Families of Children with Special Needs

Introduction

This chapter considers the child within the context of his/her family to ensure that the needs of every family member are acknowledged. Having a baby or a young child with special needs can be traumatic in many ways such as:

- possible feelings of grief and loss
- confronted with a diverse range of ‘expert’ professionals, each having their own perspective on the child
- possible feelings of lost control over decision-making
- feeling confused within an unfamiliar and complex system.

Different family members are likely to deal with their own issues in their own time, so it is important that early years practitioners understand and respect each of the individuals involved. If we support the needs of each family member then, in turn, we support the child. Effective interagency working systems will support this process but it is imperative that we do not make assumptions about parents’ needs and views. We should listen to, and attempt to understand and respect, their perspectives and feelings.

Children and their families

Today’s family is often far from the stereotypical image of two parents with two children. In the mid-twentieth century there were fewer broken marriages and more extended family members who usually lived nearby and supported their families, particularly the young and elderly.

In my early childhood perhaps I was fortunate to live with both parents, behind the family shop. Both parents were, for the most part, on hand at all times, but when they were ill or away from the house, my grandmother, who lived locally, was available to help out. Similarly, when I had my own children my mother was able to support me when I returned to full-time work, so nei-
ther my own children nor myself needed to use daycare provision. In contrast my own daughters, who do not live nearby and who have a mother who is still working full time, will need early childhood services for their children.

**Family structures**

Besides these fundamental changes the structure of families has also changed dramatically and we should reflect briefly on the range of family structures that currently exist and in which the children we work with are growing up. Barnes (1995) suggests five family structures:

- **conjugal nuclear** – two married people of the opposite sex living together with their children
- **non-conjugal nuclear** – two people living as man and wife but not being legally married (co-habiting or common law)
- **lone parent** – generally as the result of death, separation (for a range of reasons) or divorce where a parent lives apart from his/her partner/spouse
- **reconstituted or ‘blended’** (Hayman, 1999) – when one lone parent establishes a relationship with either another lone parent or a single person
- **extended** – when more than one generation from one family lives together.

In addition there are also relatively new family structures such as:

- same-sex families, for example, a mother and an aunt taking parental responsibility
- gay/lesbian families
- adoptive families
- foster families
- care homes
- grandparents, aunts or other relatives taking care of their young relatives.

Family structures vary considerably and, if we accept that family members have significant influence upon the children growing up, there are implications for early years practitioners.

**What support does a family provide?**

There are four key features of family support:

1. To provide a safe and secure environment in which children can develop their full potential.
2 To pass on culture, for example, how we behave, aspects of history, languages.

3 To pass on norms and values. (Religious organisations and schools also do this.)

4 To pass on family biology.

Naturally, different families have differing standards, so norms and values passed on to children vary. Acceptable behaviour within one family may be considered unacceptable in another. The effects of different standards of behaviour are evident in early years settings, and practitioners need to respond appropriately. Children are not born behaving inappropriately but adapt to and learn from behaviours modelled around them. We would like all young children to demonstrate positive behaviours at all times, but must acknowledge the behavioural learning that has taken place within the home and community, and consider working with parents as well as the child to alleviate difficulties and support the child.

Practitioners should also acknowledge that inappropriate behaviours are often a child’s attempts at achieving independence and that they, the practitioner, may inadvertently compound a child’s difficulties. Tasks that are too hard or too easy may bore a child, as they see no valid reason for trying to complete them. In this position children may resort to unacceptable behaviours as a way of avoiding the task but this may result in the child being reprimanded for ‘not getting on with their work’. The outcome is that the child is being blamed for the practitioner’s inappropriate planning.

