-base in capacity-building family-centred practice.

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Information + Advice

ecii
Intervention Resources

WHAT IS THE PRACTICE?

All parents seek information and advice from a range of sources, to build their skills and knowledge, and find out about services, resources, activities and supports. The information and advice that parents of a child with a disability or developmental delay seek from their Key Worker is often, at the start at least, to do with their child's disability, services that are available, general child development and strategies to use with their child. It is important to let parents know that information and advice is also available for family needs.

WHAT DOES THE PRACTICE LOOK LIKE?

Information and advice needs to be provided respectfully and with cultural sensitivity. Provide clear, easy-to-read written information on a subject, with the name of a book or website for further information. If a family discusses a decision they need to make, provide information to help inform the decision and, with their permission, help them to evaluate options by assisting them to identify and give priority to what is most important to them.

HOW DO YOU DO THE PRACTICE?

Individualised information – There is an endless amount of information available to families and they can feel swamped by it. Families prefer their information to be tailored to their needs. Consider:

- Timing – Where is the family at in relation to diagnosis, current knowledge, transition and competing demands? What information do they need now and what can wait until later?

- Amount – Different people prefer different amounts of material. Some want a brief synopsis while others will want to know all there is to know.

- Family need – The Key Worker has a relationship with the whole family and needs to source information according to their needs, preferences and circumstances.

Capacity Building – The Key Worker will not be with the family forever. The family, however, will continue to need information and have to make decisions about their child's development and the resources they need. Families need to build their skills and confidence in getting

information. Key Workers need to ensure that they build this capacity in the way they provide information and advice.

Presentation – Families prefer information to be holistic and comprehensive, and not fixed along professional boundaries. They want information based on current research, accessible, non-threatening and jargon-free. Written information needs to be visually attractive and easy to read, using headings, pictures, bold fonts and indexing. Verbal information needs to come from a person who knows the family, listens respectfully to them, and has good knowledge and communication skills along with an understanding and approachable manner.

HOW DO YOU KNOW THE PRACTICE WORKED?

- Families use information and advice to build on current knowledge and skills.

- Information and advice is holistic, accurate, unbiased, current and accessible.

- Each family knows what they need and has information to match.

- Families have the skills to access information independently.

- Families have the capacity and confidence to make informed decisions and take action.

INDIVIDUALISED INFORMATION

Fiona and John have three children aged under seven. The oldest has just started school, the middle child, Angus, has recently been diagnosed with autism, and the baby is keeping the whole family awake at night. Before the baby was born, Fiona had six weeks off work and requested Lucinda, their Key Worker, to give her more detailed information on autism as she had the time to read it. Lucinda gave her some written information and some advice about sourcing current evidence-based material on the web. She also passed on the titles of a couple of books recommended by other parents and colleagues. Since the baby was born, neither John nor Fiona has had the time or energy to read anything. Lucinda has told them about support services available in relation to their sleepless baby, and after discussing advice from John's mother, their experience with their first two babies, and information from some recent training Lucinda had done, Fiona and John have come up with a plan of action that suits their needs, preferences and parenting styles.

CAPACITY BUILDING

Yolanda and Boris were trying to decide which school to send their five-year-old daughter Helena to next year. They were not confident about making such a big decision and asked their Key Worker, Tamsin, to tell them which one to choose. Tamsin gave Yolanda and Boris the contact details of the local primary school, the closest Special School, and a nearby Catholic school, as the family is Catholic. She talked with them about what is important to them in selecting a school. The couple wanted Helena to be with her friends from the neighbourhood but were concerned about whether or not her educational needs would be met at the local primary school. Boris would like Helena to go to a Catholic school but was concerned about the fees. Together with Tamsin, they came up with a list of questions they would like to ask each of the schools. Tamsin went with the family to the first school and supported the couple in asking their questions. Having gained confidence from this experience, Yoland and Boris went without Tamsin to the other two schools. They then weighed up all they had learnt about the schools, together with their personal preferences, and made a decision they felt was right for Helena.

PRESENTATION

Kym and Thanh are an Australian-born Vietnamese couple with a four-year-old son called Bao. They live with Thanh's mother, who does not speak English. Bao has some speech and gross motor delays. His Key Worker, Josie, has developed a strong and respectful relationship with the whole family. Kym and Thanh do not want Thanh's mother involved every time they meet with Josie, but on the occasions they do want her there, Josie organises for an interpreter to be present. Working with the interpreter, Josie has become better and better at keeping jargon out of her language as there is often no way to translate these technical words. This has improved her communication not only with Kym and Thanh, but with all the other families she works with as well. She has given Kym and Thanh a booklet from the council about all the services and activities available in the local community. The booklet is clearly indexed and easy to read, and its pictures make it of some use in discussion with Thanh's mother, who recognised the picture of the community hall where the Vietnamese playgroup is held and was able to take Bao there herself one day when Kym was sick.

Information + Advice

REFLECTION & DEVELOPMENT - Early Childhood Intervention Practitioner Competencies

The majority of competencies below are taken directly from *Early Childhood Intervention Practitioner Competencies* (ECIA Vic 2009) available at www.eciavic.org.au. The competencies in *italics* have been added and content has been reordered and recategorised. Please read through and assess yourself against these statements by selecting a level on the scale below.

Once you have assessed yourself please look at which items you have marked yourself relatively high and relatively low. Use this as a basis for reflection and goal setting on the final page. Goals may centre on developing your skills or knowledge in particular areas or they may centre on how you might share your skills and knowledge with your team. Please then use the completed form as a tool for discussion in your next supervision session.

This Is New To Me	Beginning To Learn This	Reasonable Knowledge & Skills	Good Knowledge & Skills, Sometimes Challenged	Very High Knowledge, Confident Teaching Others
1	2	3	4	5

Competency	1	2	3	4	5
KNOWLEDGE					
Apply knowledge of typical childhood development to recognise characteristic developmental achievements.					
Describe the core needs of all children.					
State critical development pathways and milestones for all children and discern a child's readiness to undertake each.					
Recognise all children as learners and describe different ways of learning.					
Recognise the role of play and a child's daily activities.					
Describe typical socialisation patterns and peer group formation.					
Apply knowledge of atypical childhood development and awareness of its many causes.					
Identify indicators/signals which show that a child's development is compromised.					
Find and interpret information which indicates the interplay of complex/ multiple conditions.					
Propose ways that a child may access critical development pathways and have core needs met.					
Apply knowledge of environmental influences on a child and recommend appropriate interventions.					
Encourage stimulating and engaging environments and positive, responsive relationships which are safe for a child.					
Identify potentially inclusive services/locations/venues which are best placed to meet a child's development needs at key transition times.					
Identify useful and accessible generic support networks and community resources.					

	This Is New To Me	Beginning To Learn This	Reasonable Knowledge & Skills	Good Knowledge & Skills, Sometimes Challenged	Very High Knowledge, Confident Teaching Others
	1	2	3	4	5

Competency	1	2	3	4	5
Knowledge cont'd					
Consider available service and support pathways from 0-6 years of age and propose corresponding service options.					
Incorporate into proposed service options: • relevant research & practice-based evidence • relevant philosophical and policy frameworks • and communicate these clearly and simply to family and other professionals.					

HOW KNOWLEDGE IS SHARED

	1	2	3	4	5
1. Communication Skills					
Use a family's language and symbols in one's communication with the family.					
Interpret findings of assessment and communicate these to relevant people in an accessible manner.					
Document activities, results and outcomes in an efficient and effective way.					
Sensitively present information which may be difficult for families to acknowledge and/or accept.					
Articulate how one's consultancy facilitates improved outcomes for a child, family and community.					
Inform others of own and agency's capabilities, approaches and professionalism.					
Describe own and agency's methodologies using systematic methods.					
Quantify the value to the end recipient which is added through proposed methodologies, along with potential risks.					
Engage others.					
Check understanding through repeating, rephrasing, paraphrasing and summarising.					
Actively seek feedback.					
Suggest perspectives which balance multiple or competing interests where these are present.					
2. Family-centred practice					
Work in partnership with families to ensure their needs are addressed.					
Promote and support family members' participation within planned interventions.					
Frame and solve problems collaboratively.					
3. Capacity Building					
Enable families to develop their strengths.					
Assist carers to become more self-reliant in identifying and using services.					
Empower and enable others while managing realistic expectations.					
4. Strengths-based Practice					
Convey positive attributions about a family's behaviours which can be used with their child.					
Reinforce and build confidence in carers that they possess good knowledge of their child.					

Reflection on my strengths and areas for development

Goals for Learning, Development or Mentoring

1.

2.

3.

03

IDENTIFYING AND
ADDRESSING NEEDS

"Unless we can clearly define our needs, we can't fulfil them."

Kevin Ryerson (1997)

Identifying + Addressing Needs

THE FAMILY

Families often bring a long history of uncertainties and fears to their first meeting with their Key Worker. When a child has been diagnosed with a disability or a developmental delay, parents may experience shock or grief and they may worry about what the future holds for their child. Goals or dreams for the child, held consciously or unconsciously, may be overturned and the parents may be unclear about what they want or need, what they could or should desire, what is possible for their child and family.

> **"Initially our world was turned upside down. What does the future hold for her? All you ever want really is a healthy child." (Val, parent - Ochiltree & Forster 2010)**

> **"When you get the diagnosis even though you have had an instinct you get a horrendous shock because you don't know what it means for him and for your family. I was very grief stricken." (Patricia, parent - Ochiltree & Forster 2010)**

> **"...with him I see the future with fear. I don't know what is going to happen. The fear is that he's not going to be able to cope, that he won't have any friends, he won't interact with people in the right way or that he is not going to be happy and that his life is not going to be fulfilled..." (Helen, parent - Ochiltree & Forster 2010)**

WHY IS RESPONDING IMPORTANT?

To design an intervention that is both meaningful and relevant (Jung 2010), the ECI professional and the family must first identify their needs and set priorities. The overarching needs are "for the child to acquire skills and function well" and "for the family to be able to support the child's development and learning" (McWilliam 2010).

It has become increasingly clear over recent years that the success of an intervention lies in the degree to which the child's family (or caregivers) are able to support his or her learning and development. The Key Worker role in early childhood intervention has been established primarily to support the parents to support the child, because families have the greatest opportunities to have a positive impact on their child's development, and family stressors can undermine these opportunities.

1. **Families have the greatest opportunities to have a direct impact on the child's development.**

   - While ECI professionals have few opportunities for direct impact, they have considerable opportunity for indirect impact by providing the family with the support and information they need (Jung 2010).

   - As family is the principle context in which child development takes place (Kelly et al 2005) and the well-being of the family has important consequences for the well-being of the child, early childhood intervention needs to look at what is stressing or supporting the family system when identifying and addressing needs.

   "Teachers teach for a year and I am his mother for life." (Judy, parent - Ochiltree & Forster 2010)

2. **Family stressors have an impact on child outcomes.**

Guralnick's Developmental Systems Model (2005) prompts us to consider:
   - the personal characteristics of the parents, including their mental health, intellectual ability and child rearing attitudes and practices
   - the financial resources available to the family
   - social supports, including the marital relationship and the broader social network of friends and family
   - characteristics of the child, such as temperament.

These characteristics or stressors influence:
   - the quality of parent-child transactions
   - family-orchestrated child experiences
   - health and safety provided by family.

These family patterns of interaction then affect the child's development. The process of identifying and addressing needs in early childhood intervention based on this model would involve assessing those family characteristics or stressors, and identifying supports that either address these or take them into consideration.

Research has shown that family characteristics such as parent mental health, family functioning and coping styles, family environment, social support and parenting attitudes, all contribute to family and child outcomes and, according to Kelly et al (2005), this has informed early childhood intervention. They point out that there have been many studies on the effects of parental mental health issues on children in the short and long term, and given the high prevalence of these issues (12% of mothers who have recently given birth suffer depression and 8% of mothers suffer depression at any given time), ECI professionals need to know something about them. Research suggests that the rates of psychiatric concerns for mothers and fathers of children with disabilities can be 2 to 2.7 times that of parents of typically developing children of the same age (cited in Success Works 2009). Kobe and Hammer (1994) found that the association between maternal depression and child depression held true for children with disabilities. Children of parents who are depressed are at increased risk of social, educational, behavioural and vocational difficulties (Downey & Coyne 1990).

Low maternal IQ has been found to be a risk factor because of the effect on mother-child interactions. Interventions need to support the mother's ability to provide sensitive and responsive care.

The financial resources available to a family have also been shown to have an effect on child outcomes, but the impact of low income can be softened by other family characteristics (Kelly et al 2005).

Family coping skills and problem solving abilities has been shown to have a significant impact on how families respond to stressors. Kelly et al (2005) looked at a range of research in this area, which showed that:
   - Seeking social support as a way of coping predicted greater family strength.

   "Friends are not necessarily helping out but just to talk to them is supportive." (Andrea, parent - Ochiltree & Forster 2010)

   - Problem-focused coping (problem solving) was related to less distress in mothers of children with disabilities.
   - Parents' reports of ways of coping significantly predicted their reports of family strengths, above and beyond family demographics.

"I'm a more patient mother now... I don't get upset about the little things because there are bigger things, bigger worries." (Bronwyn, parent - Ochiltree & Forster 2010)

- Families who coped effectively reported higher family cohesion.

"We were very fortunate with both sides of our family, my husband's family live around here and his parents live next door. They were terrific and my family lives several hours away but my Mum and sisters were all very supportive." (Val, parent - Ochiltree & Forster 2010)

- Families who were highly cohesive saw themselves as capable of meeting family needs. They reacted to stress with creative problem solving and they reported healthy marital relationships.

"In a way it does strengthen you because you are supporting each other and you are in this together." (Parent - Ochiltree & Forster 2010)

- Strong families accepted their child with disabilities, had realistic expectations of the child's ability, and were committed to creating an environment that contributed to the growth of all family members.

"He's moderate to severe (autism) and I accept that but my goal is that he learns to live as happy and independent life as he can but as long as he's happy." (Bronwyn, parent - Ochiltree & Forster 2010)

- Families who coped well were able to gain access to resources that relieved stress.

Crockenberg (1988) describes the various benefits of social support for parents:
- The number of stressful events can be reduced by providing "instrumental support" such as babysitting, financial assistance or parenting advice.
- The impact of stressful events can be ameliorated by "emotional support" from people in the social network.
- Social supports may assist a parent in actively developing better strategies to cope, such as helping them to improve their child-rearing skills "or other positive initiatives that benefit the child".
- Crockenberg (1988) also draws on the work of Crittenden (1985), which proposes that emotional support can have a positive effect on a parent's self-worth "as a person deserving of care and capable of caring for someone else". This can then enhance the parent's capacity and propensity to nurture their child.

Support in addressing needs enhances children's functioning in their daily routines (McWilliam 2005). Specifically:
- Emotional support provides encouragement.
- Material support provides the necessary resources for children to be able to do things independently (e.g. equipment) and for families to be able to meet basic needs (e.g. financial resources).
- Informational support leads to intervention.

HOW DO YOU RESPOND?

Discovering a family's goals for their child is one of the first tasks in ECI. Focusing on what support a family needs to pursue and achieve those goals is the principal role of the Key Worker.

Dunst (2000) categorises supports as formal and informal, and states that families find the latter more helpful.

The Success Works (2009) report on the Key Worker role outlines the boundaries of the role, listing the following as being within those boundaries:

- helping families identify goals and priorities for the child and family together
- applying for or providing resources, equipment, funding referrals etc
- organising interpreters to enable the communication of information relating to the child or family's care of the child.

Tasks outside the boundaries of the role were listed as:

- marital counselling
- babysitting
- addressing major clinical issues for siblings or parents
- addressing sexual assault or family violence (counselling)
- fund raising
- religious or spiritual guidance.

In McWilliam's (2010) assessment, "We are not required to babysit while parents have time for themselves or to go out together, to provide safe housing, to buy vehicles or to employ parents. But we can give parents emotional support and information about financial and other resources to address their family level needs."

By assessing child and family needs in the context of daily routines, information provided is likely to be "meaningful and relevant" (Jung 2010) and so more likely to be used. The Routines-Based Interview (discussed in pages 49-50) provides a process for identifying family-directed outcomes or goals, and the services and supports that families need to achieve their goals. These are then applied to improving the daily lives of both the child and the primary carers, through a family support plan and an individualised program plan.

"The first couple of years, [my child] was okay laying down and doing stretches and this and that but after three and half years, that's it, they just won't have a bar of it and you're making it hard on yourself... [Since incorporating it into his play] I've never looked back, it's the only way to do it, because you are not fighting against them and it becomes second nature for them too." (Parent - Moore and Larkin 2005)

"I feel guilty if I don't do what therapists ask me to do – there's this pressure to perform. When you have a child with a disability you always feel guilty as there's never enough time to do everything you are asked to do." (Parent - Moore and Larkin 2005)

Other people who share significant routines with the child, such as early childhood educators, need to be involved in and committed to the plan as they also have significant opportunities to influence the child's development. It is important to find out what they see as needs in the routines they share with the child and address these functional needs in program planning. This has the added benefit of giving caregivers the message that they are listened to and they play an important role in the child's development.

