

Early Support

Helping every child succeed

Working in Partnership through Early Support: distance learning text

Family structures by Barry Carpenter with Jo Egerton



Families and Early Support

The *Early Support family pack* and accompanying *Early Support professional guidance* (Department for Education and Skills (DfES), 2004a) are set in a clear framework of service delivery and family interaction. With *Together from the Start* (DfES/Department of Health (DoH), 2003), they advocate “flexible, family-centred support that is competent, compassionate, comprehensive, continuous, well-coordinated and culturally sensitive”. However, without first investigating how individual families work together, professionals cannot begin to deliver a service which can respond to the changing needs of those families. This chapter seeks to involve readers in considering family characteristics and their own ethos of responsive and inclusive practice.

The policy perspective

As *Together from the Start* (DfES/DoH, 2003) reminds us:

“There are many common issues for parents of disabled children, but no two families are the same or have identical needs. Families can be diverse in terms of their experience, resources and expectations as well as their cultural, religious and linguistic influences.” (p9).

The importance of the family in nurturing children came to the fore in the 1980s and has become increasingly emphasised through policy and in service approaches. The publication of *Supporting Families* (Home Office, 1998) generated the Family and Parenting Institute, founded upon the premise that, “Families are at the heart of our society and the basis of our future as a country.” The Institute’s three core tenets are:

- Children must come first
- Children need stability
- Families raise children.

In the field of special educational needs, the parents’ role in the parent-professional relationship was emphasised through the *DfES Code of Practice on Special Educational Needs* (DfES, 2001) which states that:

“Parents hold key information ... They have unique strengths, knowledge and experience to contribute to the shared view of their child’s needs and the best ways of supporting them.” (p16).

In the *2001 Home Office Citizenship Survey*, the Home Office Research, Development and Statistics Directorate (2003) asserts:

“...improved understanding of family networks is necessary for the development of effective policy to support families.” (p113).

However, the *Early Support professional guidance* (DfES, 2004a) takes this a stage further, stating:

“Early Support goes beyond the concept of partnership with parents. The starting point is respect for the daily reality of family life for parents who are raising young children in a situation which presents them with repeated, unusual and unpredictable challenges and which is often highly emotionally charged. Improved service provision means joint decision-making, the right information at the right time and enough continuity of support to enable parents to take decisions and initiate positive action to help their child.” (p19).

This is the hub around which today's professionals aim to develop their working practice.

Blacher and Hatton (2001) write that, "The impact of disability on the family is clearly reflective of the political and economic climate". Policy and legislation support for the family within early childhood interventions has never been stronger (Campbell, 2005; Carpenter and Egerton, 2005; Ford, 2005; Russell, 2005). The stance taken by Early Support is underwritten by a raft of government publications – *Every Child Matters* (DfES, 2003), *Removing Barriers to Achievement* (DfES, 2004b), *Together from the Start* (DfES/DoH, 2003), *the National Service Framework for Children* (DoH, 2004), *Improving the Life Chances of Disabled People* (Prime Minister's Strategy Unit, 2005) – and supported by the government programme, Sure Start (www.surestart.gov.uk). Early Support endorses family-centring approaches, such as the Key Worker Model (Limbrick, 2004, 2005; Limbrick-Spencer, 2000) and the Portage Home Teaching Programme (Cameron, 1997).

The Office of National Statistics (Melzer, Gatwood, Goodman and Ford, 2000) confirms that now, in the UK, one in five children has special educational needs. Today, disability is manifested in different ways from those that we have traditionally known. Research suggests an alarming increase in children's disability arising from substance and alcohol abuse (1 in every 300 babies are born with Foetal Alcohol Syndrome Disorder; Boseley, 2004), very premature birth (76% of babies born at 25 weeks' gestation have some form of disability; Marlow et al, 2005) and assisted conception (70% of multiple births due to in vitro fertilisation result in disability; Russell, 1998). Therefore, as professionals, we have a responsibility to modify and adapt our practices to cope with alternative family patterns of caring associated with new patterns of disability (DfES/DoH, 2003). In order to provide relevant and effective early childhood interventions, we have first to appreciate the context in which they will be delivered – the family.

A personal perspective¹

For a 10-year period during in the 1980s, in both Essex and Warwickshire (UK), my wife Susan and I worked together developing Early Intervention groups for very young children with special educational needs and their families (Carpenter and Carpenter, 1997). For us, this coincided with the start of our own period of parenting. This was a unifying factor which led to deep bonds being established with many of our families which still exist today despite the changes in our professional lives.

The majority of referrals to these groups were received from various professionals – social workers, health visitors, pre-school teachers, paediatricians. We found ourselves working with some very disorientated parents, dismayed at the events life had bestowed upon them. However, what we encountered without fail from all of these families was their love for their child. This is a crucial ingredient for successful parenting, and one which, as evidence-based practitioners, we are often reticent to articulate. It is this natural love that will drive the parents of these children on through the inevitable challenges that will arise as part of the child-rearing process. In Meyer's (1995) collection of essays by fathers of children with disabilities, one father writes:

"Peering into the crib of a child with a disability in the pre-dawn moonlight can bring tears of truly unconditional love – love that will not be based on report

¹ See also the Early Support distance learning text chapter by Mark Brown and Olivia Trimbee – *Changing Perceptions* – for their personal perspectives.

card performance, scores as a star quarter-back, or excellent performance as a respected trial lawyer. This love is for who this person **is**, for their qualities, their trials, and for the inner strength they must develop to take their place. It is their struggle – we can only hope and help, watch and love.” (p25).

Do professionals have real insights into how the birth of, and life with, a child with a disability impacts on the family? At times, we may assume that we know what families need, but often we do not understand the range of emotions experienced. In the recent past, professionals assumed that parents would want to distance themselves from their child who has disabilities, and have based their advice upon this. Manuel (1996), a parent, writes:

“What is often not recognised is that mums and dads and brothers and sisters have love for the child. They don’t necessarily want to abandon that child. Because it’s their child.” (p2).

In our civilised society, the term ‘abandon’ may seem inappropriate, but examples can still be found of situations where parents were put under pressure to relinquish responsibility for their children. Jan and Dave recall how their baby, Sarah, contracted meningitis when she was eight days old and, after spending three months in intensive care, how she was left with profound and multiple disabilities (Carpenter, 2001). Two professionals saw them before they took Sarah home: one talked of disability benefit allowances (for which Sarah was not eligible until she was much older); the other of immediate respite care for whatever period the parents chose. As Jan retorted:

“This is my baby. I look after my baby. I am not giving up my baby to anyone.” (Personal correspondence; Carpenter, 2000, p135).

Another parent, quoted by Espe-Sherwindt (2005), stated emphatically:

“I brought home a baby, not a syndrome.”

If we are to work effectively with families, it is important that we value their context – the home environment – and are prepared to work with the network of family support which sustains them (Appleton and Minchom, 1991). The demands of the multi-professional team on parenting and family life are often intrusive and need to be reconciled with the family’s daily functioning (Carpenter, 2004; Porter, 2002; Redmond and Todd, 2003). Both professionals and families have a common basis for communication and a shared goal; our communication is based upon the needs of the child, and our goal is to enable that child to develop. However, children do not develop in isolation from the family context (Carpenter, 1998). Parents, siblings, grandparents, relatives and ‘significant others’ (eg friends, neighbours, etc.) are the child’s first and most enduring educators (Qualifications and Curriculum Authority/Department for Education and Employment, 1999), and it is they who nurture their child. As Sheila Wolfendale (2000) wrote: “parents are the informed experts on their children.” (p149).

Responses to the birth of a child with disabilities

Two American writers, Philip Ferguson (a parent) and Adrienne Asch (who has a disability) offer this powerful thought:

“The most important thing that happens when a child is born with disabilities is that a child is born. The most important thing that happens when a couple become parents of a child with disabilities is that the couple become parents”. (Ferguson and Asch, 1989, p24).

While a family's journey may follow a different route to that which they had anticipated prior to the birth of their child who has disabilities, their destination is the same as that for any other child – the fulfilment and celebration of their child's potential. It is the child not the disability that should be uppermost in people's minds. However, Ferguson and Asch's words affirm what is often not taken to be the case at all. Kearney and Griffin (2001) note that, in Western society, the birth of a child with a disability is still viewed as a tragedy. Suddenly, in the eyes of some professionals and areas of society, that family is no longer an 'ordinary' family. Parents become 'Down's parents'; babies become 'brain-damaged babies'; the child becomes 'the epileptic child'; the family becomes 'the disabled family'². Rod Wills, a parent himself, reminds us:

“Some of the roles assigned to parents cause great pain. What is imposed on parents is often based on mistaken belief, historical prejudice and myths. Negative attitudes towards disability have strongly shaped what we do to people who are disabled, how it is done, and the consequences for their family”. (Wills, 1994, p249).

Families describe differing reactions to the birth of their child with a disability. These can affect family dynamics and determine the ways in which professionals can offer optimum support. It is important that professionals discover and respect these responses, so their intervention programmes are appropriate instead of a result of their own assumptions about the family.

Often professionals assume that families will be devastated by the news of their child's disability, but it is important to remember that some families will not. Jill Davies (2005), carrying out interviews with families as part of the First Impressions project (Foundation for People with Learning Disabilities (FPLD), 2005) was told by a mother who was delighted with the birth of her baby (who had Down syndrome): “If someone had offered their commiserations I would have been very upset”. Davies noted, quoting Kearney and Griffin (2001); (Davies, 2005), that some professionals find it difficult to accept such a stance, assuming that parents who do not show distress after the diagnosis are in a state of denial:

“Every time I expressed my joy to the staff at the hospital, they said, ‘She's denying reality.’ I understood the reality of my child's situation but, for me, there was another reality.” (Kearney and Griffin, 2001, p583).

Other families' responses may be different. As Beckman and Beckman Boyes (1993), writing from the professional-parent perspective, observe, “The news that a child has, or is at risk from a developmental disability, is often among the most frightening and confusing pieces of information that parents will ever receive.” (p1).

Many families describe feelings of grief and mourning associated with the traumatic period following the disclosure of diagnosis shortly after the birth of their baby. Smith (1997), a mother, writes:

“It is like being hit by an express train. First of all the engine hits you with the news that your baby has serious problems. Perhaps the birth was difficult, and she didn't breathe properly. Perhaps she hadn't developed in the womb. But here she is, hanging on to life by a thread, and suddenly life becomes very fearful. Days or weeks later, the first coach hits you with the news that she has brain damage. No one can say what the effects will be.

² For more on this topic see the Early Support distance learning text chapter by Philippa Russell chapter - *Improving access and inclusion in early years services*.

“The second coach, after weeks or months, brings her blindness or deafness, maybe both, and then the third coach: perhaps cerebral palsy, epilepsy or inability to sit or eat.

So it goes on. The train might have other coaches yet to come: parents separating under the strain; job, car, home lost because of the need to be with your baby; or, the greatest blow of all, your baby dying”.

The track on which the train is running is harsh in the extreme. A continuing sequence of your baby’s illnesses, hospital re-admissions, sleepless nights, exhausting days and questions to which there are no answers: ‘Why did this happen?’; ‘Will she ever learn to smile...sit...play?’; ‘What will she be like when she is older?’” (pp2–3).

In addition to this, mothers whose babies have also been born prematurely may experience physiological as well as emotional trauma (Champion, 2005).

The bereavement response

In our work with families, we need to keep in mind what a disorientating process deep grief can be. Those who have experienced it will understand. The world goes at one pace, but you are in the slow track; people are talking at speed, but you are having difficulty in articulating even one word; tiredness seems unending, and those around you are bursting with energy. In this state, how can parents be expected to absorb and understand complex and emotionally charged information? How can they be expected to make sense of the endless round of appointments that is suddenly becoming part of the daily life cycle?

Some parents say that although they accept their child, they never come to accept the disability completely. This bereavement response may remain with some parents for many years, and tinge their interactions with professionals. They may never seem to share fully the joy of their child’s achievements, always grieving for that lost normality. A grief response is also possible as children begin school, for, as one mother of a child with learning disabilities said: “In realising his academic limitation, I realised the loss of my own dream for his future.” (Parent response, Sunfield Family Survey 1998, reported in Carpenter and Woodgate, 1999). Bowdery (1997), the mother of a young man with disabilities, reminds us that the ever-unfolding pattern of life brings new and painful insights:

“Just occasionally, there is a tantalising glimpse of the son that might have been. This is not the baby, the adolescent or adult I thought I would have.” (p6).

However much professionals may reassure, guide or offer support, these feelings cannot always be rationalised. As a society, we are far too dismissive of emotional responses; we need to acknowledge that they are an important feature of the adjustment process. If a child with disabilities is to be accepted as a full family member, then each family member must come in their own way to value and appreciate the many and diverse talents of the child and, moreover, to acknowledge the child as a person in their own right.

Some parents leave grief behind (if ever a bereavement response was a reality for them), but they may have periods of recurring distress. One explanation for this is the ‘Chronic sorrow model’ (Olshansky, 1962). This model has had various phases of popularity, and in the 1980s (Wikler, 1984), 1990s (Gabba, 1994), and even this

century (Roll-Pettersson, 2001) it has been the subject of some debate. Again, for some parents, there may be some identification with this pattern of response. It is important to remember that parents may experience periods of grieving at later stages in their child's life without being poorly adjusted to their child. The parent who continues to feel sadness about a child's disability can still be confident and caring, but their state of mind may affect the way they respond to professionals. This has been described as a state of "constant vulnerability" (Carpenter, 1997b) which may manifest itself in hypersensitivity, short temper and an inability to cope with criticism of their child or themselves. For the parent, such responses may be symptomatic of the dread of further unanticipated bad news or the desire to protect their child in the face of a social structure whose capacity to care for that child is being continually eroded. One mother, responding to the Mencap 2001 Survey, *No Ordinary Life*, stated:

"We live in a Society that sees people like my daughter as worthless. Why then, would it be one that delivers high quality services?"

It may not be only parents who need time to adjust to the birth of a baby with disabilities into their family. Other family members may have difficulty adapting to the altered family situation. Although families' adjustment to rearing a disabled child may be primarily positive (Glidden and Schoolcraft, 2003), mental health issues can have an impact (Guralnick, 2004), and these families may also be susceptible to depression (Champion, 2005; Olssen and Hwang, 2001).

The practical impact of caring for a child with disabilities³

For most parents of a child with a disability, the desire to secure a life of dignity for their child is at the heart of their personal motivation for ensuring that their child receives a range of quality services which increases his/her quality of life. But to achieve this, many parents find themselves battling with either service overload or service impoverishment. Husbands (1996) writes:

"I was struck by the enormous juggling act that parents are required to perform between appointments, home, work, family life and the needs of other children, as well as the needs of the disabled child. This is a daily reality for many parents; is it any wonder that they feel they are not in control, and as the years pass these feelings may become exacerbated." (p2).

As professionals, we must be aware that families of a child with disabilities may be at risk from the following impacts identified by Olssen and Hwang (2003):

- Financial hardship
- Strained emotional relationships
- Restricted social life
- Higher stress levels
- Modifications to family activities and goals
- Time restrictions caused by care demands.

Runciman and McIntosh (2003) further note that these families are likely to experience:

- Sleep deprivation

³ See also the Early Support distance learning text chapter by Mark Brown and Olivia Trimbee – *Changing Perceptions* – for their experiences of the practical impact of caring for a disabled child.

- Performing unpleasant procedures
- Lack of baby-sitters.

Poverty

In the *Child Poverty Review* (HM Treasury, 2004), it was found that 55 per cent of families with a disabled child live, or have lived, in poverty, and it is estimated that the cost of bringing up a disabled child is three times that for a non-disabled child (Dobson and Middleton, 1998; Gordon et al, 2000; Russell, 2005; Wooley, 2004). The Prime Minister's Strategy Unit (2005) reports that:

“Having a disabled child can also mean that parents find it harder to maintain full-time employment, their housing can be inadequate for their child's needs and expenditure on basic needs is increased.” (p102).

Further UK-specific statistics are summarised in a very useful policy briefing document, *Poverty and families with disabled children in Wales* produced by Contact a Family Wales (2006).

Lifestyle impact

The Mencap survey (2001), *No Ordinary Life*, revealed startling facts in relation to caring for a child with profound and multiple learning disabilities. It found that 60 per cent of parents spent more than 10 hours per day on basic physical care. Parents were woken on average three times per night. Forty-eight per cent received no support from outside the family to help with their care tasks. Randall and Parker (1999) state:

“The severity of the child's disorder, at any level, can leave parents exhausted to a degree that is dependent on their stress tolerance. Many of them experience chronic pessimism and risk breakdowns in their functioning. Early Intervention should seek to divert this bleak outcome. It should seek it vigorously and with great endeavour.” (p121).

Researchers for the Foundation for People with Learning Disabilities' 'First Impressions' project (2005) interviewed 22 parents of disabled children and asked them to describe the challenges which faced them in negotiating day-to-day life. They found that:

“Finding a suitable parking space and an appropriate shopping trolley, using public transport and sourcing a strong enough buggy when the child outgrows their pushchair, all create stress. Public transport is particularly inaccessible for disabled children and adults.” (p12).

Some parents in this study were overwhelmed by the number of appointments they had to attend:

“One mother had to attend four appointments in the same hospital in one week. Not only was this time-consuming, it was also expensive – she had a 16-mile return journey and had to pay a parking fee at the hospital car park.” (p12).

However, many families do cope well, and difficulties are not inevitable (Barnett et al, 2003). Families show how they can overcome feelings of negativity and hopelessness, and find joy and love in their child. Relationships are re-cast; families find the power of optimism (Larson, 1998).

Structure of the family⁴

However well families cope, the trauma of their child's diagnosis remains, and this continues to influence family adaptation (Carmichael et al, 1999; Green, 2001). In their empowerment model, Appleton and Minchom (1991) identify the family as a system, and emphasise the importance of the families' social network in maintaining that system⁵. Social support is crucial to the quality of family life (Home Office Research, Development and Statistics Directorate, 2003; Manuel et al, 2003) and in countering negative psychological and social impacts (Emerson, 2003). When one of the children within a family has a disability, the need for that family to be part of an effective social structure becomes even more important. As McConkey (1999) writes:

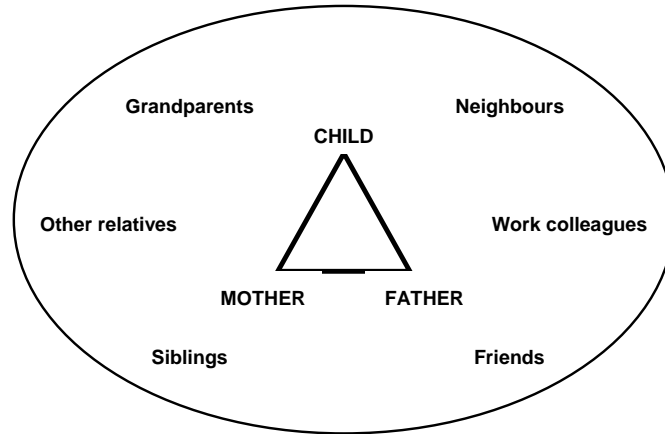
“Our services need to recognise and strive to mobilise the mutual support that family members can be to one another.” (p2).

The stereotyped notion of 'the family' – two married parents of the opposite sex, with two children, who rely upon only the father's income – is the reality for an ever-decreasing number of families (Roll, 1991). The patriarchal model which comprised blood relatives and included safety nets for the aged, infirm or other dependent kin is far less a feature of modern European life than it was at the beginning of this century (Mitterauer and Sieder, 1982; Sieder, 2003). Traditional role definitions within the family could in fact hinder professional interactions with families if we adhere to them (Carpenter, 1998), yet the family is still seen as the major vehicle within which to rear children, and its importance is persistently highlighted in European (Leskinen, 1994; Soriano, 2005) and international (Mittler, 1995; Guralnick, 2004) studies.

Despite anxieties about the destruction of the family, research indicates that it is the 'forms' rather than the 'functions' of the family that have changed (Dahlström, 1989). In the 21st century, many families are self-defined (see following figure, A model of the self-defining family, Carpenter, 2005) – not all are relatives, but nevertheless they form a closely knit social network, carrying out the roles traditionally associated with the patriarchal, blood-related family, with a focus upon mutual support and interest in each other. Patterns of interaction may vary within this group, but they function in much the same way as the traditional extended family. They spend time together, enjoy each other's company and share experiences.

⁴ See also the Early Support distance learning text chapter by Chrissy Meleady – *Equality and Diversity*.

⁵ See also the the Early Support distance learning text chapter by Peter Limbrick – *Team Around the Child*.



A model of the self-defining family (Carpenter, 2005)

The Maori culture of New Zealand has a helpful concept known as the 'Whānau'. A 'Whānau' is a family social structure incorporating people of all ages, interests and experiences (Ballard, 1994). It constitutes an extended family in many respects, including a range of significant people who take a genuine and shared interest in each others' lives and who will advocate for each other.

The ecology of the family is first and foremost the family's domain. We all have different family maps, and it is important for that map to be shared with key workers and other professionals working closely with families so that professionals can take this into account when planning early interventions.

'Inclusion' has to be the principle by which professionals sustain families. Legislative changes in the UK have made it possible for people outside the family to support them as 'advocates' in meetings with local authorities, and Early Support encourages professionals to recognise and include these self-defined family members in their interactions with families by providing, within the Early Support family file (DfES, 2004a), a page on which families can list people who are significant to them.

However, are we as professionals prepared to interact meaningfully with families who self-define their supporting social system? Do we accord respect and recognition to those 'family members' who offer much support to a family, both emotionally and practically, and are a significant source of information about the disabled member of that family, but are ultimately not related by blood? Are the documents used to register a child and its family for our service designed to elicit information about non-traditional family members?

Winton (1990) captures the essence of the modern family:

"Families are big, small, extended, nuclear, multi-generational, with one parent, two parents, and grandparents. We live under one roof or many. A family can be as temporary as a few weeks, as permanent as forever. We become part of a family by birth, adoption, marriage, or from a desire for mutual support. A family is a culture unto itself, with different values and unique ways of realising its dreams. Together, our families become the source of our rich cultural heritage and spiritual diversity. Our families create neighbourhoods, communities, states and nations." (p4).

Family members and family roles⁶

In their work with families, professionals need to keep the pattern of real family relationships in mind. Role-stereotyping by services can place limitations on families when they most need the self-support of their own internal structures. In empowering all family members through inclusive practices, professionals can strengthen and empower the whole family network (Dempsey, 1993) and, in doing so, decrease the risks of family breakdown and promote a better quality of life (Schalock, 1996) for the child and their family members. In wanting to support and sustain the family as an interactive and holistic unit, it is important to appreciate the dynamics of the role and potential contribution of each family member. Not all grandparents undertake emotional support; not all older siblings support childcare; not all fathers are the sole wage-earner; not all mothers cook family meals (Carpenter, 1997b). In this section, the roles of mothers and fathers are considered briefly and more discussion is centred around other family members. The chapter by Mark Brown and Olivia Trimbee – Changing perceptions – looks at the roles of mothers and fathers further. Their chapter discusses the different and important contributions each make – and the difficulties they often encounter.

Mothers

Mothers are pivotal in many families. In her international study, Mittler (1995) found that mothers typically remained the major carers throughout all the regions of the world. This is a finding reflected by many researchers, who have shown that they carry out the bulk of household chores and childcare. Kurt et al (2004) found in a survey of 195 mothers that while the mothers perceived they had significant support from other family members, they felt that they bore the burden of responsibility and problem-solving for their child with disabilities. The outcome of a study by Hendriks et al (2000) also found that mothers felt the 'burden of care' more than other family members, and were more likely to express a need for 'someone to talk to' outside the family. Hautamäki (1997) has produced findings from a cross-Nordic study where she contrasted over 1,000 mothers of children with Down syndrome with mothers of non-disabled children. She found that these mothers, compared with mothers of typical children, had increased care-taking responsibility, had often amended their 'life project' goals, had more restricted leisure activities and different work patterns and, when they did work, there were high levels of leave from work due to illness.

Many services, through their delivery, make the mother in her nurturing role the sole focus for their communication. Is this a fair burden when much of the information that a mother will receive about her child with a disability will be emotionally laden for both parents? When fathers are excluded from the dialogue of care, services fail to access a major resource for the family.

Fathers

The traditional definition of fatherhood is no longer totally helpful to modern families. Role-stereotyping dictates the view that the mother is the primary carer, and has day-to-day management of the child. Professional dialogues and documents are often mother-orientated (Carpenter, 1997b). Professionals and services need to change their expectations and assumptions to accommodate fathers in their nurturing role. One father, Ian, expresses the prejudices he encountered:

⁶ See also the Early Support distance learning text chapter by Mark Brown and Olivia Trimbee – *Changing Perceptions* – for their discussions on family roles.

“One of the special difficulties in being a father on my own is convincing people that I am capable of looking after a child with special needs. I am facing two lots of difficulties – one showing that I can look after a child at all, and the second that I can look after a child with special needs.” (Donald Beasley Institute, 1997, p51).

Although today we readily acknowledge the wide variety of roles filled by fathers within their family, is this any more than lip service, or do we relegate fathers to the 19th century image of the emotionally uninvolved, protecting father (David, 1994)? Many fathers feel that after the birth of their child, they are assigned a subsidiary role by professionals (Carpenter and Herbert, 1995; Herbert and Carpenter, 1994).

In his compelling collection of essays by fathers, Meyer (1995) indicates how the birth of a child with disability brings about life-transforming experiences for many of these fathers. For some, it is a challenging experience which allows them to display aspects of their personality they had not previously acknowledged. For others, it brings about ‘relentless stress’ disorientating their life goals and affecting their work patterns.

In a New Zealand study, Bray et al (1995) identified within their cohort of fathers two main types of love displayed by fathers: unconditional and transforming. First, there were those fathers who displayed utter devotion to their children by just accepting whatever they did and patiently standing by them through all of their endeavours. Second, there were others who felt that, by their transforming acts (eg converting a room in the house, building special play equipment in the garden), they could affect their child significantly and enhance his/her opportunities.

The majority of support services work only during the day when many fathers are at work. It would be unrealistic to expect this to change radically. But is it impossible to think that one visit every six months by a health visitor, for example, may take place during the evening when the father is present, or indeed that families are given as much notice as possible about appointments so that the father can make his own choice about whether he takes time off work? Professionals do not like to work unsocial hours, but the father needs to be included within the parent-professional dialogue if families are to have effective support.

In the recent First Impressions study by the FPLD, Davies (2005) found that only two fathers came forward to become part of the study. Her awareness of the need to talk to fathers, described by McConkey (1994) as ‘the hard-to-reach parent’, led to a further report, *Recognising Fathers* (FPLD, 2006), funded by the Mental Health Foundation and chaired by the author of this chapter. Early findings suggest that:

- ⇒ Fathers are keen to talk about their experiences, but have had little previous opportunity.
- ⇒ Services and organisations are wanting to involve fathers.
- ⇒ A number of fathers’ groups (eg SunDads), run by men and fathers, exist around the country.

Further information about the *Recognising Fathers* research can be found on www.learningdisabilities.co.uk and the Social Care Institute for Excellence briefing sheet (no. 18) can be downloaded from www.scie.org.uk/publications/briefings.

Siblings

As with fathers, it is important that consideration is given to the specific needs of siblings as family members. In her Cornish study, Glynne-Rule (1995) found that after the parents, the siblings of the child with disabilities are often the main relatives providing help, care and education. Studies have found that siblings seldom have full information on their brother or sister's disability (Newson and Davies, 1994), although the continuing emergence of literature specifically directed at siblings to help them understand their brother or sister's disability has been particularly helpful (eg Gorrod, 1997; Hames and McCaffrey, 2005; Meyer, 1997). Giving siblings opportunities to talk and ask questions empowers them. At one of Newson and Davies' research workshops, a sibling commented:

“Before I didn't know much about [my brother]. Now, I know quite a lot – why he behaves in the way he does.” (Sibling, aged 10, p261).

Another sibling described the relief of being able to share emotions:

“I had all these feelings inside me, and I had to spill them out... [In the group] I was able to.” (Sibling, aged 10, p261).

Studies have shown that siblings often express feelings of guilt and isolation, and say they have experienced bullying and teasing at school (Atkinson and Crawforth, 1995; Glynne-Rule, 1995; Opperman and Alant, 2003). However, these siblings also display 'fearless advocacy' on behalf of their brother or sister with disabilities (Meyer and Vadasey, 1997; Carpenter, 1997b) and have a genuine concern for the future of their disabled sibling (Conway and O'Neill, 2004). Other studies found that siblings of children with disabilities show no difference in emotional and behavioural disturbance when compared with siblings of typically developing children (Byrne et al, 1988; Tritt and Esses, 1988). In fact, they have often been found to be well-adjusted and mature and to show a responsible attitude which goes beyond their chronological age (Dale, 1996; Seligman and Darling, 1989).

Meyer (1997) in a collection of writings by the siblings of children with disabilities included humorous, thoughtful stories offering insights into the needs and perceptions of those growing up with a brother or sister with special needs. Justin (aged 10) writes:

“There are good parts about having a brother who has autism. My brother, Jacob, is old enough to play with, and he understands some things. But unfortunately, there's a bad part. Sometimes my brother gets out of hand and hits people; even me!” (p23).

The complexity of the relationship between siblings is highlighted by the NCH Action for Children study (Atkinson and Crawforth, 1995) in which interviews were carried out with 29 siblings of children with disabilities. The majority of siblings (60%) said that they did not mind helping to care for their brother or sister, however the cohort also described:

- ⇒ Being embarrassed about their brother or sister's behaviour in public (70%).
- ⇒ Feeling jealous or angry at the time parents spent with their brother or sister (70%).
- ⇒ Having their sleep disturbed (55%) and sometimes feeling tired at school (45%).
- ⇒ Having difficulty in completing homework due to interruptions by their brother or sister (45%).
- ⇒ Feeling angry or upset because family outings were infrequent and limited (40%).

⇒ Having disturbed mealtimes (40%).

What provisions for siblings of children with disabilities are available in your area? Are there any Saturday events where dads can take their children along – maybe a whole family swimming session, not just a session for the child with a disability? Meyer (1997) has developed an invaluable workshop model, Sib Shops, which enables siblings to explore their attitudes and emotions towards a brother or sister with a disability, and has also developed opportunities for siblings to chat on line (www.thearc.org/siblingsupport/). Sibs (www.sibs.org.uk/) provides support for siblings in the UK, and Contact a Family (www.cafamily.org.uk/) has published a very useful siblings factsheet (Contact a Family, 2003) which is available either as a leaflet or on the internet (www.cafamily.org.uk/siblings.html).

Grandparents

A common source of support for the family may be the child's grandparents and, for many parents, they are the people to whom they feel most able to disclose their full range of emotions. However, as Hastings (2000) states, there is very little research evidence about the support that grandparents offer families, and much that there is comes from outside the UK. Hastings et al (2002), Sandler et al (1995) and Mirfin-Veitch and Bray (1997) all discovered a positive relationship between support by grandparents and emotional adjustment of parents, and reported that grandparents often offered valued practical help such as babysitting and buying clothes. Katz and Kessel (2002) reported that involvement with their grandchild also strengthened relationships between grandparents as well as with the child's parents.

Some reports have suggested that many grandparents have difficulty in adapting to their grandchild with disabilities, and attempt to deny the reality of the disability or to reject the child, which can lead to a breakdown in the relationship between parents and grandparents. Hornby and Ashworth (1994) presented evidence of low-level support from grandparents, and Hastings et al. (2002) found that disagreements between parents and the maternal grandmother led to increased parental stress and worry.

Grandparents who care for their grandchild regularly can provide professionals with valuable insights. However, Hastings (1997; 2000) suggests that grandparents too need to be supported. Where it is known that a grandmother is struggling with accepting her grandchild's disability, and is permanently worried for his long-term welfare, is an individual appointment offered for her with a health professional who can explain directly to her (rather than through the emotional veil that exists when her daughter speaks) about the implications of her grandchild's disability? Limbrick (2005) describes how a key worker coordinating a 'Team Around the Child' (TAC) supported a family facing this situation by organising professional support for different family members, providing hands-on training opportunities and supporting family members' involvement with the child.

Significant others

The literature on 'significant others' in the lives of children with disabilities is sparse. Mittler (1995) notes that the support that is available to families, particularly in the locality in which they live, is 'crucial in determining their quality of life' (p51). Families interviewed as part of this international study variously reported isolation from neighbours (Family Maro, Tanzania) or that friends were encouraging and offered child-minding (Family Murthy, India). While some families received sympathy from

friends (Family Chawdhury, Bangladesh), others were directly attacked by members of their neighbourhood (Family Eed, Jordan).

Carpenter (1997a) carried out a series of semi-structured interviews with 20 families of children with severe learning disabilities (aged 5–16 years) which revealed that for these families the following non-blood relatives offered support:

- Neighbours
- Friends
- Work colleagues
- Church members
- Teachers and assistants
- Link families
- Volunteers (from charitable organisations).

Further discussion with the families revealed that the main types of support offered (ie reported by more than five families in the sample) were: baby-sitting and child-minding, transport, respite care, social activities, meals out for the child and/or family, practical help in the home (household chores, maintenance tasks) and empathetic listening. All families in this study reported that without the help of their 'self-defined family', their patterns of living would have been severely disrupted, and that their capacity to function effectively would have been damaged.

Family change

Families systems are influenced by many factors: the ethnic and cultural background; the stage of the family life cycle; environmental events; external factors; individual relationships; and the personal and collective experiences of family members. Individuals in a family develop roles, rules to live by, communication patterns, ways to negotiate and solve problems, and methods for completing tasks of daily living (Goldenberg and Goldenberg, 1985). Families provide social support and sustenance, and share commitments and responsibilities. They are 'contexts' for learning and growth, and have a particularly decisive influence on the social and emotional development of children.

In 21st century society, now more than ever, changing demographic trends are reflected in the changing constitution of families. One factor is the ever-increasing breakdown in marriages. Mittler (2000) notes that 25 per cent of children over the age of 16 will have experienced parental divorce. This will lead to families becoming reconstituted, with a corresponding shift in responsibilities and access.

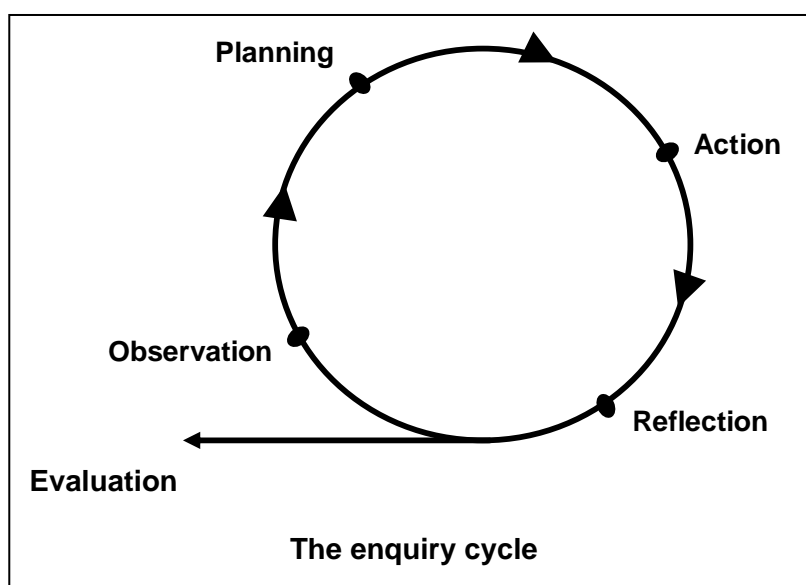
Parents and professionals grow and change; families also grow and change. The structure of a family one year may not be the same the next; an older sibling may have married, gone out to work or away to university. This could have a major impact on a family. The child with learning disabilities may not understand where their much-loved sibling has gone. A key supporter in the family, for example, a grandmother, may no longer be around to help with baby-sitting. The person who listened to the mother's anxieties is no longer there to 'counsel'. Professionals need to be sensitive to this. Listening to and understanding each other's points of view is critical. Professionals can do much to strengthen parent-child and within-family relationships.

Research and families

To meet the needs of new and changing patterns of disability, more professionals are being encouraged to carry out their own research and to test the efficacy of different approaches within their working environment (eg General Teaching Council for England, 2004, 2006). Within traditional research, families are often assigned the subordinate, passive role of 'subject'. However, Beresford (1994) recognises that parents actively manage the difficulties they face. Families modify their lives around multiple professional services and models. It is they, beyond discipline-specific professionals, who are arguably best placed to test the efficacy of different approaches within their context. Shotter (1993) observes:

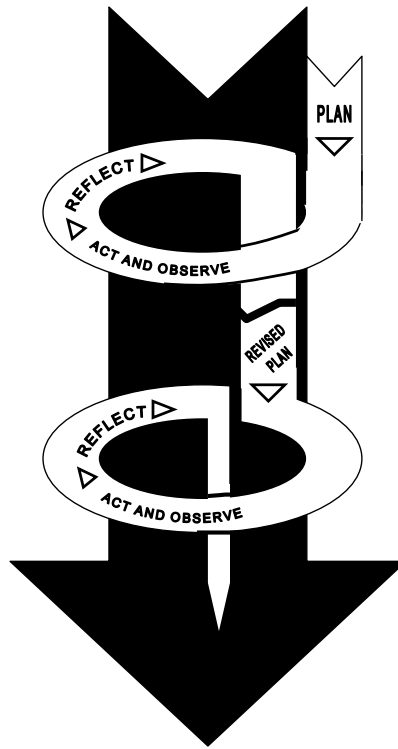
“No matter how benevolent we may be towards those we study – no matter how concerned we are with ‘their’ liberation, with ‘their’ betterment, the fact is that we do not make sense of ‘their’ lives in ‘their’ terms.” (p48).

In 1997, Carpenter proposed the 'parent as researcher' paradigm. In a comparative study of early childhood intervention approaches in New Zealand and Australia (Carpenter, 1997a,b), he had found there was evidence of parents investigating, enquiring, discovering information, planning, delivering services, monitoring and evaluating – all skills pertinent to research. Parents are natural enquirers within their family – the seekers of knowledge and information that will fulfil needs within their family, specifically in relation to their child with a disability. Their activities reflect the action research approach to problem-solving (Robson, 2002) – planning, acting, observing and reflecting.



Another approach is the participatory action research spiral proposed by Kemmis and Wilkinson (1998), (see also Holmes, 2005). Such thinking has more recently been reflected in the 'coaching' process (Espe-Sherwindt, 2005; Hanft et al, 2004), which involves the family and the professional in:

- Initiating
- Observing
- Acting
- Reflecting
- Evaluating.



**The participatory action research spiral
(Kemmis and Wilkinson, 1998: 22)**

In this approach, family and professional participation is voluntary, non-judgemental, accountable and collaborative (Espe-Sherwindt, 2005; Hanft et al, 2004). This is empowering to the family. It enables them to problem-solve and decision-make from within their own resources, using professionals as a reference point and ‘critical friend’ who can help them to access networks and resources when needed.

From semi-structured interviews with ten families of children with disabilities who had received Early Intervention services in the previous two years, Carpenter (1997a) found that in all ten cases, parents said that they had experienced the ‘enquiry cycle’ (see diagram on previous page) and gave ecologically valid reports. Eight parents had actually kept written evidence of such a process. This is reflected in books written by parents in which the enquiry cycle can be identified – eg Pat Fitton (1994), Jacqui Jackson (2003), Charlotte Moore (2004) and Stephen Venables (2006).

For some parents, the ‘parent as researcher’ paradigm could offer them an emotional outlet for the pressures of parenting a child with a disability. It could give parents a practical focus for their sometimes overwhelming concern about their child with disabilities and an alternative to a state of powerlessness characterised by one parent as “unrelenting stress... draining our time and energy.” (Meyer, 1995). Inevitably, because of their varying backgrounds, many parents choosing to become researchers will need partners in the research process, and this is where professional researchers would have a very necessary role. To date only a few researchers and professionals (eg Carpenter et al, 2007, in press; Russell, 2004;) have involved parents in directing research.

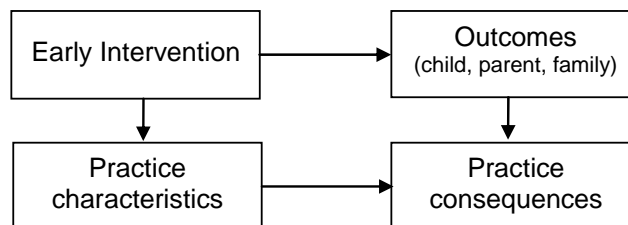
If we wish to progress family-focused models of service delivery, then we must evolve parent-inclusive patterns of research. This is not to deny the validity of other types of research, with or without families, or the capacity of this research to extend the body of knowledge; rather, it is to make the statement that if we wish truly to empower parents of children with disabilities, then part of that enabling process must be to offer them, as an option, the role of researcher. We must acknowledge their right to investigate their own family functions; indeed, we must acknowledge that this is already part of the process they engage in.

Families' hopes for interventions

Although there is still some debate around family-focused Early Intervention approaches versus child-skill development (Odom et al, 2003), many researchers and practitioners feel that family-centred models are more humane and dignifying to the child and their family (Wellings, 2005). They acknowledge the child's context, with its associated demands and limitations, and introduce appropriate and sustainable interventions. Such approaches are also aimed towards increasing the capacity of families to provide resources to other families, to assist in problem-solving and to build self-supporting and self-sustaining practices.

Sensitive interactions between families and professionals are crucial if the family is to be allowed to make its contribution in the ever-changing, uncharted scenario of their child's development. We will need to be creative in the strategies we employ to ensure family involvement in our services (Carpenter and Egerton, 2005; Hutchinson, 2005). The framework proposed by Dunst et al (2002) is shown below. It displays the relationship between interventions and outcomes.

Framework for relating practice characteristics to practice consequences (Dunst et al, 2002)



This framework encourages us to consider the implications for our practice of intervention outcomes for, and potential contributions of, all family members including 'significant others'? Are family structures strengthened by the interventions through tangible means?

As this parent writes:

"The greatest gift we can give to our children is a caring, supportive family. Families are often very unsure of the best ways to help their child with a disability, and I believe if they are given flexible, responsive and sensitive support, this will not only strengthen their role in the short-term, but will also increase their capacity for the future. It is the families who usually provide the most constant ongoing interest and support in a person's life, so any investment of time and energy, by schools and professionals, I believe is well

spent.” (A parent, Sunfield Family Survey, 2000, reported in Carpenter, 2001, pp281–282).

Although families themselves will provide the key to support, the need for support from professionals is crucial. As Davies (1998) points out:

“If parents are overwhelmed by the extreme stresses of the situation, they will be unable to cope with the child’s problems and will find it difficult to provide the love, security and responsive stimulation essential to the well-being and development of the child.” (p1).

Carpenter (1997b) found that families particularly appreciated the positive approach of many professionals. The hallmark of practice of these professionals was that they had treated the family with respect and dignity and acknowledged the uniqueness of that family. They had not viewed the family as carrying a terrific burden, but rather as a family that would be self-sustaining, but who at times, like all of us, would need some support. These professionals enabled the families to be positive and not to become a ‘disabled family’. These professionals had valued the contribution of all family members – had allowed siblings to contribute to the review meetings, had listened to various family members and had not dismissed their contribution because of their age or because they were not blood relatives. Their intervention strategies had enabled the child with a disability to be seen as a contributing family member, and there was an expectation of success for the child and celebration of his/her achievements.

In working with the Early Intervention groups in Essex and Warwickshire, it became clear over the years to Susan and me that networking between families themselves was a powerful structure for mutual support. An added dimension came for us with the arrival of our daughter, Katie, who has Down syndrome, and the subsequent birth of our daughter, Eleanor, who sadly died of the rare disability, Sacralagenesis. This deepened our communion with the parents with whom we were working.

Fundamentally, as co-supporting families within the groups, we began to see our role as empowering each other in order to empower our children. As Manuel writes:

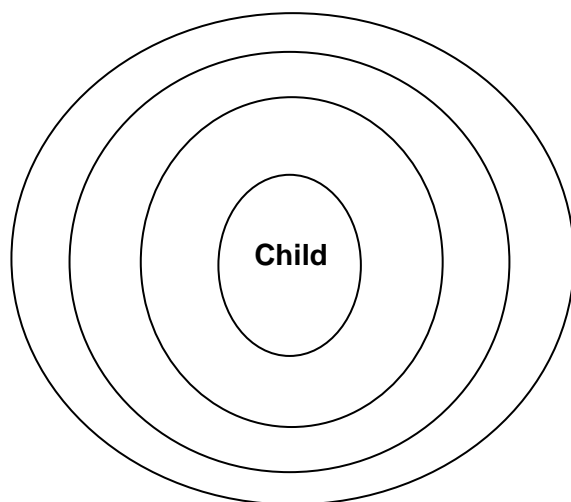
“The professionalism on which you stand is not a different road to the one on which we tread ... It’s also the road that’s cushioned and softened by the laughter and the smiles of love, and tears of our children. That road is the same road, and, when we relate to each other, we have the partnership that dreams are made of. From the educational psychologist who sits with you and tries to translate the vision you have for your child in the way his or her report is written, to the occupational therapist who’ll make a separate attachment to your child’s wheelchair so the cat can curl up next to your child, to the midwife who finds a lovely position you can feed your child in even though it’s completely against her textbook knowledge... These are professionals who are working in the spirit of the term ‘partnership’.” (Manuel, 1996, p3).

The reality for the family of a child with special educational needs is that they face recurrent and unpredictable challenges. Not only do they require appropriate Early Intervention, but they require access to ongoing support at points when they need to push the button. The families of children with special educational needs do not seek sympathy, do not want to be patronised. They do want to be valued and treated as equals. They are not interested in being converted to particular educational ideologies or medical or therapeutic doctrines. They desire recognition of the individuality of their child and the uniqueness of their family.

Activities

What follows are three activities that relate to the topics raised in this chapter. These activities support your learning in this area, and you should consider using these activities to support your reflective diary entries.

Activity 1: Who supports you?



Think of a family you work with, or your own family. Who do you think the family relies on for support?

Take a moment to look at the model of the 'self-defining family' shown in the 'Family structures' section and then begin to map your family support using a diagram like the one on the left.

Place the child with disabilities in the middle of the network, and then arrange other people in the other rings according to how much support they give. Place them in a ring close to the centre if they give a lot or in a ring further away if they help less.

Keep this map so you can change or add to it.

Activity 2: Implications of the family map

If you are a professional

- Look at your family map. What implications does the map have for your practice?
- Write down a 'wish list' of changes you would like to make.

If you are a parent

- From your family map, choose one professional you work with.
- Write down a 'wish list' of ways in which they could help you by changing the way they work.

Activity 3: Interventions and the family*If you are a professional*

Taking Dunst, Trivette and Cutspec's model in the section 'Families' hopes for interventions', consider the following questions:

- ⇒ What are the practice characteristics of a particular intervention you have carried out with a family?
- ⇒ What were the outcomes for the child, parent, family?
- ⇒ What were the practice consequences for you as a professional?
- ⇒ What changes would you make in the future?

If you are a parent

Think of a time when you tried out a new intervention with your child and how you carried it out. Look at the features of the 'coaching process' (Espe-Sherwindt, 2005; Hanft et al, 2004) listed below:

- Initiating
- Observing
- Acting
- Reflecting
- Evaluating.

How do each of these features relate to your experience of the intervention?

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