**How does a family impact on a child?**

What is a family? Barnes suggests:

‘Those who have loved us’ may be parents, siblings, grandparents, other relatives, teachers or peers. Although other groups and social factors affect socialisation, the family is typically seen as the most influential agency in the socialisation of the child. It is the context within which the most direct and intimate relationships are forged. Our concept of family is greatly influenced by our personal experiences and our culture. (Barnes, 1995: 84)

While accepting this perspective, society should also acknowledge that, sadly, not all children are loved in this way. However, if, as Barnes suggests, ‘family’ comprises those people who love us and each member is a great influence on our development, then we need to begin to explore all those individuals and groups that impact on the lives of children which will extend far beyond the primary notion of the immediate family. Bronfenbrenner (1979) offered an ecology of human development extending beyond the immediate family to national and societal levels through four distinct levels:
1 Microsystem – comprising all family members, the home environment and early years providers, all of whom spend considerable amounts of time with the child. Thus each of their behaviours informs the child’s development.

2 Mesosystem – extending beyond the home and provider, where links and interaction develop between them.

3 Exosystem – including the social networks of the family, the local neighbourhood and the employment of family members, each of which can directly or indirectly affect the child.

4 Macrosystem – relevant national policies, education and welfare systems, economic systems and cultural systems.

While we may initially consider that only the immediate family affects the child, it is clear to see that, directly or indirectly, there are many influences on a child’s life on which we should reflect.

Goldenberg and Goldenberg (1985: 136) highlight key family features: ‘Families are systems influenced by many factors; the ethnic and cultural backgrounds; the stage of the family life cycle; environmental events; external factors; individual relationships and the personal and collective experiences of family members.’ Therefore, when considering a child’s development we should consider all positive and negative influencing factors, including the family, or, at least, as many as are practically possible. The changing faces of any one family must also be considered, as the family itself is an evolving entity that will change, develop and grow through interaction with significant others and wider society.

**Government initiatives for family support – SureStart**

The government SureStart initiative has been an investment in young families specifically aimed at fighting deprivation. Millions of pounds have been spent on developing SureStart programmes across the country in an attempt to break the existing cycle of deprivation. The key philosophy is one of empowerment. Through giving initial direction and professional support, staff work to enable families to develop their own support and provision. The government summarises its intentions as:

SureStart aims to improve the health and well-being of families and children before and after birth so children are ready to flourish when they go to school. It does this by:

- Setting up local SureStart programmes to improve services for families with children under four.
- Spreading good practice learned from local programmes to everyone involved in providing services for young children. (Internet 1)
Reflecting on the whole child

If we are to consider the individual, and sometimes special needs of each of the children with whom we work, we should understand their differing backgrounds and the resulting effects in order to assess the ‘whole child’ in a holistic manner. In some instances specific familial issues may compound a child’s difficulties and be beyond our control. If we are aware of and acknowledge these difficulties we can still support the child effectively.

Children with special needs and their families

Perspectives of families of children with special needs

While the preceding discussion of the family equates to all families, those bringing up children with special needs undergo a range of experiences that can have additional positive and/or negative effects on individuals. Parents of children with special needs may have different perspectives on development, learning, opportunities and the future for their children, themselves and the family as a whole. Attwood and Thomson (1997: 130) identified five distinguishing features of parents of children with special needs:

1. They are long-term players.
2. They tend to become isolated.
3. They are more concerned for their own children than others.
4. Their emotional involvement is heightened.
5. They know that the welfare of their children is much more dependent on the continued effectiveness of the family.

Research is readily accessible to identify specific, individual family needs, for example, Carpenter (2000b), Dale (1996) and Hornby (1995), identifying a need for professionals to acknowledge and understand the perspective of each family member. Carpenter (2000b: 49) concluded that: ‘Where professionals can enable support for the whole family, including siblings, then parents are more likely to acquire better adjustment. Often the child with disabilities is the focus for the professionals involved but this may only be one of the family’s concerns.’