> "Justin was very unsettled when he started child care. You would assume that if the director of a child care centre accepted a child with autism that they would try to do things with him, but the [Key Worker] would go out there and show her things to do with him but they just weren't doing it." (Andrea, parent - Ochiltree and Forster 2010)

As the model of practice in ECI services has moved from a clinical, discipline-specific, child-focussed approach to a transdisciplinary family-centred approach, the way ECI professionals identify what goals to work on has also had to change. Today, a Key Worker will need to look at a child holistically within the context of their family and community in a strengths-based way, and establish from the family's point of view what the priorities are, what interventions will fit in with their routines and preferences, and how they would like the ECI professional to support these goals in other everyday environments such as kindergarten and child care.

While family assessment has become "a routine part" of early intervention (Krauss 2000), there may still be a "deep-seated ambivalence" about it from early intervention professionals and families for a range of reasons. For example:

- ECI professionals tend to have expertise in child development rather than family systems.
- There is an enormous array of assessment tools to choose from, but most were designed for a different purpose and context.
- There are concerns that the use of formal tools may not always help to empower families and establish partnerships between parents and families.
- There are concerns about the validity of the more informal tools.
- There is a potential for cultural and class bias with both formal and informal methods.
- There are also concerns about intrusiveness.
- Family assessment can be time-consuming and ECI professionals usually have substantial demands on their limited available time.

The following traits, practices and tools have been selected for discussion as they appear to overcome some of these challenges.

1. Key worker characteristics and practices required to identify and address family needs

Success Works (2009) describes Key Workers as:
- Open-minded, flexible, listening to families and using their perceptions and skills to help families to express themselves and identify their strengths and their needs.

> "Our Key Worker is really good at noticing the changes in Astrid that I think sometimes we miss because we're so close to it, so she's been really good at drawing our attention to the progress that [Astrid is] making and then highlighting what the next steps might be for her development, which is really great because it gives us some sense of progress and structure and direction. Sometimes it can be overwhelming if you don't know what to focus on." (Megan, parent - The Key Worker DVD 2010)

- Breaking down strategies into manageable chunks to give a sense of achievement for families and provide a clear starting point.

> "It sort of made us realise what we need to focus on even if it is just short-term and not sort of looking at the big picture and thinking 'My God, is he ever going to get there one day', that sort of thing, focussing on little things, one day at a time, one week at a time." (Rochelle, parent - The Key Worker DVD 2010)

Krauss (2000) discusses the traits required of professionals embarking on any kind of family assessment in early childhood intervention. He emphasises the need to develop respectful relationships, to be open and non-judgemental, and to remember that it is something done "with" the family rather than "on" or "to" them. The purpose is always to identify goals rather than expose deficits. Drawing on Beckman et al (1996), he identifies six skills necessary for establishing relationships with families:

- Join the family – listen without judging.
- Use active listening – listen not only for what is said, but also how it is said.
- Use questions effectively – strike a balance between factual and open-ended.
- Reflect and clarify – rephrasing and expanding parents' comments.
- Provide information – concrete assistance.
- Reframe – redefine things in a positive way.

2. Family support and Eco-Mapping

"Friends helped. I had friends that would come and watch my younger child for me so I could take Jack to therapy and that was an enormous support. Another girlfriend used to come every day and check that I was okay..." (Judy, parent - Ochiltree and Forster 2010)

There is evidence that informal supports are more helpful for families than formal supports (Jung 2010). The natural supports that spring from a family's social and community network should be the mainstay, with formal services filling gaps and complementing, not replacing, these natural supports (Dunst 2000). Social support is one of the most important mediators for reducing the effects of family stressors (Kelly et al 2005), and Pearlin et al (1990) found it to be one of the two primary characteristics that mediated stress for caregivers – the other being coping strategies. Emotional support from friends and family can protect parents from stressors (Kelly et al 2005).

Eco-Maps are a tool developed by a social worker, Ann Hartman, in 1975 (Eco-Maps are also relevant to Emotional Support, Section 1). Developed by the family and professional together, an Eco-Map sets out visually all the systems that are involved in a family's life, ranging from friends and family to social networks and formal support services. An Eco-Map can show both the range and strength of a family's supports and connections. The process of creating an Eco-Map with a professional, and the "more natural feeling, casual conversation" (Jung 2010) it involves, can help to engage a family in a way that the "often sterile feeling of traditional questionnaire style intake paperwork" can fail to do. The Eco-Map process "results in a picture [in which] the people in and connections of a family are literally visible, allowing them to see their family in a new way" (Jung 2010). This visual depiction can be helpful for any family, but particularly for parents with literacy issues or from a non-English speaking background. Another strong advantage from the point of view of many culturally and linguistically diverse families is that it values extended family support. The Eco-Map process will elicit information on existing family supports and enable any interventions to be designed around the supports already available to a family. Creating an Eco-Map with a family at the start also creates an opportunity to repeat the exercise down the track to see any development in the network of support.

Cochran and Niegro (1995) recommended that early childhood intervention should include network change as a possible outcome, and that measures of network-related consequences should be a part of any overall assessment strategy.

3. Routines-based interviews (RBI)

"Professionals kept asking me what my 'needs' were. I didn't know what to say, I finally told them, 'Look I'm not sure what you're talking about. So let me just tell you what happens from the time I get up in the morning until I go to sleep at night. Maybe that will help'." (Parent - Bernheimer & Weisner 2007)

"Where is that fifteen minutes (to carry out the intervention plan) going to come from? What am I supposed to give up? Taking the kids to the park? Reading a bedtime story to my eldest? Washing the breakfast dishes? Sorting the laundry? Grading student papers? Because there is no time that hasn't already been spoken for, and for every fifteen minute activity that is added, one has to be taken away." (Parent - Bernheimer & Weisner 2007)

The RBI explores the daily functional needs of a child and family through examining daily routines and frequently occurring events with the parents and others who spend a significant amount of time with the child. "Children learn all the time from their natural caregivers, so services should be designed to support caregivers for times between visits and sessions" (McWilliam 2010). The RBI looks at three areas that are central to a family-centred approach to early intervention in natural environments:

- the child's participation in home and community routines
- the child's independence in these routines
- the child's social relationships in these routines.

According to McWilliam (2010), the RBI has a tendency to influence the development of Family Service Support Plans and Individualised Program Plans and the provision of services in the following ways:

- The family's voice is predominant in the meeting.
- The outcomes identified are specific and clear.
- The outcomes are functional for the child and the family.
- The plan is written in the family's words with minimum or no jargon.
- The outcomes are not discipline-specific, so the plan supports a transdisciplinary model.
- Fewer specific ongoing service providers are needed.

"In general the RBI has important effects on the delivery of EI beyond simply asking families what their days are like." (Parent - McWilliam 2010)

In summary, the RBI:

- provides an opportunity to identify with a family their functional needs
- provides a framework to set priorities among those needs
- identifies supports (resource, emotional, informational) required to meet those functional outcomes
- identifies learning opportunities in the child's routine
- provides an intervention that incorporates the needs of both parents and child, and can have a direct and positive impact on both the child's development and the family's quality of life
- provides capacity to engage other service providers in the plan
- by focussing on daily routines, enables parenting issues, support needs and family concerns to "surface naturally" (Kelly et al 2005).

4. Family Outcomes

The U.S. federal government has funded the Early Childhood Outcomes Center, Bailey et al (2005) to promote the development and implementation of child and family outcomes for infants, toddlers and pre-schoolers with disabilities. The Center has developed three outcomes for children and the following five for families:

- Families understand their child's strengths, abilities and special 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.

These outcomes form the basis of the Family Outcomes Survey. Noah's Ark Key Workers have found that the 18-question survey can also be used when they begin work with a family to identify areas of need and set priorities.

The Canadian Occupational Performance Measure (COPM) is one of a number of goal setting tools that supports the family to identify areas of need and set priorities. This provides the basis for developing and implementing a program. The COPM is used again to measure the change in performance and satisfaction and provides a basis for developing new goals and reviewing outcomes.

WHAT DOES IT LOOK LIKE WHEN WE HAVE RESPONDED?

When families and Key Workers have identified and addressed a family's needs for emotional support, material support and information, the family is likely to be better equipped to manage and adapt to their new situation. "Seeing possibilities in the future and creating new dreams enabled them to gain a sense of control. Parents were empowered by realising that they had choices about the way they viewed their situation" (King et al 2005).

In a review of the literature on social support for families of children with disabilities, Dunst et al (1997) found that greater support from a person's social network related to:
- better personal functioning in the parent
- more positive perceptions of the child's behaviour
- better family functioning
- more positive parenting behaviour
- more positive and less negative child affect.

Interventions are more likely to be implemented and sustained if they are meaningful and relevant to the family and fit in with their routines and goals. If supports are able to help children to function better – if children are more able to engage and participate in activities and routines, develop their independence, have positive relationships with others, and communicate – then the family's quality of life is also likely to be enhanced. Indeed, McWilliam (2005) proposes that family satisfaction with routines is an indicator of family quality of life.

> **"It means there are challenges in place but it doesn't have to be a negative experience. I think differently about it than I once would have." (Val, parent - Ochiltree and Forster 2010)**

SUMMARY

Understanding each family's unique network of support, knowing what goes on in their daily lives, what they enjoy and what they find challenging, enables ECI professionals to work in partnership with families and design interventions that are meaningful and relevant

(Jung 2010). As families have the greatest opportunities to have a direct impact (both positive and negative) on a child's development, early childhood intervention needs to focus on reducing stressors, enhancing supports and enabling parents to make the most of those opportunities (Guralnick 2005). Families tend to have a range of both formal and informal supports; it is the informal supports that should be the primary means for strengthening families, complemented but never replaced by formal supports (Dunst 2000).

Eco-Maps are a valuable tool for identifying children's and families' needs and providing information on family connections, resources and supports. This enables the

family and the ECI professional to design together "an intervention that responds to their entire family's needs and makes use of the best resources and supports available" (Jung 2010). A major focus of Eco-Maps is social support, which has been shown to be very powerful in strengthening families and buffering them from stress.

Routines-based Interviews (RBI) are another method for identifying needs and setting priorities with families. Based on the child's participation, independence and social relationships in regular activities in their natural environments, this tool provides a framework that can elicit functional needs for the child and resource needs to facilitate outcomes. It provides an avenue for engaging in the plan significant people in the child's life, and this can have a direct and positive impact on family quality of life.

Regardless of the tools chosen, the literature emphasises the need to establish respectful relationships with families and work in partnership with them to identify needs, set priorities and address those needs. ECI may assist in addressing needs either directly through emotional, resource or informational support or indirectly through provision of information or referrals.

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Identifying + Addressing Needs

WHAT IS THE PRACTICE?

Effective intervention starts with the family's goals and needs. Each family will see these differently. While ECI aims to develop children's skills and functioning, this actually occurs through family members and other key people in the child's life agreeing on the most effective and sustainable ways to maximise the child's learning opportunities, and acting on this.

WHAT DOES THE PRACTICE LOOK LIKE?

A major role for the Key Worker is to discover the family's goals for both child and family, and what supports may be required to achieve them. This can be documented in a Family Service Support Plan that is functional, holistic and family-centred. Needs may be addressed through both formal and informal supports, providing emotional or material support, or information. The focus is on building the capacity of the family, carers, community and early childhood educators to make the most of the learning opportunities that children have in their daily lives. There are a number of family-centred, strength-based, holistic tools that can assist. The approach is collaborative and transdisciplinary, and the focus is on meeting family goals. At times broad family needs may take priority.

HOW DO YOU DO THE PRACTICE?

Child in the context of family – Families have the greatest impact on the child's development. They will take action when the action fits into their beliefs, routines or family culture. It is important to address issues for parents such as mental health problems, financial problems or lack of social supports, as these can have a significant impact on a family's capacity to support their child's development. Building strong, respectful relationships with families, listening without judging, and being open-minded and flexible, all support a partnership approach to identifying and addressing needs.

Natural routines and environments – Tools such as the Routines-based Interview (RBI) help identify the family's functional goals for their child in everyday situations and daily routines. Children spend time away from the family in child care, kindergarten and community activities, or with other carers, so a Family Service Support Plan needs to consider these other

people and environments and their impact on the child's development. The RBI is a tool that can, with the family's permission, be used inclusively across all of the child's environments, promoting consistency for the child and unified goals amongst key people in the child's life.

Build on strengths – In developing interventions, Key Workers need to look at the child's strengths and interests and the family strengths and interests. What supports are already in place? Informal supports can be more helpful for families than formal supports and can continue after ECI services have ceased. Eco-Maps are a tool that can assist in identifying what supports exist and any gaps, while the RBI can reveal the learning opportunities that already exist in a child's everyday routine. Focussing on improving the family's quality of life will enhance the family's capacity to make the most of these learning opportunities.

HOW DO YOU KNOW THE PRACTICE WORKED?

- Family Service Support Plans are family-centred, holistic and functional.
- Families are clear about their goals and support needs.
- Families have a range of formal and informal supports.
- Family Service Support Plans consider all of the child's natural environments and build on strengths.

THE CHILD IN THE CONTEXT OF FAMILY

Mandy Trickett is a cheerful four-year-old girl who loves to play with her soft toys and enjoys going to the park with her mother. She has just started four-year-old kindergarten. Mandy has delays in her speech and gross motor development. She lives with her mother Pam, her father Ned and her baby sister Cecily. Neither Pam nor Ned is in paid employment. Pam has suffered untreated post-natal depression since Cecily's birth 10 months ago. She rarely leaves the house as she finds the task of organising the children to go out overwhelming. Since Ned lost his job two months ago, he has been drinking more frequently and he and Pam have begun to argue over small things on a daily basis. After many months on a waiting list, the family has been allocated a Key Worker called Vera, and she has been to visit them a couple of times. She is warm and respectful. She listens to them without judgement and focuses on the whole family. She has explained the role of the Key Worker and how she is going to work with them on their goals – what they want for Mandy and what supports they need to pursue their goals.

NATURAL ROUTINES AND ENVIRONMENTS

Pam and Ned were unclear about their goals for Mandy and the family. After Vera explained how a Routines-based Interview (RBI) might help, they decided to give it a go. Pam and Ned did not feel comfortable talking with the kindergarten teacher about all of the family issues, so they chose to have the interview at home with just Vera.

Arising from the RBI, Pam and Ned came up with several goals they wanted to work towards:

1. Mandy will be able to eat her breakfast independently.

2. Pam will be able to take Mandy to the park once a week.

3. Ned will look after both children two afternoons a week.

The discussion around these goals brought out the family's need for supports and resources to help them get there. The couple found the interview very helpful and asked if Vera would come with them to the kindergarten to talk with the teacher about the routines during Mandy's time at kinder. This meeting resulted in a fourth goal:

4. Mandy will use her words when choosing an activity at kindergarten.

On her next home visit, Vera talked more with Pam and Ned about what needs came out of the goals. Pam decided that she would see her GP about her depression and they asked for information about counsellors in the local area. Mandy needed a supportive chair before any intervention could proceed regarding her feeding skills. Pam asked Vera for support in building her skills and confidence to take Mandy to the park, and the couple asked if Vera could also offer support to the kinder teacher.

BUILDING ON STRENGTHS

Vera also talked with Pam and Ned about how it can be helpful, when looking at goals and needs, to look at strengths. This applies to Mandy's skills and interests and looking at how to encourage these and build upon them. It also applies to the whole family – looking at what formal and informal supports they currently have and building on these. Pam and Ned decided to do an Eco-Map with Vera. The discussion the three of them had while doing the Eco-Map highlighted the importance of Pam's relationship with her sister and Ned's desire to make contact with his old friends from work. It showed that Pam has good support from the local Maternal & Child Health Nurse and that Pam's best friend would happily babysit if Pam asked her. It revealed that one of Ned's hobbies was gardening but that he hadn't done any since Mandy was born. The conversation helped Vera see the bigger picture of the family's lives and it gave them a visual picture of the support they had already in their lives – the base on which they could build. It helped them to think not only about how Vera might be able to help them but also about what they could do themselves to build both formal and informal supports into their lives.

Identifying + Addressing Needs

ecii
Intervention Resources

REFLECTION & DEVELOPMENT– **Early Childhood Intervention Practitioner Competencies**

The majority of competencies below are taken directly from *Early Childhood Intervention Practitioner Competencies* (ECIA Vic 2009) available at www.eciavic.org.au. The competencies in *italics* have been added and content has been reordered and recategorised. Please read through and assess yourself against these statements by selecting a level on the scale below.

Once you have assessed yourself please look at which items you have marked yourself relatively high and relatively low. Use this as a basis for reflection and goal setting on the final page. Goals may centre on developing your skills or knowledge in particular areas or they may centre on how you might share your skills and knowledge with your team. Please then use the completed form as a tool for discussion in your next supervision session.

This Is New To Me	Beginning To Learn This	Reasonable Knowledge & Skills	Good Knowledge & Skills, Sometimes Challenged	Very High Knowledge, Confident Teaching Others
1	2	3	4	5

Competency	1	2	3	4	5

KNOWLEDGE

1. Child Development

	1	2	3	4	5
Apply knowledge of typical childhood development to recognise characteristic developmental achievement.					
Recognise the role of play and a child's daily activities.					
Apply knowledge of atypical childhood development and awareness of its many causes.					