So it becomes clear that we have a responsibility to address the needs of the whole family as well as individual family members, as this in turn will support our direct work with the child. Lee (2005: 65) suggests that: ‘Parents of young children with special needs often tread a path that is steep, rocky and fraught with pitfalls.’
The father's perspective

Current national processes and systems for the identification, assessment and intervention of special needs occur most frequently during the working day, immediately prohibiting attendance and participation for many working fathers. Their understanding of discussions is therefore often second-hand and may lack clarity and/or depth. As one of the main carers for children, and therefore a key influence, it is imperative that fathers are included fully in all decision-making and information giving meetings. Carpenter (2000a: 137) concluded that: ‘They (fathers) need to be offered increased access to information and support, to be provided with opportunities to network with other fathers and to have their need for information and support within the family addressed. In order to achieve these aims, greater training and awareness among professionals is necessary.’

While we may not be able to accommodate paternal involvement at all meetings and discussions, or to change paternal working conditions, we should at least address the issues by ensuring that local systems are in place to inform and support fathers.

The professional perspective

Mallett (1997) highlighted that as professionals we enter a chosen career and those who work with children with special needs often progress to this work after an initial period of working within mainstream settings. We therefore choose to work with children and families experiencing difficulties and many are paid an arguably respectable salary. Ongoing training and support are available and, theoretically, we can leave work behind at the end of the day (although in reality few achieve this).

Parents, on the other hand, may have had little or no advance warning of having to bring up a child with special needs and, in many cases, were expecting a healthy child for whom they had plans and aspirations. Suddenly their dreams and expectations are eradicated and they are faced with a barrage of professionals, confusing systems, some lack of control of events, possible rejection by their friends, community and family, and a possible overwhelming feeling of failure and disappointment.

The way parents are supported is crucial to their future, their child's future and the future of other family members.

Parental acceptance of special needs at or soon after birth

Children experiencing complex disabilities are often diagnosed at or soon after birth, as are children with specific conditions such as Down syndrome. Some-
times parents may have known during the pre-natal period, but to many the news will be totally unexpected and will arrive at a time when they are already experiencing tremendous emotional turmoil.

During the first days and weeks following childbirth, parents experience major adjustments to a totally new way of life. There is extreme joy and celebration of the event plus excitement and anticipation for the future, but this sometimes conflicts with the overburdening sense of responsibility for this brand new, totally dependent life. When one parent is feeling that the responsibility is overwhelming, hopefully, their partner will be able to support them, and vice versa. Extended family and friends will be visiting, so time for the new family can often be interrupted and compromised by well-meaning visitors. So what happens when this turbulent period is interrupted by the news that the much loved, newborn child has special needs? Dale (1996: 49) suggests: ‘Parents rarely expect their child’s disabling condition or life-threatening illness. The confirmation or diagnosis, whether at birth or later, often creates an immense crisis of changes, expectations and hopes, and parents may experience intense reactions during the early days.’

The impact of the initial diagnosis

Undoubtedly parents need to know if their child is experiencing difficulties and to be informed as soon as practically possible by a professional who is aware of the implications of the specific difficulties and able to respond to any questions or issues raised, but at this emotional time the handling of this initial discussion will be crucial. Coming to terms with an early diagnosis can be made easier or more difficult by professionals and there are many reports highlighting parents’ negative experiences, resulting in increased difficulties over and above the natural turbulence of emotions at the time. Birrell offers such a report highlighting one family’s passage from delivering an apparently healthy little girl to discovering she has considerable difficulties:

Then he (the paediatrician) requested that we got Iona dressed before telling us, in a gentle voice: ‘I am afraid it appears that Iona is profoundly brain-damaged.’ They (the words) seemed to reek of despair, of hopelessness, of her condition being incurable, her life unbearably bleak. Our hopes for her, and for us, seemed to plunge further into the abyss with each echo. (Birrell, 1995: 1)

Such examples only begin to give professionals an inkling of the feelings parents experience. Unless we have actually been through a similar experience, and naturally there are practitioners who have, we cannot fully appreciate the implications and effects on each and every member of the family. Carpenter (2000a: 135) suggests that too often at this very difficult time: ‘The professional
approaches were insensitive and ill-timed as they did nothing to enhance their quality of life or parenting confidence."