2. Natural Environments

	1	2	3	4	5
Apply knowledge of environmental influences on a child and recommend appropriate interventions.					
Recognise environmental factors and how these may positively and/or negatively affect a child.					
Identify the cumulative effects of environmental conditions on the child's development.					

3. Children's Learning

	1	2	3	4	5
Use knowledge of a child's disposition, personality, learning styles, interests and strengths to understand their motivations and capabilities.					

4. Families

	1	2	3	4	5
Recognise features of family systems.					
Define family as it relates to the child and his/her circumstances and identify the role of the child within that family.					

This Is New To Me	Beginning To Learn This	Reasonable Knowledge & Skills	Good Knowledge & Skills, Sometimes Challenged	Very High Knowledge, Confident Teaching Others
1	2	3	4	5

Competency	1	2	3	4	5
4. Families cont'd					
Recognise carers as primary agents of a child's development and well-being.					
Appreciate a child's role as part of a family unit and the different relationships and interactions between carers – child – sibling and extended families.					
State ways in which specific circumstances affect family dynamics.					
5. Supports available					
Identify sources and priority of material, social and emotional assistance, both urgent and non-urgent, which support child and family wellbeing.					
Identify useful and accessible generic support networks and community resources.					
Consider available service and support pathways from 0-6 years of age and propose corresponding service options.					
6. Inclusion and participation					
Promote inclusive environments.					
Use principles of universal design to identify and create opportunities for natural learning.					
Identify barriers to participation and negotiate changes to these.					
7. Assessment					
Analyse health, eating, hygiene, physical and exercise behaviours, where required, to meet a child's needs.					
Identify the particular environments and strategies which are most likely to promote access and participation for each individual child.					
Assess a child's ability to participate confidently at home and in a local community.					
Observe the child and family and form meaning from observations.					
Use appropriate assessment methodologies and tools to develop a rich, strengths-based account of the child which includes family perspectives.					

STRENGTH-BASED PRACTICE

Competency	1	2	3	4	5
Enable families to develop their strengths.					
Empower families to identify and build strengths.					
Reinforce and build confidence in carers that they possess good knowledge of their child.					
Recognise individuals with roles and strengths which may promote inclusion.					

FAMILY-CENTRED PRACTICE

Competency	1	2	3	4	5
Work in partnership with families to ensure their needs are addressed.					
Negotiate goals which meet both the child and the family's individual needs and circumstances.					
Promote and support family members' participation with planned interventions.					
Design service-based on objectives agreed by carers/family.					
Collaborate with the family to formulate a plan, including play-based learning in natural environments, described in terms of strategies and timelines.					

Identifying + Addressing Needs *Checklist*

	This Is New To Me	Beginning To Learn This	Reasonable Knowledge & Skills	Good Knowledge & Skills, Sometimes Challenged	Very High Knowledge, Confident Teaching Others
	1	2	3	4	5

Competency	1	2	3	4	5
Family-centred Practice cont'd					
Gauge a family's readiness, realism and rate of change expectation.					
Frame and solve problems collaboratively.					
Recognise the other person's current situation.					
Accommodate another person's preferences regarding times, places and ways in which consultations occur where possible.					

OUTCOMES FOCUS

	1	2	3	4	5
Define desired outcomes of the intervention, along with measures/indicators of these.					
Reflective practice					
Continually analyse and evaluate efficacy of proposed interventions and adjust delivery accordingly.					

BOUNDARIES

	1	2	3	4	5
Adhere to the ethical guidelines/code of conduct specified by own agency and relevant professional bodies/associations.					

OTHER

	1	2	3	4	5
Propose means of increasing positive effects (protective and supportive factors) and where feasible, minimising negative effects (risk factors within the environment).					
Identify and define current challenges and their effects.					
Envision a desired future situation or potential result which is meaningful to others.					
Work with others so they can: - generate options which are both possible and realistic - plan own actions to achieve the desired future state - develop skills to solve problems and resolve own issues - offer alternatives if expected outcomes exceed own agency's capacity or scope - engage others.					

Reflection on my strengths and areas for development

Goals for Learning, Development or Mentoring

1.

2.

3.

04

ADVOCACY

"I won't take no for an answer if I think that's what my kids need."

Parent of a child with a disbility (Wang et al1997)

Advocacy

THE FAMILY

All parents may need to advocate for their child from time to time but parents of children with additional needs may have greater calls upon them to do so (Wang et al 2004). Once a child is diagnosed with a disability or a developmental delay, families enter a world full of professionals, services, application forms and jargon.

> **"My son was born very prematurely. I was instantly thrown into the world of doctors, hospitals, social workers, and, eventually, disability." (Liz, parent - O'Hanlon & Griffin 2004)**

> **"I felt bombarded at times by the amount of people involved." (Parent - Moore and Larkin 2005)**

There are so many new things to learn about and families may not know what their rights are.

> **"There's a lot of information I don't know and people don't tell you. Things the paediatrician is meant to tell you. You can apply for a healthcare card. He didn't give me the information and you've been outlaying for 12 months and someone else said, 'do you know you can apply for that?' No. 'You know you're entitled to a ...?' No. 'You know you're entitled to a ...?' No. 'You know there's this school that...?' No!" (Parent - Moore and Larkin 2005)**

Once they have worked out what they want and need, families may experience knock-backs, waiting lists, issues with people's attitudes and insufficient resources.

> **"I find it amazing that the equipment and the therapy has to be fought for and I'm learning to be pragmatic but I feel it is really wrong." (Parent - Moore and Larkin 2005)**

> **"Putting in for these things that the kids really need, yet we've got to wait twelve months for the funding to come through…" (Parent - Moore and Larkin 2005)**

> **"I hoped that we would get a lot of help to address (his) needs, like really intense and comprehensive help, and I guess it took me a while to learn that the funding was very limited and wouldn't be available." (Parent - Moore and Larkin 2005)**

> **"I felt out of place. I didn't feel right there. I felt like I was judged although I may not have been but that is how I felt." (Parent - Ochiltree and Forster 2010)**

At times these parents may require support from others as they try to obtain what they believe their child or family needs (CCNUK Cavet 2007). The Key Worker can play a role both in providing this support and in assisting parents to develop skills, knowledge and connections that can enhance their advocacy role into the future.

WHY IS RESPONDING IMPORTANT?

1. Advocacy acts in, and safeguards, the best interests of the child.

The overt purpose of advocacy in early childhood intervention concerns the pursuit of services, resources and information to meet the additional needs of a child with a disability or developmental delay. Most of the literature on advocacy for these children focuses on parents acting as advocates for their child and/or professionals supporting parents in their advocacy endeavours.

Burke (2004) prompts us to consider the child directly, as well: "It would be foolish not to recognise that parents may speak ably for their children, but it would be equally wrong not to make every effort to communicate in whatever way possible with the children themselves, and children include not only those with disabilities but siblings too. It should not be a matter of competition either – of whose rights will be served; the rights of children should be in balance and equally considered and when issues of child protection arise, the needs of the child come first".

2. Advocacy acts to improve the family's quality of life.

The measure of success for advocacy activities is usually to do with whether or not the service in question improves in quality or accessibility. Wang et al (2004) point out that it is also important to look at outcomes for families – to what degree does the advocacy activity have an effect, positive or negative, on Family Quality of Life (FQOL)? FQOL is defined by Poston et al (2003) as "the conditions under which the family's needs are met, family members enjoy their life together as a family, and family members have the chance to do things that are important to them".

> **"I don't want my whole life to be about disability! I want to salvage at least part of my career. I want to continue with my marriage. I don't want to think that the next fifty or sixty years is all going to be about my daughter's disability." (Parent - Moore and Larkin 2005)**

Wang et al (2004), in research involving 104 families in focus groups and interviews, found that parents believe that advocacy can enhance coping. This is generally because families need to learn many skills in order to be able to advocate effectively for their child, including:

- understanding the child's disability
- knowing their rights
- knowing how to get resources and information
- knowing how to ask for help
- documentation skills.

With these skills, parents can become more self-confident and assertive. Advocacy activities can also widen parents' social network as they work with other parents, professionals and support groups.

3. Advocacy can help to reduce family stress and thereby improve child developmental outcomes.

Family-centred practice holds at its core the principle that parents know their child best and want what is best for their child (Rosenbaum et al 1998). It follows that responsibility to advocate for their child falls to the parent. Advocacy can be complex and challenging, and many parents may feel ill-prepared for it (Law et al 2003).

It is increasingly expected that families will need to act as advocates for their children, and advocacy is now often included as an outcome for early childhood intervention; for example, "Families know their rights and advocate effectively for their children" (Early Childhood Outcomes Centre 2005). This expectation may, however, run counter to what some parents want and it may be inconsistent with the cultural values of some families (Wang et al 2004). Early Childhood Intervention Australia (Victorian Chapter) lists one of the ECI family goals as: "Families will be able to advocate for themselves and their family, to the degree they choose" (ECIA Vic 2005).

> *"Ninety-five percent of the time it was a fight... It's the parents who have to, the parents who have to prove why they think their child needs the service, and I don't think that's the way it should be."* (Parent – Wang et al 2004)

Wang et al's (2004) study also found that advocacy causes stress, which can be a drain on parents' physical and emotional resources. Advocacy involves "adversarial struggles" and can be a "life-long battle". Parents in the study wished they did not have to fight to get the services and resources their child needs. They wished that professionals would deliver their services in ways that reduce the parents' need to advocate.

> *"And so, you have to just use every bit of strength you've got to keep yourself together and just keep advocating and keep chugging and keep going, when you're emotionally drained, physically exhausted, spiritually, you know."* (Parent – Wang et al 2004)

According to Guralnick's Developmental Systems Model (2005), the primary task of early childhood intervention is to prevent or minimise stressors and to strengthen the family via an array of supports. This is to allow optimal family patterns of interaction, which will support optimal developmental outcomes for the child. In accordance with this model, it is the responsibility of the Key Worker to support parents in their advocacy endeavours when those endeavours are causing the family stress, and to do whatever possible to reduce the need for these endeavours.

HOW DO YOU RESPOND?

Parents as advocates

> *"Well, I feel that I am my son's greatest advocate. Because there is no one else that is going to speak up for my son but me."* (Parent – Wang et al 2004)

According to research (Wang et al 2004), parents see advocacy in two ways: 1) as an obligation – as a parent you are responsible to be your child's greatest and sometimes only advocate, and 2) as a means to improve services both for their own child and to improve the system more generally. Parents saw their most common advocacy activities as:
- making phone calls
- writing letters
- following up on commitments
- contacting someone in authority
- educating professionals about their child's strengths and weaknesses
- networking throughout the community and state to improve linkages between services.

O'Hanlon & Griffin (2004) are both parents of children with disabilities who became advocates and then went on to become professionals in the field of disability. They have two different approaches to advocacy: "top-down" and "bottom-up."

> **"I call it Big-Picture Advocacy. The purpose of my brand of advocacy is to concentrate on systems change through infiltration. Parents and professionals form partnerships with system-level experts to provide a personal and professional point of view." (Liz, parent – O'Hanlon & Griffin 2004)**

> **"My philosophy is to change the world – one child, one family, one program at a time." (Amy, parent – O'Hanlon & Griffin 2004)**

Professionals as advocates

Success Works (2009), in their report on the Key Worker role, see the following as within the boundaries of advocacy:
- advocating for families with new service providers (e.g. schools, child care)
- supporting families to access early childhood services (kinder, child care etc.)
- supporting families to communicate their needs to other agencies.

Outside the boundary of the role are:
- migration assistance
- negotiation of mortgages
- liaising with employers on behalf of parents
- contacting Ministers or local MPs
- contacting or speaking with the media.

According to Mukherjee et al (2000), working across agencies is a core component of the Key Worker model. The degree to which families require assistance in dealing with other agencies will vary from family to family, as will the form this assistance will take. Some families may just require information about what services are available. Some families will require what Dale (1996) refers to as "enabling" – empowerment to take more control of the services they are receiving, while others will require advocacy – having someone represent their views on their behalf. This may be required when a parent is unable for some reason to advocate themselves (on behalf of their child), where expert representation is needed, or where a parent has been "actively marginalised or disempowered" (Dale 1996).

Supporting parents to develop their advocacy skills

A lot of families will require support with meetings involving multiple services. According to Cavet CCNUK (2007), the Key Worker has a role to play in helping families prepare for those meetings, in making sure that the family's views are represented, and in ensuring that actions arising from the meeting are implemented. Over the years when a Key Worker is involved with a family, before the child starts school, there may or may not be many meetings to attend and the numbers present at those meetings may not be high. These years provide an opportunity for the Key Worker to work with parents to build their advocacy skills and support networks, in preparation for the meetings that will come once the child enters the school system.

> **"I went to the meeting alone – it made no sense to sacrifice my husband's income as well as my own. I was shown into a meeting room where 12 people already sat around a large table. Who were they!? There were no introductions. Someone was invited to begin. For the next hour, the people around the table each took their turn to describe how my child could not do this and would not do that. I was asked if I had anything to say, but I just knew if I spoke I would end up in tears. I said, 'No'."**

> **"The meeting was over. No one had taken notes, and no action plan was developed. I walked numbly to my car and burst into tears. What had just taken place was our 'team' meeting. I wondered, 'How could this have been done better?' (Parent - Law et al 2003)**

CanChild Centre for Childhood Disability Research created some fact sheets (Law et al 2003) on advocacy for both parents and professionals. These include definitions of advocacy, information on when you should advocate, what makes advocacy seem difficult and how people may try thinking about advocacy as a positive experience (e.g. Think of advocacy as educating people. Be aware that your listeners may not have the same facts or understanding of the situation as you. Believe that the people you are talking to are well-intentioned, etc).
In relation to professionals, the fact sheets suggest that Key Workers:

- help parents identify and sort through the systems they must work with

- open doors for parents by identifying other sources of help

- link parents with networks or support groups

- give parents the information they need to make decisions.

There are supports and services specifically set up to provide advocacy for parents of children with disabilities. Some of these are parent-run groups and employ professional staff. Families should be given information about these advocacy services and support networks in case they need them now or in the future. Families with high advocacy needs may need a referral to one of these services.

The Association for Children with a Disability (2009), an organisation that provides information, support and advocacy to families across Victoria who have a child or young adult with any type of disability or developmental delay, provides advocacy tips for parents:

- Be clear about what you want.

- Find out who is responsible or accountable for the decision or action you seek.

- Listen to other people's points of view.

- Think about the points others may raise and how you may respond.

- Be open-minded.

- Ask a friend or professional to help you if you need some support.

Reducing the need for advocacy

Wang et al's (2004) research identified two main factors that reduced the need for parents to engage in advocacy. The first was the quality of services provided – the higher the quality of service provided, the less need there is for a parent to advocate. The second was the relationship between the family and the professional. When professionals engage in partnerships with families to gain quality services for children, there is less need for parents to advocate. "Parents will be expected to engage in far less advocacy when professionals assume their advocacy obligations as part of their duties and responsibilities of working with children with disabilities" (Mlawer 1993).

Taking this into account, together with the implications for practice outlined by Wang et al (2004), the Key Worker could consider, "what can I do to reduce the need for advocacy or to enhance the process and results of advocacy for the families I am working with?"

Success Works (2009) report that Key Workers are most effective in advocacy when they are respectful, knowledgeable and experienced, communicate clearly with families, are open and honest, engage the whole family and the child's multiple environments, and develop strategies in partnership with the family, starting from the point of view of the family and what they want to achieve.

"You're talking to somebody that understands YOUR problem because they understand ... where you are coming from." (Parent – Wang et al 2004)

Essentially, Wang et al (2004) see improving the quality of the service and improving partnerships with parents as helping to reduce the need for parental advocacy. They provide some tips to help to achieve this, and how to support parental advocacy when it is needed:
- Provide services in a way that is consistent with families' values.
- Provide all related information to families during all phases of the service delivery process.
- Provide information and help to facilitate families' resources.
- Develop cross-cultural competence to work better with families from culturally and linguistically diverse backgrounds.
- View families as equal partners in the decision-making process.
- Show respect for families' values and beliefs.
- Listen to families without being judgemental.
- Recognise families' opinions and expertise about their child's strengths and needs.
- Communicate with families about their child's strengths.
- Be friendly and use words that families can easily understand.
- Be responsive to families' requests and concerns.
- Protect families' privacy.
- Avoid conflict even when disagreeing with families' opinions.

Knowledge of rights

The U.S.A. has legislation in place, such as the Individuals with Disabilities Education Act (IDEA 2004), that includes protection of children's rights and those of their parents or guardians. Knowing how to inform parents of their rights in Australia is not quite as straightforward. Australia is a signatory to the Convention on the Rights of the Child (CROC), which in general terms, (Jones 1998) concerns itself with:
- the participation of children in decisions that affect their own destiny
- the protection of children against discrimination and all forms of exploitation
- the prevention of harm to children and
- the provision of assistance for their basic needs.

There are 54 Articles in the CROC (UNICEF) of which the following three stand out for their particular relevance to children with disabilities:
- Article 2 (non-discrimination) – no child should be treated unfairly on any basis.
- Article 3 (best interests of the child) – the best interests of children must be the primary concern in making decisions that may affect them.
- Article 23 (children with disabilities) – children who have any kind of disability have the right to special care and support, as well as all the rights of the convention, so that they can live full and independent lives.

Australia also has the *Commonwealth Disability Discrimination Act 1992* (DDA) (see Law Library Congress 2010) which stipulates that it is unlawful for any person to be discriminated against on the basis of a disability. The Disability Standards for Education 2005 made under the DDA "require education providers to develop policies and programs that eliminate harassment and victimisation". However, neither the DDA nor the Education Standards "require changes to be made where such changes would impose unjustifiable hardship on a person or organisation.[62]" (Law Library of Congress 2010). This is the loophole that has been used at times by childcare services and schools to exclude children with disabilities.

In 2007 Australia became a signatory to The United Nations (2006) Convention on the Rights of Persons with Disabilities. Article 7 focuses on children with disabilities and the need to ensure their full enjoyment of all human rights and fundamental freedoms on an equal basis with other children, the need to take into account their best interests and to ensure their right to express their views freely. Article 24, on Education, states that children with disabilities should not be excluded from the general education system. As of the 1 January 2012, a new National Quality Framework has been established, which applies to most long day care, family day care, preschool (or kindergarten) and outside schools hours care services (Early Childhood Education and Care Settings). The National Quality Framework has been enacted through the Education and Care Services National Law (2010). The Guide to the National Quality Standard (ACECQA, 2011) advises that services are to benefit all children, with specific references to children with additional needs. The effectiveness of these measures to support full participation by children with disabilities is yet to be tested.

It is important for Key Workers to have knowledge of child protection issues (Greco et al (2005). In Victoria, *The Children, Youth & Families Act 2005* provides the legislative basis for the provision of services to vulnerable children, young people and their families. The legislation "places children's best interests at the heart of all decision-making and service delivery" (Department of Human Services 2006). It enshrines in law the right of children to be protected from harm (emotional, physical and sexual) and free from neglect.

WHAT DOES IT LOOK LIKE WHEN WE HAVE RESPONDED?

The following family outcomes developed by the Early Childhood Outcomes Centre (2005) in the U.S.A. are the basis for the Family Outcomes Survey used as an outcome measure at Noah's Ark:

- Families understand their child's strengths, abilities and special 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.

While the second outcome is clearly about advocacy, the other four may also be the subject or outcomes of advocacy endeavours.

SUMMARY

"The key to effectiveness is learning to respect and celebrate our different opinions. Our distinct problems add to the richness of our solutions." (Liz and Amy - O'Hanlon & Griffin 2004)

Advocacy in the context of early childhood intervention refers to parents actively interceding on behalf of their child with a disability or their family, generally to access the information, services or resources they feel their child or family needs. Key Workers may also take on this advocacy role and/or connect the family with other supports, when a family is unable to do so or requires support whilst building their skills in this area.

Advocacy is important to safeguard the best interests of the child and ensure that the child and family have access to what they require to meet their additional needs. Research has shown that parents can improve their family's quality of life by taking on an advocacy role. Key Workers, by supporting parents in their advocacy role, can reduce family stress and strengthen the family, thereby supporting optimal developmental outcomes for the child.

Overall, the literature indicates that the following are helpful in reducing a parent's need to advocate or to enhance the process and results of advocacy:

- respectful partnerships between parents and professionals
- providing parents with information, both about their rights and to assist their decision-making
- professionals understanding that advocacy is one of the responsibilities of their role
- linking families with parent networks or support groups
- providing a high quality service.

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Advocacy

WHAT IS THE PRACTICE?

Parents are usually the main, and sometimes the only, advocates for their children – asserting themselves with professionals to get the services, resources and the respect their children need. Sometimes parents need support from others in these endeavours and may seek it from their Key Worker.

WHAT DOES THE PRACTICE LOOK LIKE?

Advocacy can involve many practical activities such as making phone calls, writing letters, following up with people on commitments they have made, organising meetings, and contacting people with authority to make decisions. Parents spend time educating professionals about their child's strengths and needs, both to improve services for their child, and to network with other parents and professionals to request better services for all. Having accurate information, knowing your rights, having clear communication and building respectful relationships are cornerstones to successful advocacy. For the Key Worker, supporting families to be successful advocates is one way to assist them to be able to meet the needs of their child into the future.

HOW DO YOU DO THE PRACTICE?

There are three main ways Key Workers can assist families to be advocates for their children:

Provide parents with information they need - For parents to advocate effectively for their child they need information about the child's disability, on services and resources available, and on their rights. They can seek support from friends and family and other parents in similar situations. at times they may need information on professional advocacy services or parent support networks.

Build parents' skills in advocacy - Families vary in how much support they require in advocacy. Some may need support in communicating concerns to other professionals but are happy to take a lead role; others would prefer that the Key Worker take a lead role and model strategies they may be able to use in future. Building a family's skills and confidence in communicating

their needs, and in meeting with and following up professionals, will empower them into the future.

Reduce parents' need to advocate – This can be done by providing high quality services that are respectful of a family's culture, values, beliefs and opinions, building relationships with the whole family that are friendly, responsive and non-judgemental, and encouraging other services to adopt similar values and behaviours.

HOW DO YOU KNOW THE PRACTICE WORKED?

- The family can identify what they need and are informed about access and availability.
- The family can communicate their child's and family's needs and articulate what else they want.
- The family is confident to discuss any concerns they have with service providers.
- The family is able to access the services they want.
- The child's best interests are being met across a range of settings.

CHILD CARE CHALLENGE

Sally Williams has a two-year-old daughter called Poppy. Sally is looking to return to work but the childcare centre near their home was concerned about including Poppy as she has Down Syndrome. Sally discussed this with her Key Worker, Belinda, who informed her that Poppy had a right to be included and gave Belinda information on this and the supports available. Sally felt that the childcare staff were probably not confident to take Poppy because they had not cared for a child with Down Syndrome before. She called the director of the childcare centre and set up a meeting, taking Belinda along for support. Together they talked with the director about Poppy's needs and the supports available, and the director accepted Poppy's enrolment.

PARENTS UNITE

Thomas Banks is a very active five-year-old boy. His mother Rhonda says his world opened up amazingly when he got access to an electric wheelchair. She cried with happiness when she saw him chase his first flock of seagulls, hooting with joy as they flew away. The wheelchair was very expensive and government funding only covered a portion of this. Rhonda wrote letters to several charities and made phone calls to the chair of a funding committee, and she was able to secure the funding she needed to cover most of the gap. Thomas will need a new wheelchair when he outgrows this one and Rhonda also had concerns about other children in similar situations. Thomas' Key Worker gave Rhonda some information about a parent support group who are also interested in this issue. Rhonda is happy to have banded together with others to take action and she's made some new friends too.

KINDERGARTEN SUCCESS

David Nguyen attends four-year-old kindergarten in his neighbourhood. After an incident where David, who has been diagnosed with autism, hit another child in the group, his teacher, Mrs Briggs has told his family he can only come to kindergarten for an hour per session, when she has extra help. David's parents are Vietnamese and are not fluent in English. They are very respectful of professionals and are not confident to discuss this decision with Mrs Briggs. They asked their Key Worker Paula for help. After talking with the family Paula set up a meeting with Mrs Briggs, the family and an interpreter. She helped Mr and Mrs Nguyen prepare by letting them know what they might expect in the meeting and by gaining a clear understanding from them about what they wanted for David. She also had a talk with David about what he likes and doesn't like about kindergarten. In the meeting Paula listened carefully and respectfully to Mrs Briggs about her concerns and then discussed with her calmly and clearly how David saw things, and several strategies that may assist both Mrs Briggs and David. Paula followed up with visits to the kindergarten and visits to the family for the rest of the term to support both Mrs Briggs and the Nyugens in meeting David's needs.

Advocacy

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Intervention Resources

REFLECTION & DEVELOPMENT – **Early Childhood Intervention Practitioner Competencies**

The majority of competencies below are taken directly from *Early Childhood Intervention Practitioner Competencies* (ECIA Vic 2009) available at www.eciavic.org.au. The competencies in *italics* have been added and content has been reordered and recategorised. Please read through and assess yourself against these statements by selecting a level on the scale below.

Once you have assessed yourself please look at which items you have marked yourself relatively high and relatively low. Use this as a basis for reflection and goal setting on the final page. Goals may centre on developing your skills or knowledge in particular areas or they may centre on how you might share your skills and knowledge with your team. Please then use the completed form as a tool for discussion in your next supervision session.

This Is New To Me	Beginning To Learn This	Reasonable Knowledge & Skills	Good Knowledge & Skills, Sometimes Challenged	Very High Knowledge, Confident Teaching Others
1	2	3	4	5

Competency	1	2	3	4	5
STRENGTH-BASED PRACTICE /CAPACITY BUILDING					
Enable families to develop their strengths.					
Reinforce and build confidence in carers that they possess good knowledge of their child.					
Empower and enable others while managing realistic expectations					
REDUCE THE NEED FOR ADVOCACY					
1. Inclusion					
Promote inclusive environments.					
Identify barriers to participation and negotiate changes to these.					
Within a child's community, encourage the capacity of individuals who can support inclusion.					
2. Family-centred practice					
Work in partnership with families to ensure their needs are addressed.					
Promote and support family members' participation within planned interventions.					
Create conditions which enable a family to advocate for their child to the degree they choose.					
Frame and solve problems collaboratively.					
Recognise the other person's current situation.					
Accommodate another person's preferences regarding times, places and ways in which consultations occur where possible.					

|				1	2	3	4	5
This Is New To Me	Beginning To Learn This	Reasonable Knowledge & Skills	Good Knowledge & Skills, Sometimes Challenged		Very High Knowledge, Confident Teaching Others			
1	2	3	4		5			

Competency	1	2	3	4	5
3. Reflective Practice					
Actively seek feedback.					
Reflect on own and team member's practice.					
Make time with team to consciously and critically reflect on practice.					
Identify and test assumptions and seek conflicting evidence.					
Constructively challenge other's thoughts and actions to enable practice improvements.					
4. Boundaries					
Adhere to the ethical guidelines/code of conduct specified by own agency and relevant professional bodies/associations.					
5. Communication/relationships					
Engage others.					
Encourage others to: • view the child positively • interact with the child • develop a child's abilities • act as advocates and supporters of the child.					
Describe the purpose of one's service in terms of enshrined rights for children.					
Suggest perspectives which balance multiple or competing interests where these are present.					
Envision a desired future situation or potential result which is meaningful to others.					
Initiate and maintain dialogue especially in sensitive situations.					
Understand different perspectives, language etc and be able to communicate effectively with all stakeholders.					
Use clear, respectful, jargon-free communication that is socio-culturally sensitive.					
6. Service quality					
Manage priorities and available time to ensure service delivery meets objectives and required standards.					
KNOWLEDGE					
Demonstrate knowledge of child and family rights.					
Apply knowledge of advocacy support services and how to refer.					
Apply knowledge of the importance of both formal and informal support networks for families and how to support families to build these networks.					
ADMINSTRATION					
Demonstrate administrative skills in calling, chairing and minuting meetings.					

Reflection on my strengths and areas for development

Goals for Learning, Development or Mentoring

1.

2.

3.

05
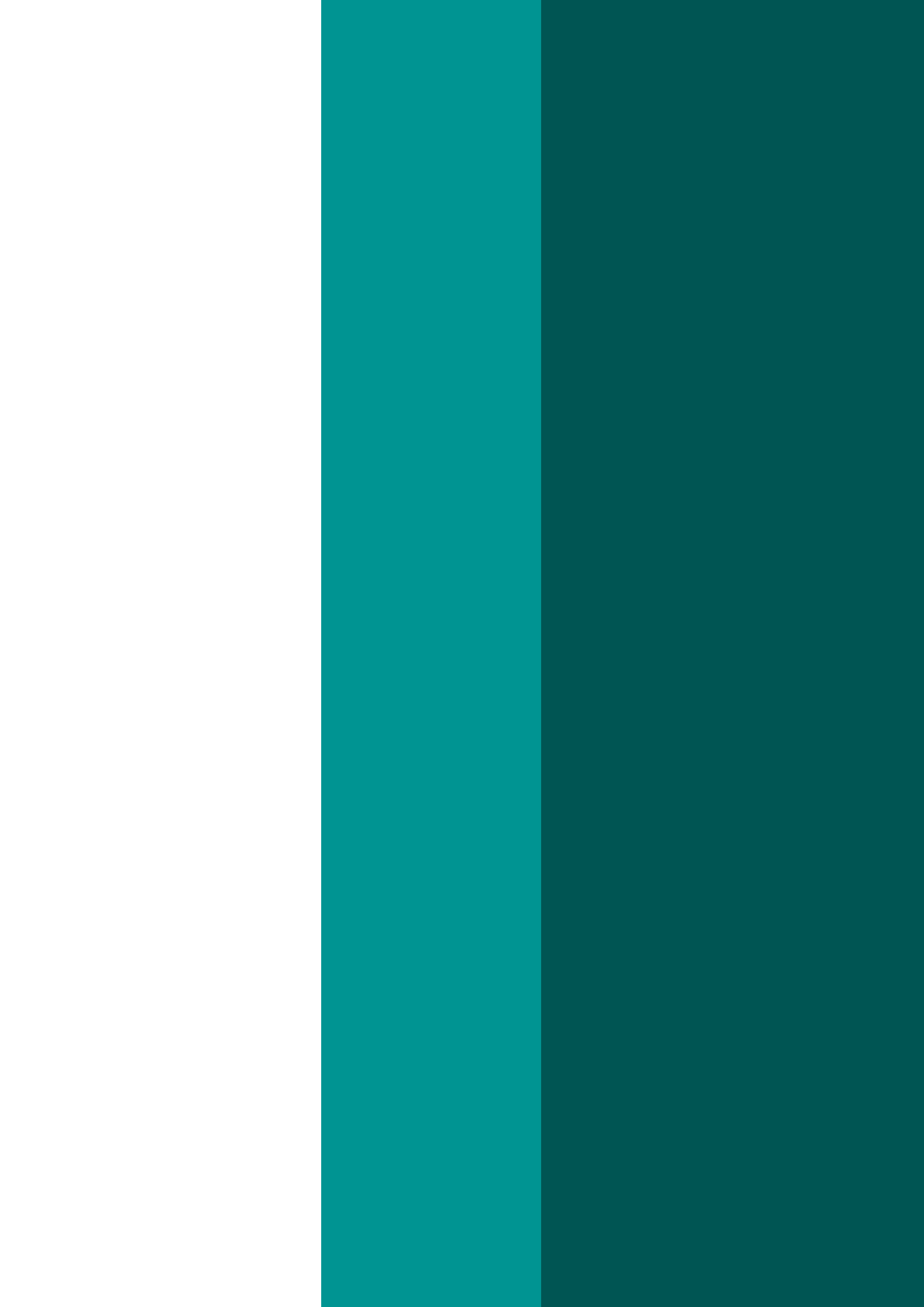
SERVICE
COORDINATION

"The key to this effort is coordination."

John E. Lange

Service Coordination

THE FAMILY

When families of children with additional needs first meet with a Key Worker, many have been struggling for some time to negotiate a maze of service providers. Even without additional needs, the early years of family life generally introduce a range of new professionals and services to parents' lives, services they may have known little about before having children. First there are the professionals involved with the birth, then the maternal and child health nurse, and possibly a playgroup, or child care, and then kindergarten. Having a child with a disability can multiply the number, intensity and complexity of professionals and services involved. There may be paediatricians, medical specialists and therapists.

> **"I felt bombarded at times by the amount of people involved." (Parent – Moore and Larkin 2005)**

It is well documented that having a child with additional needs can cause individual, relationship and family distress. For example, 2003 Australian Bureau of Statistics data tell us that 33% of parents who were primary carers for their child with a disability reported that their caring role had placed strains on their relationship with their spouse or partner (Australian Social Trends Report 2008), and 18% of these primary caring parents had been diagnosed with a stress-related illness.

> **"Initially he processed it very differently to me. He acted like everything was fine. I can see why relationships don't last because of this." (Parent - Ochiltree & Forster 2010)**

Having a disability can also lead to financial strain. Parents of children with a disability are significantly less likely to be in the workforce than parents of typically developing children, so income is reduced, and the costs of raising a child with a disability "are estimated to be three times that" of raising a typically developing child (Sloper & Beresford 2006). These extra individual, relationship, family and financial strains can bring with them additional professionals and services – counselling, family support services, financial services.

> **"I have as much help as I can cope with." (Parent – Moore and Larkin 2005)**

Children with a disability are three to four times more likely to have challenging behaviour than typically developing children (Baker et al 2002, Baker et al 2003, Volkmar & Dykens 2002). They are also, according to Sullivan and Knutson, 3.4 times more likely to be abused or neglected than children without a disability. These issues increase the likelihood of further professionals and services being involved – respite services, foster care or Child Protection.

> **"...Child Protection was blaming me for his condition. They said I deliberately isolated my child and blamed me for his delayed development. A neighbour reported me." (Carol, parent – Ochiltree & Forster 2010)**

If the family is from a non-English speaking, refugee or indigenous background there may be additional services involved – immigration services, interpreters, bi-cultural workers.

While all of the services above are designed to assist families, the demands of getting to multiple appointments, retelling their story over and over again, and trying to respond to the "homework" or strategies recommended by numerous service providers, can be a significant source of stress. The Transdisciplinary Key Worker role aims to minimise the numbers of people the family need to interact with from early ECI, but it cannot remove the need for some of these external services.

> **"...but it's never going to take away the number of appointments that you need with, you know, and the specialist or, it doesn't take those away because that's who you have to go and see and your care co-ordinator (Key Worker) can't replace that person." (Parent - Greco et al 2005)**

WHY IS RESPONDING IMPORTANT?

1. Service coordination reduces family stress

Greco et al (2005), researching the Key Worker role, found that most families said that their Key Worker had reduced their stress levels considerably. The families attributed this reduction to the services provided to them (e.g. respite care), and to having to spend less time looking for information, writing letters and making phone calls. Attending to the additional care needs of children with disabilities is time-consuming for parents (Roberts & Lawton 2001), and trying "to find time to 'chase up' professionals in addition to this is stressful for parents"; by taking on these tasks, Key Workers "relieved stress" (Greco et al 2005).

> **"We have a mental list of people to phone, things to do… and it's very difficult sometimes if you've got a child with special needs to think, right, well I'm going to make a phone call now… or to take a phone call, you might be in the middle of feeding, you might be in the middle of doing some physio stuff and sometimes it's very difficult and… you try to phone somebody and they're not in 'Can you phone back in half an hour?'… and sometimes it's just something you can pass over to [the Key Worker] and… she'll do that for you…" (Parent - Greco et al 2005)**

The Early Years "service system" has become increasingly complicated for families to navigate. There are an increasing number of funding streams for service delivery, all with different application processes, and there are many reforms going on across systems, e.g. child care, kindergarten, ECI services (Bruder 2005). Providing information and advice about services and systems is the base level of support from Key Workers, and helping with service coordination provides families with an additional level of support.

Research in the UK has shown that families of children with disabilities may "be in contact with up to ten different professionals and have more than 20 visits to health care services in any one year" (Sloper & Turner 1992). Unsurprisingly, they can find it difficult to know "what services are available and how to access them", as well as understanding the roles of all the different agencies and professionals they have contact with (Sloper et al 1999). The Transdisciplinary Key Worker, by coordinating services within the team, can reduce the number of professionals and appointments. Families can find it "a constant battle to negotiate access to services through the different agencies" (Greco et al 2005). Key Worker support in coordinating external services can make access to services easier for families, and thus reduce a source of stress for them.

> **"…for years you don't know what you are doing, you haven't had the right information, you're grasping at straws." (Parent - Mitchell & Sloper 2000)**

2. Holistic and cohesive service provision improves outcomes for children and families

Practice has evolved over the years in ECI, moving from multidisciplinary to interdisciplinary to transdisciplinary models in an endeavour to provide more "joined-up" services for families (CCNUK Cavet 2007). "More services provided more frequently by more practitioners was negatively related to parent well-being and functioning"

(Dunst et al 1998). Different disciplines can provide different skills, knowledge, perspectives and ideas. Transdisciplinary practice can be thought of in terms of coordinating services within the team, sharing competencies and enhancing team members' abilities, while providing a service that is less intrusive into family life. "Furthermore… a transdisciplinary model facilitates emotional support, as families have an opportunity to develop a relationship with the primary service provider" (McWilliam & Scott 2001).

ECI services cannot possibly meet all of the needs of families, in particular those with complex needs, and there has also been a growing appreciation of the need for these services to see themselves as part of the broader service system, working together "to provide holistic integrated services to families" (Harbin et al 2000, Pilkington & Malinowski 2002, Rosin & Hecht 1997 quoted by Moore 2005).

> **"I would love to see… all the services together … rather than one over here and one doesn't talk over there; there's some sort of business going on over there and between here; … if they all got together the work would be met." (Parent – Moore and Larkin 2005)**

Communication across services is a basic element of external service coordination. ECI professionals and other service providers cannot provide a holistic service without sharing knowledge. For example, ECI professionals need to access "health and medical information to determine how a child's health status affects not only overall development but also how it influences interventions with the child" (Bruder 2010).

> **"That's probably my biggest criticism… it's this lack of communication. It seems incredible to me to waste resources by not communicating and I don't think it benefits children's outcomes at all." (Parent - Moore and Larkin 2005)**

Lack of service coordination can undermine service access and UK research has found that difficulties in accessing services for children with disabilities can result in:
- high levels of unmet need
- high levels of parental distress
- impacts on children's cognitive, social and behavioural development
- family social exclusion
- lowered quality of life (Greco et al 2005).

HOW DO YOU RESPOND?

According to Briggs (1997), the role of the service coordinator is to bring together decisions made by the team and blend the goals of other disciplines into the one treatment plan – which in the local context would be the Family Service Support Plan (FSSP). This could describe a Key Worker in a transdisciplinary model coordinating just the input from his or her own team (internal coordination), or it could also include coordinating input from other professionals involved with the family (external coordination).

In the local context, the Key Worker in a service coordination capacity would definitely take up the following responsibilities from the list Bruder (2010) gives of the responsibilities of a Service Coordinator in the U.S.A.:
1. Coordinate and implement evaluations and assessments.
2. Facilitate and participate in the development, review, and evaluation of the FSSP.
3. Inform families of the availability of advocacy services.

Individual circumstances, complexity of needs and the role of other services involved will mean that the Key Worker's level of responsibility for the following tasks listed by Bruder (2010) will vary from family to family, and over time with the same family:
1. Assist the family in identifying available service providers.
2. Coordinate and monitor the delivery of available services.
3. Coordinate with medical and health providers.
4. Facilitate the development of a transition plan to pre-school services.

> "I know there is a lot of shortcomings in the intervention funding, but [my child's] needs are huge, massive and overwhelming and I still feel that. I think I've managed to negotiate the services that he needs from a few sources that we're reasonably happy with at the moment but it took a lot of research and negotiating to do that." (Parent – Moore and Larkin 2005)

Bruder (2010) also states that it is the role of the Service Coordinator to ensure that all services and supports are:

- provided (or accessed) as outlined in the FSSP
- delivered in a timely fashion and at times and places convenient to the family
- reflect current research concerning evidence-based practices
- coordinated with one another
- continuously evaluated for their effectiveness.

Service coordination in the Key Worker role, according to Success Works (2009), involves:

- linking the family with other services (sourcing services and resourcing families)
- supporting families through transition between services
- consulting with other team members (about discipline-specific issues)
- networking with private therapists
- providing information to other service providers (general practitioners, providers, maternal and child health nurses, teachers, pre-school field officers).

Involvement with other service providers

> "I've learnt how to fill in forms." [laughs] "That's something, all these complicated forms. Yeah, I'd probably say forms more than anything but I mean, you know, because I do, I get so many forms that I do have to fill in and some of them are quite complicated but, you know, and she does help me fill them in and, but I'm getting used to them now." (Parent - Greco et al 2005)

In the local context, the Key Worker in a transdisciplinary model will clearly be responsible for coordinating the services within his or her team and acting as the main, or sometimes only, contact with the family from the ECI team. The Key Worker's involvement with service providers outside of the ECI team will vary across a continuum. At one extreme, the Key Worker may not be involved at all with other service providers. This may be because the family:

- does not have any other service providers, so there is no need for collaboration, communication, information sharing, coordination or follow-up
- has no need of any other services, so there is no need to identify services, make referrals or plan transitions
- does not permit contact between services.

Many families do receive services from a range of agencies, which may include kindergarten, child care, private therapists, medical professionals, child protection, maternal and child health nurse, or family support services. The extent of the Key Worker's role in identifying available service providers, coordinating and monitoring the delivery of those services, and smoothing transition processes, will depend upon:

- how skilled and confident the family is in doing this independently
- the family's goals and needs
- whether or not there is a service providing case management to the family
- complexities regarding the family or the services provided.

"Yeah, she actually coordinates it, she's chairperson, whatever, and before it I have a meeting with [the Key Worker] on my own and put any relevant points that I've got to say… cos I forget, halfway through the meeting I trail off into a different conversation and I'll come home and oh I never mentioned this. So I always have half an hour with [the Key Worker] prior where she notes everything down for me." (Parent – Greco et al 2005)

"[The Key Worker] really, has a supportive role. She comes along and she doesn't really contribute verbally to the discussion but she is there and she will just help beforehand if I've asked for say the educational psychologist to be present at a meeting she will arrange that." (Parent – Greco et al 2005)

Greco et al (2005) in their research on the Key Worker role found that when families were not happy with their Key Worker, it was often because the Key Worker was "not proactive enough in meeting the family's needs and coordinating services". The researchers found that some Key Workers "limited themselves to giving the family advice, rather than actually chasing up other professionals and making sure the family's needs were met". For example, a Key Worker "suggested that parents do a search on the internet for information about a service they needed", rather than the Key Worker obtaining the information and providing it to the family; another Key Worker provided "parents with another professional's telephone number, rather than making the telephone call themselves". It was reported by the families in the study that some Key Workers "would not take any action for the family unless the family suggested it themselves and some families had learned that if they did not take action themselves, nothing would ever get done". Some families complained that their Key Worker was not providing service coordination at all and that they "were coping alone or had found other professionals who could help them informally".

It is a challenge for the Key Workers to find a balance between helping families enough to reduce their stress without creating dependency, and missing the window of opportunity ECI provides to empower families by developing their skills to manage service coordination independently. Early childhood intervention ceases when the child goes to school, and after this only a very small proportion of families will have access to any professional service coordination support. We may do families a disservice by being too helpful. Perhaps the issue is whether or not the Key Worker is explaining well enough to families why he or she is providing the phone number rather than actually making the call.

Categories, traits and practices

"I think it's got to be someone that you get on with, someone that you feel comfortable with as well isn't it, someone that's approachable and you know you can trust as well, trust and confidentiality, there's lots of things. But I think it's got to be someone that you like and they like you, you know, and that they, they do get on with the children, that they're used to dealing with disabled children." (Parent - Greco et al 2005)

When looking across agencies, each team in ECI will include a range of service providers who bring with them different professional disciplines, each of which has its own philosophy and jargon. The service providers may come from a number of agencies, and again, each of these may have different processes, priorities and practice. At an interpersonal level "children, their families and the professionals who work with them all bring their own characteristics and experiences to the situation. Each person brings his or her own personality, goals, and expectations, as well as style of interaction and way of communicating those goals and expectations" (Bruder 2005).

Park and Turnbull (2003), in a review of the literature on service coordination, found that the factors that determine successful (and unsuccessful) service coordination fall into two categories – interpersonal and structural. Interpersonal factors include the characteristics of relationships that enhance and encourage collaboration. The interpersonal characteristics found to be associated with successful service coordination included, but were not limited to:

- communication skills
- openness
- honesty, and
- family-centred help-giving.

Structural factors relate more obviously to coordination of services across agencies. They include the nature of relationships among agencies and how service coordination is "conceptualised and practised." The structural factors associated with successful service coordination include, but are not limited to:

- blended service provision
- service coordinator flexibility
- fluid interagency and intra-agency communication and
- a broad-based approach to service provision.

Roberts et al (2005) found that service coordinators who had a "dedicated" service coordination model (i.e. service coordinator does not provide developmental intervention) were found by families to be "less helpful and they had more difficulty contacting them" than service coordinators who had a "blended or integrated" model of service coordination (i.e. service coordinator also provides developmental intervention). Taking into account their own research as well, Bruder and Dunst (2008) conclude that U. S. "states that have adopted dedicated service coordination models may inadvertently 'water-down' the breadth and depth of service coordinator practices." They suggest that this is because caseloads are larger in dedicated models, and this limits "the amount of time the service coordinators have to contact and work with families".

Bruder (2010) discusses three practice categories in Service Coordination: help-giving, collaboration and administration.

Help-giving

"She never ever looked at her watch … I'm sure … she was very aware of her next appointment but she never let us feel that she didn't have time for the last question" (Parent - Greco et al 2005)

According to Dunst et al (2007), the service coordinator needs to:
- build a relationship with the family
- treat families with dignity and respect
- be culturally and socioeconomically sensitive to family diversity
- provide choices to families in relation to their priorities and concerns
- disclose information to families so that they can make decisions
- use communication strategies to empower and enhance a family's competence and confidence.

Collaboration

Collaboration is a key part of service coordination – collaboration with the family, collaboration within the transdisciplinary team, and collaboration with external service providers. Collaboration is essentially about teamwork. It is important for the service coordinator to ensure that there is collaborative teamwork at every stage of an assessment – "before (planning), during (process) and after (reporting)" (Bruder 2010).

On the basis of her personal experience in helping her parents move house, Neugebauer (2004) describes what they learned about teamwork:
- Be flexible.
- Don't take anything personally – even the random compliments (but be grateful for them).
- Expect interruptions. Learn to welcome them.
- Take breaks and time out.
- Remember that everyone else is trying just as hard as you are.
- No one gets to be boss all the time.
- Accept that you're going to aggravate people you care about.
- Even best intentions can and will be misunderstood.
- Know when to give in gracefully or give up.
- Systems are critical – locations for necessary supplies, what is finished, what needs to happen next.
- Make "yes" your first response to any suggestion.
- There's more than one right way to do everything.

Administration

Family Service Support Plans (FSSPs) can vary in the extent to which they involve other professionals, ranging from no involvement at all, to discussion within the family's own ECI team, or gathering information through reports supplied by the parents or through phone calls with professionals from other agencies. Alternatively, an FSSP meeting may be arranged with the family and the other professionals involved.

Ideally the parents would organise and chair such a meeting, but as many families do not feel confident to do this, especially early in their involvement with ECI, the Key Worker may undertake and model these tasks or support the parents to do them. According to Bruder (2010), development and review meetings involving the whole team (including family and professionals from other services) are important in the provision of high quality ECI.

> **"She is my representative so to speak, because they may be saying things that I'm thinking oh I don't quite understand what they want there, but [the Key Worker] would stop that meeting and she will say 'Now can you make that a little bit clearer?'" (Parent – Greco et al 2005)**

When these meetings do occur, there are ways they can be made "more productive" (Bruder 2010). One way is by asking (or having a parent ask) everyone at the start to provide an overview of their role generally and specifically in relation to the FSSP process. This sharing of information can encourage discussion and create "a sense of equality among its members", and it may help the family to be more informed and more comfortable about the process. Bruder (2010) gives further advice about how to go about these meetings:

- Prepare an agenda for every meeting to keep the team focussed on the same issues, and distribute it before the day of the meeting.
- Keep and distribute printed minutes of each meeting to enhance team communication. Notes should include who attended, issues addressed, recommendations made, who is responsible for implementing the recommendations, and timelines for completing tasks.
- Prepare all team members for the meeting by providing questions or issues to consider, helping them organise their thoughts ahead of time, and facilitating their participation in discussion during the meeting.
- Translate all the information from the meeting into outcomes for the FSSP. This requires synthesising available information (the family's concerns, priorities, resources and activities and routines that have been reviewed in the meeting) and making decisions among competing priorities. It also requires negotiation, collaboration and problem-solving.

WHAT DOES IT LOOK LIKE WHEN WE HAVE RESPONDED?

In studies quoted in Bruder (2010), outcomes of high quality service coordination include the following:

- Families have access to support, information, and education to address their individual needs.
- Families are able to communicate the needs of their child.
- Families make informed decisions about services, resources, and opportunities for their child.
- Agencies and professionals are coordinated.
- Children and families receive quality services.
- Children and families participate in supports and services that are coordinated, effective and individualised to their needs.
- Families acquire and/or maintain a quality of life to enhance their well-being.
- Families meet the special needs of their child.
- Children's health and development are enhanced.

According to Bruder (2005), effective service coordination (by which she means coordination across all services involved with a family) should result in better outcomes not just for the child and family, but for "everyone involved" – productivity is increased and stress is decreased for all. This is achieved by ensuring that "everyone is working towards common goals, communicating openly, sharing effective intervention practices and continually monitoring child and family status" (Bruder 2005). Services and funding streams will be used more efficiently and effectively across services and service duplication will be reduced (Bruder & Bologna 1993). Families and professionals can be assisted by these "collaborative efforts" to locate and manage more efficiently the varied resources, supports and services required by a family (Dunst & Bruder 2002).

With the complexity of the service system and the complexity of the circumstances of each child and family encountered in Early Childhood Intervention, a team approach is likely to provide a more robust response. Lehrer (2010) discusses the work of Kevin Dunbar, whose research on the process of discovery in biochemistry laboratories found that most breakthroughs came about as the result of group discussions involving multiple disciplines rather than from solitary work or groups from a single discipline or speciality.

SUMMARY

In the local context, the primary task of service coordination in a Transdisciplinary Key Worker model is to coordinate the input of the team so that there is one blended plan and the family has most if not all of their contact with one ECI professional. The level of involvement the Key Worker has with external professionals working with families will vary from family to family and across time with the same family.

Whether dealing with internal service coordination or coordination across services, Key Workers will require a skill set (and will need to build this skill set in families) that includes:

- communication
- knowledge of services available
- negotiation, sometimes with services with different philosophies underpinning their model of service
- consultation
- chairing meetings
- record keeping.

Also important are a set of interpersonal qualities, including:

- family-centredness
- flexibility
- openness
- honesty
- respectfulness
- sensitivity to family diversity - culturally and socioeconomically.

Service coordination can enhance the quality of service delivery in ECI by allowing the most holistic service to a family to be delivered with the least intrusion into family life. Service coordination can reduce the stress for families involved in meeting the additional needs of their child and reduce the stress for the other professionals involved with the family, providing a more efficient service with less double-up. The challenge for Key Workers is to find the right balance between reducing family stress by taking on more of these tasks, and empowering parents to manage their own services, as they are likely to need to manage independently once their child moves on to school.

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Service Coordination

WHAT IS THE PRACTICE?

Most families in ECI have a number of professionals providing services within their life. Key Workers can help by linking families in with relevant services, supporting them in the transition between services, consulting with other professionals where necessary, sharing information, and following up on the provision of services. Service coordination can enhance the quality of service delivery, enabling the most holistic service to be delivered with the least intrusion into family life.

WHAT DOES THE PRACTICE LOOK LIKE?

A Key Worker coordinates the input from his or her own team so there is one blended plan, and the family has most if not all of its contact with the one ECI professional. The team for each child and family is made up of the family, the Key Worker and the ECI team. Over time, there will be others involved with the family such as the kindergarten teacher, child care, maternal and child health nurse, medical professionals or family support services. Coordination involves linking, supporting, networking and sharing information. It requires respect, clear communication, flexibility and common goals.

HOW DO YOU DO THE PRACTICE?

Key Worker/family relationship – An effective partnership between the Key Worker and the family is based on respect, openness and honesty. The Key Worker may provide the family with information to make initial decisions about services they want to use, and will then monitor, with the family, whether the services are meeting their needs.

Teamwork – Regardless of whether or not the "team" is internal (family and ECI team) or external (involving other professionals) the principals of good teamwork apply: having common, family-centred goals; clear, respectful and jargon-free communication; and flexibility. The Key Worker's role in coordinating services depends on how confident the family is to manage their own arrangements, how complex the needs and goals are, and who else is involved.

Capacity building – Most families receiving an ECI service will not have professional assistance in coordinating services once their child goes to school. Families need to build their skills and confidence in managing the services they use, so they are able to independently:

- call other professionals
- negotiate, organise and chair meetings
- keep records.

HOW DO YOU KNOW THE PRACTICE WORKED?

- Families have access to linked services that share information.
- Families and professionals work in partnership to develop blended, functional plans.
- Services are integrated and holistic, and minimise family stress.
- Families are building their knowledge, skills, and independence.
- Professionals are family-centred and communicate clearly with other professionals.

KEY WORKER/FAMILY RELATIONSHIP

Barbara is the Key Worker for the Robinson family. The Robinsons have four-year-old twins Ben and Derek, who were born three months prematurely. Both boys have mild cerebral palsy and Ben also has a vision impairment. In reading the file from Central Intake before she made initial contact with the family, Barbara saw that there were several other services involved – a consultant from Vision Australia, a kindergarten teacher, and a respite foster family who care for the boys every second weekend. The Robinsons had consented to reports from these services being placed on the file and Barbara read these thoroughly. Barbara built rapport with the Robinsons aided by her clear, open communication, sensitivity, respect and family-centredness.

TEAMWORK

Due to the wide range of needs the Robinsons expressed for their children and family, Barbara consulted with her entire ECI team. To minimise intrusion into the family, she was their main contact with the ECI service, needing to take a team mate with her only on a few occasions to consult. The Robinsons decided in partnership with Barbara that they would get a more holistic and effective plan if they involved all of their service providers in a meeting. This would enable everyone to be clear about their goals, ensure that everyone knew what each other was doing so there was no double-up, and ensure that information was shared amongst everyone involved. After talking through the options, the Robinsons decided that they would like a Routines-Based Interview, as this would result in a functional plan that would help them, the kindergarten teacher and the foster carers.

CAPACITY BUILDING

Barbara was aware that the Robinsons had been under considerable stress in parenting the boys. While she wanted to reduce their stress, she was also aware that in 18 months time the boys would be moving onto school and ECI service would be ceasing. Barbara talked with the Robinsons about wanting both to alleviate their stress but also to build their skills and confidence to manage independently. The Robinsons thought it best to make the most of Barbara's support while they had it. Barbara called the kindergarten teacher to arrange a time and place for the meeting while the Robinsons sat with her. The Robinsons then took it in turns to ring the consultant and the foster family. Barbara and the Robinsons talked about what the Routines-Based Interview would look like. This made the couple more relaxed about the meeting, which went well and resulted in one blended, functional plan. Over time the Robinsons became very confident in calling the people who provided their services and bringing them together every six months to review the plan. Though Barbara continued to coordinate services within her own ECI team, by the time the boys went off to school, the family were coordinating all their other services.

Service Coordination

REFLECTION & DEVELOPMENT - **Early Childhood Intervention Practitioner Competencies**

The majority of competencies below are taken directly from *Early Childhood Intervention Practitioner Competencies* (ECIA Vic 2009) available at www.eciavic.org.au. The competencies in *italics* have been added and content has been reordered and recategorised. Please read through and assess yourself against these statements by selecting a level on the scale below.

Once you have assessed yourself please look at which items you have marked yourself relatively high and relatively low. Use this as a basis for reflection and goal setting on the final page. Goals may centre on developing your skills or knowledge in particular areas or they may centre on how you might share your skills and knowledge with your team. Please then use the completed form as a tool for discussion in your next supervision session.

This Is New To Me	Beginning To Learn This	Reasonable Knowledge & Skills	Good Knowledge & Skills, Sometimes Challenged	Very High Knowledge, Confident Teaching Others
1	2	3	4	5

Competency	1	2	3	4	5
KNOWLEDGE AND COMMUNICATION					
Support others to guide the child to master key developmental tasks where possible.					
When required, accurately document aspects of a child's disability and development and provide to other agencies.					
Identify useful and accessible generic support networks and community resources.					
Interpret findings of assessment and communicate these to relevant people in an accessible manner.					
Consider available service and support pathways from 0-6 years of age and propose corresponding service options.					
Incorporate into proposed service options: • relevant research and practice-based evidence • relevant philosophical and policy frameworks • and communicate these clearly and simply to family and other professionals.					
Describe specific activities and processes of mutually agreed interventions.					
Describe the model of service provided by own agency and respond flexibly to changes in one's agency's model of service.					
Explain own professional role, objectives and boundaries.					
Describe own agency's resource potential, along with constraints and limitations, which are available to the child and family.					
Understand own discipline in the context of other disciplines.					
Articulate how one's consultancy facilitates improved outcomes for a child, family and community.					
Inform others of own and agency's capabilities, approaches and professionalism.					

This Is New To Me	Beginning To Learn This	Reasonable Knowledge & Skills	Good Knowledge & Skills, Sometimes Challenged	Very High Knowledge, Confident Teaching Others	
1	2	3	4	5	

Competency	1	2	3	4	5
Knowledge and Communication cont'd					
Describe own and agency's methodologies using systematic methods.					
Offer alternatives if expected outcomes exceed own agency's capacity or scope.					
Elicit information from another person using questioning and clarifying.					
Check understanding through repeating, rephrasing, paraphrasing and summarising.					
INCLUSION					
Promote inclusive environments.					
Identify potentially inclusive services/locations/venues which are best placed to meet a child's development needs at key transition times.					
Within a child's community, encourage the capacity of individuals who can support inclusion.					
RELATIONSHIPS/COLLABORATION					
Collaborate with other practitioners.					
Work collaboratively within a cross-disciplinary team and with external agencies to develop and achieve mutually agreed outcomes.					
Collaborate with universal support personnel to develop standard processes and methods of meeting an individual child and family's needs.					
Participate in professional networks to provide a seamless multi-service system to families.					
Suggest perspectives which balance multiple or competing interests where these are present.					
Frame and solve problems collaboratively.					
Recognise the other person's current situation.					
Envision a desired future situation or potential result which is meaningful to others.					
Work with others so they can: • generate options which are both possible and realistic • plan own actions to achieve the desired future state • develop skills to solve problems and resolve own issues.					
Engage others.					
Actively seek feedback.					
STRENGTHS-BASED PRACTICE/CAPACITY BUILDING					
Enable families to develop their strengths.					
Reinforce and build confidence in carers that they possess good knowledge of their child.					
Assist carers to become more self-reliant in identifying and using services.					
Enable and empower others while managing realistic expectations.					
FAMILY-CENTRED PRACTICE					
Work in partnership with families to ensure their needs are addressed.					
Promote and support family members' participation within planned interventions.					

This Is New To Me	Beginning To Learn This	Reasonable Knowledge & Skills	Good Knowledge & Skills, Sometimes Challenged	Very High Knowledge, Confident Teaching Others
I	2	3	4	5

Competency	I	2	3	4	5
BOUNDARIES					
Adhere to the ethical guidelines/code of conduct specified by own agency and relevant professional bodies/associations.					
Recognise own and agency capacity and limitations in meeting identified needs and refer to other professionals and agencies accordingly.					

Reflection on my strengths and areas for development

Goals for Learning, Development or Mentoring

1.

2.

3.

FURTHER READING + INFORMATION

From Research to Practice

HOW RESEARCH ON CHILD DEVELOPMENT HAS LED TO THE KEY WORKER ROLE

THE EVOLUTION OF PRACTICE IN EARLY CHILDHOOD INTERVENTION

Knowledge of how children learn best and how they develop within the context of their families has grown dramatically over recent years, and in response, the ECI service model is gradually changing across many countries. This understanding of the importance of the family environment in children's development has led to substantial changes in the way ECI professionals interact with families and attend to their strengths and stressors. The evolving model of practice has seen the development of the Transdisciplinary Key Worker role, where one ECI professional is the main or only contact for the family, using input from their team to support the key people in the child's life to make the most of the child's natural learning opportunities.

This overview summarises a wealth of research, theory and practice knowledge to explain how and why the Transdisciplinary Key Worker role has evolved, and it looks in detail at the central part of this role, the family liaison, or Key Worker, component. It includes the following;

- Children's Learning and Development
- Families
- Theories of Practice
- Transdisciplinary Key Worker model
- Key Worker Elements.

CHILDREN'S LEARNING AND DEVELOPMENT

It is now known that:-

- "Children develop through their relationships with the important people in their life" (Moore 2010).
- "Sensitive and responsive caregiving is a requirement for the healthy neurophysiological, physical and psychological development of a child" (Moore 2010).
- "Relationships change brains neurologically and neurochemically, and these changes may be for the better or for the worse" (Moore 2010).
- "The attachments that children form with parents and caregivers create the central foundation from which the mind develops" (Moore 2010).
- Parents' use of everyday activities to provide natural learning opportunities is "associated with positive consequences in nearly all outcome measures", while ECI professionals "implementing their practices in everyday activities had little or no positive effect, and in several cases had negative effects on parent functioning" (Dunst 2007, p169). In one study, parents were three times more effective than ECI professionals using the same strategies (Dunst 2007, p169)
- Children learn throughout the day from the social and other experiences provided by their everyday environments (home, community and Early Childhood Education) (Dunst & Bruder 1999 as quoted in Dunst 2006).
- Children need to practice skills to develop competency (Dunst 2006).
- Children need to learn skills in the context in which they are required (Horn et al 2000, Venn et al 1993 quoted in Odom & Wolery 2003)
- Children's learning is influenced by interaction with their peers (Odom & Wolery 2003).
- Inclusive environments facilitate learning and development (Odom and Wolery 2003).
- ECI professionals see children for a tiny fraction of their waking hours and are therefore not the main providers of children's learning environments. This role is taken by parents, caregivers and Early Childhood Educators (Dunst 2007, p172).

FAMILIES

If the relationship between parents and children is so important and families are the main providers of children's learning opportunities, ECI services need to look at how families can be supported to optimise those relationships and maximise learning opportunities. This involves informing and coaching parents on child development, their particular child's needs, and strategies to use with their child. Equally important is to ensure that families feel able, engaged and motivated to do what is required. Thus, ECI professionals need to pay close attention to the family environment – what the stressors are and how families can best be supported.

Guralnick (2005) identifies three aspects of family interaction that are critical in child development:
- the quality of the parent/child transactions – reciprocating, sensitive, warm, communicative, non-intrusive
- child experiences that are orchestrated by the family – providing appropriate materials and activities, choosing quality child care, incorporating child into family routines, arranging social activities – especially with peers
- health and safety provided by the family – immunisation, nutrition, protection from harm.

When a child is born with a disability, the stress that families may experience can have a negative impact on these patterns of interaction. Stressors can include:
- the need for information on the disability and likely developmental patterns, and information to inform decision-making regarding specialists and intervention programs and activities
- interpersonal and emotional distress – for example, grief, isolation, stigma, the impact of child's behaviour
- resource needs – the child may require extra resources and the family's income may be reduced because of the child's need for care
- threats to confidence – the cumulative impact of all these stressors can undermine parents' confidence in their ability to meet their child's needs.

THEORIES OF PRACTICE

The task of ECI in Guralnick's model is to prevent or minimise any negative impact of these stressors on family patterns of interaction and to strengthen the family and their patterns of interaction in ways that support the child's optimal development. This requires a relationship between the ECI professional and the family that is very different to that required previously under an individual or group therapy model. This is because:
- Families need to feel comfortable with the ECI professional to talk about these stressors.
- Families need to feel that their skills and parental role are valued and supported by the ECI professional, to overcome the threats to their confidence.
- ECI professionals need to get to know families well so that information, advice and support fit with the family's needs, preferences, routines and beliefs. If there is a mismatch here, families will not adopt advice and strategies and the intended intervention will not succeed.
- If families are to work effectively with their child, they need to feel and know they are important.
- To ensure the family's capacity to support their child's development, some families will need to address various family-related issues.
- There needs to be a consideration of both child and family outcomes, as the former can depend on the latter.

Dunst's (2005) Framework for Practicing Evidence-Based Early Childhood Intervention and Family Support includes four major practice elements:

1. **Children's learning opportunities** – those that enhance development are ones that are interesting, engaging, build competency and develop a sense of accomplishment.

2. **Parenting supports** – "reinforce existing parenting abilities, provide opportunities to acquire new parenting knowledge and skills and strengthen parenting confidence and competence".

3. **Family/community resources** – "to ensure that parents have the supports and resources necessary for them to have the time and both physical and psychological energy to engage in child-rearing responsibilities and parenting activities".

4. **Family-centred practices** – the "active engagement of parents and other family members in obtaining desired resources and achieving family-identified goals. Family-centred practice places families in central and pivotal roles in decisions and actions involving child, parent and family/community resources that strengthen existing capabilities and promote child, parent and family competence" (Dunst 1995, 1997 quoted in Dunst 2005).

Dunst goes on to discuss three intersecting practice elements, that is, practice elements that become important because of what happens when the four elements above interact with each other:

1. **Everyday activity settings** – important in the intersection of Children's Learning Opportunities and Family/Community Resources. Everyday activity settings should offer learning opportunities that are interesting and engaging, and build competency and a sense of achievement. They are also vital in enabling parents to have the time and the physical and emotional energy to provide such opportunities.

2. **Parenting styles and instructional practices** – important in the intersection of Children's Learning Opportunities and Parenting Supports. The parenting styles and instructional practices most likely to enhance a child's development are those that are responsive to child-initiated and directed behaviour, and provide children with the opportunity to practise and build on their skills.

3. **Participatory parenting opportunities** – important in the intersection of Parenting Supports and Family/Community Resources. The family's social support network and the experiences and opportunities it offers can provide emotional and practical support, and influence parents' attitudes, beliefs and behaviours.

Odom and Wolery's (2003) Unified Theory of Practice (see all references in the section below) looks at the shared beliefs among academics and practitioners in early childhood intervention and early childhood special education under the following eight headings:

1. **Families and homes are primary nurturing contexts**.

   • Families and homes are primary nurturing environments for infants and young children with disabilities (except in cases of abuse and neglect). "The operating assumption is that children with disabilities who live with their family and participate in community life are more likely to be similar to their siblings and age-matched peers without disabilities than if they lived in a facility with only individuals who have disabilities."

- "Dunst (2000) proposed a conceptual model in which social support promotes family well-being which in turn allows families to engage in responsive interaction styles with their children, thereby providing the children with opportunities and help in learning important skills. The professional's role in this model is to work collaboratively with families; to strengthen families by helping them secure needed supports and resources; to provide individualised and flexible help; and to capitalise on families' existing competencies and strengths" (Trivette & Dunst, 2000).

2. Strengthening relationships is essential.

- In relationships between parents and children, attachment is very important and "interventions designed to promote positive interactions between mothers and infants have resulted in positive increases in reciprocal interactions, in parenting styles, and in collateral effects on children's development" (e.g. Girolametto et al 1994).

- Children with disabilities need positive relationships with other children. "For all young children, establishing positive peer relationships is a critical developmental task built on peer related social competence." "Evidence is mixed about the effectiveness of inclusive placements when specific programming to promote social integration is not provided" (Guralnick 1999, Jenkins et al 1989).

- "Relationships among professionals can have a direct impact on children with disabilities and their families." "Cohesive communication can lead to greater engagement for children with disabilities in inclusive programs" (McCormick et al 1998).

3. Children learn through acting on and observing their environment.

- "Whereas infants' and young children's learning was once seen as emerging from biological maturation or from environmental shaping, the current perspective is that infants actively adapt to, learn about, master, control, and understand their worlds" (Sameroff & Fiese 2000). "As such, their experiences – interactions with their social and physical environments – are opportunities for learning" (Dunst et al 2000). "To foster positive outcomes, service providers must influence large portions of children's experiences" (McWilliam 2000). "Thus interventions must be mediated through" the people who are spending the most time with the child (Odom & Wolery 2003).

4. Adults mediate children's experiences to promote learning.

- This "requires planning, is goal-directed, and is systematically practised. For young children, most intervention should a) be used during play and other routine activities b) be embedded into and distributed across activities (Losardo & Bricker 1994) and c) occur when they are contextually relevant" (Horn et al 2000, Venn et al 1993).

5. Participation in more developmentally advanced settings is essential.

- "Inclusive settings may provide a developmental press through a more cognitively, linguistically, and socially stimulating environment than occurs in non-integrated special education settings. Given the necessary and appropriate assistance, this developmental press could lead to the acquisition of more advanced skills and successful participation in the inclusive settings."

6. Practice is individually and dynamically goal-oriented.

- This is because "of the varied characteristics of children with disabilities and the range of severity"; because "parental input about goals is valued"; and because "young children and the settings in which they spend time change rapidly, goals require careful monitoring and frequent adjustment" (Wolery 1996).

7. Program transitions are enhanced by adult or experiences.

- Young children experience a lot of transitions, e.g. from home to child care, to kindergarten and to school. These "place new demands on and create opportunities for children" and their families.

- "Preparing children with disabilities for new settings is theorized to support successful participation and learning" (Ager & Shapiro 1995).

8. Broader ecological contexts influence families and early intervention/early childhood special education programs.

- "Bronfenbrenner (1979) conceptualised these factors as occurring at the microsystem (e.g. home, kinder), mesosystem (e.g. transition planning, professional collaboration, family issues), exosystem (e.g. social policy) and macrosystem (e.g. culture) levels."

CORE ELEMENTS OF THE TRANSDISCIPLINARY KEY WORKER MODEL

1. Family-centred practice (Moore 2010)

- "When service providers and families work collaboratively to identify family goals and priorities, services are more likely to address families' most important needs.

- "When service providers and families work as partners to determine what action should be taken, there is a greater probability that the desired outcomes will be achieved.

- "When service providers listen to families and establish good working relationships with them, parents are more likely to listen to what the professionals have to say and to make better use of professional services.

- "When service providers support family decision-making, families are more likely to develop the confidence, competence, and ability to make decisions about their child and family over their lifetime.

- "When service providers and parents share and respect each other's knowledge and expertise, better solutions for the child and family are likely to be found.

- "When child and family needs are met solely or primarily through professional sources of help, families are more likely to become dependent upon professional services.

- "When service providers help families identify and mobilise family and community sources of help, their dependence on scarce professional resources is reduced."

2. Transdisciplinary practice

- Having one main person providing service enables the development of a relationship that is conducive to emotional support (McWilliam & Scott 2001).

- The practice reduces intrusion into family life and the stress for families from the demands of seeing multiple professionals (King et al 2009 as quoted by Moore 2010 p126).

- Research has shown that "more services provided more frequently by more practitioners was negatively related to parent well-being and functioning" (Dunst et al 1998 quoted in Dunst 2007).

- There is good evidence that parents prefer and do better with a single case worker (Bruder 2002, Sloper 1999; Sloper et al 1999 as quoted by Centre for Community Child Health 2010 p126).

3. Natural learning environments/routines-based

- The ultimate goal of early intervention for children is to enable them 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 childcare, preschool or school programs, and in the community" (The Early Childhood Outcomes Centre 2005).

- Children learn everyday through their experiences and learn skills best in the context in which they need to be used (Horn et al 2000, Venn et al 1993 quoted in Odom & Wolery 2003).

- For interventions to be relevant and meaningful (Jung 2010), they need to relate to people's everyday lives in the context of their family and community.

- Research has shown that inclusive environments facilitate children's learning and development, e.g. "Guralnick, Connor, Hammond, Gottman and Kinnish (1996) found that children with disabilities in inclusive play settings engaged in more advanced forms of play and more frequent social interactions than when they were in groups that consisted solely of peers with disabilities" (Odom 2003).

4. Strength-based practice

- Children learn best when you follow their interests and help them consolidate the skills they are mastering (Dunst 1999).

- Assuming that "responsibility for child rearing rests within the family", the role of professionals working with the family is to intervene in ways that identify and build on a parent's strengths to empower them to "carry out child rearing responsibilities effectively and efficiently" (Dunst 2007, p163).

In a strengths-based approach, workers are concerned with building people's capacities and potential as opposed to rescuing or doing things for people (McCashen 2005).

5. Capacity building

- ECI is only involved in a family's life for a short time in the context of the life-cycle. This is an opportunity to build a family's capacity for now and into the future.

- Evidence has shown that when parents are actively involved in "procuring desired supports and resources", they have a greater sense of personal control (Trivette & Dunst 1998).

- Participatory help-giving, that is, helping people do for themselves rather than doing things for people, has been found to have a significant effect on parenting competence, confidence and enjoyment (Dunst 2007).

- Logically, parents who feel more competent and confident and who are enjoying their parenting role are more likely to do the things they need to do to meet their child's needs.

HOW DOES ALL OF THIS LEAD TO THE KEY WORKER ROLE?

"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 as quoted in Centre For Community Child Health 2009 p25).

The Key Worker (or Family Liaison) part of the Transdisciplinary Key Worker role has arisen from all of the above to:

- enable one person to develop a relationship with the family that can facilitate their ability to provide learning opportunities for their child

- build on the family's strengths and reduce the stress

- enhance the family's capacity now and into the future

- increase the family's quality of life.

To address these aims the Key Worker (or Family Liaison) part of the role includes the following five elements:-

1. Emotional support

- Engage parents to understand the importance of their role.

- Motivate parents to want to do what they need to do to meet their child's additional needs.

- Build parents' knowledge, skills and confidence.

- Build parents' capacity so that they can continue to do what they need to do long after ECI service is gone.

- Minimise family stressors that may act as a barrier to any of the above.

2. Information and advice to families

- Families report this is as their primary and most immediate need.

- What does this diagnosis mean?

- How do I get the resources I need?

- What am I meant to be doing with my child?

- Knowledge empowers parents to make informed decisions and actions.

3. Identifying and addressing needs

- A family's unique combination of beliefs, routines, culture and preferences will influence how the Key Worker and family work together to achieve positive outcomes for the child and family.

- What are the family's goals and dreams?

- What emotional, material and informational support does the family need to be able to support their child's additional needs effectively?

- What stresses may be impeding their ability to provide positive learning experiences for their child?
- What strengths can be built on?

4. Advocacy

- Once the Key Worker and the family have identified goals and needs and set priorities, the need for other services may arise, e.g. kindergarten, child care, family support services, funding for resources etc.
- If there are difficulties with access to or availability of these services or resources, parents may find they need to advocate for their child or family.
- Some families may need support from their Key Worker in building their skills and confidence in advocacy and to understand their rights.

5. Service coordination

- Once the services are have been engaged, communication and coordination will be needed both internally (from the transdisciplinary team) and externally (e.g. kindergarten, child care, etc) so that services are delivered smoothly and efficiently, without double-up and with the best chance of all parties working towards the same goals.
- Coordinating services for families initially may help to reduce family stress. In the longer term, parents need support to build their capacity to manage their own services.

SUMMARY

The wealth of knowledge about childhood learning and development has changed the focus of research and practice in early childhood intervention. An understanding of the importance of the context of family and community has not only meant a move towards working in home and community settings, but has changed the way ECI professionals relate to families. The relationship the practitioner builds with a child's primary carers is the vehicle through which early intervention occurs. The relationship parents have with their children is crucial to their learning and development, as are the experiences parents create for their child. The additional stressors for parents of a child with a disability may have an impact on the parent-child relationship and on the family's capacity to create positive experiences for their child. ECI is focussed on reducing stress and building strengths so that families can do what is needed to meet their child's additional needs.

The elements of the Key Worker role are designed to build this relationship and the resources and capacity parents need to enable them to foster their child's learning and development. The Key Worker tasks are **emotional support** to help parents feel good about their parenting role and what they can and have achieved; **information and advice** to empower parents to make informed decisions and actions; **identifying and addressing needs** to ensure families have the formal and informal supports and resources they need; **advocacy** to support parents' capacity to advocate for their child now and into the future; and **service coordination** to reduce stress, enhance service quality and build parents' capacity to manage the supports they require.

In summary, the Key Worker part of the Transdisciplinary Key Worker role is designed to build family capacity to meet the additional needs of their child now and into the future.

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The Transdisciplinary Key Worker Role

AN OVERVIEW

WHAT IS THE ROLE?

One ECI professional, the Transdisciplinary Key Worker, is allocated to a family and provides all or most of the ECI service. The Transdisciplinary Key Worker is family-centred, forming a relationship with the family and working in partnership with them to address their goals and needs. Transdisciplinary Key Workers are supported by colleagues from a range of disciplines. Their approach focuses on the strengths of both family and child, and works with them to build that capacity further. Learning and therapy are embedded in the child's natural environments and everyday activities.

> **The purpose of early childhood intervention is "to promote children's participation in family and community life in ways that support and strengthen child functioning and which improve child and family quality of life." (Dunst 2000)**

Transdisciplinary Key Workers use a range of skills. They:
- work with families
- use the skills and knowledge of their own professional discipline
- use transdisciplinary skills, i.e. skills learned from their colleagues
- consult with other team members and families
- consult to children's services.

WHAT ARE THE CORE PRACTICES?

Transdisciplinary practice

> **"Dunst, Brookfield & Epstein (1998) found that more services provided more frequently by more practitioners was negatively related to parent well-being and functioning." (Dunst 2007)**

> **"Furthermore, according to McWilliam and Scott (2001) a transdisciplinary model facilitates emotional support, as families have an opportunity to develop a relationship with the primary service provider." (Younggren 2003)**

Different disciplines can provide different skills, knowledge, perspectives and ideas; transdisciplinary practice enables these to be shared, enhancing each team member's abilities and underpinning a service that is less intrusive into family life. The Transdisciplinary Key Worker allocated to a family is the main and sometimes only point of contact for the family. The Transdisciplinary Key Worker may consult with the team about the plan he or she is creating in partnership with the family, and they may need, at times, to involve one or more team members more directly, through professional-to-professional consultation and discussion, team discussion, or a team member providing a service directly to a family, preferably with the Key Worker present. Transdisciplinary practice requires clear, respectful and jargon-free communication across the team. It requires flexibility, trust, and an openness to learning and sharing knowledge with others. The Transdisciplinary Key Worker builds his or her general child development knowledge from the fund of competencies on the team.

Family-centred Practice

Liabo et al (2001), in a review of the evidence concluded that:-
- "If they [a family] receive a key worker service, the overall quality of life for families is improved."
- "Specific outcomes are better relationships with services, better and quicker access to services and benefits, and reduced levels of stress."

The Transdisciplinary Key Worker understands that children develop within the context of their family. A respectful, honest and empathic partnership with families, which is sensitive to their socio-cultural diversity, is the foundation for effective early childhood intervention. The Key Worker's relationship with the family can be strong and intimate, visiting the home and discussing personal issues such as child-rearing (Hanson & Lynch 2010), and from time to time this may entail providing emotional support to the family. It is important that the Key Worker encourage the family to strengthen their informal support network, to ensure they will have sources of emotional support beyond the Key Worker.

> **"...the task of the early intervention system is to minimise or prevent these stressors from creating nonoptimal family patterns of interaction, thereby maintaining a family's strengths. This can be accomplished by first assessing the stressors and then, where appropriate, working together with families to develop and implement an array of resource supports, social supports, and information and services. If carried out properly, then families will be strengthened in a manner that permits them to maintain as optimal a level of family patterns of interaction as possible ... When this occurs, evidence from intervention science suggests that child developmental outcomes improve substantially." (Guralnick 2005)**

The Key Worker may provide families with information and advice about their child's developmental needs, strategies to use with their child, resources and services available, and the child and family's rights.

The Key Worker helps the family to identify their goals and needs, and set priorities. The overarching needs are for the child to develop their skills and functioning, and for the family and other key people in the child's life to be able to support this development and maximise learning opportunities. Another key goal may be for the child and family to increase their quality of life. Families have the greatest opportunity to have a direct impact on their child's development, but they will not implement programs that are not relevant or meaningful to them (Jung 210), or do not fit into their beliefs, routines or family culture. Stressors can also disrupt a family's ability to address their child's needs. Thus it may be important to address the family's needs first, to enhance their capacity to meet the child's needs.

Once a family has identified their goals and needs, the need for advocacy may arise if they cannot access resources or high quality services. The Key Worker may model advocacy skills such as communication, negotiation and respectful relationships, to help the family build their skills and confidence to advocate for themselves and to seek information and advice independently.

> **"…research has shown that families with Key Workers have better relationships with services, fewer unmet needs, better morale, more information about services, higher parent satisfaction and more parental involvement with services than families not receiving such a service."** (Glendinning 1986, Liabo et al 2001 quoted in Sloper 2006 and Rahi et al 2004 quoted in Success Works 2009)

The Key Worker coordinates services from within the ECI team so that there is one blended, functional plan and one key person to relate to. This streamlines service delivery for the family and minimises the stress that arises from having multiple service providers. Families may also require other child and family services external to ECI service; the Key Worker assists the family to build their skills in gaining access to the services they need.

Natural environments / everyday settings

A child's natural environment is anywhere that children typically are – for example, home, child care, kindergarten, or the community. Children learn best in natural environments and from their natural caregivers – primarily their parents but also staff at childcare and kindergarten. The Transdisciplinary Key Worker focuses on building the skills and confidence of natural carers in natural environments, to make the most of the learning opportunities in the child's daily routines.

> **"Some simple calculations indicate that a twice-a-week hourly intervention or therapy, in the absence of parent involvement, accounts for only 2% of the total waking hours of a 1-year-old child …hardly enough time for any kind of intervention to make a meaningful difference in a child's life."** (McWilliam 2000 quoted in Dunst 2007)

> **"The evidence that is available suggests that service-based early intervention is not effective and in some cases has negative effects."** (Dunst 2007 p171)

> **"For all children, including those with disabilities, the nature of their relationships with parents and caregivers is absolutely critical for their development."** (Moore 2010)

> **"…the effect size for parents' use of everyday activities as an early intervention was three times larger than that for practitioners' use of early intervention in everyday activities."** (Dunst 2007 p169) That is, when parents use a strategy with their own child it is three times more effective than when an EI worker uses the same strategy with that child.

Routines-based practice

> **"A key role for ECIS providers is analysing children's environments and identifying ways of increasing their engagement through activities and their opportunities to practise key skills."** (Moore 2010)

Children's routines are their everyday activities, such as waking up, eating, getting dressed, and going places. Children learn and develop in a cumulative way through engagement with people, objects and activities. The more often they are engaged, the more they get to practise and build on their skills. Early intervention will have its maximum impact when it focuses on the learning opportunities in children's everyday lives. An intervention plan in which therapy is part of everyday activities is relevant and meaningful for families and fits in with their everyday lives. It is also important that other key people in the child's life (such as early childhood educators) are committed to the plan; they need to be involved in looking at the issues and learning opportunities throughout the child's day, so the plan has the best chance of being implemented across all the child's regular environments and activities.

Strength-based practice

"The connection between people's strengths and their aspirations is the key to every successful action for change." (McCashen 2005)

In developing interventions, the Transdisciplinary Key Worker needs to look at the child's strengths and interests and how the child may be encouraged by family and other key people in their life to build on these. The Key Worker also needs to look at existing family strengths and interests. What skills and knowledge do they already have? What supports are already in place? Confidence is built more easily when the focus is on strengths rather than deficits. In strengths-based practice, according to McCashen (2005, p37), the worker:

- listens, validates and explores the context of issues
- does not jump to solutions or attempt to move ahead of people
- assists in identifying issues, goals, strengths, exceptions and steps
- supports people to mobilize their strengths, supports and resources
- accesses additional resources, when necessary, in ways that complement people's strengths and resources
- assists in noticing and measuring change
- ensures that practice is transparent, honest and participatory
- does not know the answer but rather shares knowledge and skills to help facilitate change
- actively seeks feedback and evaluation throughout the change process.

Capacity-building

"Responsibility for child rearing rests within the family", so professionals need to work with families "in ways that support and strengthen parent capacity to carry out child-rearing responsibilities effectively and efficiently" (Dunst 2007).

ECI ceases once the child moves on to school, and most families who have had support from an ECI service will not go on to receive services in addition to what is available in the school system. Informal supports can be even more helpful for families than formal supports at any time in their life and can be crucial once the ECI service has ceased. If a family does not go on to receive formal support services, they may need to do many things independently: access information and resources, manage significant transitions, speak up for their child or family if they are being unfairly treated, meet the emotional needs of all family members, organise a meeting with professionals, make informed decisions on behalf of their child and family, and optimise opportunities for their child's continued development. Key Workers need to look beyond the period of their own involvement and grasp the opportunity to help families to build their capacity for the future.

"...when practitioners support parents and parents in turn support their children, both parents and children realize a heightened sense of confidence and competence." (Dunst 2007)

McCashen (2005, p9) sets out the assumptions that underlie strength-based capacity building:

- All people have strengths and capacities.
- People can change. Given the right conditions and resources, people's capacity to learn and grow can be harnessed and mobilised.
- People change and grow through their strengths and capacities.
- People are experts on their own situation.
- The problem is the problem; the person is not the problem.
- Problems can blind people to noticing and appreciating their strengths and capacity and finding their own solutions.
- People have good intentions.
- People are doing the best they can.
- The power for change is within us.

What outcomes are we seeking?

Early Childhood Intervention Australia (Victorian Chapter)(2005) identifies the following outcomes:
- Children gain functional, developmental and coping skills that are appropriate to their ability and circumstances.
- Children show confidence and enjoyment in their everyday life.
- Children participate meaningfully in home and local community activities to the extent of their ability.
- Children experience and enjoy family life and community activities that are preferred by the family.
- Families will be able to nurture and support their child according to their values and preferences. Families will be able to identify and address the needs of their child(ren) and family.
- Families will be able to advocate for themselves and their family, to the degree they choose.
- Families will participate in social and community activities to the degree they choose.
- Families will feel supported by personal networks and local 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.

FAMILY-CENTRED KEY WORKER

There are five members of the Conroy Family – parents Jill and Joseph, nine- year-old Clarissa, five-year-old Andrew and two-year-old Josephine. Andrew has been diagnosed with autism and the family has been allocated a Transdisciplinary Key Worker, Liz, who began work with them last year. Liz has developed a strong relationship with the whole family based on respect, honesty and trust. She knows their strengths and interests and can flexibly adjust to their changing priorities. She works in partnership with the family, tailoring information and advice to their particular needs, and she helps them to identify and address their needs. With the permission of Jill and Joseph, Liz communicates with the other professionals in the family's life to share information and promote cohesive service delivery and the pursuit of common goals. On one occasion, the Conroys sought support from Liz in talking with the manager of the local swimming pool, as he had not been open to the idea of Andrew joining a class. Sometimes on home-visits, Jill and Joseph can become tearful when they talk about their struggles with Andrew's behaviour and the impact they fear this has on Clarissa and Josephine. Liz listens to them respectfully and validates their feelings rather than jumping in with her own solutions. She encourages the family, when they are ready, to develop their own solutions, and she supports this with information, advice and referrals when required.

NATURAL ENVIRONMENTS & ROUTINES

Andrew is in long-day care two days a week, and he attends a four-year-old kindergarten program at the same centre for three sessions a week. Jill and Joseph both work part-time and share equally in the childcare responsibilities. The Conroys requested that Liz meet with them together with the kindergarten teacher and the room leader from childcare to work out a plan to provide some consistency for Andrew across his different environments. They feel that the stress he is experiencing currently in moving between different people and places is affecting his learning. Jill and Joseph had also expressed concern to Liz about implementing any "therapy" for Andrew as they were so busy juggling work and family they were not sure how they would manage it. While they had been on the waiting list for ECI services, Andrew had had private speech therapy. They tearfully confessed to Liz one day that they had very rarely done any of the exercises the therapist had given them, and felt tremendously guilty about this. Liz suggested they look together at the learning opportunities in Andrew's day. She said that his therapy could be embedded into his day and there would be no need for any separate therapy or exercise sessions. Liz supported the Conroy's to set up a meeting with the kinder teacher and the room leader. The meeting resulted in five goals, some of which related to just one environment (e.g. home) while others related to all three environments.

TRANSDISCIPLINARY TEAM WORK

Liz's professional background was in early childhood teaching. She'd worked as a kindergarten teacher prior to becoming an ECI professional, and this had equipped her with a strong knowledge of typical and atypical child development, children's learning, and children's behaviour. From working on a transdisciplinary team in ECI she had also built her skills and confidence in relation to early language development, facilitating gross motor skill development and implementing toileting programs. Liz discussed with her team the goals the family had arrived at from the meeting. The team included an occupational therapist, a speech therapist, a psychologist, a physiotherapist and a social worker. They exchanged ideas from their own professional backgrounds and from their experience as Transdisciplinary Key Workers. It was agreed that the speech therapist would come on a visit to the kindergarten with Liz to provide a direct consultation, and it was also agreed that the occupational therapist would consult further with Liz about sensory issues but at this stage did not need to become directly involved. Liz appreciated what all her team members brought to the table, while Jill and Joseph were happy to have such a good relationship with Liz. They felt it would not have been helpful to have a series of visits from different professionals each looking at Andrew through a single lens; rather, they felt that Liz understood them as a family and were happy that she was being supported by her team.

STRENGTH-BASED CAPACITY BUILDING

The Conroy's knew that when Andrew went to school next year, Liz would have to exit their lives by the end of first term. This thought troubled them from time to time; they had found the service so positive and supportive, they wished they could keep Liz forever. Conscious of the time-limited nature of her involvement, Liz had always been mindful of building the Conroys' skills, confidence and knowledge to speak independently with professionals about Andrew's strengths and needs, seek the information they need to make decisions and support Andrew's development, obtain the resources they needed, and build their network of social and emotional support.

Liz had always helped the family to identify, use and build on their formal and informal supports. She noticed when any family member took a step forward, and reflected this back to them. She supported the parents to follow and encourage Andrew's' strengths and interests. At times she modelled skills the family had not yet mastered and encouraged them to take an increasingly participatory role until they gained the confidence to take the lead themselves.

When it was time for Liz's involvement with the family to end, they were sad about saying good-bye to her, but felt proud of how far they had come since their anxious time on the waiting list. They felt they had developed almost as much as the kids had over the past two years! They knew they would still have challenges to face from time to time but felt confident they had the knowledge and skills to meet these challenges and to find information, supports and resources if they needed them. The Conroys knew their strengths and felt positive about the future.

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Intervention Resources

The Key Worker Role
in Early Childhood Intervention

WHAT IS THE PRACTICE?

Transdisciplinary Key Workers use a range of skills to inform and carry out their work with families and children. They:

- work with families
- use the skills of their own discipline
- use transdisciplinary skills
- consult with other team members and families
- consult with children's services.

This tip sheet is about the core of this work, the actual involvement with families – that is, the Family Liaison or Key Worker part of the Transdisciplinary Key Worker role.

WHAT DOES THE PRACTICE LOOK LIKE?

Key Workers understand that children develop within the context of their family. They build a relationship with the whole family and have each family's needs at the centre of service delivery. In responding to the family's goals and needs, the aim is to enhance the family's capacity to support their child's development and maximise the child's learning opportunities. Key Workers work in partnership with families and are sensitive to socio-cultural diversity. They focus on strengths and on building the family's confidence, capacity, resilience and quality of life.

HOW DO YOU DO THE PRACTICE?

There are five elements of the Key Worker role:

- **Emotional support** – The relationship the Key Worker develops with a families is key to effective early childhood intervention. The relationship is based on trust, honesty and respect. Key Workers listen to families and validate their feelings. By supporting parents to understand their own and their child's strengths and recognise what they have achieved, and to use the strengths of their own support network, the Key Worker can help them to build emotional resilience.

- **Information and advice to the family** – The information and advice that parents of a child with a disability or developmental delay seek from their Key Worker may initially focus on their child's disability, services available, general child development and strategies to use with the child. Information and advice needs to be individualised to a family's current

needs and preferences. The Key Worker also needs to ensure that the way the information and advice is provided builds the family's independence and ability to make informed decisions.

- **Identifying and addressing needs** – Families may require support from their Key Worker to work out their goals, set priorities, and work out how to achieve them. Family Service Support Plans need to be functional, holistic and family-centred, focussing on the child's natural, everyday environments. Supports may be formal or informal and may cover emotional, material and informational support. Building the capacity of the family, carers, community and educators to make the most of the learning opportunities children have in their daily lives is central. Families may need to be supported with broader family issues as well as child-specific issues.

- **Advocacy** – Parents are usually the main, and sometimes the only, advocates for their children and at times they may have to assert themselves with professionals and others to get the services, resources and respect they need. Making phone calls, writing letters, following up with people on commitments they have made, organising meetings, and contacting people with authority to make decisions are all common advocacy activities. Some families may independently advocate for their child, others may seek support from their Key Worker to build their advocacy skills.

- **Service coordination –** A Transdisciplinary Key Worker coordinates the input from their internal team so that there is one blended functional plan and the family have most if not all of their contact with the one ECI professional. The Key Worker sees the team as including themselves, the family, and the other ECI professionals on the team. It may also include other services such as the kindergarten teacher, child care, maternal and child health nurse, medical professionals or family support services. Service coordination involves linking, supporting, consulting, networking, referring and information sharing. It requires respect, clear communication, flexibility and common goals.

HOW DO YOU KNOW THE PRACTICE WORKED?

- Families understand their child's strengths, abilities and needs.
- Families know their rights and are able to 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.

MEETING THE PAPADOPOULOSES

Phoebe Jones became the Key Worker for three-year-old Nicholas Papadopoulos, otherwise known as Nick. Nick lives with his seven-year-old sister Stella and his parents Aminta and Demetrius. Phoebe read the file she had received from Central Intake before contacting the family and making a time to visit them. It told her that Nick had an acquired brain injury from falling off the change table when he was a baby and that he was experiencing some delays in all areas of his development. She also knew from the file that the family was bi-lingual and Greek Orthodox. She knew from her experience of working with several other Greek families that this told her nothing concrete about the family or their particular views about parenting or disability – she knew she would have to discover their views and feelings through developing a relationship with them, and she would have to be sensitive to the family's view of Nick and the world.

Phoebe met the whole family on her first visit and engaged each member in a positive and friendly way. She explained her role and said that she would be working with them to help build the knowledge, skills and confidence and access the resources they may need to help Nick's learning and development. She told them that the work they did together would be based on the family's goals for Nick, and their particular strengths and needs. Phoebe never looked rushed. She was warm, listened carefully to the family, and was respectful. The family told her that they wanted Nick to start three-year-old kindergarten next year but they were worried about whether or not the teacher would accept him. Aminta told Phoebe that her parents couldn't help them as they lived in Greece, and while Demetrius' parents were a great help with Stella, they were uncomfortable about Nick's disability and not confident to babysit him. Nick had a private speech therapist whom the family were keen to continue with, and he was also seeing a paediatrician every few months.

Phoebe explained to the family that as their Key Worker, she would be the main or perhaps the only person from her team to work directly with them. She talked about her team and the different backgrounds they had and how she would use their knowledge and skills to help with Nick. She told them that she would support the family to identify and address their needs, and provide them with information and advice as they needed it and in ways that suited the family. Phoebe explained that with their permission she would communicate with other key people such as the private speech therapist, the paediatrician and the kindergarten teacher to ensure smoother service delivery. She also explained that the longest she would be able to work with the family would be until the end of the first term when Nick went to school. Therefore, during their time together she would focus on building the family's skills and confidence, so they could seek information and resources themselves, advocate for Nick and the family, communicate their needs and preferences to professionals, and build their informal network of support. This would be in addition to the work they would do to support Nick's development and make the most of his learning opportunities at home, at kindergarten, and in the community. Phoebe offered the family some written material on her role and arranged to see them again soon. She realised it was a lot of information for them to absorb and that she would need to go over some of it again in the coming visits.

After the first visit Phoebe and the Papadopoulos family parted feeling positive about their new relationship and the work they would do together to help Nick develop and learn, build the family's quality of life, and strengthen their capacity to do the things they needed to do for their children as a family.

Your Key Worker
A guide for families

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Your Key Worker aims to:

- help you build your child's skills
- help childcare and kindergarten build your child's skills
- make sure you have resources and support
- support your family to know your rights
- support your family to be more confident
- support your family to do things you want to do.

Your Key Worker will:

- listen to you and your family
- give you information and advice
- get advice from their team
- make a plan with you
- visit you at home, or wherever is easiest for you
- visit your child at childcare and kindergarten
- teach you how to help your child learn
- if needed, get someone else from the team to visit
- support you when you need it.

Your Key Worker will be:

- a qualified occupational therapist, speech therapist, early childhood teacher, social worker, psychologist or physiotherapist
- part of a team
- the main or only contact you have on the team.

THE KEY WORKER COMES TO VISIT

Tom Smith is two years old. He lives with his six year old sister Jenny, his Mum and his Dad. Tom has a pet rabbit. Tom is not able to walk or talk. One day a woman called Amanda came to the house. She said that she would be his Key Worker. Amanda had a chat with Tom about his rabbit. She spoke with Jenny about her doll and about school. Mr and Mrs Smith invited Amanda into the kitchen. They all sat around the table and talked. Mr and Mrs Smith talked about their family.

Amanda talked about what a Key Worker does. She explained that she could:
- Meet them where it was easiest for them.
- Help them with their goals for Tom and the family.
- Help other people in Tom's life (e.g. grandma and childcare).
- Get help or advice when needed from her team.

Over time Amanda got to know the Smith family really well. Together they wrote a plan about what goals they would work on. They talked about what other help they might need. They talked about all the times every day when Tom was learning. This included eating his breakfast, getting dressed, patting his rabbit or having a swing at the park. With what Amanda knew herself and the advice she got from her team, she taught them how to build on this learning. Tom's therapy was happening every day doing the things he wanted and needed to do.

Amanda worked with the Smith family until Tom went to school. During that time they learnt a lot about how to meet his needs. They felt good about themselves as parents. They knew how to find out things and get the things they needed. Amanda encouraged them to build on the support they had from family and friends. By the time Tom went to school, the Smiths were feeling good about the future. They were clear about Tom's strengths and needs. They knew how to help him learn and develop. They felt strong as a family. They were able to enjoy the things they wanted to do.

ABOUT THE AUTHORS

Stacey Alexander

Stacey Alexander is a psychologist who initially pursued her passion for working with families within the child protection system. She then moved into Disability Services, undertook studies in Family Therapy and extended her interest to system change and service development. This included setting up a Child and Family Team and investing effort in practice and organisational change which resulted in specifically dedicated resources for child and family services that continue today. Stacey brought her extensive experience of working with families in crisis and with complex needs to the Early Years sector when she joined Noah's Ark in 2007. Stacey's work is driven by the belief that supporting and informing best practice and thereby empowering families will improve outcomes for children, families and the community. Stacey is the Services Development Manager at Noah's Ark.

John Forster

John Forster is CEO of Noah's Ark Inc. and has had an extensive career in advocating for disadvantaged people and improving the availability and quality of services. John's understanding of disadvantage developed while working for the Brotherhood of St. Laurence where his responsibilities ranged across children's and family services, employment programs, aged care and the broader impacts of poverty.

Since John joined Noah's Ark Inc. in 2000, it has become a leading exponent of the inclusion of children with disabilities in children's services in Australia; publishing a series of reports reviewing the international research on the inclusion in the early years and policies and practice in Australia and Victoria. He is motivated by his understanding of both the high costs of disadvantage to individuals and society and the potential of all individuals to enrich our community. One of John's children has a disability, which keeps him focused on the daily realities of all people having the opportunity to participate meaningfully in the community.

ABOUT NOAH'S ARK

For over 40 years Noah's Ark Inc. has been supporting young children with a range of disabilities and developmental delays and their families in the years before school. Noah's Ark is a community-based and not-for-profit organisation that works closely with families, recognising that families are the experts on their own child. Currently, Noah's Ark works with over 1600 families who have a child with a disability and supports over 2000 child care services and kindergartens across metropolitan and regional Victoria.

ABOUT ECII

ECII (Early Childhood Intervention and Inclusion) is a project of Noah's Ark Inc, a Victorian agency that provides services for children with additional needs and their families, including Early Childhood Intervention Services (ECIS) and Inclusion Support Agencies (ISA). ECII has been established, as part of the celebration of Noah's Ark's 40 years involvement, to produce resources that support services for children with additional needs that are designed specifically for Victoria and Australia. The development of these resources is part of our commitment to using evidence based practice, recognising that the translation of research to practice needs to reflect both the culture of different communities and the types of services available.

Visit **www.ecii.org.au** to view more of our resources.