The SureStart guidance, *Supporting Families Who Have Children with Special Needs and Disabilities*, offers advice and guidance on this difficult period for parents, as well as generally, highlighting that:

How a parent is told of their child’s special needs or disability can significantly affect their subsequent view of support services and have a positive or negative influence on their willingness to use them. News of a disability will come as a shock to many parents, but it is possible to lessen the potential impact of this event by giving information in a way that shows respect for the parents and their child. (SureStart, 2002: 14)

**Including the father**

In this difficult period professionals often spend most time with the mother who is seen as the primary carer. Fathers can too easily be overlooked as they are expected ‘to be the strong one’. Herbert and Carpenter’s study of seven fathers highlighted this ‘marginalisation’ of fathers after mother and baby had returned home:

All help was focused on the mother and baby. The father’s needs were not addressed or, perhaps, even noticed. They were seen as the ‘supporters’ and as such adopted the role society expects – that of being competent in a crisis (Tolston, 1977). All seven fathers talked of returning to work and trying to search for normality and keep a sense of reality in their lives. (Herbert and Carpenter, 1994: 27)

If we acknowledge that mothers and fathers affect their children individually, then it follows that we should support them individually. The more involved the father, from the day of conception onwards, the more informed and empowered he can become.

**Maternal issues**

Quite often new mothers of babies with special needs are moved to a side ward for ‘privacy’, theoretically to support sensitivity, but these parents are immediately being segregated from other new mothers who may well be incredibly supportive. While the reasons behind this policy can be appreciated and some mothers may wish to be segregated, each case should be considered individually. A generalised assumption for all is not necessarily helpful. Professionals may avoid conversations with new mothers of children with special needs as they feel uncomfortable and do not know what to say, but this can isolate mothers even further.

If professionals can begin to at least acknowledge some of the difficulties experienced, then perhaps we can support parents positively at this time. Any
professional dealing with this emotive situation must demonstrate empathy, understanding, respect, tact and diplomacy. They must be informed and well trained to deal with questions, whether they relate to the condition, the future, the baby or the parents and their handling of the news. Sensitivity is an essential personal characteristic needed, but is sensitivity a quality that can be taught or learnt?

**Parental acceptance of special needs at a later stage**

As previously mentioned, many specific conditions and/or complex disabilities will probably have been identified prior to, at or soon after birth. Other special needs may emerge at a later stage or develop gradually over a period of time, raising concerns by parents, family members, friends and/or professionals.

**When initial concerns are raised**

Parents may observe a gap between the development of their young child and older siblings or friends’ children, and raise the issue with the general practitioner (GP) or health visitor (HV). However, in many cases it will be the GP or HV who notices delayed development or specific problems such as hearing impairment. Alternatively, it may be the early years practitioner who identifies difficulties and undertakes a period of observation and assessment to confirm or dispel the concerns before raising the issue with parents.

**Discussing concerns with parents**

At this point we are again faced with discussing concerns with parents in a sensitive and caring manner, and the professional issues raised previously apply equally here. General practitioners and health visitors may be trained to deal with such situations but this may not necessarily be the case for early years practitioners. Under the Schools Standards and Frameworks Act 1998 (DfEE, 1998) which introduced Early Years Development Plans, all registered early years providers have a qualified early years teacher attached to the group to advise and support. This teacher could directly or indirectly support discussions with parents. In addition, every registered provider must have ‘due regard’ to the Code of Practice (DfEE, 1994; 2001d) and have a member of staff responsible for SEN provision. As special educational needs coordinator (SENCO), he/she would be involved in any discussions with parents and will be supported by an Area SENCO.

**Parental resistance to acceptance**

Having identified special needs, practitioners must be prepared for parental resistance to acceptance for a variety of reasons: