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Effects on fathers of children with disabilities

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by

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DEDICATION

This thesis is dedicated to the memory of my father,
Albert Hornby

SUMMARY

This thesis investigates the effects on fathers of parenting children with disabilities. In the first chapter, models of family functioning and parental adaptation to disability are discussed. This is followed by an overview of the effects of disability on family members and a review of the literature on fathers in general.

The second chapter consists of a review of the literature on fathers of disabled children. Included is a review of personal accounts by such fathers, followed by discussion of previous studies and previous reviews of the literature. The review concludes with consideration of the research evidence in support of seven assertions, about effects on fathers, on which there is a consensus in the literature.

Chapter three describes the methodology employed in the current study. From a representative sample of 111 fathers of children with Down's syndrome, 97 were interviewed and 87 completed a booklet of questionnaires. The interviews were semi-structured in order to gain fathers'

perspectives of the effects on themselves and their families. The booklet of questionnaires included instruments designed to measure: demographic variables; adaptation; stress; personality; social support; and, marital functioning.

In chapter four, the results of questionnaire and interview data were considered in relation to the seven assertions about fathers which emerged from the literature review. Overall findings provided little support for the majority of these assertions. The interview data were analysed into 28 categories of fathers' comments which provided a description of fathers' perspectives of their experiences.

The final chapter includes a discussion of the findings from questionnaire and interview data in relation to the existing literature on the effects on fathers. It is concluded that the existing literature may provide a somewhat erroneous picture of the experiences of such fathers. The chapter ends with a discussion of the major weaknesses of the current study, areas for future research, and implications for practitioners.

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CHAPTER ONE

INTRODUCTION

Handicap is beyond doubt a disruptive event in the life of the family as a whole and it therefore has repercussions for the lives of each family member (Kew, 1975, p156).

The impact of children with disabilities on other family members has long been a concern of professionals (Kanner, 1953; Philip and Duckworth, 1982; Ross, 1964; Seligman, 1991). Evidence for the continued validity of this concern has come from recent studies of such families. In two studies, families with disabled children were found to experience higher levels of stress than other families (Beckman, 1991; Dyson, 1991) and in a third study, 34 out of 39 families were found to have faulty family systems (Shulman, Margalit, Gadish and Stuchiner, 1990).

The majority of research on families of children with disabilities to date has focussed on the effects on mothers or siblings. This thesis investigates the effects on fathers of parenting a child with a disability.

It is now widely acknowledged that families both affect and are affected by their members in various ways (Bell, 1968; Bell and Harper, 1977; Belsky, 1981; Clarke-Stewart, 1978; Lewis and Rosenblum, 1974; Sameroff, 1980; Sameroff and Chandler, 1975). That this applies equally well to families with disabled members has been reinforced by the recent application of family systems theory to such families (Berger, 1984; Foster and Berger, 1985; Coopersmith, 1984). It is therefore considered that a focus on individuals within such families, without regard to wider family functioning, may present an inaccurate perspective of that individual's situation (Berger and Foster, 1986; Chilman, Cox and Nunnally, 1988). Thus, an understanding of family dynamics is necessary in order to gain an appreciation of the impact of having a child with a handicapping condition on individual family members such as fathers.

In this chapter, there will be a consideration of models of family functioning, and of the process of adaptation to the diagnosis of disability. There will also be a brief discussion of the effects on other family members, such as mothers and siblings, of the child with a disability. The effects of fathers on child development and the effects on fathers of being a parent will be discussed. Finally, there will be a brief overview of research on fathers of children with disabilities.

Models of Family Functioning

Several different models of family functioning have emerged in recent years which have begun to have an impact on research and practice with families of people with disabilities. Three of these are described below. These are: the transactional model; the ecological model; and family systems theory.

Transactional model: in this model development is believed to result from a continual interplay between a changing organism and a changing environment (Bell, 1968; Sameroff, 1980). Thus, families are considered both to affect and be affected by their disabled member (Mink and Nihira, 1987). Also, as people with disabilities pass through different developmental stages they will affect their families in different ways. For example, an infant with a disability will have a different effect on parents than an adolescent with a similar condition. Likewise, the effect parents have on their child with special needs will depend on the particular stage in the life cycle in which they find themselves. That is, a child with a handicapping condition, who is the first born child of young, recently married parents is in a very different situation to a child with the same condition born to older parents who already have several other children (Schilling, Schinke and Kirkham, 1988).

Ecological model: in this model human development and behaviour cannot be understood independently of the context in which it occurs. Environment influences behaviour and this occurs at several levels (Bronfenbrenner, 1977, 1979). Thus, the effects on parents of caring for a child with a disability are strongly influenced by the environment in which they are living, including the extended family, services available and community attitudes.

The family of a child with a disability is considered to constitute a microsystem with the child, parents and siblings reciprocally influencing each other. This family microsystem is influenced by the mesosystem in which it is embedded. The mesosystem comprises the range of settings in which the family actively participates, such as the extended family, school and work settings. The mesosystem is itself influenced by the exosystem. The exosystem level consists of settings in which the family is not actively involved but in which events occur that affect the family, such as the mass media, education system and voluntary agencies. Finally, there is the macrosystem which comprises the ideological systems inherent in the social institutions of a particular society such as religious, economic and political beliefs (Mitchell, 1985). Thus, the development and behaviour of a family with a disabled person are influenced, not only by interactions

within the family's microsystem, but also by its interactions with other levels of the entire social system.

Family systems theory: in this model the behaviour of family members is considered to be a function of the system of which they are a part (Berger and Foster, 1986; Foster and Berger, 1985). A change in the family system will inevitably lead to a change in the behaviour of each of the family members. Likewise, a change in an individual's behaviour will cause the family system to change. However, the functioning of the family system is considered to comprise more than just a summation of the contributions of its individual members. Intervention at the level of the family system is therefore likely to have more impact than intervention aimed at one of its members (Coopersmith, 1984; Berger, 1984). The implication of this model is that the whole family system needs to be taken into account when considering the effects on an individual within the family.

In order to elucidate the various elements of the family system, a Family Systems Conceptual Framework has been developed by Turnbull and her associates (Turnbull, Summers, and Brotherson, 1984; Turnbull and Turnbull, 1986). This framework is made up of four components:

family interaction, family resources, family functions, and family life-cycle. These are discussed below.

The family interaction component refers to the relationships that occur among and between the various sub-systems of family members. That is, the spousal sub-system (husband-wife interactions), the parental sub-system (parent-child interactions), and the sibling sub-system (child-child interactions). It also refers to extra-familial interactions such as those between children and grandparents or those between a father and his workmates.

The family resources component consists of descriptive elements of the family, including characteristics of the disability such as type and severity; characteristics of the family such as size, cultural background and socio-economic status; and personal characteristics such as health and coping styles.

The family functions component refers to the different types of needs for which the family provides, such as economic, physical care, recuperation, socialization, affection, self-definition, educational and vocational needs.

Finally, the family life cycle component represents the sequence of developmental changes that affect families as they progress through various stages in the life cycle, such as unattached adulthood, marriage, birth of children, school-entry, adolescent children, children leaving home, and retirement.

Within the family life cycle, the individual life cycles of each of the family members need to be considered. Regarding fathers, Levinson (1978) from his research with 40 men aged 35 to 45 years, suggested that the adult male life cycle consists of three major stages and three transition periods, as follows:

age 17-22 years, early adult transition

age 22-40 years, early adulthood

age 40-45 years, midlife transition

age 45-60 years, middle adulthood

age 60-65 years, late adult transition

age 65-80 years, late adulthood.

Each stage and transition period have associated tasks which need to be completed in order to live effectively. Two themes run through the entire life cycle: the 'life structure' and the 'dream'. The life structure consists of such things as family, friends, work, and leisure pursuits which help form a man's personal identity and his aims in

life. Whereas the dream is the man's idea of the life he wants.

In the early adult transition the developmental tasks for men are to: begin on a career; establish a home independent from parents; build up a social network; and develop an intimate relationship with a woman. Thus, in this period, both life structure and dream are evolving. In early adulthood men typically attempt to consolidate on the above tasks and begin on the task of becoming a parent. At around thirty years of age many men take stock of the extent to which their life structure is leading to their dreams. This can lead to changes in life structure in order to make the dream more attainable, or to changes in the dream if it is clear that it is not going to be achieved. Thus, by age forty, men aim to have attained a stable life structure which is in reasonable agreement with their dream.

In the midlife transition men often face the reality that some aspects of their dreams will not be realized and may make major life changes in an attempt to revitalize their life structures or have a 'last shot' at their dreams. In midlife the family may assume a new role as children are beginning to move away and wives experience more freedom to develop their lives. The major task of

middle adulthood is to integrate the modified midlife structure into a stable lifestyle.

Levinson (1978) does not provide details of the later stages of development as the men in his study were in the early stages of middle adulthood. However, Levinson's perspective is reinforced by Robinson and Barret (1986) who suggest that,

Knowledge about adult development provides a framework through which to view fathers interacting with their children. There is danger in isolating the father role and drawing conclusions without seeing fathers as men who are deeply involved in a larger maturing process that influences everything they do (p.11).

Finally, in addition to considering the likely effects of individual and family life cycle factors, it must be remembered that these life cycle variables affect family functions and resources, which in turn affect family interaction patterns. These four components of the family system are considered interdependent (Turnbull, Summers and Brotherson, 1984; Turnbull and Turnbull, 1986). This therefore requires that an understanding of all four components of the family system is needed when considering the impact of any event on an individual member of the family, such as the father.

Models for the Adaptation Process

Several models have been proposed to explain the process which people experience in adapting to a family member with a disability. Four of the most widely cited models are discussed below.

Stage model: Many writers (Bicknell, 1988; Drotar, Baskiewicz, Irvin, Kennell and Klaus, 1975; Gargiulo, 1985; Lansdown, 1980; MacKeith, 1973; Seligman, 1979) describe stage or phase models of adaptation to disability similar to the one proposed by Hornby (1982), which is a summary of earlier models. In this model, it is suggested that the process of adaptation can be viewed as a continuum of reactions, beginning at the diagnosis of disability, through which people pass in order to come to terms with the disabling condition.

The first reaction to occur is reported to be one of shock, in which people report feeling confusion, numbness, disorganization and helplessness. This may last for a few days and be followed by a phase characterised by denial or disbelief of the reality of the situation. Next people are said to experience anger, which may be displaced onto a spouse or the professionals involved. Underlying the anger may be feelings of guilt about somehow being responsible for the disability. Sadness may follow, but

is a reaction which is often reported to pervade the whole process to some extent. Later, people are said to experience a sort of detachment, when they feel empty and nothing seems to matter. Even later is reported to come the phase of reorganisation which is characterised by realism about the situation and hope for the future. Finally people are considered to reach a point when they have come to terms with the situation and exhibit a mature emotional acceptance of the family member and the disability. They are fully aware of the person's special needs and strive to provide for these. However, he or she is treated, as much as possible, as just another member of the family, which does not revolve around him or her.

The adaptation process is considered to be a normal healthy reaction to the diagnosis of disability and can be viewed as a form of grieving similar to that which follows any traumatic loss, such as a bereavement (Kubler-Ross, 1969; Worden, 1983). However, in various surveys which have been conducted (Hornby, 1987; Wright, Granger and Sameroff, 1984) many people have reported that they experienced feelings associated with more than one phase at certain times. Some did not experience a particular phase, while others reported being fixated at one phase for a considerable time before being able to move on. Some people say that they experienced the phases in a different

order. Thus, the process appears to be qualitatively different for each person.

This variability in people's responses has led some writers to question the accuracy of stage or phase models of adaptation (Allen and Affleck, 1985; Blacher, 1984). The major objections raised about such models are: theoretical difficulties in accepting a formal stage model with clearly defined stages; and, the lack of research evidence to support a stage model of adaptation (Allen and Affleck, 1985). Therefore it has been suggested that, rather than working through a continuum of reactions in order to come to terms with the disability, people are more likely to experience sadness or grief which may always be present to some extent (Blacher, 1984).

Chronic sorrow: This has led some writers to suggest that, rather than a grieving process which can be worked through with feelings to some extent resolved, parents of children with disabilities experience 'chronic sorrow' (Olshansky, 1962; Wikler, Wasow, and Hatfield, 1981). It is suggested that the reactions which are evoked such as anger, sadness and denial are not resolved but become an integral part of the parents' emotional life (Max, 1985). Thus, there will be various occasions when these reactions may be re-experienced. This reworking of parental reactions can occur at various transition points

in the disabled child's development, such as school entry, the onset of puberty, leaving school and leaving home (Wikler, 1981 and 1986). It can also occur when an additional disability is diagnosed at some time later than the original diagnosis (Featherstone, 1981).

Existential conflicts: An alternative perspective on the adaptation process experienced by family members is provided by Roos (1978). He suggests that, although people do experience the reactions discussed above to some extent, they may be more affected by various fundamental existential conflicts which are exacerbated by having a child with a disability. The existential conflicts identified by Roos include disillusionment. He considers that experience gradually erodes the high expectations which people develop as children, leading to disillusionment with ourselves, others, and life in general. Many people therefore channel their unrealistic expectations into their children. However, a handicapped child is usually an unsuitable vehicle for fulfilling these expectations and therefore represents a major disillusionment.

Another conflict he calls aloneness. The fact that one is ultimately alone in one's passage through life is something that everyone must eventually come to terms with. Many people, however, attempt to avoid dealing with

this conflict by establishing intimacy with their children. Since this is generally much more difficult with a child who has a handicapping condition, parents are often forced to face up to their existential loneliness. Vulnerability occurs because, as people mature they lose childhood fantasies of the omnipotence of their parents and themselves and begin to realize the tenuousness of their control over life, and therefore their personal vulnerability. Diagnosis of disability in a member of the family can be a painful reminder of this vulnerability.

Inequality, Roos suggests, occurs because children grow up with the notion that fairness and justice ultimately prevail in life. Therefore, when faced with a disability in the family, people may feel overwhelmed with the enormity of the apparent inequity, which can present a challenge to their ethical and religious beliefs. Also, maturity brings with it the realization of personal insignificance. Most people strive to find some meaning in life, perhaps through fulfilling satisfying social roles such as husband and father. When they are frustrated in achieving a rewarding parental role, because the child has a disability, people may find it difficult to achieve meaning in their lives and therefore become vulnerable to feelings of insignificance.

Another conflict Roos terms past orientation. Thus, while most parents anticipate their children's future with enthusiasm, parents of children with disabilities tend to view the future with apprehension. Hence, whereas most people are future orientated, such parents typically focus on the present or the past. Finally, he suggests that loss of immortality is another conflict. He explains that a common approach to coping with existential anxiety about one's own death is to seek symbolic immortality through one's children. When a child is disabled, however, this potential avenue to immortality is threatened. Particularly when the child is an only child, parents may be forced to face up to this existential conflict.

Developmental tasks: Yet another way in which the adaptation process can be viewed, as applied to parents of children with disabilities, has been proposed by Mitchell (1985). Parents are seen as progressing through a series of developmental stages, each of which is characterised by a set of tasks which must be at least partially mastered if they are to successfully adapt to the presence of a disabled child in the family. Mitchell discusses the tasks in four broad stages of development: initial diagnosis; infancy and toddlerhood; childhood and early adolescence; and, late adolescence and adulthood.

The tasks proposed for the inital diagnosis stage include:

- deciding whether to pursue aggressive medical care
- deciding to keep the child or seek alternative care
- accepting the reality of the handicapping condition
- coming to terms with one's reactions to disability
- understanding the nature of the disability
- maintaining or enhancing self-esteem
- establishing a positive parenting relationship
- coming to terms with reactions of family and friends
- maintaining or enhancing relationship with spouse.

The tasks associated with infancy and toddlerhood include:

- making contact with other families of similar children
- accessing appropriate support services
- establishing working relationships with professionals
- coping with reactions of the broader community
- advocating for the rights of the disabled child
- establishing a balanced family and personal life
- developing skills for facilitating child's development
- coping with day to day tasks of caring for the child.

The tasks of childhood and early adolescence include:

- participating in decisions regarding special education
- maintaining working relationships with professionals
- accepting the prolonged dependence of the child
- facilitating adaptation of, and to, the community
- helping the child understand his or her disability.

The tasks of late adolescence and adulthood include:

- accepting the disabled person's right to independence
- accepting the disabled person's sexuality
- accepting disabled person living outside family home
- participating in decisions regarding jobs and training
- becoming familiar with the legal rights of the disabled
- ensuring future provision for disabled person.

The issue here is not so much whether adaptation of family members should be viewed as a continuum of emotional reactions characterised by chronic sorrow, or existential conflicts, or by stages of developmental tasks, but more that each model focuses attention on different aspects of the adaptation process. Each model is useful in providing insight into the lives of members of families with disabled children, thereby facilitating the understanding necessary for appreciating the effects on individual family members, such as fathers.

Effects on families and their members.

The importance of considering the effects on families due to one of their members having a disability has been increasingly realized in recent years. Whereas most of the existing literature refers to effects on parents, the vast majority of research has been conducted with mothers. Comments about fathers, siblings and other family members

have often been gained from surveys conducted with mothers, whose perceptions of the reactions of other family members may not always be accurate (Byrne, Cunningham and Sloper, 1988). With this reservation in mind, the literature regarding the effects on such families and their members will now be briefly reviewed.

Families: The social life of many families with disabled members is reported to be restricted (Lonsdale, 1978; Philip and Duckworth, 1982). Leisure activities such as participation in sports and other clubs and family activities such as visiting friends, having picnics and attending family gatherings are often affected. Many families are restricted in the use they can make of community facilities such as beaches, restaurants and public transport. There are also limitations in the type of holidays which families can take. The extent of the social restriction is greatest when the children are young, when physical handicap or behavioural problems are present and when the degree of handicapping condition is severe (Gallagher, Beckman and Cross, 1983).

Families with disabled children are also reported to have to meet additional expenses (Lonsdale, 1978; Murphy, 1982). These are most often for medical care, clothing and transport. The family's income may also be reduced since one parent is prevented from going out to work

because of the daily care requirements of the disabled child (McAndrew, 1976). Most countries have various financial benefits available to assist such families. However, surveys have shown that many parents do not receive the benefits to which they are entitled (Hornby, 1987; Philip and Duckworth, 1982).

Marriage: Much has been written concerning the potential marital difficulties faced by parents of children with disabilities (eg. Featherstone, 1981; Max, 1985). These difficulties are considered to be related to the additional demands of caring for a child with a disability, and various other factors. It is suggested that spouses may disagree about the child's care or treatment and have insufficient time to resolve their conflicts. Having to deal with several professionals may increase the strain on parents, particularly since it is usually the mother who sees the professionals, and who has to re-interpret the meetings for the father. It has also been suggested that, because of greater involvement with professionals and the child, mothers sometimes move through the adaptation process more quickly than fathers, creating more room for conflict. Difficulties in sexual relationships may result from a lack of privacy, fatigue, a sense of isolation on the part of each spouse, or the fear of producing another disabled child (Featherstone, 1981).

Several studies have investigated the prevalence of marriage breakdown in such families. Overall, the results have been inconclusive, with reports of high marriage breakdown and low marital satisfaction (Gath, 1977; Murphy, 1982; Tew, Payne and Lawrence, 1974) being balanced by findings of average, or above average, levels of these variables in other studies (Furneau, 1988; Roesel and Lawlis, 1983). One result which has been consistently found is that a stable and satisfying marriage appears to reduce the stress experienced by parents in coping with a disabled child (Gallagher et al., 1983; Minnes, 1988). These findings have led some researchers to suggest that having a child with a disability in the family tends to strengthen strong marriages and weaken fragile ones (Brotherson, Turnbull, Summers and Turnbull, 1986).

Mothers: Many studies have shown that the bulk of the housework and child care in families with disabled members is carried out by mothers (Fewell and Vadasy, 1986; Parke, 1986; Vadasy, Fewell, Meyer, Schell and Greenberg, 1984). Despite the increased demands which a disabled person makes on these aspects of family life fathers generally do not make a bigger contribution than they make in ordinary families (Gallagher, Scharfman and Bristol, 1984; McConachie, 1986). Another fairly consistent and probably related finding is that mothers

of disabled children exhibit higher levels of stress than mothers of non-handicapped children (Minnes, 1988). Some studies have reported that this has led to such mothers suffering a higher incidence of stress-related physical and mental disorders than mothers in ordinary families (Gallagher, et al., 1983; Philip and Duckworth, 1982).

Siblings: Much has been written about the possible harmful effects on the siblings of children with disabilities. There are several factors which can contribute to sibling maladjustment (Seligman and Darling, 1989). Siblings may be given excessive caretaking responsibilities or may feel the need to overachieve to compensate for parental disappointment with the disabled child. Children may also wonder whether parents will expect them to care for their disabled sibling in later life and may worry about finding a spouse who would be willing to share such a responsibility (Featherstone, 1981). Other concerns are anxiety about "catching" the disability or about the future possibility of producing handicapped children themselves (Crnic and Leconte, 1986; Simeonsson and McHale, 1981).

There are, however, several reports of the positive effects on sibling adjustment of having a disabled family member. One example of this is that many siblings are reported to choose careers in the helping professions such

as teaching or social work (Furneaux, 1988). Other researchers have suggested that siblings of children with disabilities tend: to be more insightful and tolerant of others' difficulties; to be more certain of their goals in life; to demonstrate greater social competence; and, to develop a maturity beyond their years (Crnic and Leconte, 1986; Ferrari, 1984; Grossman, 1972).

Grandparents: A common source of support for the family is the disabled child's grandparents. Grandparents can provide emotional support, guidance about child care, access to community resources, as well as help with shopping, babysitting and financial support (Sonnek, 1986; Vadasy, Fewell and Meyer, 1986). However, some reports have suggested that many grandparents have difficulty adapting to the situation and either attempt to deny the reality of the handicap or reject the child (George, 1988; Seligman and Darling, 1989). Another reported problem is the paternal grandmother's resentment of her daughter-in-law for not producing a normal child (Pieper, 1976). These difficulties can lead to a breakdown in the relationship between parents and grandparents, which is then likely to have a pervasive effect on family members. For example, Waisbren (1980) reports that fathers engage in more activities with their disabled children if they perceive their parents to be supportive.

Effects on and of fathers with regard to parenting

For most of this century the role of the father in child development and family functioning has been paid less attention than that of the mother. This is in stark contrast to previous centuries when the father was viewed as being the most influential figure in family life. The change seems to have come about gradually over several decades due mainly to the adoption of more child-centred views of parental roles (Lowe, 1982; McKee and O'Brien, 1982).

The father's influence was diminished even further earlier this century by the publication of Freud's theories which promoted mothers as primary in the development of children (Arlow, 1984; Lewis, 1982; Robinson and Barret, 1986). Further weight was added to this trend by Bowlby's (1951, 1965) work which implied that the father's role in child development was secondary to that of the mother (Lewis, 1982a; Beail and McGuire, 1982). Therefore, until the 1970's the importance of fathers in family functioning, while by no means ignored (Lewis, 1986), did tend to be under-rated, and more attention was paid to mothers.

This situation has undergone a marked reversal in the last twenty years. This is illustrated by changes in the

perception of the father's role in various editions of the most widely read child-care book for parents (Spock, 1945, 1958, 1979, 1990). In the 1945 edition Spock stressed the support which fathers should provide for mothers. In the 1958 edition he suggested that fathers become involved in all aspects of child care, though as secondary to mothers. In the 1979 edition he stressed that the father's responsibilities in child development should be equal to that of the mother. Finally, in the 1990 edition, he provided clarification of this equal status in a separate chapter on fathers.

This doesn't necessarily mean that a father must give exactly the same number of bottles and baths and change exactly the same number of nappies as his wife does.... He should do enough so that he's one of his baby's regular caregivers....All this... helps him develop a sound, deep relationship with her right from the beginning (p.41).

Further evidence for the elevation of the importance of fathers has been the rapid expansion of both popular and academic publications on this theme in the last few years, suggesting that there is now considerable interest in fathers (Beail and McGuire, 1982; Cosby, 1986; Hanson and Bozett, 1985; Jackson, 1983; Lamb, 1981, 1983, 1986; Lewis, 1986; Lewis and O'Brien, 1987; Lewis and Salt,

1986; McKee and O'Brien, 1982; Parke, 1981; Parke, Power, Tinsley and Hymel, 1980; Pedersen, 1980; Pirani, 1989; Robinson and Barret, 1986; Russell, 1983; Samuels, 1985,1989; Seel, 1987).

This increase in interest appears to have come about for several reasons. First, the growing number of mothers who work has focussed attention on alternative caretakers for children, fathers being an obvious possibility. Second, shortening of the working week has meant that fathers are able to have more time with their families. Third, the spread of unemployment has meant that many men are spending considerably more time at home. Fourth, changes in legal policy regarding the custody of children have led to an increase in the number of fathers who are solo parents. Fifth, the growth in feminism has led to a relaxation in traditional sex roles so that the identification of women with motherhood and men with breadwinning is becoming less rigid, thereby allowing for more involvement of fathers with their children. Sixth, the adoption of models of family functioning based on systems theory has necessarily meant that the father's role is viewed with equal interest to the mother's. Finally, the limited information on fathers, in contrast to the extensive literature on mothers, has focussed research attention on their role (Beail and McGuire, 1982;

McKee and O'Brien, 1982; Parke, 1981; Robinson and Barret, 1986).

Effects of fathers: Fein (1978) has characterized the study of fathers during the last five decades in terms of the evolution of three research paradigms. Firstly, during the 1940s and 1950s he considered that the traditional paradigm operated. Fathers were perceived to be aloof from their children, with a major role of supporting the mother in her relationships with them. Whereas research in the 1960s was guided by the modern paradigm. Here research emphasis was on father absence from the home and a developing awareness of the effects that fathers could have on their children's academic achievement, sex-role identities, and on the prevention of delinquency. Finally, during the 1970s and 1980s the androgynous paradigm has emerged. Researchers have come to place equal emphasis on the effects of both fathers and mothers on child development.

The majority of past research with fathers has been carried out under the modern paradigm, with a focus on the effects which fathers have on their children (Richards, 1982). In recent years, under the androgynous paradigm, the emphasis has switched to an examination of the types and quantity of fathers' involvement in their families. There has also been a limited amount of research on the

effects on fathers of parenting children. Findings from these three types of research are discussed below.

Lamb (1981, 1983) and Parke et al. (1980) have reviewed the literature regarding the effects fathers have on their children and reported several well supported findings, which are summarized below:

1) children form attachments to both mothers and fathers by age six to eight months, even when their mothers are the primary caretakers and their fathers spend relatively little time with them;

2) from early infancy mothers and fathers adopt differentiable roles - mothers typically take responsibility for nurturance and physical childcare, whereas fathers tend to take responsibility for play and ensuring children conform to cultural norms;

3) fathers are more involved in the socialization of sons than of daughters;

4) fathers are more influential than mothers in the development of sex roles of both their sons and daughters;

5) fathers play an important role in fostering their children's academic success, particularly for their sons;

6) paternal nurturance is associated with social competence, whereas father absence, or psychological distance, is associated with psychological maladjustment, in both sons and daughters;

7) fathers' relationships with mothers affect the way mothers treat their children.

These findings have implications for two theories which have been influential in past research and policy with regard to child development. First, the findings provide evidence for the inaccuracy of Bowlby's (1951, 1965) theory of maternal deprivation, which suggested that mothers have greater importance than fathers in the development of young children. It is clear from the above findings, in addition to other research (Rutter, 1972), that fathers do have an important role in child development.

Secondly, the findings have implications for the theory, proposed by Parsons and Bales (1955), that in families, mothers adopt an 'expressive' or nurturant role, while fathers take on an 'instrumental' or controlling role. The reviews indicate that, while parents do tend to adopt differentiable roles, it is not as clear cut as Parsons and Bales suggested. Besides their instrumental role fathers also fill an expressive role, and their

fulfilment of this role is important in the healthy development of their children (Lamb, Pleck and Levine, 1987).

Uncertainty about the role of fathers in the family has been noted by Seel (1987) who pointed out that, whereas 'to mother' literally means to comfort and nurture, 'to father' literally means only to sire. Jackson (1983, p.13) addressed this point when he suggested,

Fatherhood.....is not about fertilizing the maximum number of females and leaving behind the maximum number of offspring. That is what nature might once have dictated. It is about love and relationship and quality in living..... Fatherhood is a cultural invention. Otherwise, perhaps, all men would be like the digger wasp - mating and sipping nectar.

Even though fathering clearly means much more than playing a part in the conception of children it has proved difficult to define exactly what a father is and what he typically does. It has been suggested that there is no clear 'job description' for paternal involvement, which leads to many fathers experiencing 'role confusion' (Lewis, 1986).

Seel (1987) has suggested that there are different styles of fathering which can be arranged on a continuum from the traditional to the active. These are characterized by two main qualities: the amount of participation in child care, and the balance of power in the home. Traditional fathers have little involvement in child care but make all major decisions concerning the family. Active fathers have equal involvement in child care to that of mothers and make family decisions democratically along with mothers. The vast majority of fathers fall somewhere between these two extremes. However, Seel suggests that the current trend is one of considerable movement towards the active end of the continuum, to such an extent that fathering could be said to be in a period of transition.

Backett (1987) has suggested that the behaviour of fathers in families can be categorized into three areas. One, dealing with general domestic and family matters, such as sharing responsibility for family finances, leisure activities, and the children's education. Two, negotiating acceptable paternal behaviour in relation to that of the mother by: adopting a supportive attitude to the emotional and physical demands of her child rearing activities; relieving her of these demands when both parents are present; and, acting as a substitute when she wishes to have time away from the family. Three,

developing direct relationships with the children. She found, however, that although most couples stressed the overwhelming importance of the third area, most paternal behaviour fell into the first two categories. In other words, direct involvement of fathers with their children was quite limited.

In fact, Lamb, Pleck, Charnov and Levine (1987) report that, it is only in more recent times in affluent societies that fathers have been able to incorporate appreciable direct involvement with their children into their family roles. They note that, in most cultures, direct paternal involvement is discretionary whereas breadwinning is mandatory.

Lamb et al. report evidence from both observational and interview studies which indicates that, when fathers do have direct involvement with their children, the interaction most often takes the form of play whereas mothers' interactions tend to be related to child care tasks.

Lamb et al. categorize paternal involvement into three components: interaction; availability; and responsibility. Their summary of the findings from recent studies suggests that fathers' direct interaction with their children is, on average, about one third of that of mothers. Whereas

their availability to their children (without necessarily interacting with them) is about half that of mothers. However, the findings show that fathers take far less responsibility for the day-to-day care of children than mothers. The authors do emphasise however, that there is great variability in each of these components across families, and that in some non-traditional families the involvement of fathers is equal to that of mothers.

Russell (1983) also found that there was a considerable range in the levels of paternal involvement. He identified four types of fathers. First, there was the uninterested and unavailable father, who was rarely at home, and when he was, spent little time with his children. The second and most common type was the traditional father, who took little responsibility for the day-to-day care of his children but who was available and played with them regularly. Third, there was what mothers described as the good father. These men had greater involvement than traditional fathers in that they helped mothers with child care tasks such as bathing, feeding and nappy changing. They were seen as good because they were willing to help, but their involvement was not equal to that of mothers. Finally, there was the non-traditional, highly participant father. These men carried out, on average, 46% of the child care tasks each week, compared with 9% for

traditional fathers, but generally had less overall responsibility for the children than their wives.

In summary, with regard to paternal involvement, it is clear that although fathers generally have a lower level of involvement than mothers, there is a considerable range in the levels of involvement, and the trend is towards fathers having greater involvement. However, the increases which have been found have typically been small (Lamb, Pleck, Charnov and Levine, 1987; Lewis, 1986) which suggests that the typical father continues to have considerably less involvement with his children than the typical mother. This has led some writers to discuss the 'myth of the new father', particularly since the popular literature on fathers abounds with comments on increases in paternal involvement, and surveys of mothers indicate that many mothers believe this is the case (Lewis and O'Brien, 1987). However, the reality of the situation is somewhat different, as discussed above.

Effects on fathers. As was indicated earlier in this chapter, in addition to fathers affecting family functioning in general, and their children's development in particular, there are also likely to be effects on fathers themselves (Bell, 1968; Sameroff, 1980). Parke (1981) has suggested that,

Men are affected by fatherhood as well. Being a father can change the ways men think about themselves.

Fathering often helps men to clarify their values and to set priorities. It may enhance their self-esteem if they manage its demands and responsibilities well, or alternatively it may be unsettling and depressing by revealing their limitations and weaknesses. Fathers can learn from their children and be matured by them (pp.21-22).

Research regarding the effects on fathers of parenting children has begun to emerge in recent years. The studies which have been conducted to date have mainly focussed on either, men's experiences of fatherhood in single-parent or remarried families (Burgoyne and Clark, 1982; Hipgrave, 1982; Lund, 1987; O'Brien, 1982, 1987); or, on the transition to fatherhood, including pregnancy and birth (Beail, 1982; Lewis, 1982b; Richman, 1982; Scott-Heyes, 1982; Woolett, White and Lyon, 1982).

Few studies have considered the typical effects on fathers of parenting children. However, three North American studies have addressed this topic (Heath, 1976, 1978; Hoffman and Manis, 1978). Heath's (1978) study investigated the hypothesis that fatherhood may further a man's maturity. Forty-eight college-educated fathers were interviewed and completed a battery of tests. The results

suggested that the two most significant factors which contributed to fathers' maturity were their spouses and their jobs. These men rated fatherhood as having only a moderate impact on them. A further study by Heath (1976) reported that a substantial percentage of fathers of school-age children feel inadequate as fathers. 38% of all fathers sampled reported feeling inadequate, while 74% of highly educated professionals expressed such feelings.

In another study of school-age children Hoffman and Manis (cited in Bradley, 1985) surveyed 465 black and white fathers concerning the value of children. They reported that 67% of black fathers and 60% of white fathers said that children were of great value in providing love and companionship. Almost as many (55% and 67%) commented on the satisfaction they got from having fun with their children. 41% of black fathers and 32% of white fathers reported seeing children as expansions of themselves. 7% of black fathers and 20% of white fathers thought children helped them achieve adult status and social identity.

All British studies of effects on fathers to date have focussed on the experience of fathering very young children (Jackson, 1983; Lewis, 1986; Simms and Smith, 1982). In one study 100 fathers were interviewed during the first three months of pregnancy, again immediately

after the birth, and again in the early stages of the child's life (Jackson, 1983). The findings of this study will now be discussed, followed by the findings of the other two studies, which considered men's experiences of fathering infants.

Jackson recruited his sample of 100 fathers from hospital records. He selected first-time fathers from typical families (that is, there were no adolescent fathers or fathers from minority groups), so that a 'normal' picture of fatherhood could be gained. For the interviews conducted during the pregnancy he obtained 100% participation of fathers, although he notes that in 99 of these interviews mothers insisted on being present. All 100 fathers were seen again after the birth, and an unstated proportion of them were seen for a third time while the children were quite young. Jackson reports the findings from these interviews in terms of major impressions of fatherhood which he gained.

One such impression is the wide variation in the roles which fathers play, from fathers who are out at work during most of the children's waking hours, to fathers who, because of their wife's employment or their unemployment, spend most of their time at home with the children. Three styles of fatherhood were observed within this variety of roles. First, there was the traditional

father who saw himself as the figure of authority in the family. Next, there was the absent provider who saw his role as one of working hard and long to ensure the economic survival of the family. Finally, there was the nurturing father who realized the value of his direct involvement with the children.

Two themes which emerged from the interviews are the limitations placed on fathering: by men's pre-occupation with defining their masculinity; and, by the lack of opportunities available for men to express tender feelings.

It was noted that men gained a new status, a new personal and social identity, through fatherhood. Fathers typically saw themselves as providing contact with the outside world, leaving their wives to maintain the security of the home. They also tended to become more aware of themselves as economic providers.

Jackson remarks on the paradox of Western society, that at just the time when most men are becoming fathers they are in the early stages of developing a career and setting up a home and therefore are likely to spend many hours at work away from the family home. This time of maximum alienation from the family typically occurs at the optimum time for their involvement with their children.

The second piece of research was conducted as part of a study of teenage mothers. Simms and Smith (1982) included a survey of the mothers' partners, in order to obtain information about their experiences of fatherhood. 369 of these mainly young working class men were interviewed within a few months of the birth of their child. Interviewees were 59 per cent of the possible sample, and the authors report that there were indications that the fathers not interviewed had less stable relationships with their partners, were less pleased about becoming fathers, and were less involved in child care than the men who were interviewed.

For the four-fifths of the sample who were married, there was a high degree of satisfaction with marriage, with only one per cent saying that their marriage was not happy. A high proportion of the fathers claimed to have helped their partner with domestic tasks the previous week, only five per cent saying they had not helped with anything. Virtually all the men claimed to have helped look after their child at least occasionally, 96 per cent saying they had bathed the baby.

In the light of the research reviewed earlier in this chapter these findings certainly are surprisingly positive. These findings may be due to the sampling problems noted by the authors, to the relative novelty of

the marital and parental states these young men were experiencing, and perhaps to the optimism of youth! Either way it does suggest that the findings above and those which follow should be interpreted with caution.

What the men liked most about being fathers were: watching the child grow and develop; the sheer fact of having a child; and, having something that was admired by others. What they liked least were: changing nappies; the noise; dependence on baby-sitters; and, the lack of freedom to go out.

Almost three-fifths of the men thought they had changed since becoming a father, in nearly all cases for the better. They felt they had matured and become more responsible citizens as a result of fatherhood.

The third piece of research also focusses on the first year of fatherhood. Lewis (1986) interviewed 100 men from a wide social spectrum in order to investigate their experiences of being fathers. Lewis used child-health records to contact 124 men within two weeks of their child's first birthday. He limited his sample to married men living with their wives, and one or two children, so that he could focus on early fatherhood. He considered his final group of 100 men (84%) to be a representative sample of such fathers.

When asked to comment on their marital relationship, many fathers (70%) said they felt in some ways closer to their wives, many (68%) felt at least slightly further apart, and some (35%) felt both closer to and distanced from their wives. Clearly there was widespread agreement about the fact that parenthood had had an impact on the marriage, but considerable ambivalence about the direction of this.

Forty per cent of the men thought that fatherhood had brought about positive changes in them. They felt more mature, happier or more fulfilled. However, a similar proportion of fathers focussed on the less positive aspects of parenthood. Twenty-three per cent felt they had more responsibilities, and a further 23 per cent felt life was more restricted. Restrictions on family life were due to increased financial constraints, the need for baby-sitters, and a change of interests to more family-centred activities. Most of the fathers also suggested that, as they took on the responsibilities of parenthood they gradually lost contact with their friends.

Three aspects of psychological change associated with fatherhood were frequently mentioned by fathers. Firstly, the intensity of feelings which they experienced continually surprised them. It seemed that involvement

with the baby exposed the intimate side of men's personalities. Fathers were surprised by the intensity of their emotional involvement and by the the anger and worry the had felt. Some fathers were struck by the sense of wonder, enjoyment or fulfilment they felt. Others were surprised by the intensity of their hostility towards, or fears for, their child.

Secondly, it appeared that, although fulfilling the role of both father and worker could cause stress, having more responsibilities commonly made the men perceive the world in different ways. The majority of men felt that the demands of their work reduced their involvement as fathers. However, many also felt more mature or responsible as a result of becoming fathers. Fatherhood seemed to have increased their status among their work-mates. Thirdly, being a father appeared to allow the men to be altruistic or expressive, and also enabled them to consider the future and measure their success as adults. Lewis concludes,

Just as fatherhood usually heightens a man's emotions and influences the way he perceives his social status and relationships, it also has the potential to change or reinforce many of his basic ideals (1986, p.164).

Research on fathers of children with disabilities:

Bristol and Gallagher (1986) have suggested that there have been five phases in the evolution of psychological research with fathers of children with disabilities. The first phase, evident in the 1950's, was characterized by studies which concentrated on the effects of mothers on their children while fathers were generally considered unimportant. Research with such families focussed on how parents cause handicaps in their children. An example of this is a study in which the causation of Down's Syndrome was blamed on alcoholism in the mother (Hayden and Haring, cited in Bristol and Gallagher, 1986).

In the second phase, the effects which children could have on their mothers were acknowledged, while fathers were still regarded as peripheral. The study by Cummings, Bayley and Rie (1966) discusses the effects on mothers of parenting mentally retarded, chronically ill and neurotic children.

The third phase, evident during the 1970's, was characterized by assumptions that both mothers and fathers could directly affect child development, and that children could affect both mothers and fathers (Bell, 1968). There was little acknowledgement of the impact on and of children due to the mother-father relationship. However, in this phase serious attention began to be paid to

studying fathers. An example of this was Cummings' (1976) study of fathers of mentally retarded and chronically ill children. In the fourth phase, the impact of children on the marital relationship began to be studied, for example Gath's (1977, 1978) work with parents of Down's Syndrome children. The fifth phase, which is currently regarded as the most appropriate, is one in which the family is seen as an interdependent system, with mothers, fathers, handicapped and normal children reciprocally affecting each other. It is also recognised that the family is affected by the formal and informal systems in which they are embedded (Bronfenbrenner, 1977, 1979). This approach to research with families of handicapped children has been elaborated by Crnic, Friedrich and Greenberg (1983).

Bristol and Gallagher (1986) emphasize that, in outlining these sequential phases in the evolution of research with fathers, they do not wish to disparage earlier research models. In fact, they state that, "So little is presently known regarding fathers of developmentally disabled children that information at all levels is needed" (p.95).

In the following chapter the existing literature on fathers of children with disabilities is reviewed.

CHAPTER TWO

REVIEW OF THE RELATED LITERATURE

The research provides valuable broad-based scientific information; yet, without the inclusion of a more phenomenological perspective, any understanding of the experience of disability in the family is bereft of the richness of personal experience (Seligman and Darling, 1989, p.viii).

Following this statement, Seligman and Darling go on to state that both empirical investigations and personal accounts are important in obtaining a thorough understanding of effects on family members. They suggest that one of these sources alone will provide an incomplete picture of these effects. Therefore, in this review of the literature, as in the research that follows, there will be input from both research conducted with fathers, and from fathers themselves.

First, it is necessary to consider the aims of the literature review and to describe how it was conducted.

Integrative reviews summarize past research by drawing overall conclusions from many separate studies that are believed to address related or identical hypotheses. The integrative reviewer hopes to present the state of knowledge concerning the relation(s) of interest and to highlight important issues that research has left unresolved (Cooper, 1989, p.13).

Cooper (1982, 1989) suggests that integrative reviews of the literature should include five stages or phases. These stages correspond closely with the six tasks proposed by Jackson (1980), which were addressed in this review, and which are outlined below.

The first task proposed by Jackson is: selecting the research questions. The four sources used in developing questions are: available theory on the topic; previous reviews; research studies; and, one's intuition, insight or ingenuity. The major research question of interest in this thesis is: what are the effects on fathers of parenting children with disabilities? This question emerged from the writer's experiences of working with such fathers as both a teacher and an educational psychologist, in addition to a familiarity with the theoretical and research literature related to this topic.

The second task is: sampling. Jackson suggests that

indexes, abstracts and bibliographies can be used in order to locate as many existing studies on the topic as possible. Studies should be excluded from the review only if there is 'good evidence of biased findings (p.445).' For this review a computer search of the literature on fathers of children with disabilities was carried out using the following DIALOG databases: ERIC: PSYCHINFO; British Education Index; and, Sociological Abstracts. This was supplemented by a manual search of Current Contents for the Social and Behavioral Sciences, plus the bibliographies of the material located.

Jackson's third task is: representing characteristics of the literature. This involves deciding what should be included in the review and how this is best organised. Since the literature related to the effects on fathers of disabled children is still relatively limited, it was decided to include all studies which specifically focused on such fathers, all previous reviews, and all personal accounts by fathers, which could be located.

From a reading of the articles which reported actual studies, it was considered that these could best be organised under three headings. First, published studies which actually focused on the effects on such fathers. Second, published studies which investigated paternal involvement regarding their disabled child. Third, the

unpublished studies of such fathers, which tended to focus on fathers' relationships with their disabled children.

In order to prevent the phenomenological perspective becoming overshadowed by an analysis of the research, the personal accounts by fathers are considered first. Then, the published and unpublished studies are described and analysed. Consideration of previous reviews comes last since all of the reviews include discussion of one or more of the above studies, and some of them also include material from the published accounts by fathers.

The fourth task is: analyzing the material included. This involves evaluating the adequacy of the sampling used and other possible threats to internal and external validities. The fifth task is: interpreting the results. Findings are interpreted in the light of methodological inadequacies which have emerged from the analysis, and implications for future research are stated. The sixth and final task is: reporting the review. The review should report on the sampling, measures, analyses, and findings of the studies.

Reports of findings, methodological analyses, and interpretation of findings of the studies and personal accounts considered are included at relevant points in the review which follows.

Review of the Literature on Fathers of Children with
Disabilities

Eleven published studies specifically focussing on fathers of children with disabilities were located (Cummings, 1976; Eisenberg, 1957; Erickson, 1974; Gallagher, Cross and Scharfman, 1981; Linder and Chitwood, 1984; Margalit, Leyser and Avraham, 1989; Markowitz, 1984; McNeil and Chabassol, 1984; Mercer, 1974; Vadasy, Fewell, Greenberg, Dermond and Meyer, 1986; Vadasy, Fewell, Meyer and Greenberg, 1985).

In addition, six unpublished studies specifically focussing on such fathers were located in Dissertation Abstracts International (Delaney, 1979; Gleason, 1989; Mitchell, 1980; Roth, 1985; Shannon, 1979; Schwartzman, 1983).

Also, there are eight existing reviews of the literature on fathers of such children (Bristol and Gallagher, 1986; Brotherson, Turnbull, Summers and Turnbull, 1986; Lamb, 1983; McConachie, 1982; Meyer, 1986a and b; Meyer, Vadasy, Fewell and Schell, 1982; Price-Bonham and Addison, 1978). These reviews have been able to draw upon the studies cited above plus studies which have had siblings, mothers, mother-father differences, or parent-child relationships as the focus.

Finally, there is a limited amount of published material written by fathers of disabled children about their experiences (Biondello, 1988; Greenfeld, 1972; Hannam, 1975, 1980, 1988; Harris, 1985; Marburg, 1985; Roos, 1978; Turnbull, 1978, 1985; Wilson, 1988).

Material written by fathers themselves

The earliest published personal account by a father of a child with a disability, which could be located, is that by Josh Greenfeld (1972). Greenfeld, who is a professional writer, presents the account of his experiences in the form of extracts from his diary. He begins with the birth of his second son Noah, shortly after returning to New York from Japan with his wife Founi and elder son Karl.

By the time Noah was nine months old the couple were concerned about his delayed development. They decided to seek professional advice and began a seemingly endless round of visits to specialists in order to obtain a diagnosis. While most specialists appeared unable or reluctant to provide a diagnosis, some of them suggested therapy for the Greenfelds, who took great exception to this.

Greenfeld reports spending a lot of time and energy thinking about Noah, trying to work out what was wrong with him. "It is hard to look at your own baby and say he may not be normal. But I think we have to" (p.36). He talks of experiencing considerable sadness as he considers the likely cause of Noah's disability to be either autism or mental retardation. "I must try not to feel more sorry for myself than for Noah, but some days I forget" (p.98).

Also evident are feelings of self-blame, and denial of the extent of Noah's disability. "I dream continually of a normal Noah" (p.177). Josh reports experiencing existential conflicts, "... because of him nothing seems to make sense any more" (p.84). In fact, throughout the account he communicates a feeling of helplessness in the face of a bewildering crisis.

Greenfeld discusses the escalating effects on the marriage, due to his feelings about his son, coupled with the uncertainty over the diagnosis, and the constant strain of caring for Noah.

I also notice that I have become more distrustful of Foumi...because she has borne me Noah. Even though genetically, I suspect, it is I who am the cause....At first I thought it would draw us closer together, necessarily cement our relationship. Now Foumi and I

have to be wary that it doesn't draw us apart (pp.84-85).

He comments on the time spent talking with his wife about Noah, trying to decide what treatment he should get, and into which pre-school programme he should be placed. He describes how they considered local and residential schools for mentally retarded children, along with multi-vitamin therapy, the Doman-Delecatto programme in Philadelphia, and the behavioural training offered by Ivar Lovaas in California. In the end, Noah was placed in a local pre-school for mentally retarded children, and also began a course of multi-vitamin therapy.

A short while later the family moved out to California for a few months to enable Noah to receive assessment and intervention from the programme headed by Lovaas at UCLA. Greenfield comments positively on the help provided by the programme both for Noah and for the parent training which he and his wife received. He also expresses concern about the effects on his other son, Karl, of having Noah in the family.

Greenfield recounts thinking that eventually Noah would have to be put into an institution. The constant strain of care, particularly coping with Noah's incontinence and disturbed sleep seemed to take its toll. "I must confess

something: sometimes I hope Noah gets sick and dies painlessly" (p.141). He talks about finding it difficult to accept himself as, "...the father of a Noah" (p.147).

Of course, it is easy to sentimentalize: how having a Noah gives meaning and definition to one's life....How a Noah teaches one the value of all the old verities. Bullshit! Without Noah we'd be free to explore the boundaries of our own lives instead of constantly trying to pierce his perimeters (p.169).

Throughout the account there are references to the beneficial effects Greenfeld experienced through meeting other parents and their retarded or autistic children. For example, "...we left the Rimland home feeling hope about the future" (p.168).

The account ends, when Noah is five years of age, with Greenfeld commenting on how it had become much easier to cope with Noah by this time. The reader is left with the impression that, after the crisis, normal family life has resumed.

Subsequently, Greenfeld (1978) has updated his account, describing the period in which Noah moves from five to twelve years of age. Again the account is presented in the form of extracts from his diary, which document vividly

the continued strain which caring for Noah placed on family members. In this second book the major theme is one of finding appropriate educational and residential placements for Noah. Early in the book he comments that, "Since Noah is five now that means we should figure on having him for another five or six years at best. Or worst. (p. 10)"

However, at several points in the book the strain of coping with Noah pushes Greenfeld into thinking that the time for Noah to be placed outside the home appears to be near.

The simple truth: Noah can't take care of himself and we can no longer take care of him. We have to find a place for him soon.... In July it will be seven years that we've put up with him (p. 112).

Throughout the book Greenfeld recounts the continual search for a suitable residential placement for Noah, including many visits to potential institutions. But all these institutions turned out to be unwilling to take Noah, or to be too expensive, or were considered unsuitable.

Another constant source of frustration for Greenfeld was Noah's school placement. Throughout the book he

comments on his unhappiness about the teaching Noah receives. Greenfeld is also not impressed by the education his other son Karl is getting, even though he is placed in a group for gifted children. His feelings about teachers in particular, and indeed most professionals involved with Noah, become very negative. Even the assistance with behaviour modification which they received from Loavaas, who was praised in the first book, comes in for criticism in the second.

Greenfeld recounts that Noah continues to have a restricting effect on family life. His tantrums, incontinence, and disturbed sleep are commented on throughout the book. In discussing the wider effects on the family Greenfeld considers that without him, they would probably be living somewhere else, that his wife would have been more productive as a painter, and that there would perhaps have been another child in the family. He describes the sadness he feels about Noah, and how he is apt to become upset and cry in certain situations, such as seeing older mentally handicapped children, or watching the special olympics on television.

However, there are positive aspects of the situation: the pride he takes in Noah's achievements, limited though he considers them to be; the nightly walks they take together by the sea; and the pride he has in his wife,

Foumi, when she establishes a day-care centre for children like Noah.

As Noah approaches ten years of age the Greenfelds begin to place him in respite care for short periods and find that family life becomes more manageable and enjoyable when they do so. But this does not stop Greenfeld experiencing the extremes of emotion concerning his son. On the one hand he comments, " How I love Noah.... He can be so endearing - putting his face up to mine to be kissed"(p. 275). On the other hand he recounts, " A horrible weekend. I thought continually that soon I will have to kill Noah" (p. 299).

The search for an appropriate residential placement goes on right up to the end of the book when, on the final page, Greenfeld states,

I bemoan the kids, especially Noah, but I cannot visualize a life without him. Just as I cannot visualize a life without Karl. Without Foumi. No matter what I say. No matter what I do, I love Noah more than I can say or do. I want him in my house. I want him in my home. That is his place (p. 307).

So although the account concludes in a positive tone, the reader is left with the impression that Greenfeld has

become somewhat embittered by his experiences of parenting Noah. He seems to feel that life has dealt him an unfair blow, and the overall tone of this book is more negative than the first one.

The next account by a father of his experiences of parenting a child with a disability was that by Charles Hannam (1975). Hannam's account of his own experiences comes as an introduction to reports of interviews he conducted with several families of mentally handicapped children. It is the only account written by a father in the U.K., which could be located. The book has subsequently undergone two revisions (Hannam, 1980, 1988) with additions of more interviews and a continuation of Hannam's personal story.

In the first book, written when his son was eight years of age, Hannam frankly and poignantly describes how he reacted to being told, within minutes of the birth, that David had Down's syndrome. He reports experiencing: shock; guilt; resentment; disappointment; anger; and, denial. He discusses the hurt he experiences due to the insensitivity of some professionals and other people. Hannam notes the beneficial effects of the supportive counselling he received and of the support obtained from the special school which David attended. He also comments on the relief he felt when he told his wife about the

disability, and on the difficulty he found in telling other people, especially members of the family. He reports that, when his wife was pregnant with their second child, he was very anxious about the possibility of the child being handicapped, but that the birth of this child and of the third son, were very important in helping him come to terms with David.

A theme which runs through this first account is the conflict between the author's beliefs and values, and his feelings about his son. This is exemplified by the conflict between the powerful emotions, of wanting to kill the baby, and his beliefs about the sanctity of human life, plus his interest in educating children with special needs (Hannam was at that time a lecturer at a College of Education). A further conflict was between his views on how children's behaviour should be managed, and the strict discipline he found himself using with David.

I hate the thought of bringing up children to unquestioning obedience or squashing their initiative, but then I am always doing what conflicts with all our beliefs (p.36).

The author mentions briefly his concern over who would look after David in the future. The account finishes with

Hannam discussing the benefits of professional counselling and talking with other parents.

The second account was written when David was 18 years of age (Hannam, 1980). Hannam reports that David had become easier to live with over the years and was more independent than he had believed possible. However, he experienced the constant strain of supervision and the frustrations of David's repetitive behaviours and limited ability.

The pleasure over small achievements and the recognition of his development was one side of the story, but the clumsy, monotonous tedium of his company was the other (p.42).

A theme running through this second account is the agonizing and ambivalent feelings about putting David into residential care.

A few evenings ago I was thinking again that I could not stand his stupid face; thank God he was going into hospital for three months - if only they would keep him there for good. Then David held out his hand to me and we sat hand-in-hand and I realized that his face isn't stupid all the time, he can smile warmly and he

only looks stupid when he is anxious, and I often make him anxious. (pp.45,46)

In fact, the negative feelings which Hannam had about his son is another theme which runs through this second account. He gives the impression that he feels guilty for not being a better father and that this is exacerbated by him working in the field of special education and having a humanistic philosophy of life. He seems to think that he should feel more positively towards his son and searches for an explanation for why he doesn't. He suggests that, "deep down I have never been able to forgive him for the genetic confusion which produced him" (p.49).

When David did finally go into long-term care, an eventuality prompted by the collapse of his wife through nervous exhaustion, Hannam reports that he, "cried like a baby" (p.48), touched by the sadness of the situation, tinged with feelings of failure.

The third, brief, account was written when David was 23 years of age (Hannam,1988). By this time David had been living in the hospital for the mentally handicapped for five years and his mother and father had separated. Hannam's contact with David was limited to a fortnightly day's outing from the hospital. He describes his feelings

on these days, as he thinks back over the years spent with David.

The disappointment remains, but now, once a fortnight, there is also real pleasure and enjoyment of each other (p.45).

Hannam's ambivalent feelings about having David in care appear to be re-triggered by news that the hospital is to close, and it is hoped to place him in a hostel.

I wanted to get on with my own life and felt an enormous sense of relief, but the grief remains. Here is a son who cannot come up to my hopes and aspirations (p.46).

The major theme of this last account is to do with Hannam adjusting to, or coming to terms with, his son with Down's syndrome. The emotional tone is much lighter than in the previous two accounts. Though concern is expressed about David's future care, a more optimistic picture is painted.

I can accept him as my son and, in his detached sort of way, he seems to acknowledge a relationship which had begun so badly. It is good to know that acceptance and reconciliation are possible (p.47).

Thus, over the course of the three books Hannam has documented the turbulent process he experienced in coming to terms with his son's disability.

The next two accounts by fathers, of their experiences of parenting children with disabilities, were published in 1978 as chapters in a book edited by Turnbull and Turnbull (Roos, 1978; Turnbull, 1978). The first chapter to be discussed is that written by Roos.

Like Hannam, Roos was also professionally involved in the field of disability before his child was born, having trained as a clinical psychologist. But unlike David, his daughter Val was not diagnosed at birth. Roos vividly describes the agonizing process he and his wife went through in order to confirm that his daughter was mentally retarded. He emphasises that, because of his training and position, they should have found it easy to obtain competent professional assistance, but instead they were forced to experience a series of traumatic interactions with professionals which echoed the complaints he had so often heard from other parents.

Our pediatrician next referred us to a neurologist. Since this worthy professional was a consultant to the large state institution for the retarded of which I was the superintendent, I felt confident that he would

immediately recognize the obvious signs of severe retardation in our child. Imagine my consternation when...the learned consultant cast a baleful eye on my wife and me and informed us that the child was quite normal. On the other hand, he continued, her parents were obviously neurotically anxious and he would prescribe tranquilizers for us (p.246).

Roos goes on to discuss how, from his experiences, he developed concepts of 'referral ad infinitum', 'professional ignorance' and 'the deaf ear syndrome'. His account manages to be remarkably humorous despite all the frustrations he describes.

Roos reports that, although he experienced some of the reactions he observed in other parents, such as shame, ambivalence and depression, he was more preoccupied with existential conflicts such as inequity, aloneness and loss of immortality, which he has written about in the professional literature (Roos,1963) and which were discussed in chapter one.

The second chapter was written by Turnbull (1978) when his son Jay was eight years of age and was updated when Jay was 16 (Turnbull, 1985). Like Roos, Turnbull recounts, in vivid detail, the agonizing process which he and his wife went through in obtaining a diagnosis of severe

retardation. He was particularly annoyed by the way the professionals involved attempted to keep information from them.

As with Hannam the trigger for deciding to seek residential placement for his son was his wife's breakdown. This occurred when Jay was three years of age. Jay stayed in care for three years during which time Turnbull had become divorced from Jay's mother and had married a psychologist who worked in the field of mental retardation. Turnbull himself is a lawyer by profession and he too had become involved in the field. However, despite their involvement the Turnbolls were taken aback by the consequences of bringing Jay home from the group home where he had been living.

We were advisors in a professional capacity to a host of state and local mental retardation agencies....Sad to say, neither of us was fully prepared for some of what lay ahead. We learned, for example, that the community could be inhospitable. Some friends and colleagues recoiled when Jay went to shake their hands, as though he were contagious.....And strangers, curious about this lad with the strange gait and large head, stared even as he devoured his ice cream cone like an ordinary kid (p.114).

Turnbull ends this first account by commenting that it was not possible to write it "without recalling enormous amounts of pain and an equal quantity of joy" (p.114).

In the updated account Jay was 16 years of age and Turnbull was concerned about his transition from school to adult services. He reported that Jay's behaviour had become more problematic and that changes in his routine would often lead to him having a seizure. Therefore, family activities had to be planned around Jay.

Life without Jay is sometimes far easier for us and for him too. But it is a life lived deliberately without one's son, and that is no reason for joy (p.120).

Turnbull talks about the sadness he feels about his son's condition. About how Jay's disability deprives him of a normal father-son relationship.

Like Roos (1978) Turnbull considers that, "retarded children exacerbate their parents' existential quandries (p.121)." He talks about how having Jay has turned his life upside down and sent him into entirely different directions to what he had anticipated. He considers that Jay has helped him accept his own limitations, thereby adding to his personal and professional integrity. Turnbull also considers that Jay has taught him how to

practise tolerance and endowed him with a reciprocal sensitivity to other people.

The second edition of the book by Turnbull and Turnbull (1985) included a chapter written by George Harris. Harris reports that, although his daughter Jennifer was premature, he had little reason to suspect that she would later be diagnosed as deaf, retarded and autistic. He talks of experiencing 'burning rage' because his daughter is handicapped and of his difficulty in accepting that the world is unjust. He also mentions becoming aware of being affected by unconscious irrational myths, such as that handicap is due to the sins of the fathers, and of experiencing a feeling that his family had been cursed.

He explains that it has been difficult to adjust to Jennifer because he never knew what to expect. Also that he still thought of her as his little girl even after she had started menstruating. He considers that Jennifer has taught him many things, not least how to be silly and enjoy himself, as he had been a rather serious person in the past.

A theme which runs through the account is his concern with finding a suitable long-term residential placement for Jennifer. He reports that at the time of writing, when

Jennifer was 13 years of age, he and her mother had been divorced.

Harris has a doctorate in counselling and is involved in training professionals who work with families of children with disabilities. He has subsequently written a book about his experiences of parenting Jennifer (Harris, 1983).

Another piece of writing by a father appeared as a journal article (Marburg, 1985). It consists of an extremely moving account of a father's reactions to the birth of a child with Down's Syndrome, and the impact of subsequent medical problems on him and his marriage. Galen Marburg recounts that, within a few minutes of the birth of his daughter Laura Lin, the obstetrician told him and his wife that a problem was suspected, so a pediatrician had been called in. He vividly describes the meeting in the recovery room shortly afterwards.

Our pediatrician began, 'Your daughter has Down's syndrome.' It was though a shock went through my head, and everything which I knew vanished from my mind. I couldn't think or remember anything, but I knew that Down's syndrome was something bad (p.7).

A few hours later Marburg was informed that Laura Lin was developing serious medical problems. It was made clear to him that she might not survive but that if she did, would be severely handicapped. Marburg reflected on the situation:

It became clear to me that I was not up to it. Jan, on the other hand, wanted to raise Laura Lin regardless of any future medical difficulties or problems. An enormous rift began to develop in our relationship (p.9).

He recalls the conflicts which he and his wife had over whether to agree to surgery for their daughter's worsening medical condition. Sessions of psychiatric counselling were found helpful but this didn't stop him feeling that their marriage was headed for termination. A few days after extensive surgery Laura Lin died. Marburg recounts, "I was totally stunned. It was as if the earth was shaking beneath me, and my legs were not strong enough to hold me up (p.12)."

Finally, two brief journal articles by fathers were published in 1988. Sal Biondello (1988) discusses how living with his three year old disabled son Zeppy has made him re-consider his values and change from competitive life goals to more social goals.

From Zeppy I have learned.... that it is far more important to traverse the path of life leaving behind a positive impact on those we come in contact with than to be in some way exemplary in achievement (p.43).

James Wilson's (1988) article is an abridged version of the first chapter of a book he was writing about his experiences with his son Sam, who has hydrocephalus. He discusses his shocked reaction on receiving the diagnosis and the reactions of other people when he is out with Sam. Generally he finds that men feel uncomfortable and ignore him, while women will often stop and have a chat.

Summary and analysis of fathers' accounts.

While each of these personal accounts by fathers is quite different, emphasizing the range of reactions which fathers may experience, there are several common themes which run through them. First, nearly all the fathers discuss their initial reactions to the diagnosis of disability and the high intensity of their feelings at this time is evident. A second theme is the process of adaptation which they describe, and the existential conflicts which they experience. Third, is the negative feelings fathers have towards the professionals involved and members of the public. Fourth, is the stress of caring for a disabled child and the consequent negative effects

on their lives, and their marriages. Fifth, is concern about finding suitable care for their disabled child outside the home, particularly in the longer term. Sixth, is the high intensity of the positive and negative feelings which fathers experienced towards their disabled children. Finally, there is an acknowledgement of the personal growth which parenting a disabled child has brought about for some of the fathers.

It is clear that the published accounts by fathers provide valuable insight into their perceptions. Without exception the accounts are poignant and, although there are positive features, focus mostly on the negative aspects of the situation. However, it must be remembered that these writers are unlikely to be representative of fathers of children with disabilities in general. For example, all except four of the fathers cited above had, or were working towards, doctoral degrees. Of the four who didn't, two were professional writers, one was a qualified lawyer, and the fourth had a Masters degree in social work. Thus it is possible that the experiences of these fathers may not be representative of fathers of children with disabilities in general.

In the following section, the research studies which focussed on fathers of children with disabilities, are reviewed.

Published studies focussing specifically on fathers of children with disabilities.

The eleven published studies of fathers of children with disabilities have been separated into two sections. The first section includes studies which have focussed on the effects on fathers of parenting a child with a disability. The second section includes studies which have focussed on fathers' involvement in early intervention or parent education programmes.

In addition there have been six unpublished studies which have focussed on various aspects of the father-child relationship.

The eleven published studies and six unpublished studies will each be briefly described and methodological weaknesses highlighted. First to be addressed are the six studies which have focussed on the effects on fathers of parenting a child with a disability. These six studies were published over a period of thirty-two years, during which time opinions of the role of fathers in family life and the sophistication of consequent research conceptualizations have gone through several changes, as discussed in the previous chapter (Bristol and Gallagher, 1986). A summary of the studies of the effects on fathers is presented in Table 1.

Table 1 (cont.): Studies focussing on effects on fathers.

SUBJECTS				METHODOLOGY			
Author/Year	Purpose	Sampling	Fathers (demographics)	Children	Design	Instruments	Analysis
Collaeger, Cross & Schirman (1981)	to explore the influence of dad on fathers in caring for children with handicaps in: - stress experience - support perceived - time played	- recruited through child's attendance at pre-school centers - slightly larger number of fathers in average groups refused to participate	50 fathers - middle income - agreed to participate - intact family - had been read either successful or average by dad	- age under 5 years - moderately to severely handicapped	- questionnaire survey - comparison of "average" and "successful" groups	- stress - social support - family role - father and child - Schedule of Family Experiences - Family Environment - Global Measure of Satisfaction from the Family	descriptive and inferential statistics
Results	48% of fathers reported yield to major levels of stress - successful fathers more support than "average" - main role of father perceived as provider, nurturer, supervisor - father's role in family home & equipment, recreation and social activities as consequences of child - "average" father would not differentiate as another consequence - father gave their wives a high rating for social support - successful fathers thought they should be more involved with child	Conclusions	- debilitating stress should not be assumed for these fathers - handicapped child change social life of family - father job strong support from spouse and friends - father's role in family follow traditional pattern - general satisfaction with family role except fathers need for more involvement with child	Study Strengths	- one of the few studies to investigate stress and social support with fathers	Study Flaws	- non representative sample to which "average" fathers - use of self ratings and informant families for handicapped children - no control group - measures restricted to self-administrative instruments
Margalit, Lavyer & Grolman (1999)	to investigate the impact of disabled children on their fathers - see data on participation rate	- recruited from fathers living on one of 47 kibbutzim - see data on participation rate - recruited through special education department of the kibbutz movement	44 fathers of disabled children, 74 fathers of non-disabled children - mean age = 44 years - education = 13.6 years	- disabled children were 59 males and 16 female 20 with learning disabilities 19 with mental retardation, 19 emotional disability, 8 with sensory or physical disability - age = 15.9 years - mean = 12.2 years	questionnaire survey with control groups administered to father at home	- family climate - sense of coherence - satisfaction with family life - Sense of Coherence Scale - Family Environment Scale - Global Measure of Satisfaction from the Family	inferential statistics mainly MANOVAS
Conclusions	- the emotional reaction to fathering a disabled child was pronounced, even though the kibbutz provides them with resources for all their material needs.	Study Strengths	- employed control group and large number of subjects	Study Flaws	- restricted range of measures - no data on participation rate or recruitment		

Studies focussing on the effects on fathers.

The earliest published study of fathers of children with disabilities was that conducted by Eisenberg (1957). This was carried out at a time when Bristol and Gallagher (1986) suggest researchers were focusing on how parents cause handicaps in their children. Eisenberg (1957) studied the case notes on 100 fathers of children diagnosed as autistic at a hospital based children's psychiatric service. He found that 85 out of the 100 fathers showed evidence of serious personality disorders characterized by an obsessive, detached and humourless personal style. Whereas a comparison group of 50 fathers who were private patients did not exhibit these personality traits. However, Eisenberg's report is written entirely on the basis of clinical impressions with no attempt to establish the reliability of his judgements. Further, he provides no details of the procedures used to select the two groups of fathers for study, so it is difficult to estimate the extent of any bias in the sampling. Clearly then, considering the prevailing attitudes of the time towards finding pathology in parents, the possibility of biased samples, and findings based on the uncorroborated impressions of one clinician, the reported conclusions from this study must be viewed with a great deal of caution.

The second study of fathers of children with disabilities was published by Mercer (1974) at a time when Bristol and Gallagher (1986) suggest that researchers had become aware that both fathers and mothers could affect, and be affected by, their children. Mercer (1974) reported the findings of two case studies of fathers whose daughters had been born with a defect. One father, whose daughter was born with a cleft lip, had difficulty expressing grief, his male identity appeared threatened, and he was unable to be empathic with and supportive of his wife. Whereas the other father, whose daughter was born with Down's syndrome, openly expressed feelings of grief and concern, was understanding and supportive of his wife, and didn't appear to experience a threat to his identity as a man.

Thus, the study illustrates the possibility of both positive and negative reactions of fathers to the diagnosis of disability. However, since the conclusions of this paper are based solely on clinical impressions of two, non-randomly selected case studies, it is not possible to estimate the generality of its findings.

The third study, published by Erickson (1974) in the same year as that above, focussed on fathers of young children with Down's syndrome. Involved in the study were eighteen fathers of children with Down's syndrome, aged

from 10 months to two years, who attended a child development centre. Three groups of six fathers attended a series of six discussion sessions, each lasting from one and a half to two hours. The agenda for the group sessions were left open so that fathers could talk openly and the author could learn about their concerns and needs.

The major topics discussed by the fathers were their difficulties in accepting the disability, their views about how they were given the diagnosis, and the problems they had in telling other people about the disability. They also expressed concern about the lack of up-to-date information available to them at the time of diagnosis, and about their apprehensions about their children's futures. Also there was some discussion about how they could offer their wives more support. Finally, from comments made by fathers, the author considered that they needed reassurance that their reactions to the children's disability were normal.

However, because these findings were based simply on clinical impressions from discussion groups involving a non-randomly selected sample of fathers it is not possible to estimate the representativeness of these findings with such fathers in general.

The fourth piece of research with fathers of children with handicapping conditions is the much cited study conducted by Cummings (1976). It is one of the few studies of fathers to employ control and comparison groups. As with the above study, this work was carried out at a time when Bristol and Gallagher (1986) suggest researchers were aware of reciprocal causality between parents and their children. Cummings (1976) recruited 240 fathers through contacts with physicians, social agencies and clinics. There were 60 fathers each of mentally retarded, chronically ill and neurotic children, plus 60 fathers of healthy children who were used as a control group. All fathers completed four self-administered tests at home and returned them by post. The tests included measures of self-esteem, prevailing mood, interpersonal satisfactions and attitudes to child rearing. Statistical comparison of scores from the four groups of fathers indicated that fathers of mentally retarded children reported more negative effects than any of the other groups of fathers. Specifically, they were more depressed, had a lower level of self-esteem, more feelings of inadequacy as fathers, and less satisfaction from family relationships.

However, there are two problems with this study which could have serious consequences for the validity of the findings. Firstly, although Cummings provides no details on how the 60 fathers were selected for each group he does

comment that participation rate for fathers was about half that for their wives, who also participated in the research (see Cummins, Bayley & Rye, 1966). Thus, Cummings' results may be biased by the fact that only a relatively small proportion of fathers who were invited to participate in the study actually provided data. Secondly, Cummings provided no detail regarding the level of mental retardation of the children whose fathers participated in the study, which limits the generality of the findings.

The fifth study was conducted by Gallagher, Cross and Scharfman (1981) at a time when effects on siblings and the marital relationship were recognised, in addition to the reciprocal effects between parents and their children (Bristol and Gallagher, 1986). It is one of the few studies to investigate the effects of stress and social support on fathers. Subjects were 50 pairs of parents of moderately or severely handicapped children who were enrolled in a programme for pre-school handicapped children. Subjects were selected on the basis of both parents being present in the home and being willing to participate in the research. Another selection criterion was that they had been rated by staff as 'successful' or 'average' in their adaptation to life with a handicapped child. All subjects completed measures of parental

stress, social supports, parental role function and satisfaction.

The results showed that approximately half of the parents (both mothers and fathers) reported mild, moderate or major stress, whereas the other half did not report feeling stressed. Both fathers and mothers identified limitations in vacations, social activities and recreation whereas only fathers reported sexual difficulties. Mothers and fathers both perceived family roles to be along traditional breadwinner/homemaker lines. In fact there was generally a strong positive relationship between the attitudes of separate spouses to each other. For example, in couples for which high father support for mothers was reported this was reciprocated by the spouse. Both mothers and fathers reported strong support from spouse and friends but not from neighbours. There was general agreement among both parents that there should be more father involvement with their handicapped children.

However, these findings must be treated with caution since there are serious problems with the study. First of all, Gallagher et al. do not say whether the subjects' children were either mentally, physically or sensorially handicapped or a combination of the three. This limits the generalisability of the findings. Secondly, the rating by staff, of parents as successful or average in

their adaptation, as a part of the selection procedure, may have biased the sample. Third, the study did not include a control group of parents without handicapped children so it is not possible to say whether the findings are specific to parents with handicapped children or whether similar results would be found with parents in general. Finally, procedural details, such as how the measures were administered (eg. by mail) were not reported making replication of the study impossible.

The sixth study (Margalit et al., 1989) was conducted at a time when Bristol and Gallagher (1986) consider that researchers viewed families with disabled children as dynamic systems affected by their individual members and by their environments. In fact, Margalit et al. refer to the family system as, " a set of interrelated elements, each of which influences and is influenced by the other (p.92)."

Subjects were 66 fathers of disabled children and a control group of 74 fathers of non-disabled children, matched for personal and child variables, who lived on the same Israeli kibbutzim as experimental group fathers. Both sets of fathers were administered three self-rating questionnaires, which measured: sense of coherence; family climate; and satisfaction with family life. Results indicated that fathers of disabled children viewed their

families as providing fewer opportunities for personal growth and placing less emphasis on supportive relationships. They also expressed significantly lower levels of satisfaction with life, and viewed themselves as less coherent and less confident than the fathers with non-disabled children.

The major strengths of this study are that it employed a large number of subjects and a control group. However, there is a lack of detail about recruitment procedures and participation rates, so that it is not possible to determine the representativeness of the sample of fathers of disabled children. Also, although fathers were seen in their homes, the measures used were limited to three self-rating scales. No interview data were reported. This restricted range of measures, along with uncertainty about the representativeness of the sample, limits the weight which can be attached to these findings.

Summary of findings of studies of effects on fathers.

Three of the six studies found serious negative effects on fathers' psychological functioning including depression and personality difficulties (Cummings, 1976; Eisenberg, 1957; Margalit, et al., 1989). Whereas, two of the studies found that, while some fathers experienced negative effects, others did not (Gallagher, et al., 1981; Mercer, 1974).

Two studies found that the patterns of family life had changed since the birth of the disabled child (Gallagher, et al., 1981; Margalit, et al., 1989). One study found that fathers tended to fill traditional male roles within the families (Gallagher, et al., 1981). Another study found that fathers were concerned about future difficulties regarding their disabled child (Erickson, 1974).

Overall findings from these studies suggests that parenting a child with a disability can lead to fathers experiencing substantial negative consequences. However, it is clear from the studies that this is not the case for all fathers.

Studies focussing on fathers' involvement in programmes.

The five studies discussed below were all published between 1984 and 1986. This was a period in which Bristol and Gallagher (1986) suggested that it was generally recognised by researchers that families with disabled children are dynamic systems affected by their individual members and by their environments. A summary of the studies focussing on fathers' involvement in their children's educational programmes is presented in Table 2.

Table 2: Studies of fathers' involvement.

Author/Year	Purpose	Sampling	Subjects (demographics)	Children	Design	Measures	Analysis	Results	Conclusions	Study Strengths	Study Flaws
Milroy (1984)	to explore factors influencing fathers' participation in early intervention programs	15/19 directors of early intervention programs from throughout USA	no data	age range 0-4 years - study in severely handicapped, behavior-disordered, chronically ill, high risk population	telephone survey, using schedule of directors of early intervention programs	questionnaire - nature of fathers' role - related factors - family structure - fathers' participation - changes in fathers' participation over time - telephone interview	descriptive statistics	- fathers participate in wide variety of activities - fathers tend to participate with mothers - father-child activity tend to be active - father work schedule influenced participation - fathers of more severely handicapped children more likely to participate - older/more educated fathers participate - fathers' participation has positive effect on family functioning - fathers' participation has increased over years - fathers likely to participate in 1-1 activities more than group sessions - fathers at times related better to male staff	- many fathers do want to be involved in early intervention - staff on early intervention programs should increase efforts to involve fathers	- focus on fathers' involvement in the education of their children with disabilities - large number of fathers - focus on fathers' needs	- data based on responses of fathers asked by program directors - no control group
Underwood (1984)	To investigate the needs of fathers of handicapped preschoolers for parent education	fathers recruited through the early intervention centers which their children attended of 393 questionnaires sent out only 165 were returned and 152 (39%) used in the analysis	majority of father (white) and under 40 years 87% were from programs in urban area	30% infants 47% pre-school age 3% no data 91% biological children	Questionnaire survey	question regarding - informative desired - current sources of information desired - format for getting information - interaction - information's activities and services - self awareness of present state of coping - questionnaire developed especially for study	descriptive statistics	- time spent with handicapped child is similar to that for other fathers 83% considered education of child a joint responsibility of both parents - information was delivered on child's education and resources available - for 70% stress was the major source of concern - fathers open to several types of information dissemination - 33% considerably were coping well - 23% concerned with long term impact on family - 46% willing to participate in future programs - many fathers concerned on positive effects	- fathers are interested in their child's education and want to become more involved in a variety of parent educational and information activities - father are more concerned about future educational than current coping	- large number of fathers - focus on fathers' needs	- limited sample possibly unrepresentative - no control group

Table 2 (contd.): Studies of fathers' involvement.

Author/Year	Purpose	Sampling	Subjects (demographics)	Children	Design	Measures	Analyse	Results	Conclusions	Study Strengths	Study Flaws
McHale & Chaswal (1994)	to explore the nature of fathers involvement in the care and treatment of their hearing impaired child	20/25 intact families with one or more children with hearing impairment in Casadua city	20 fathers - mean age 34.1 years - 17/20 employed - 1/20 had some tertiary education - intact family	21 children with hearing impairment - mean age 10.2 years - 15 boys, 6 girls	survey using schedule and rating scale interviews - conducted at home, lasted 90 minutes - interviews averaged - interview schedule prepared specifically for study	<ul style="list-style-type: none"> - fathers involvement with child - fathers involvement in meetings, programs and teaching child 	descriptive statistics	<ul style="list-style-type: none"> - majority of fathers consider they are very much involved with child, and that work commitments do not limit this. - their involvement is different to mothers - no marital conflict due to mother's passing on information to fathers, but fathers do want information and training themselves - fathers want more contact with professionals eg through programs aimed at both parents 	<ul style="list-style-type: none"> - fathers who participated in the program reported less stress and depression and greater satisfaction with social support than severely enrolled fathers 	<ul style="list-style-type: none"> - only study to focus on father of hearing impaired children 	<ul style="list-style-type: none"> - no control group - small unrepresentative sample - questionnaire structure may have elicited more socially acceptable responses
Volney, Frewell, Meyer & Greenberg (1983)	to evaluate whether fathers program would reduce depression, increase self-esteem and social support	fathers who participated in fathers program, for 13 years (n=7); severely enrolled (n=16)	21 fathers - 65% of fathers had some tertiary education - all were white and middle class - intact families	<ul style="list-style-type: none"> - mean age of children 22 years - most moderately delayed - n=20 had Down's Syndrome 	<ul style="list-style-type: none"> - questionnaire survey - comparison of severity enrolled and fathers 	<ul style="list-style-type: none"> - depression - family relationships - satisfaction with social support - stress - grief and information inventory (short form) - Family Environment Scale - Inventory of Parent/Experiences - Questionnaire on Resources and Stress (short form) - Parent Needs Inventory 	<ul style="list-style-type: none"> - statistical comparison using ANCOVA 	<ul style="list-style-type: none"> - program fathers had lower depression - program fathers had better family relationships - program fathers were more satisfied with the social support they received - program fathers reported less stress - program fathers had lower levels of grief and greater knowledge of local resources and child development 	<ul style="list-style-type: none"> - fathers who participated in the program reported less stress and depression and greater satisfaction with social support than severely enrolled fathers 	<ul style="list-style-type: none"> - first study of effects of a fathers program 	<ul style="list-style-type: none"> - small unrepresentative sample - no control group - newly enrolled fathers had younger children and therefore have less time to adapt - both groups had low stress and high life satisfaction
Volney, Frewell, Greenberg, Desmond & Meyer (1984)	to evaluate the effects of a Fathers Program on stress and coping ability	fathers from intact families who attended the Fathers Program in Seattle	45 fathers - mean age = 30 years - a high percent has a Bachelor degree	<ul style="list-style-type: none"> - age range = 0-5 years - majority were mildly or moderately handicapped - over half of them had Down's Syndrome - about equal numbers of boys and girls 	<ul style="list-style-type: none"> - pre-post test, using questionnaire instruments 	<ul style="list-style-type: none"> - depression - family relationship - satisfaction with social support - stress - grief and information inventory (short form) - Inventory of Parent Experiences - Parent Needs Inventory - Questionnaire on Resources and Stress 	<ul style="list-style-type: none"> - multivariate and univariate statistical analysis of pre and post scores 	<ul style="list-style-type: none"> - decrease in father's depression stress and grief - increase in father's social support - fathers with lower stress had more satisfying friendships - fathers used for information decrease - fathers information need lower the greater their attendance at the program - fathers pessimism about the future increased - SEFAM Information Needs Measure - Family Environment Scale 	<ul style="list-style-type: none"> - fathers who participated in the program reported less stress, depression and grief, and greater information, satisfaction with social support, and pessimism about the future 	<ul style="list-style-type: none"> - one of first studies of a fathers group experience - focus on father of young children - pre-post design 	<ul style="list-style-type: none"> - unrepresentative sample - no control group

The first study to be reviewed in this section was that conducted by Linder and Chitwood (1984). The stated aim of this study was to investigate the needs of fathers of handicapped pre-school children for parent education. Subjects were recruited through the early intervention centres which their children attended. 393 questionnaires were distributed to fathers but only 152 (39%) were returned sufficiently completed to be included in the analysis. Questionnaire items focussed on: the information needed; the desired formats for information dissemination; current sources of information; and, a self-assessment of fathers' present state of coping.

Results indicated that fathers required specific information about their child's education and the resources available, and that they were open to various formats of information dissemination. 70% of fathers reported that their wives were their major source of information. 33% considered that they were coping fairly well with parenting their handicapped child. 23% reported that they were concerned about the long-term impact of the disability on the child and their family. However, the generalizability of these results are limited by the low response rate of fathers who were surveyed (39%). This suggests that the fathers who responded may not have been a representative sample of this population.

Another study, published the same year (Markowitz, 1984), was carried out to explore the factors influencing fathers' participation in early intervention programmes for children with mild to severe handicapping conditions. Directors of such programmes throughout the U.S.A. were surveyed by telephone in order to determine the nature of, and factors related to, fathers' participation. Also included in the telephone survey were questions about the reactions of family members to fathers' participation, and about changes in fathers' participation over time.

Results suggested that fathers did take part in a wide range of programme activities, mostly along with their wives. Fathers of more severely handicapped children and those who were older or more educated were more likely to participate. It was considered that participation of fathers has positive effects on family functioning and that the proportion of fathers involved with programme activities has increased over the years. However, it must be noted that these results are based entirely on the impressions of fathers gained by programme directors, without any data being provided by fathers themselves. This poses serious questions about the validity of these findings.

A third study (McNeil and Chabassol, 1984), published in the same year, was conducted to explore the nature of

fathers' involvement in the care and treatment of their hearing impaired children. Subjects were fathers from twenty out of twenty-five intact families with hearing impaired children in a Canadian city. A telephone survey was conducted in which fathers were asked five open-ended questions about their involvement with their child with hearing impairment, and five 'yes/no' questions about their involvement in the child's educational programme. In addition, they were asked to complete a thirteen item rating scale covering similar topics to the above.

The majority of fathers considered that they were very much involved with their hearing impaired child, that this involvement took a different form to that of their wife, and that work commitments did not limit it. Fathers did not consider that marital conflict was caused by mothers passing on information about the child, but did want more contact with professionals, mainly through programmes aimed at both parents. Many fathers were worried about vocational opportunities, others reported being embarrassed in public by the child. Some fathers reported that they had become closer to their hearing impaired child than to their other children.

However, these results must be viewed with caution as they are based on a small, unrepresentative sample of fathers of children with hearing impairment.

The fourth study was conducted by Vadasy et al. (1985). Subjects were 23 fathers of young handicapped children (20 with Down's Syndrome) who were involved in a university based programme for fathers. Seven fathers had been in the programme for one to three years, whereas the other 16 were newly enrolled. All fathers were administered measures of depression, family relationships, social support, stress and self-concept (the first four of these were also completed by their wives). Results showed that fathers who participated in the programme reported less stress and depression and greater satisfaction with social supports than newly enrolled fathers. The wives of fathers who had taken part in the programme reported a similar pattern of gains over the wives of newly enrolled fathers. Thus, it appears that the fathers' participation in the programme had beneficial effects on their wives.

However, enthusiasm about these results must be tempered by an awareness of the limitations of the study. Firstly, the sample size was quite small (n=23) and non-randomly assigned into the two groups. In fact, newly enrolled fathers had younger handicapped children than fathers already in the programme. This factor alone could be responsible for the differences between the groups and therefore poses a threat to the validity of the results. Secondly, the lack of a control group prevents statistical comparison with fathers of non-handicapped children. In

fact, the authors report that both groups of fathers appeared to have relatively low levels of stress and high life satisfaction which they suggest is possibly due to their higher than average levels of income and education. Thirdly, the authors report that the literature suggests that stress levels are higher in parents of older and more severely handicapped children. If this is indeed the case then, since the children in this study are of pre-school age and are reported to be only moderately delayed with few medical complications, these factors could also account for the lower stress levels found.

The fifth study (Vadasy et al., 1986) was a follow-up evaluation of the effects of the fathers' programme considered above. In this study a pre-post test design was used to investigate the effects of the programme on fathers' stress and coping ability. 45 fathers of young children with disabilities, over half of whom had Down's Syndrome, took part in the study. Fathers (and their wives) were administered questionnaire measures before and after their involvement in the programme.

Results suggested decreases in fathers' grief, stress and depression following the programme. There was also a decrease in their needs for information about their disabled child, and an increase in satisfaction with social support and in pessimism about the future. For

their wives there was a decrease in stress and depression, and an increase in satisfaction with social support. However, these findings must also be interpreted cautiously as this study suffered from similar limitations to the earlier one. That is, the sample was small and unrepresentative, there was no control group, and the age-range of the children was quite restricted.

Summary of studies of fathers' involvement. All three studies of fathers' involvement in the early care and development of their disabled children found the majority of fathers to be interested in their children's education programmes (Linder and Chitwood, 1984; Markowitz, 1984; McNeil and Chabassol, 1984). In the first two of these studies fathers sought greater involvement in their child's programme, whereas in the third, fathers considered they were already heavily involved. In two of the studies (Linder and Chitwood, 1984; McNeil and Chabassol, 1984) fathers were more concerned with future difficulties than with current coping.

Both studies evaluating fathers' programmes (Vadasy et al., 1985 and 1986) found positive effects on fathers, including reduced stress and grief, along with increased satisfaction with social support. However, they also found that fathers were more pessimistic about the future.

Overall findings from these studies suggest that fathers want to be involved with their disabled child's educational programme, and that they can benefit from involvement in fathers' programmes. They also suggest that worry about future difficulties regarding their disabled child is a significant concern for fathers.

Unpublished studies of fathers.

The first three of the six unpublished studies, described below, were carried out at a time when Bristol and Gallagher (1986) suggested researchers were aware of the reciprocal effects between parents and their children (Delaney, 1979; Mitchell, 1980; Shannon, 1979). Whereas, the other three unpublished studies were conducted in the period when Bristol and Gallagher suggested researchers would consider families to be dynamic systems affected by their individual members and their environments (Gleason, 1989; Roth, 1985; Schwartzman, 1983). A summary of the six unpublished studies of fathers is presented in Table 3.

The aim of Delaney's (1979) study was to investigate the theory that increasing fathers' awareness of child development would facilitate attachment between fathers and their handicapped infants. Seven fathers of severely handicapped infants were recruited through a programme providing services for their children.

Table 3: Unpublished studies of fathers.

Author/Year	SUBJECTS			METHODOLOGY			Study Strengths	Study Flaws			
	Purpose	Sampling	Fathers (demographics)	Children	Design	Instruments			Analysis	Results	Conclusions
Doherty (1979)	to investigate the theory that involves 8 fathers' involvement in child development facilitates attachment between father and handicapped child	recruited from a program at a school for children with handicaps	7 fathers	7 children all severely handicapped	one-on-one AB design, 2 baseline observations, 5 observations during 2 hour sessions	10 minutes video-taped observations of father-child interactions - observation schedule designed specifically for study	statistical regression analysis and ANOVA	statistically significant declines in ignoring behavior (frequency and duration) between baseline and intervention sessions - no significant changes in other variables	increasing fathers' awareness of children's development significantly reduced amount of ignoring behavior on part of fathers	employed observations of father-child interactions	small sample - All designs not adequate to show change was due to intervention - no follow up trial period of intervention time
Skuse (1979)	to investigate fathers' interactions with their handicapped children	recruited through pre-schools, social agencies and pediatricians - all fathers from 2-parent family and within SES	29 fathers - 14 fathers of handicapped children - 15 fathers of non-handicapped children	- aged 3-5 - 14 with handicapped conditions - 15 with non-handicapped conditions - all attended local pre-school programs	group comparison	- videotaped time sample observation of father-child interactions and recorded on unannounced playroom - interviews in playroom re: frequency of participation in activities and curricula activities	- blind analysis of videotape observations - videotape and unstructured analysis - observation and interview scheduled specifically designed for study	the hypothesis that fathers of handicapped children did not interact in curricula or non-curricula activity at any different frequency than fathers of non-handicapped pre-school aged children	employed concealed group - employed observations of father-child interactions	small unrepresentative sample	
Schvartzman (1983)	to investigate fathers' interaction with typical children	recruited through data on fathers of normal 5-year olds taken from a published study	2 fathers plus data on fathers of normal 5-year olds taken from a published study	2 x 5 year old sons with pervasive developmental disorder	group comparison	rating of video observations of father-child interactions - rating of observations using the Interpersonal Behavior Construct Scale	analysis of rating on observation scale	fathers of D.D. children found to be more controlling and physically intrusive than fathers of non-handicapped children	employed observations of father-child interactions	no data on recruitment - small unrepresentative sample	
Roth (1983)	to investigate the patterns of involvement of fathers in activities related to school needs and to analyze the coping strategies used by fathers to manage stress	recruited through early intervention programs of children enrolled in	50 fathers	children all under 6 years of age	interview survey	No details provided	No details provided	fathers of first-born children had a higher level of involvement - four patterns of fathers involvement emerged 1. father highly involved and/or concerned about the needs, interests and behaviors of fathers in a more planned way 2. fathers moderately involved 3. fathers with low involvement	focus on father involvement and stress management	unrepresentative sample of fathers	

Table 3 (contd.): Unpublished studies of fathers.

Author/Year	SUBJECTS			METHODOLOGY			Conclusions	Study Strengths	Study Flaws	
	Purpose	Sampling	Fathers (demographics)	Children	Design	Instruments				Analysis
Chasen (198)	to investigate the roles adopted by fathers of handicapped children: the consequences of these	recruited through the family support services for which the author worked 71% of fathers contacted agreed to interview 22/41, 3 couldn't be used	29 fathers selected on basis that they were of low S.E.C.	aged 6 years or under severely handicapped	interview survey 24/29 conducted in fathers homes	in depth interviews, audio-taped	qualitative analysis - analyse of taped interviews	<ul style="list-style-type: none"> - fathers generally fill traditional roles etc involvement with their children - they don't take much responsibility for child care from mothers - fathers experience stress because of the tension between the role they adopt and the needs of the handicapped child and their wives - fathers identify their wives as their major source of support re their child 	<ul style="list-style-type: none"> - employed in-depth interview - involved fathers of low S.E.C. 	<ul style="list-style-type: none"> - because of homogeneous sample of low S.E.C. fathers being severely handicapped children groups, stability of results are limited
Mitchell (1983)	to investigate fathers interactions with or without their Downe Syndrome children	recruited through early intervention program, children enrolled in	16 fathers, including 8 fathers of Downe Syndrome children	2 children with Downe Syndrome 8 matched on basis of social maturity	group comparison by questionnaire and home observation	Talbot's Adaptability Scale - Child's Psycho-social Inventory - Observation II Home	adjustment - adaptability - observation score and Checklist	<ul style="list-style-type: none"> - fathers of Downe Syndrome children did not differ from other fathers in other variables or other activities - they were more likely to be found talking to their children and to be watching TV 	<ul style="list-style-type: none"> - employed control group - used observational measures in addition to questionnaire 	<ul style="list-style-type: none"> - small sample possibly unrepresentative

A time series AB design, with fortnightly videotaped home observations, was used to assess changes in father-child interaction. In addition to conducting two baseline measures, 10 minute observations were also carried out during five two hour intervention sessions. The results suggested that increasing fathers' awareness of their children's development significantly reduced the amount of ignoring behaviour on the part of fathers.

A major strength of this study is that it is one of the few to employ actual observations of fathers' interactions with their disabled children. However, a major limitation of the study is in the use of an AB design, which is not adequate for establishing that the decrease in ignoring behaviour was due to the intervention alone. There are many other plausible explanations for this result including the increased attention which fathers were receiving. Also, the sample of fathers was small and non-randomly selected, and therefore probably unrepresentative. Finally, the period of intervention was short (10 weeks) and no follow-up measures were reported, making it impossible to assess the durability of the change.

The second study reviewed (Shannon, 1979) was another to employ direct observations of father-child interactions. The aim of this research was to study

fathers' interactions with their pre-school handicapped children. 29 father-child dyads were recruited through pre-schools, pediatricians and social agencies. All children were aged from 3 to 5 years and attended pre-schools in the same city. 14 of the children had handicapping conditions, 15 did not.

Father-child dyads were observed interacting in a playroom setting in both structured and unstructured situations. Observations were videotaped and rated blind with regard to the frequency of fathers' touching, looking, gesturing and vocalizing behaviours. Fathers were also interviewed regarding their participation in various nurturance and caretaking activities.

The results suggested that the fathers of children with handicapping conditions did not differ from the other fathers, in their interactions with their children, or in the frequency of their participation in nurturance or caretaking activities. However, one limitation with this research is the small size, and non-random selection, of both groups of fathers. Another limitation is the restricted age range of the children involved in the study.

The central question in Mitchell's (1980) study was whether fathers of developmentally delayed children

differed from other fathers in their parenting of these children. Eight fathers of children with Down's Syndrome were recruited through the early intervention programme in which their child had been enrolled. A further eight fathers with non-disabled children, matched with the experimental children on the basis of social maturity, were used as a comparison group.

Both groups of fathers completed questionnaire measures of adjustment and adaptability. Also, observations of father-child interactions were carried out in the homes of both groups of fathers, just prior to the children's bedtimes. Recording of observations was by both narrative notes and coded checklists.

The results of the study indicated that there were no significant differences between the two groups of fathers on adjustment or adaptability. Also, the interactions of the fathers with their children were found to be quite similar, except that fathers of children with Down's Syndrome were more likely to be found teaching their children or watching television.

The strengths of this study were that observational measures were included in addition to questionnaires, and that a comparison group was employed. However, the results

must be viewed cautiously as they are based on data from small, non-randomly selected samples of fathers.

The fourth study reviewed also included direct observations of father-child interactions. Schwartzman's (1983) study aimed to investigate the nature of the interactions between fathers and their atypical children. Two fathers of 5 year old boys with pervasive developmental disorders were studied. Ratings of videotaped father-child interactions were compared with published data on the interactions of fathers and non-handicapped 5 year olds.

Results suggested that the fathers of developmentally disordered children were more physically intrusive and more controlling than fathers of non-handicapped children. However, because of the small sample, and lack of an actual comparison group on which the same measures were used, this finding must be viewed with caution.

Roth (1985) investigated the patterns of involvement of fathers in activities related to their children with special needs. 50 fathers of children with special needs under 6 years of age were recruited through the early intervention programme in which their children were enrolled. The results of interviews conducted with these

fathers suggested that there were four main patterns of involvement.

Some fathers were highly motivated, interested and involved in activities with and for their children with special needs, such as being present during home visits. Other fathers were involved, it seemed by necessity, in these activities. Yet other fathers were moderately involved but left most things regarding their child with special needs to their wives. Finally, some fathers had low, or almost no, involvement in activities with and for their children with special needs. An additional finding was that fathers with higher levels of involvement were more likely to have first born children with special needs. However, these findings must be viewed with caution since they are based on a possibly unrepresentative sample of fathers.

Gleason's (1989) study investigated the roles adopted by fathers of handicapped children and the consequences of these roles for the fathers. 29 fathers were recruited through the family support service for which the author worked. Fathers were selected for study on the basis that they had a low socio-economic status and had a severely handicapped child under the age of six years. Fathers were interviewed in their homes and a qualitative analysis of the audiotaped interviews was carried out.

Results indicated that fathers tended to fill the traditional roles of breadwinner, support for mother, child socializer and playmate. Fathers tended not to take much responsibility for child care from their wives. This typically led to them experiencing stress because of the conflict between this role and their children's and wives' needs for assistance. Most fathers were trying to manage this conflict by using denial. They appeared to want to adapt their roles in order to better meet their children's needs but seemed not to know how to go about this. A few fathers, however, had moved away from traditional roles and adopted more expressive relationships with their handicapped children.

Gleason's study is one of the few studies of fathers of children with disabilities which have included a qualitative analysis of in-depth interviews. One limitation of the study was the lack of a matched comparison group of fathers. Without this it is not possible to know whether this pattern of roles is due to the presence of a disabled child or to other factors, perhaps related to the fathers' socio-economic status. Also, by specifically focussing on fathers from families with low socio-economic status the ability to generalize the findings to a wider group of fathers is somewhat limited.

Summary of findings from unpublished studies. Of the three studies which investigated fathers' interactions with their disabled children, as compared with fathers of non-disabled children, two found differences (Mitchell, 1980; Schwartzman, 1983) while the third did not (Shannon, 1979). The fourth study found that fathers differed markedly in their levels of involvement with their disabled children (Roth, 1985). The fifth study found that fathers adopted traditional roles which seemed to create conflict in the family (Gleason, 1989). The sixth study found that the level of fathers' involvement with their disabled children could be increased by making them more aware of the children's development (Delaney, 1979).

The overall findings of these studies do not reveal any clear pattern regarding fathers' interactions with their disabled children. The only common theme is one of a diversity of levels and types of interactions of such fathers and children.

Summary of methodological problems with the seventeen studies of fathers of children with disabilities.

The seventeen studies which have been reviewed above demonstrate that the level of sophistication in research on fathers of children with disabilities has increased

over time, in line with Bristol and Gallagher's (1986) evolutionary sequence, which was discussed in Chapter One. However, all of the studies exhibit serious weaknesses.

A major weakness, which is common to all seventeen of the studies, is that the subject groups are either small and/or are inadequately sampled. Subjects are therefore unlikely to be representative of fathers of disabled children in general. Related to this, for the 14 studies in which the ages of the disabled children were indicated, 10 of these reported the children to be less than six years of age. Thus, most of the research has been conducted with fathers of young children, which limits the generalizability of the findings.

Another weakness is in the research designs which were employed in some of the studies, such as: case studies (eg. Mercer, 1974); a time series AB design (Delaney, 1979); and pre-post test designs without control groups (eg. Gallagher et al., 1981; Vadasy et al., 1986). With these designs it is not possible to say whether the reported effects are due to the factors suggested or to confounding variables (Campbell and Stanley, 1963; Cook and Campbell, 1979).

Ten studies used survey methodology. However, only one published study (McNeil and Chabassol, 1984) and two

unpublished studies (Gleason, 1989; Roth, 1985) employed in-depth interviews. The other studies used mainly self-rating questionnaires and mostly included only a restricted range of measures.

Also, it is notable that all but one of these studies were carried out in North America. One study was conducted in Israel, but none in the United Kingdom. Therefore, it is possible that there is a North American cultural bias to the reported findings which may limit their generalization to fathers from other countries.

Given the limitations outlined above it is clear that a degree of caution must be exercised in interpreting the findings of studies on fathers of children with disabilities.

In the following section the previous reviews of the literature on fathers of children with disabilities are considered.

Previous reviews of the literature.

In addition to the studies discussed above, reviewers of the literature on fathers of children with handicapping conditions, have a reasonable amount of other material available. Additional material on fathers comes from studies of families of children with disabilities which have as a focus: mothers (eg. Cummings et al. 1966); siblings (eg. Grossman, 1972); or marital relationships (eg. Gath, 1977). Another source is studies which have attempted to elaborate differences in mothers and fathers of such children (eg. Gumz and Gubrium, 1972). Finally, there are occasional references to fathers in the vast literature on children with disabilities, upon which reviewers can draw (eg. Lansdown, 1980).

The eight reviews of the literature will now be discussed. This will be followed by a summary of the conclusions regarding effects on fathers about which there is a consensus among the reviewers.

The earliest review was published by Price-Bonham and Addison (1978), and focuses on fathers of mentally retarded children. Their review did not include any of the studies discussed above, but summarized the material on fathers included in the literature on mothers, siblings and father/mother differences. The authors concluded that

mothers and fathers did react differently to parenting a mentally retarded child. They suggested that the emphasis on mothers (which was mainly the case up to that time) should be revised and fathers' attitudes, and roles in the family, should be researched.

Two reviews were published in 1982, one by McConachie in the U.K., the other by Meyer, Vadasy, Fewell and Schell in the U.S.A.

McConachie's (1982) review included material from one of the eleven published studies discussed above (Cummings, 1976) and from the previous review (Price-Bonham and Addison, 1978). She also reviewed considerable material written by fathers themselves, in addition to that gleaned from the literature on mothers, siblings and father/mother differences. McConachie's review focuses on participation of fathers in the family, particularly their involvement with the handicapped child. She states that the literature on fathers of handicapped children up to that time was based mainly on clinical opinions and interviews with mothers about fathers. Further, McConachie notes that the fathers who have been studied, and those whose own accounts have been published, are not representative of fathers overall.

The brief review by Meyer et al. (1982) included material from two of the eleven published studies (Cummings, 1976; Gallagher et al., 1981) and from the previous review (Price-Bonham and Addison, 1978). It is set in the context of a summary of the research on fathers of non-handicapped children which focusses on the reciprocal influences between fathers and infants. The authors consider that the difficulties reported to be experienced by fathers of children with disabilities, and their reported lack of social support, provides a rationale for organizing programmes designed specifically for fathers, such as the fathers' programmes conducted by Meyer and his colleagues (Vadasy et al., 1985, 1986).

Lamb's (1983) review was published one year later and included material from one of the eleven published studies (Cummings, 1976) but neither of the two previous reviews. He summarized research with fathers of non-handicapped children which indicated that the father's role in child development is important and different from that of the mother's. Lamb also included many of the studies on mothers of disabled children, siblings and mother/father differences, covered by the previous reviewers, and came to similar conclusions. He pointed out that, up to that time, most of the research had been conducted with the families of mentally retarded children, and suggested that

attention needed to be paid to families of children with other handicapping conditions.

The other four reviews were all published in 1986. The first to be discussed has been referred to earlier. Bristol and Gallagher (1986) described the sequential evolution of research with fathers in general and exceptional fathers in particular. Their article included material from three of the published studies (Cummings, 1976; Eisenberg, 1957; Gallagher et al., 1981) but none of the previous three reviews. They conclude that very little can be confidently stated about fathers of handicapped children and make a plea for research in this area not to be limited to a single methodology.

The review by Brotherson et al (1986) included material from three of the published studies (Cummings, 1976; Gallagher et al., 1981; Markowitz, 1984) and two of the previous reviews (Lamb, 1983; Price-Bonham and Addison, 1978). The authors emphasise the importance of considering the developmental life stages of the family, and its members, in forming an understanding of exceptional fathers. Comments from fathers of exceptional children themselves are included along with material from much the same research that is included in other reviews.

Meyer's (1986a) review also takes a developmental approach, considering the impact on fathers at the different developmental stages through which the handicapped child progresses. He includes material from four of the published studies (Cummings, 1976; Erickson, 1974; Gallagher et al., 1981; Vadasy et al., 1985), one of the unpublished studies (Delaney, 1979), and three previous reviews (Brotherson et al., 1986; Meyer, et al., 1982; Price-Bonham and Addison, 1978). Meyer points out that, while an increasing amount of information is becoming available on fathers' reactions to the diagnosis of handicap and to their adaptation in the early years of the child's life, research also needs to be conducted with fathers of older children.

Meyer's (1986b) review is the most extensive to date. It uses the widest range of sources of any of the reviews. Four of the published studies are included (Cummings, 1976; Erickson, 1974; Gallagher et al., 1981; Vadasy et al., 1985), three of the unpublished studies (Delaney, 1979; Mitchell, 1980; Shannon, 1979), and six of the previous reviews (Brotherson, et al., 1986; Lamb, 1983; McConachie, 1982; Meyer, 1986a; Meyer et al., 1982; Price-Bonham and Addison, 1978). It also includes a fair amount of material written by fathers themselves (eg. from Greenfeld, 1972; and Roos, 1978).

In this review Meyer again uses a developmental perspective to outline the effects on fathers at different stages of their disabled children's lives. In the course of the review he comes to many of the same conclusions about the effects on fathers as previous writers. However, he does point out that, among such fathers, there will be a wide range of reactions and experiences. He goes on to provide guidelines for professionals with regard to increasing fathers' involvement with their children, and to describe four programmes designed specifically for fathers which were operating in the USA at that time.

Summary of effects on fathers discussed in previous reviews of the literature

From an overview of the eight reviews of the literature to date there emerges a fairly clear consensus of the assertions made regarding the effects on fathers of parenting children with disabilities. These are listed below.

1. Fathers' adaptation to sons with disabilities is not as good as that with disabled daughters
2. Fathers' adaptation is related to the severity of their children's handicapping conditions

3. The stress experienced by fathers of children with disabilities is related to the age of their children
4. The adaptation of fathers to their disabled children is related to: (a) their level of social support
(b) their personality characteristics
5. Social class, educational level and income are inversely related to the stress experienced by fathers of disabled children
6. Many fathers of children with disabilities experience depression and/or personality difficulties
7. Fathers of disabled children tend to experience considerable marital distress and desert the family more frequently than the average.

These seven statements form a reasonably comprehensive summary of the assertions made in the literature about the effects on fathers to date. Each will now be considered in turn in order to consider the evidence upon which these assertions have been made, and to update them in the light of any recent research findings which are available.

Assertion 1: Fathers' adaptation to sons with disabilities is not as good as that to disabled daughters. All eight reviews support this assertion. However, their sources were not any of the 17 studies reviewed above, none of which had reported this finding, but an earlier group of studies, typically those by Farber, Jenne & Toigo (1960), Gumz & Gubrium (1972) and Tallman (1965). All of these studies were conducted in the early phases of the evolution of research on fathers and in each of them comments on sex differences in fathers' adaptation were secondary to their main focus.

The first research findings on this topic were published by Farber, Jenne & Toigo (cited in Farber & Rowitz, 1986). Farber et al. reported that there was a markedly greater impact on fathers if the retarded child was a boy. Later, Tallman (1965) found that, on some of the ratings in his adaptability measure, fathers of boys scored higher than fathers of girls, while on other ratings the opposite was the case. Ratings of fathers of boys showed a greater spread than those of fathers of girls. This led Tallman to suggest that fathers tend to react more in extremes of greater involvement or withdrawal if the retarded child is a boy rather than a girl.

Another study often cited in the reviews, by Gumz and Gubrium (1972), did not report any data on this question,

but merely suggested the possibility that fathers would perceive retarded sons differently from daughters. However, this was enough for their study to be cited by reviewers as supporting the assertion that fathers find it more difficult to adapt to a son with a handicap.

Recent research, conducted by Frey and her colleagues (Frey, Greenberg and Fewell, 1989; Frey, Fewell and Vadasy, 1989) in association with the evaluation studies of the fathers' programme discussed above (Vadasy et al., 1985, 1986), has reported on this topic. 48 fathers of young children with handicaps completed a series of questionnaires, and were interviewed at home, along with their wives. The results indicated that fathers of girls had higher levels of adjustment than fathers of boys. (Interestingly, this was also found to be the case for their wives).

Clearly then, there is some research evidence to support this first assertion, that fathers' adaptation to sons with disabilities is not as good as that with daughters. However, this research evidence is not as strong as the solid consensus in the reviews would suggest.

Assertion 2: Fathers' adaptation is related to the severity of their children's handicapping conditions.

Three reviews support this assertion (Bristol and

Gallagher, 1986; McConachie, 1982; Meyer, 1986a). However, the reviewers cite only a limited amount of research evidence in support of this. McConachie cited only a study conducted by Wishart, Bidder and Gray (1980) which found that fathers' feelings and attitudes were more negative when their children were more severely handicapped. Meyer cited a study conducted by Wikler (1981) which found that fathers' negative perceptions of their disabled children increased as the children's I.Q. scores decreased. He also cited a study carried out by Holroyd and McArthur (1976) which found that mothers of children with autism had higher levels of stress when compared to mothers of children with Down's syndrome.

Bristol and Gallagher cited a study conducted by Tavormina, Boll, Dunn, Luscomb and Taylor (1981) which compared mothers and fathers who had children with various physical disabilities or hearing impairment. The results of this study suggested that fathers of hearing impaired children fared worse than the other fathers. Thus, as with the study conducted by Holroyd and McArthur reported above, this finding was concerned with type of disability rather than severity. This was also the case for the other study cited in this review, that by Cummings (1976), which found that fathers of mentally retarded children were less well adjusted than fathers of chronically ill or healthy children.

However, the recent research carried out by Frey and her colleagues (Frey, Greenberg and Fewell, 1989; Frey, Fewell and Vadasy, 1989) referred to above, found that higher levels of adjustment of fathers of young handicapped children were correlated with higher ability levels of their children. These authors conclude, "It is clear that the severity of the child's disability has a dramatic impact on the experience of mothers and fathers (Frey, Greenberg and Fewell, 1989, p.246)." So, while the research cited in the reviews provides limited evidence to support the second assertion, the findings of this more recent research do add some support.

Assertion 3: The stress experienced by fathers of children with disabilities is related to the age of their children.

Three reviews support this assertion (Meyer, 1986a and b; Price-Bonham and Addison, 1978). The review by Price-Bonham & Addison does not cite any supporting research, but suggests that fathers' stress increases as their disabled children grow older. Both reviews by Meyer cite one of the 17 studies reviewed earlier in this chapter (Cummings, 1976) and a review article (Gallagher, Beckman and Cross, 1983). Meyer reports that Cummings (1976) found fathers of older handicapped children (9 to 13 years) showed slightly lower stress levels than fathers of younger (4 to 8 years) handicapped children. Meyer also reports that Gallagher et al.'s review studies which

suggest that fathers' stress increases as their disabled children grow older. However, an inspection of this review article reveals that the studies reviewed were both conducted with mothers. Therefore, it appears that the research evidence in support of this assertion is extremely limited.

Assertion 4: The adaptation of fathers to their disabled children is related to: (a) their level of social support; (b) their personality characteristics. Two reviews include both of these assertions (Brotherson et al., 1986; Meyer, 1986a). Firstly, Brotherson et al. (1986) and Meyer (1986a) suggest that social support is important in helping fathers adapt to their disabled children, but neither review cites research studies to support their assertions. However, a recent study by Frey, Fewell and Vadasy (1989) found that fathers' adjustment was related to the adequacy of their social network. Further, that it is fathers' satisfaction with social support, rather than the amount of support, which is the important factor.

Secondly, these two reviews also propose that fathers' adaptation to their disabled children is related to their personality characteristics. In support of this assertion Brotherson et al. cite the survey by Markowitz (1984), of 15 directors of early intervention programmes in the USA, which suggested that the values and attitudes of fathers

were key factors in the level of their participation in their children's educational programmes. Meyer cites early studies by Call (1958) and Illingworth (1967) to support the suggestion that fathers who view their disabled children as extensions of their egos or threats to their self-concepts have more difficulties in adjustment. However, the study by Call was based entirely on clinical impressions gained from small group discussions with parents, and Illingworth's conclusions were also based on clinical impressions, from his work with parents of mentally handicapped children. Therefore, it appears that the research evidence in support of these two assertions is extremely limited.

Assertion 5: Social class, educational level and income are inversely related to the stress experienced by fathers of children with disabilities. Three reviews support this assertion (Lamb, 1983; Meyer, 1986a and b). Lamb reports that both Farber (1959) and Grossman (1972), in their studies of the siblings of retarded children, suggested that lower-class parents were more adversely affected by the birth of retarded children than middle and upper-class parents. However, in a recent review of this literature, Farber and Rowitz (1986) interpret the findings of the above two studies as suggesting that, on most aspects of functioning, stress levels were higher in higher-class families than in lower-class families.

Both Meyer's reviews assert that class, education and income are inversely related to stress in parents of children with special needs. In support of this he too cites the studies by Farber and Grossman discussed above. In addition, he cites a study by Moore, Hamerlynck, Barsh, Spieker and Jones (1982). These authors conducted a survey of 448 parents of young handicapped children, 86% of whom were mothers. Findings indicated that parents in the higher income group reported lower stress levels, but parents at the higher educational levels reported higher stress levels. Therefore, the research evidence in support of this assertion is somewhat equivocal.

Assertion 6: Many fathers of children with disabilities experience depression and/or personality difficulties.

Six of the reviews support this assertion (Bristol and Gallagher, 1986; Brotherson et al., 1986; McConachie, 1982; Meyer, 1986a and b; Meyer, et al., 1982). Five of the reviews cite only the study by Cummings (1976) as providing supportive research evidence, whereas the sixth, by Bristol and Gallagher, also cites the study by Eisenberg (1957). As discussed earlier in this chapter, findings in the Eisenberg study were based entirely on clinical impressions of a non-random clinical sample of fathers. While the study by Cummings used more rigorous methodology, it was still flawed by the involvement of non-representative samples of fathers and by the

restricted range of measures employed. It seems unwise to afford the study the degree of credibility attached to it by the six reviews, especially in view of absence of other studies which have replicated these findings.

In fact, a recent study, conducted by Bristol, Gallagher and Schopler (1988), has reported contrary findings. Bristol et al. studied 31 fathers and mothers with developmentally disabled boys, and 25 with non-disabled boys. Fathers and mothers separately completed questionnaires and were interviewed in their homes. Findings indicated no significant differences between the two groups of fathers on a test of depression. Therefore, it is considered that the research evidence in support of the above assertion is quite limited.

Assertion 7: Fathers of children with disabilities tend to experience considerable marital distress and desert the family more frequently than the average. All eight reviews include this assertion, and each cites two or more of the same group of studies as providing research evidence in support. Frequently cited is Gath's (1977) comparative study of 30 mothers and fathers of infants with Down's Syndrome, and 30 mothers and fathers of nondisabled infants. Gath found that two of the marriages in the Down's Syndrome group had split up, and in a further six of these families there were severe marital difficulties.

Whereas, in the control group there was no marriage breakdown and a lower overall level of marital problems.

However, Gath also reports that, although all negative measures were higher in the Down's Syndrome group, so were all positive measures. She reports that almost half of the parents felt drawn closer to their partner and considered their marriage to have been strengthened by parenting their disabled child. Also, in a later study, not cited in the reviews, Gath and Gumley (1984) found that there were no significant differences on ratings of marital satisfaction between a group of mothers of children with Down's syndrome and a matched control group of mothers of non-handicapped children.

Other frequently cited British studies, by Holt (1958), Lonsdale (1978) and Tew, Payne and Laurence (1974), are reported in the reviews as having found high levels of marital difficulties in families who have disabled children.

Holt (1958) surveyed 201 families with mentally handicapped children in Sheffield in 1955. He reported that, in 12 (6%) of the families there was a high level of marital distress which was due to the presence of the handicapped child. In a further 10 (5%) of the families the parents had separated, but for 7 of these he

considered that this was not due to the presence of the handicapped child.

Lonsdale (1978) surveyed 60 families of children with handicapping conditions in Plymouth in 1976 and 1977. She found that 28% of the parents felt that their marriage was not affected, 17% felt that it had been improved, and 55% felt that their relationship had been strained by parenting their handicapped child. In five families (8%) the parents had separated.

Tew et al. (1974) studied 59 families of children with spina bifida, and 58 matched control families, in south Wales, for a ten year period between 1964 and 1974. The authors found that, at the time of the child's birth, 70% of parents in both control and spina bifida families were assessed as having satisfactory relationships. However, 9 years later, while the proportion of control parents with satisfactory relationships had risen to 79%, for parents of spina bifida children this had fallen to 46%. Also, while there had been three (5%) divorces in the control group, there were seven (12%) in the spina bifida group.

Two North American studies are also frequently cited by the reviewers as providing evidence to support the first part of this assertion (Reed and Reed, 1965, Love, 1973, both cited in Meyer, 1986a and b). One of the studies

(Reed and Reed) reported disproportionately high desertion rates by fathers of handicapped children. The other study (Love) reported the divorce rate among parents of mentally retarded children to be three times the national average. However, Bristol and Gallagher (1986) in their review suggest that, "Adequate data are not presented in these studies to support these claims...(p.90)." This review also discusses other research (Krause-Eheart, 1981, cited in Bristol and Gallagher, 1986), in which a study of marital happiness was conducted with families of children with various handicaps. The study found that approximately half of the mothers reported that parenting their disabled children had not affected their marriages. The remaining half of the mothers were divided into two approximately equal groups, one of which considered that the children had adversely affected their marriages, while the other half felt that the children had actually strengthened theirs.

In a study not included in any of the reviews, Roesel and Lawlis (1983) surveyed families of children with genetically determined mental retardation. 63 families were randomly sampled from a statewide genetic counselling service, and 50 families were similarly selected on the basis of their children's attendance at a state residential facility for the mentally retarded. The results showed that the divorce rate for the combined

group of families was not significantly different from a comparison group of the state population. However, when considered separately, the divorce rate for the 63 outpatient families was significantly lower than that of the comparison group.

The recent study conducted by Bristol et al. (1988), which was discussed earlier in this chapter, found that a significantly greater proportion of fathers of disabled children, than fathers of non-disabled children, were at risk for significant marital problems. However, this was not the case for their wives, who did not differ significantly from the mothers in the non-disabled group.

Other recent studies, not cited in the reviews, have also found no significant differences in marital satisfaction (Waisbren, 1980) and divorce rates (McConachie, 1986) between parents of disabled children and parents of non-disabled children.

In conclusion, it is considered that, while there is some support for this assertion in the research reviewed, overall findings of research to date on the rates of divorce and marital satisfaction in families who have children with disabilities, are somewhat equivocal.

Conclusion. It is clear from discussion of these seven assertions about fathers that the supporting evidence cited by the reviewers is such that it is difficult to have much confidence in any of them. Thus, it is considered that the current situation regarding research with fathers of children with disabilities is one in which there is now considerable interest but a limited amount of hard data. This has led to a situation in which the above seven assertions may be influencing the field despite being based on inadequate research evidence. What is needed therefore are more empirical studies using sound methodology, especially representative samples of fathers and a wide range of measures. This will provide a more accurate data-based description of the effects on fathers of parenting disabled children. It will also supply research evidence to support or refute the assertions about fathers which have been discussed in this chapter.

Aims of current study.

The aims of this study were two-fold. First, to provide empirical evidence in order to form an accurate description of the effects on fathers of parenting children with disabilities. Second, this study was designed to provide research evidence in order to support or refute the seven assertions discussed in this review.

In order to address the aims of the study, and the methodological weaknesses identified in the studies reviewed in this chapter, the current research included:

- a homogeneous sample, of fathers with children who have a well defined disability

- a large, representative sample of such fathers

- a combination of quantitative and qualitative research methods

- a wide range of measures, including semi-structured interviews and several questionnaire instruments.

Details of the research methodology employed in the current study are presented in the following chapter.

CHAPTER THREE

METHOD

Even when the quantitative reliability of survey research is essential to the research goal, the additional perspective of qualitative research is useful as a rule for the purpose of assuring validity (Kirk and Miller, 1986, p.29).

The research described in this chapter was conducted as part of a larger study of the process of adaptation in a cohort of children with Down's syndrome and their families (Sloper, Cunningham, Knussen, and Turner, 1988). The aims of the larger study were to investigate factors associated with stress and coping in such families, and those factors related to poor child development and behaviour problems.

This smaller study had two aims. First, to provide empirical evidence in order to support or refute the assertions about fathers of children with disabilities which were found in the review of the literature. Second, to provide descriptive data on the experiences of fathers who have disabled children.

Methodology

The research methodology employed in this study was selected in order to address the above two aims. Questionnaire measures were included in order to address the assertions about fathers and a semi-structured interview was used to obtain fathers' perceptions of their experiences. Thus, the study employed both quantitative and qualitative research methods. Also, a large, representative sample of fathers of children, with a well defined disability, were used.

A comparison group of fathers with non-disabled children was not included for two reasons. First, published normative data was available, on the assertions for which comparison with fathers in general were required. Second, resources were insufficient for the investigator to employ a comparison group in addition to a large representative sample.

Sample

Subjects were drawn from a cohort of 181 families of children with Down's Syndrome who had received early intervention from the Hester Adrian Research Centre. The families had all been provided with a home based programme in which they had at least one visit every six weeks until

their child with Down's syndrome was 18 months old. After that, visits were made every 12 weeks until two years and every six months until the child was five years of age.

When established the cohort represented approximately 90% of all births of children with Down's syndrome in the Greater Manchester area, within the period 1973 to 1980. Attrition has been due to deaths of the children, or family relocation, suggesting that the current cohort is a representative sample of such families (Byrne, Cunningham and Sloper, 1988).

Participation rate. Out of the 127 families in the cohort at the time of the study, 5 declined to be involved in the research, and in 11 of them the child's father was not present. 14 of the remaining fathers declined involvement in the study, leaving 97 fathers to be surveyed, a participation rate of 87%.

Regarding participation, Lewis (1986) in his study of 100 men who had recently become fathers achieved a rate of 94%. However, in the seven studies of fathers which he reviewed participation rates ranged from 23% to 72% with a mean of 49%. Lewis suggests that the low level of participation of fathers in past research has been mainly because they are less accessible to researchers and because many of them view themselves as less acceptable

than mothers as sources of data on their families. Each of these difficulties was experienced with fathers who declined to be involved in this study. Some of these fathers were adamant that it was better to talk with their wives. For others (eg. a long distance lorry driver) it was just not possible to arrange a suitable time for the interview.

It is considered that the relatively high participation rate obtained in this study was due to three factors. First, the fathers were aware that their children with Down's syndrome had previously been involved in an early intervention programme provided by the centre which was conducting the current research. Therefore, fathers may have felt under some obligation to participate. Certainly, many fathers commented, at the time of the interviews, how much they had appreciated the help their family had received from the centre in the past. Second, fathers were aware that their wives were also being surveyed at about the same time, so that they were not the only ones in the family who were being interviewed and completing questionnaires. Third, the researchers were prepared to visit fathers at any time of the day or night in order to conduct the interviews.

Social class. The social class distribution of the sample, according to the Registrar General's

Classification of Occupations (1980) and based on the father's current or last occupation, was compared with the national distribution for men of the same age range (OPCS, 1987). As shown in Table 4 the social class distribution of fathers in the study is similar to the national distribution, except for there being slightly more fathers in social class II (managerial occupations) and slightly less fathers in social class III_m (skilled manual workers). However, these differences are not statistically significant (chi-square = 3.8, df = 5, p>0.05).

Table 4: Social class distribution of fathers

	I	II	III _{n-m}	III _m	IV	V
Study Fathers (n=97)	8	27	16	30	15	1
Study Fathers (%age)	8%	28%	16.5%	31%	15.5%	1%
National %age (1985)	7%	21%	17%	38%	13%	4%
Fathers refused(n=13)	1	2	1	8	1	0
Fathers refused(%age)	8%	15%	8%	61%	8%	0%
Total fathers (n=110)	9	29	17	38	16	1
Total fathers (%age)	8%	26%	15%	35%	15%	1%

Key

- I = Professional eg. doctor
- II = Managerial eg. shop manager
- III_{n-m} = White-collar eg. clerical
- III_m = Skilled manual eg. tradesman
- IV = Semi-skilled eg. contract cleaner
- V = Unskilled eg. labourer

The social class levels of 13 out of the 14 fathers, who refused to participate in the study, were obtained from data supplied by their wives. As can be seen from Table 4, fathers from social class III_m are over-represented in this group, which to some extent explains their under-representation in the sample of study fathers. In fact, statistical analysis indicates that the social class levels of fathers who refused to participate were significantly different from those of total sample of fathers (chi-square = 19.6, df = 4, p<0.001).

Previous British studies of families of children with Down's syndrome, born in the 1960s or earlier (reported in Shepperdson, 1988), found that the social class distribution of such families did not differ significantly from that of the general population. However, Shepperdson (1988) in her survey of families of children with Down's syndrome born between 1973 and 1975, found that social classes I and II tended to be over-represented and IV and V under-represented. She suggested that this could be due to women from higher social classes (from the late 1960s onwards, when the contraceptive pill became widely available) having their families later in life, and therefore at a period of greater risk for Down's syndrome, than women from lower social classes. This factor may therefore account for slight trend, in the same

direction, which is evident in the social class distribution of the current sample of families.

Age of fathers. The fathers' ages at the time of the study, which are shown in Table 5, ranged from 27 to 62 years, with a mean of 40.88 years and a standard deviation of 7.19 years.

Table 5: Fathers ages in years at time of study (n=86)

Range	26-30	31-35	36-40	41-45	46-50	51-55	55-62
Number	6	14	23	22	11	8	2
Percent	7%	16%	27%	26%	13%	9%	2%

Educational qualifications. Fathers' educational levels (n=86) ranged from 37 (43%) with no qualifications to 20 (24%) with tertiary qualifications. Details of fathers' qualifications and comparison with national figures for economically active men aged 25 to 49 years (Central Statistical Office, 1987) are presented in Table 6. Although there are slight differences, these were not found to be statistically significant (chi-square = 4.99, df=5, p>0.05).

Table 6: Fathers' educational qualifications (n=86)

Levels (see key)	1	2	3	4	5	6
No. of fathers	37	6	17	4	20	2
% of fathers	43%	7%	20%	5%	23%	2%
National sample	39%	12%	14%	10%	21%	4%

Key 1 = No qualifications
2 = Trade apprenticeships/other vocational training
3 = GCE 'O' level; CSE; City and Guilds
Intermediate Technical Certificate/Final Craft
4 = GCE 'A' level; ONC; OND; High School
Certificate; City and Guilds Final Technical
Certificate
5 = Degree; HND; HNC; Teachers' Certificate;
Membership of Professional Institution
6 = Other

Employment status. At the time of the study 19 (20%) of fathers (n=97) were unemployed. The unemployment figure for men aged 30 to 59 years living in the North West of England was 17% for this period (Central Statistical Office, 1987).

Ethnic grouping. Three per cent of fathers were from ethnic minority groups, as compared with four per cent of fathers nationally (OPCS, 1987).

Representativeness of sample of fathers. In conclusion, it is considered that the high participation rate of fathers, along with the close comparability of the distributions of social class, ethnic groups, educational qualifications and employment status suggests that the sample of fathers who participated in this study was representative of fathers of children with Down's syndrome in general. However, the degree of representativeness may have been somewhat reduced because of an over-representation of lower class fathers in the group of fathers who refused to participate.

Father's relationship to child. 86 (89%) of the subjects (n=97) were natural fathers of the children with Down's syndrome, 5 (5%) were adoptive fathers, 4 (4%) were foster fathers, and 2 (2%) were step-fathers. No distinction was made, in the data analysis, between natural and other fathers. The rationale for this was that, since this sample of fathers was reasonably representative, it could be assumed that similar proportions of non-natural fathers would occur in the general population of fathers who have children with Down's syndrome. Thus, involvement of all fathers in the analyses would be more appropriate than

excluding non-natural fathers, in facilitating generalisation of the findings to fathers of children with Down's syndrome in general.

Children's gender. Of the surveyed fathers' children with Down's syndrome (n=97), 59 (61%) were boys and 38 (39%) were girls. Considering the cohort as a whole (n=127), the gender distribution was 79 (62%) boys and 48 (38%) girls. Therefore the gender distribution for surveyed fathers was closely comparable to that for the whole cohort.

Place in family. 10 were only children, 22 the eldest, 34 the youngest, 27 were middle children and one was a twin (n=94).

Children's ages. The ages of the children with Down's syndrome (n=97) at the time of the study ranged from 6 years 11 months to 14 years 0 months with a mean of 9 years 2 months and a standard deviation of 21 months.

Children's I.Q.s. I.Q. scores estimated from developmental assessments (see below) conducted with the children (n=96), ranged from 7.41 to 62.65 points, with a mean of 40.24 points and a standard deviation of 11.48 points.

Procedure

The initial contact with fathers was made by means of a letter from the research team to both parents requesting their involvement in the project. Then, within a month of their birthdays the children with Down's syndrome were assessed at school. In the same period their fathers were contacted by telephone, and, if agreeable, a date was arranged for them to be interviewed at home. The interviews were arranged approximately two weeks in advance, and fathers were mailed a booklet of questionnaires to complete ready to be collected at the interview.

Child measures

In order to provide a measure of the children's mental ages, and therefore levels of mental handicap, a developmental assessment was carried out with the children at the schools which they attended.

Developmental assessment. The McCarthy Scales of Children's Abilities (MSCA) (McCarthy, 1972) were used to provide a measure of the children's mental ages. The MSCA is a standardised instrument designed to assess the cognitive abilities of children aged 2 to 8 years. It consists of six scales, the combined scores from which are reported to provide a measure of general intellectual

level which is similar to the IQs obtained from instruments such as the Stanford-Binet Intelligence Scale. McCarthy suggested that the MSCA would be particularly useful for assessing the abilities of mentally handicapped children since it contains a wide range of items, many of which are suitable for very young children.

Comparison studies, of the MSCA with other established tests of children's cognitive functioning, involving mentally handicapped children, have found correlations of 0.82 with the Wechsler Intelligence Scale for Children (Revised) (Naglieri, 1980) and 0.69 with the Stanford-Binet Intelligence Scale (Bickett, Reuter and Stancin, 1984), suggesting that the MSCA has a high level of concurrent validity. These studies also found that, despite the high correlations, overall scores on the MSCA tended to underestimate ability levels compared with scores obtained on the WISC-R and Stanford-Binet tests. However this was not of major concern in the current study since the children's ability scores were used only for within group comparisons.

Another potential difficulty was that in this study the children to be assessed were aged from 6 years 11 months to 14 years, with the majority of them outside the age range specified by the MSCA. However, Kaufman and Kaufman (1977) have produced tables which allow for establishment

of a mental age (MA) score for children provided that their level of performance on the MSCA falls within the 2 to 8 year range. This was the case for all except four children whose performance was below the 2 year level. An estimate of the MA of these four children was obtained using the Bayley Scales of Infant Development (Bayley, 1969).

Mental age scores (in months) were converted to IQ equivalents by dividing by the chronological age (in months) and multiplying by 100.

The writer conducted assessments of approximately half of the sample of children with Down's syndrome. The other assessments were conducted by another member of the research team. Reliabilities on the MSCA were established by the two researchers on the first three children to be assessed using an observer-assessor procedure (Cronbach, 1970; Werner and Bayley, 1966). Following this, every twentieth assessment was conducted jointly. Agreement ranged from 90.5% to 97.9% for subtest scores of the McCarthy Scale.

Questionnaire measures

Once interviews had been arranged each father was mailed a booklet consisting of 17 different questionnaires. In

order to address the research questions of the larger study, in which this study was embedded, 11 of the questionnaires included were instruments which focused on the behaviour and development of the child with Down's syndrome, or stress and coping mechanisms within the family. The remaining 6 questionnaires addressed the research questions of interest in this study. These 6 measures are described below and rationales are provided for their use in the study.

Demographics. Instruments were needed to measure the major demographic variables included in the assertions about fathers which emerged from the review of the literature: social class; education; and income. Therefore, questions on these variables were included in the questionnaire booklet.

The most frequently used method of calculating social status in British studies is to obtain fathers' occupations in order to rate social class using the Registrar General's Classification of Occupation (OPCS, 1980). Therefore, questions were included to obtain fathers' occupations, or if they were not employed, their previous occupations (see Appendix A).

Data on fathers' educational levels were collected in a question (see Appendix A) which was based on the

classification system used in national surveys (OPCS, 1980). This system has already been presented in the above section which summarizes data collected on the educational levels of these fathers (see Table 6).

The third demographic variable, income, was considered to be too sensitive a topic to be addressed directly with a British sample of fathers. Therefore, two questions which focused on fathers' perceptions of their family's levels of financial adequacy were included (see Appendix A). A measure of perceived financial adequacy was computed by combining scores on the two questions and dividing by two in order to produce mean scores. High scores were indicative of low levels of perceived financial adequacy.

Adaptation. Three of the assertions drawn from the literature involved fathers' adaptation or adjustment to their children with disabilities. The terms adaptation and adjustment appear to be used interchangeably in the literature, to refer to fathers' reactions to their disabled children, and their progress in the process of coming to terms with the disability, as discussed in Chapter One. Since there is a trend towards using the term adaptation in the more recent literature, this is the preferred term in this thesis.

The Judson Self-Rating Scale (Judson and Burden, 1980) was used to measure the adaptation of fathers to their children with Down's syndrome. The Judson scale was originally designed as a measure of maternal adjustment and attitudes towards children with disabilities. It consists of 22 bipolar items which are rated on a 7-point scale (see Appendix B).

Burden (1978) used the scale in a study of the effects of an early intervention programme on mothers of children with handicapping conditions. He found that the Judson scale was liked by respondents and was easy to score and interpret. He considered that it discriminated well between mothers assessed as having different levels of adaptation. Test-retest reliability was calculated to be 0.89 (using Pearson's r). Also, in a previous study on the cohort of families involved in the current study (Berne, et al., 1988) it was found that mothers' Judson scores were significantly associated with maternal stress, child behaviour problems, poor ratings of mother-child relationships and marital difficulties. The findings of these two studies suggest that the Judson scale provides a reliable and valid measure of maternal adaptation to the disabled child.

The Judson scale has been used in studies of fathers of children with disabilities on at least two previous

occasions. Carter (1984) conducted interviews and obtained completed Judson scales from 24 fathers of children with handicapping conditions. She found that fathers with high scores on the Judson were rated, in the interviews, as having high levels of adaptation to their handicapped children. Whereas fathers with low Judson scores had low interview ratings of adaptation. Also, in a previous study of the cohort of families involved in this study, the Judson scale was administered to a sample of 60 fathers (Byrne et al., 1988). The authors reported no difficulties in obtaining completed Judson scales from fathers and considered that the Judson scale provided a valid measure of fathers' adaptation.

In the current study, the coefficient of internal consistency (using Cronbach's alpha) for fathers' responses on the Judson scale was found to be 0.89 (Sloper, et al., 1988). This suggests that a satisfactory level of reliability was obtained on this measure.

Marital functioning. In order to obtain a measure of marital functioning the Measure of Marital Satisfaction was used (Kelso, Stewart, Bullers, and Eginton, 1984). This instrument was designed as a questionnaire for screening parents for marital problems. It consists of 13 items, or groups of items with parts which are scored separately (see Appendix C). Most of the items are scored

on a three point scale with the lowest score given for the greatest satisfaction. Total possible scores range from 26 to 72 with higher scores reflecting greater marital dissatisfaction. Areas included are: agreement between partners on specific matters; compatibility; companionship; intimacy; satisfaction; and, conflict, including conflict regarding child rearing.

Kelso et al. established the reliability and validity of the scale in a study of 107 married and 133 divorced parents. Married parents (60 mothers, 47 fathers) were recruited from a university staff directory; divorced parents (85 mothers and 48 fathers) from court records. Results showed that mean scores of divorced parents were significantly higher ($p < 0.001$) than those of married parents, and this was the case for both mothers and fathers. This suggests that the instrument provides a valid measure of marital satisfaction for mothers and fathers. Computation of Cronbach's alpha using the scores of the whole group produced a split-half coefficient of 0.95. Also, computation of test-retest correlation, using Pearson's r , for a sample of 23 parents, over a period of two to six months, produced a coefficient of 0.81. Thus, the results of Kelso et al.'s study provide support for the reliability of the instrument.

In the current study the coefficient of internal

consistency (using Cronbach's alpha) for fathers' responses on the Measure of Matrital Satisfaction was found to be 0.91 (Sloper, et al., 1988). This suggests that a satisfactory level of reliability was obtained on this measure in the current study.

Social support. In order to measure the level of social support perceived by fathers an adaptation of the Inventory of Parent Experiences (IPE) was used (Crnic, Greenberg, Ragozin and Robinson, 1982). The IPE is a questionnaire regarding supports and satisfaction from intimate relationships, friendships and community. Split-half reliabilities of 0.69 for intimate relationships, 0.65 for friendships, and 0.50 for community supports were reported, using Cronbach's alpha, suggesting that the instrument has reasonable internal reliability. The IPE has been used in two studies involving fathers of children with disabilities (Vadasy et al., 1985 and 1986), and was considered to have provided a valid measure of perceived social support for these fathers.

For this study four questions were added to the IPE. These focused on the practical and emotional support which fathers received, and on their satisfaction with each of them. These aspects were considered important to the areas of interest in the study but were not included in the original scale. The adapted social support scale consists

of 18 items, for most of which subjects are to circle one of up to seven statements concerning their perceived level of social support, or their satisfaction with this support (see Appendix D).

Stress. The Malaise Inventory (Rutter, Tizard and Whitmore, 1970) was used to measure the stress experienced by fathers. The Malaise Inventory (MI) was designed to measure psychosomatic symptoms associated with stress and depression. It is reported to be easy to administer and score and to be intrinsically interesting to respondents (Burden, 1980). The MI consists of 24 questions concerning the respondent's general health which require a yes/no answer (see Appendix E).

Rutter et al., reported test-retest reliability of 0.91 from a study of 35 mothers. The authors did not attempt to directly assess the validity of the MI as it was based on the Cornell Medical Index which they considered to have well established validity in the measurement of emotional disturbance in mothers.

Evidence for the validity of the MI as a measure of stress in mothers of children with disabilities was found in a previous study with the cohort of families involved in this study. Byrne et al., (1988) found that mothers'

scores on the MI were correlated with a number of child behaviour problems and maternal dissatisfaction.

The Malaise Inventory has been used in several other studies of mothers of children with disabilities (Burden, 1980; Bradshaw and Lawton, 1978; Carr, 1988; Quine and Pahl, 1985; Tew and Lawrence, 1975). In all but one of these studies (Carr, 1988) the mean Malaise scores for such mothers have been found to be significantly higher than those of the normative populations studied by Rutter et al. Two of the studies found evidence of good test-retest reliability. Bradshaw and Lawton (1978) obtained a coefficient of 0.96 with 17 mothers and Quine and Pahl (1985) obtained a coefficient of 0.94 with 20 mothers. In one of these studies scores on the MI were shown to correlate well with the other measure of stress which was used, a rating of maternal mental health (Quine and Pahl, 1985).

In the current study, the coefficient of internal consistency (using Cronbach's alpha) for fathers' responses on the Malaise Inventory was found to be 0.81 (Sloper, et al., 1988) which suggests that a satisfactory level of reliability was obtained on this measure.

Personality. The Eysenck Personality Inventory (EPI) (Eysenck and Eysenck, 1964) was used as a measure of

fathers' personality. It consists of 57 items requiring yes/no responses (see Appendix F). The EPI comprises three scales reported to measure: neuroticism; extraversion; and, social desirability of responses (lie scale). There are two equivalent forms of the EPI, forms A and B. Form A was used in this study.

The authors report test-retest reliability coefficients for the three scales of Form A as: neuroticism - from 0.82 to 0.97; extraversion - from 0.84 to 0.88; lie scale - 0.78. No data are presented regarding the validity of the instrument as a measure of personality, but the authors do assert that it provides a "reasonably valid picture of the subject's habitual behaviour patterns" (Eysenck and Eysenck, 1964, p.13). The EPI and the 90-item Eysenck Personality Questionnaire, to which it is closely related, have been extensively used as personality measures in a wide range of social research in Britain.

Adequacy of questionnaire data.

Of the 97 fathers who were surveyed, 87 (90%) completed questionnaire booklets. Since 14 fathers declined to take part in the study, despite their wives participation, the 87 fathers who completed booklets make up 78% of the 111 fathers in the sample. A comparison was made of the 29 fathers who did not complete questionnaire booklets with the 87 fathers who did, using data obtained from

questionnaires completed by their wives (Sloper, et al., 1988). This indicated that there were no statistically significant differences between the two groups on any of the demographic or child variables. This suggests that the 87 fathers who completed questionnaire booklets are representative of the fathers in the sample.

Interview measures.

Interview rationale. Qualitative approaches are now being used more frequently in all of the social sciences, including special education (Heshusius, 1986; Schindele, 1985; Stainback and Stainback, 1988). They provide perspectives which are often absent in the more traditional quantitative methodology. As Walker (1985) puts it, " Qualitative research reaches parts that other techniques don't " (p18).

It has been suggested that, in order to gain the most comprehensive view of research problems, both qualitative and quantitative methods should be employed (Mittler, 1985). Further, that the two approaches can be effectively combined and are in many ways complementary (Miles and Huberman, 1984; Strauss, 1987; Walker, 1985).

Regarding research with fathers, McKee and O'Brien (1982) consider that there is no one best methodology, but

that a plurality of methods is the optimum strategy for advancement of the field. Another writer in this field has suggested that, unless the researcher tries to see the world through the participant's eyes, there is a temptation to impose the researcher's own constructions upon the data (Pedersen, 1980). Therefore, it was considered important to include a qualitative component in the current study of fathers.

However, while the major advantage of employing qualitative methodology is considered to be in increasing the internal validity of the findings, an important weakness is that ensuring reliability and external validity of the data are problematic (Hammersley, 1985; Kirk and Miller, 1986; LeCompte and Goetz, 1982). In fact, Hammersley suggests that some of these problems, notably ensuring adequate sampling and a thorough assessment of rival explanations for the findings, are much more difficult to resolve than they are in quantitative research. In order to address these and other difficulties LeCompte and Goetz provide guidelines for optimising reliability and validity in qualitative research. These will be referred to at appropriate points in the following discussion.

According to Burgess (1985) the major characteristics of qualitative research involve the researcher working in

the natural setting and attempting to obtain the participant's account of the situation under study. It also involves flexibility in research procedures to allow for the analysis to be to some extent data-driven rather than be completely pre-determined.

In the literature on qualitative methodology to date much more attention has been paid to the collection of data than to the analysis of that data. Strauss (1987) states that, compared with both the analysis of quantitative data and the collection of qualitative data, the methods of qualitative data analysis are rudimentary. He suggests that there can be no hard and fast rules for qualitative analysis, only general guidelines and rules of thumb. This suggestion is echoed by Miles and Huberman (1984) who emphasize that their sourcebook on qualitative data analysis is intended to provide only guidelines for action. They stress that specific procedures for analysis must be designed to suit each individual research situation. Walker (1985) states that, " Analysis of qualitative material is more explicitly interpretive, creative and personal than in quantitative analysis " (p3). Hyatt (1986) also considers that qualitative analysis is necessarily a creative process which is responsive to the data collected and the research questions.

However, the creative nature of qualitative data analysis poses threats to both internal and external reliability, in that it is more difficult to ensure that the results of the analysis will be agreed upon by two independent observers and that the findings of the study will be replicated by other researchers (LeCompte and Goetz, 1982). These difficulties need to be paid careful attention when establishing procedures for the analysis of qualitative data.

Hyatt (1986) has proposed that there are generally four phases involved in the analysis of qualitative data:

- 1) familiarisation - developing a thorough knowledge of the data collected;
- 2) selection and ordering - sorting out patterns and connections within the data;
- 3) description - description of the patterns and connections which have emerged from the data;
- 4) interpretation - deciding what these patterns and connections mean and how they relate to the research questions.

Phases 2, 3, and 4 are similar to the three phases of qualitative data analysis proposed by Miles and Huberman (1984). These are: data reduction; data display; and, conclusion drawing. There are also parallels with the process of inductive analysis of qualitative data described by Corrie and Zaklukiewicz (1985) which involves: identification of similarities and differences in the data, by means of a sifting process; and, discovery of groupings and relationships in the data set.

The processes involved in qualitative data analysis are illustrated by a consideration of the method of analysis of interview data reported by Jones (1985b). First of all, immediately after each interview, notes are made to record any points which appear significant (phase 1). Later, tape recordings of the interviews are used to code the data into categories (phase 2). The categories emerge from an examination of the data and provide a higher level description of the interview material (phase 3). By comparing and contrasting categories, interpretations of the meaning of the interview data can be made (phase 4).

The analysis of the interview data collected in this study followed a similar procedure to that described by Jones (1985b) (above). Details of the procedure used in the qualitative analysis of taped interviews are discussed below, following a description of the procedure employed

in conducting the interviews.

Interview procedure. Interviews with fathers were conducted by the writer and the director of the larger research project in which this study was embedded. Both were male psychologists with extensive experience of working with parents of disabled children. Although the fathers had not been interviewed before many of them had met the project director on previous occasions due to their child with Down's syndrome being involved in the early intervention project he had directed. Whereas the writer, who was a junior member of the research team, had met only a small number of the fathers who had participated in a parent-to parent training course he had led. Thus, the two interviewers held different social roles and status in relation to the fathers. Therefore, particular care needed to be taken to standardise the interviews and conduct reliability checks in order to address the threat to the reliability of the interviews posed by employing two interviewers with different roles and status with respect to fathers (LeCompte and Goetz, 1982).

Standardisation of the interview procedure involved four steps. Firstly, the two male interviewers discussed the aims of the interviews, and the features of the ethnographic approach which was to be employed (Jones,

1985a), with the two female members of the team who were to conduct interviews with mothers. Secondly, a protocol was drafted in order to provide a guide for the format of the interviews. Thirdly, the writer conducted a practice interview, using the draft protocol, with a member of the research centre staff role-playing a father of a disabled child. The three other members of the research team observed and provided feedback. Following the role-played interview and discussions between team members the interview protocol was revised and the final form produced (Appendix G).

The fourth step of the standardisation procedure was to conduct joint interviews with the first four fathers to be surveyed. The writer and project director alternated so that each interviewed two fathers and observed the other interviewing two fathers. All interviews were tape recorded in order to facilitate review. Discussions following these joint interviews enabled the major differences between the two interviewers to be resolved.

Finally, in order to ensure that the standardised procedure was adhered to, the interviewers listened to tape recordings of each other's interviews and gave each other feedback as necessary. This was carried out for approximately every tenth interview throughout the twelve months in which the interviews were conducted.

The interviews were conducted in an informal style in order to promote rapport and were semi-structured in order to prompt fathers into discussing their experiences of parenting their disabled children. The interviewer's role was to ensure that four major areas were addressed and to encourage fathers to develop aspects and issues within these areas which were of particular importance to them.

The four major areas addressed in the interview were:

(1) Fathers' views of and relationships with their children with Down's syndrome and any other children they had.

Fathers were asked to talk about their child with Down's syndrome and, if they had any others, the child's siblings. In each case fathers were prompted to comment on their relationship with each child, if they did not bring this up themselves.

(2) Fathers' perceptions of the effects on the family due to having a child with Down's syndrome.

Fathers were asked to talk about how the child with Down's syndrome has affected their families and themselves. If they only referred to past effects, they were asked if there were any current ones. Finally, they were asked if there were any other ways that having the child with Down's syndrome had affected them, either good or bad.

(3) Any important events in the family over the last year.

Fathers were asked to talk about any important events which had affected the family that had occurred in about the last year. When fathers appeared to have finished they were asked if there were any other events of importance.

(4) Any concerns which fathers had.

Fathers were asked to talk about the things that concerned them most at the present time.

Following the interview fathers were asked for feedback on the booklet of questionnaires which they had been mailed approximately two weeks earlier. Any difficulties in completing parts of the booklet were discussed. If there was only a small amount unfinished fathers were asked to complete it at this time, so that the interviewer could return it to the office. Otherwise they were provided with a stamped addressed envelope to return it by mail.

They were then asked to complete further questionnaires regarding their family and non-handicapped children, which were required for the larger study of which this research was a part. Next, fathers (and their wives if they were home and wished to join the discussion) were given feedback on the developmental assessment carried out on their child with Down's syndrome. Finally, fathers and

mothers together (typically) were asked if there were any comments or requests they would like to make.

Interviews were conducted in the family home for all but two fathers, who preferred to be seen elsewhere. One of these fathers was interviewed at the hospital where he worked and the other was interviewed at the research centre. In all, 96 interviews were completed. 64 (67%) of these were conducted by the writer and 32 (33%) by the project director. 57 (59%) interviews were conducted during the day and 39 (41%) at night.

Although the researchers asked to interview fathers alone, this was possible for only 63 (66%) interviews. For the other 33 (34%) interviews another member of the family was present for at least part of the time. This was most often the child with Down's syndrome, or less frequently the mother. Despite these intrusions only 5 (4%) interviews were noted by interviewers to be of questionable validity. Interviews ranged in length from 20 to 180 minutes with a mean of 54 minutes.

Data analysis. Analysis of the interview data was carried out using procedures similar to those reported by Hyatt (1986) and Jones (1985b) which were discussed above. The first step in the process of qualitative analysis proposed by Hyatt is one of familiarisation with the data.

The data set consists of tape recorded interviews with fathers of children with Down's syndrome. Of the 96 fathers who were interviewed one father did not wish the interview to be taped, one taped interview was accidentally erased, and in four cases the tape recorder failed to produce decipherable reproductions of the interviews. Therefore, 90 tapes were available for analysis.

The writer had previously conducted approximately two thirds of these interviews, observed two others, and listened to tape recordings of another 12 in order to check that the standardised procedure was being followed. Thus, he was already familiar with the general content of the taped interviews.

The second step proposed by Hyatt (1986) is one of sorting out patterns within the data. In Jones's (1985b) research this amounted to listening to tape recordings of the interviews and coding the data into categories. The same strategy was used in this study.

Each of the 90 tapes was listened to in turn. Statements made by fathers which were relevant to their experiences of parenting of their children with Down's syndrome were coded into categories. After 30 tapes had been coded a list of 24 categories had been formed. These

were then used to code the other 60 tapes, during which another 4 categories were formed. The first 30 tapes were then reviewed in order to check for the presence of the 4 new categories. The 28 categories which emerged from the analysis, and the number of fathers who were scored for each category, are reported in the following chapter.

In order to assess the reliability of the analysis an inter-observer reliability check was conducted, as suggested by LeCompte and Goetz (1982). The observer who carried out the reliability check was a female post-graduate student in education who had no previous experience of working with families who have disabled children. The observer was asked to study a list of the 28 categories, their definitions, and several examples of each (see Appendix H).

Two clearly audible taped interviews were chosen for training purposes. The observer was then asked to listen to the first tape and write down the categories which she identified. Differences from the list of categories identified by the writer were discussed and portions of the tape replayed until agreement was reached. This was repeated for the second training tape. Then, 15 tapes were randomly selected from the remaining 88 for analysis by the student. She was instructed to listen to each tape and list categories as before. In addition she was asked to

add to the list any other categories of response she considered to be present. One of the 15 tapes selected was unable to be analysed because the observer found it too difficult to understand what was being said.

Since the data were nominal and several categories were coded, per taped interview, by each observer, the most appropriate statistic for calculating the reliability of the coding was by simple percentages of agreement (Goodwin, Sands and Kozleski, 1991). Thus, reliabilities were calculated for each of the 14 taped interviews using the formula:

$$\text{Reliability} = \frac{\text{agreements}}{(\text{agreements} + \text{disagreements})} \times 100$$

Reliabilities ranged from 67% to 100% with a mean of 92%. Also, no additional categories were identified by the observer.

In addition to this inter-observer reliability check an analysis was carried out to assess the comparability of categories identified in tapes of interviews conducted by the writer as compared with interviews conducted by the project leader. LeCompte and Goetz suggest that it is important to conduct such an analysis when more than one interviewer have been used to collect the data.

For interviews conducted by the writer the number of categories listed per father ranged from 1 to 11 (out of 28) with a mean of 5.34 and a standard deviation of 2.03. Whereas for the interviews conducted by the project leader the number of categories listed per father ranged from 2 to 8 (out of 28) with a mean of 5.10 and a standard deviation of 1.37.

Thus, while the mean number of categories coded was just over five per tape for both interviewers, there were differences in range and standard deviation. For the interviews conducted by the writer, there was a greater range and standard deviation of categories listed, indicating greater variability in the number of categories coded for these fathers. However, a comparison of scores using the Mann-Whitney statistical test indicated that differences between the number of categories coded by the two interviewers were not statistically significant ($U = 820.5$, $p = 0.5819$). This finding provides further support for the reliability of the coding of the taped interviews.

Step three of the process of qualitative analysis proposed by Hyatt (1986), that is, description of the patterns which emerged from the analysis of interview data, is addressed in the next chapter.

CHAPTER FOUR

RESULTS

When she was born I thought it was the worst thing that ever happened to me, now I'm inclined to think its the best thing that ever happened. (Father of a girl, nine years of age).

Handicapped children make handicapped families. If I had a choice whether or not to have her - I would choose not. (Father of a girl, seven years of age).

These quotations, from two of the fathers interviewed, illustrate the range of reactions and perspectives, on being a father of a child with Down's syndrome, which emerged from the study.

In this chapter findings from both quantitative and qualitative components of the research are presented. Firstly, the results of the questionnaire measures are considered. This is followed by the results of the analysis of the interviews. Finally, the seven assertions drawn from the literature are addressed in turn.

Results from questionnaire measures

Demographics.

Social class. The social class distribution of the fathers who completed questionnaires is presented in Table 7. This was calculated using the Registrar General's Classification of Occupations (1980), and based on the father's current or last occupation, as reported in the demographic questionnaire (Appendix A). All 87 fathers who completed the questionnaire supplied sufficient information for their social class to be calculated.

Table 7: Social class distribution of fathers (n=87)

Social class	I	II	IIIIn-m	IIIIm	IV	V
No. of fathers	7	24	15	25	15	1
% of fathers	8%	28%	17%	29%	17%	1%

Key I = Professional eg. doctor
 II = Managerial eg. shop manager
 IIIIn-m = White-collar eg. clerical
 IIIIm = Skilled manual eg. tradesman
 IV = Semi-skilled eg. contract cleaner
 V = Unskilled eg. labourer

Educational qualifications. All except one of the fathers provided details of their educational qualifications. Fathers' educational levels (n=86) ranged from 37 (43%) with no qualifications, to 20 (24%) with tertiary qualifications. Details of fathers' qualifications are presented in Table 8.

Table 8: Fathers' educational qualifications (n=86)

Levels (see key)	1	2	3	4	5	6
No. of fathers	37	6	17	4	20	2
% of fathers	43%	7%	20%	5%	24%	2%

Key

1 = No qualifications
2 = Trade apprenticeships/other vocational training
3 = 'O'level/CSE; City and Guilds Intermediate Technical and Final Craft Certificates.
4 = 'A'level/ONC/OND; High School Certificate; City and Guilds Final Technical Certificate.
5 = Degree/HND/HNC; Teachers' Certificate; Membership of Professional Institute.
6 = Other

Perceived financial adequacy. All fathers answered the two questions included in the questionnaire (see Appendix A)

in order to assess their perceived financial adequacy. The results are presented in table 9. Responses ranged from a score of 1 (perceived adequacy or no financial difficulties), to a score of 4 (perceived severe inadequacy and severe financial difficulties). The mean score for the fathers was 1.52 (with a standard deviation 0.72), which indicates that the average father perceived family income to be approximately between adequate/no financial difficulties and slightly inadequate/slight financial difficulties.

Table 9: Perceived financial adequacy (n=87)

Per. fin. ad.	1	1.5	2	2.5	3	3.5	4
No. of fathers	49	6	22	3	5	0	2
% of fathers	56%	7%	25%	3%	6%	0%	2%

Fifty-six per cent of fathers considered that the money coming into the home was adequate for the needs of themselves and their families, and reported no financial difficulties. However, 44 per cent of fathers reported less financial adequacy and/or financial difficulties. For example, 25 per cent of fathers considered family income slightly inadequate and had slight difficulties. Also, 2 per cent of fathers considered family income severely inadequate with severe financial difficulties.

Adaptation.

All 87 fathers completed the Judson Self-Rating Scale (Appendix B). However, 4 fathers had omitted to rate one of the 22 items of the scale, so a midpoint score (of 4) was assigned to each of these items. On the 7 point scale used in the Judson, a score of 1 represents low adaptation and a score of 7 high adaptation. Thus, the lowest possible adaptation score is 22, the highest 154, and the midpoint score is 88. A summary of fathers' scores on the Judson scale is presented in Table 10.

Table 10: Summary of fathers' scores on Judson Scale (n=87)

Score	85-94	95-104	105-114	115-124	125-134	135-144	145-154
No. Fs.	4	1	11	16	21	26	8
% Faths	5%	1%	13%	18%	24%	30%	9%

Total scores on the Judson ranged from 87 to 154. That is, all fathers' scores fell between the midpoint on the scale and the highest possible adaptation score. The mean total Judson score for fathers was 128.02, with a standard deviation of 14.88. Thus, on the 7 point scale, the average father had an average rating of almost 6 (5.82). Also, over two-thirds of the fathers had average ratings of between 5 and 7 on the scale.

Marital functioning.

83 fathers completed the measure of marital satisfaction (MMS) (Appendix C). The one solo father in the sample was not expected to complete it, but a further three fathers omitted to fill in the scale even though they did complete other questionnaires in the booklet. Several fathers had omitted to fill in one or two of the 24 items in the scale which were scored (Sloper, et al., 1988). This was dealt with by dividing fathers' scores by the number of items they had completed in order to produce an average score for each father. Therefore, possible scores on the MMS ranged from 1 (high satisfaction) to 3 (low satisfaction), with a midpoint of 2. A summary of average scores on the MMS are presented in Table 11.

Table 11: Summary of fathers' scores on the MMS (n=83)

Score range	1.0 - 1.5	1.6 - 2.0	2.1 - 2.5	2.6 - 3.0
No. of fathers	45	32	6	0
% of fathers	54%	39%	7%	0%

Average scores on the MMS ranged from 1.2 to 2.4, with a mean of 1.58 and a standard deviation of 0.36. Thus, just over 80% of fathers obtained scores between the

highest rating of marital satisfaction and the midpoint of the scale. Whereas just under 20% of fathers scored between the midpoint and the lowest rating of marital satisfaction.

Social support.

All 87 fathers completed the social support questionnaire (Appendix D). However, although no father had failed to complete more than 10% of the questionnaire a few fathers had omitted to fill in some of the 18 questions. In some cases the missing data were able to be reconstructed from the father's replies to related questions (Sloper et al., 1988). In other cases this was not possible. This resulted in there being 87 total scores for fathers' perceptions of the amount of social support they received (questions: 1, 3, 5, 7, 9, 11 and 13), but only 82 total scores for fathers' satisfaction with their support (questions 2, 4, 6, 8, 10, 12, and 14). Since the questions on fathers' satisfaction with social support were considered to address a different aspect of fathers' perceptions to their reported amount of social support, responses to these two groups of questions were analysed separately.

Possible total scores, on the questions related to fathers' perceptions of their amount of social support, range from 7 (low social support) to 30 (high social

support). Total scores on this component of the scale ranged from 7 to 28 with a mean of 16.43 and a standard deviation of 4.97. This suggests that the average father reported a moderate level of social support such as having some involvement in organised groups, and having at least one person to share feelings with. Whereas, a very small number of fathers (6% with scores under 10) reported having minimal social support such as having no involvement in organised groups, and not having anyone to share feelings with.

Possible total scores, on the questions related to fathers' satisfaction with their social support, range from 7 (low satisfaction) to 28 (high satisfaction). Total scores on this component of the scale ranged from 12 to 28 with a mean of 23.01 and a standard deviation of 3.36. This suggests that the average father is somewhere between 'somewhat satisfied' and 'very satisfied' overall, whereas a very small number of fathers (2%) reported being dissatisfied overall with the social support they were receiving.

Results on the four questions (15, 16, 17, and 18) added to the original scale (Crnic, et al., 1982) are not included in either of the above social support total scores, and were analysed separately. All 87 fathers answered questions 15 and 17 on their satisfaction with

the practical and emotional support they were getting. Whereas, only 81 fathers responded to question 16 on the provision of practical support, and 76 fathers answered question 18 on the provision of emotional support. The results on these four questions are presented in Table 12.

Table 12: Summary of fathers' responses on the four additional questions of the social support questionnaire.

<u>Questions</u>	<u>Responses</u>	<u>Fathers</u>
Q.15 Do you feel you get enough practical support? (n = 87)	No	20 (23%)
	Yes	55 (63%)
	Don't know	12 (14%)
Q.16 Who are usually the main people who give you this support? (You may circle more than one category) (n = 81)	Immediate family	77 (95%)
	Other relatives	29 (36%)
	Friends	31 (38%)
	Professionals	12 (15%)
	Others	5 (6%)
Q.17 Do you feel you get enough emotional support? (n = 87)	No	13 (15%)
	Yes	65 (75%)
	Don't know	9 (10%)
Q.18 Who are usually the main people who give you this support? (You may circle more than one category) (n = 76)	Immediate family	71 (93%)
	Other relatives	23 (30%)
	Friends	21 (28%)
	Professionals	2 (3%)
	Others	2 (3%)

Results of question 15 on satisfaction with practical support indicate that the majority of fathers (63%) are satisfied with the practical support they receive, but a substantial minority (23%) are not. A similar result was obtained regarding fathers' satisfaction with the emotional support they received (question 17). The majority (75%) were satisfied and a minority (15%) dissatisfied.

Results of question 16 on the provision of practical support indicate that the vast majority of fathers (95%) considered that their main source of practical support was immediate family members, which in most cases means their wives. Fewer fathers reported that their main sources of support were other relatives (36%), friends (38%) or professionals (15%).

A similar result was obtained, on question 18, regarding the provision of emotional support. The vast majority of fathers (93%) reported that their main source of emotional support was immediate family members, which in most cases meant their wives. Fewer fathers reported that their main sources of support were other relatives (30%), friends (28%) or professionals (3%).

Stress.

86 fathers completed the Malaise Inventory (Appendix E). One father omitted the scale completely, and a few others omitted to fill in one or two of the 24 items. Since the total score is made up of the number of items for which fathers ticked 'yes', omitted items were treated as 'no' responses. Possible scores on the Malaise Inventory ranged from 0 (low stress) to 24 (high stress). A summary of fathers' scores on the Malaise Inventory is presented in Table 13.

Results showed that fathers' scores on the Malaise Inventory ranged from 0 to 17, with a mean of 3.76 and a standard deviation of 3.67.

Table 13: Summary of scores on Malaise Inventory (n=86)

Score range	0 - 5	6 - 10	11 - 15	16+
No. of fathers	65	15	5	1
% of fathers	76%	17%	6%	1%

A score of 6 or higher on the Malaise Inventory is regarded as indicative of a high level of stress or emotional disturbance (Rutter, Tizard and Whitmore, 1970). Of the 86 fathers who completed this measure 21 (24%)

obtained a score of 6 or more, suggesting that these fathers were experiencing high levels of stress. Thus, the results suggest that the majority of fathers (76%) were experiencing low or moderate levels of stress.

Personality.

All 87 fathers completed the Eysenck Personality Inventory (EPI) (Appendix F). However, two of the fathers surveyed had omitted more than 10% of the 57 items, so their questionnaires were excluded from the analysis. Some of the remaining 85 fathers had omitted to complete a few (typically one or two) of the items. Since the EPI is scored by counting the number of items checked for each of its three scales, unchecked items were simply disregarded in the computation of scores (Sloper et al., 1988). A summary of fathers' scores on the three scales of the EPI (neuroticism scale, extraversion scale and lie scale) is presented in Table 14.

Table 14: Summary of fathers' scores on the EPI (n=85)

<u>Scale</u>	<u>Mean</u>	<u>Standard Deviation</u>	<u>Range</u>
Neuroticism	7.52	5.29	0-22
Extraversion	11.81	4.00	2-21
Lie	3.47	1.69	0-8

Eysenck and Eysenck (1964) reported summary data from normal populations of male and female adults. These are presented in Table 15.

Table 15: Summary EPI data for male and female adults

<u>Scale</u>	<u>Mean</u>	<u>Standard Deviation</u>	<u>Sample</u>
Neuroticism	9.06	4.78	(n=2000)
Extraversion	12.07	4.37	(n=2000)
Lie	2.26	1.57	(n=651)

Eysenck and Eysenck (1964) have also reported summary data for abnormal populations of male and female adults. These are presented in Table 16.

Table 16: Summary EPI data for abnormal males & females

<u>Population</u>	<u>Neuroticism</u>		<u>Extraversion</u>	
	<u>mean</u>	<u>s.d.</u>	<u>mean</u>	<u>s.d.</u>
Anxiety neurotics (n=108)	15.80	5.06	9.45	4.04
Obsessional neurotics (n=23)	15.17	5.27	8.70	4.31
Hysteric neurotics (n=43)	15.16	4.37	11.74	4.35
Mixed neurotics (n=61)	14.41	5.47	9.95	4.35
Abnormal sample mean (n=235)	15.14	5.04	9.96	4.26

Using the data from Tables 14 and 15 it was found that the mean of fathers' scores on the neuroticism scale was significantly lower than that reported by Eysenck and Eysenck for their normal population ($t=2.9$, $df=100$, $p<0.01$). Also, using data from Tables 14 and 16, it was found that abnormal populations recorded a significantly higher mean score on the neuroticism scale than study fathers ($t=11.69$, $df=100$, $p<0.001$).

Using the data from Tables 14 and 15 it was found that the mean of fathers' scores on the extraversion scale did not differ significantly from that reported by Eysenck and Eysenck for their normal population ($t=0.54$, $df=100$, $p>0.05$). Also, using the data from Tables 14 and 16 it was found that the mean extraversion score for abnormal populations was significantly lower than that of study fathers ($t=3.48$, $df=100$, $p<0.01$).

Using the data from Tables 14 and 15 it was found that the mean of fathers' scores on the lie scale was significantly higher ($t=6.61$, $df=100$, $p<0.001$) than that reported by Eysenck and Eysenck for their normal sample.

In the next section, the results of the analysis of interview data are presented.

Results from the interviews

Results of the qualitative analysis of taped interviews.

Analysis of the 90 taped interviews with fathers, for which audio tapes were available, yielded responses which were coded into 28 categories, as described in Chapter Three. A summary of the categories which emerged from the qualitative analysis of the taped interviews is presented in Appendix I. These categories will now be described and the number of fathers whose comments were coded into each category will be stated. Thus, the presentation follows phase four of Hyatt's (1986) model for the analysis of qualitative data, which involves description of the patterns which emerge from the data.

Several examples are provided in order to illustrate the range of fathers' comments in each of the categories into which fathers' responses were coded. Some of the comments made by fathers are paraphrased, while others are quoted directly. In order to preserve anonymity, in the quotations where fathers have used children's names, these have been substituted by pronouns such as he or she, him or her. At the end of this section are reported some comments or issues which were raised by small numbers of fathers, insufficient to form a category, but which it was considered important to include.

Bright disposition: in discussing relationships with their children 41 fathers (46%) described their child with Down's syndrome as having a bright disposition. They used words such as: "happy"; "jolly"; "content"; "happy-go-lucky"; "bubbly"; "cheerful." In contrast, only 4 fathers (6%) out of the 67 who had other children living at home, in addition to the child with Down's syndrome, used such descriptions.

Lovable: 29 fathers (32%) referred to their child with Down's syndrome as being "lovable", or used similar or related words such as: "loving"; "affectionate"; "lovely." In contrast, only 6 fathers (9%) out of the 67 with other children used such words in describing them.

Active: the child with Down's syndrome was described by 21 fathers (23%) as being "active" or something similar, such as: "lively"; "vibrant"; "energetic"; "full-of-beans"; "never still"; "full-of-life." In comparison, 12 fathers (18%) used such words in describing their other children.

Sociable: 19 fathers (21%) described their child with Down's syndrome as being "sociable" or something similar, such as: "gregarious"; "outgoing"; "extrovert"; "friendly." In comparison, 8 fathers (12%), out of the 67 with other children at home, described them in this way.

Naughty: the child with Down's Syndrome was described by 24 fathers (27%) as being "naughty" or something similar, such as: "mischievous"; "cheeky"; "a handful"; "defiant"; "a little devil"; "stubborn"; "awkward"; "aggressive." In comparison, 8 fathers (12%) out of the 67 with other children described them in this way.

In fact, the most common group of words, used by these fathers to describe their other children who were living at home, referred to the children's ability level, and included the words "intelligent", "bright" and "sharp". 14 fathers (21%) referred to their other children in this way. Whereas only 4 fathers (4%) referred to their children with Down's syndrome in this way.

Revolve: 7 fathers (8%) made comments which suggested that family life revolved around the child with Down's syndrome. For example:

- "We have to have specific times for everything.
- "He comes first i'th'ouse. He shouldn't but he does"
- "We're completely dominated by him, have to arrange everything around him."
- "The house just revolves around her."
- "Everything we do is to see that she gets what she needs and is happy. Whatever we do she is taken into consideration."

One father commented that the whole sequence of events had to revolve around his son with Down's syndrome. Both his daughter's school and his own job were chosen in order to fit in with the family organisation which best suited his son.

Fitted in/no effect: 27 fathers (30%) commented that the child with Down's syndrome had fitted into family life, or had had minimal, or no effect on family life. For example:

- "He fits into the family pattern very well."
- "It doesn't stop us doing anything."
- "It hasn't really affected us."
- "He just fits in."
- "He is one of us."
- "I try not to let it affect us. We don't do anything special, he goes everywhere with us."
- "There's no bad things. He's great to be around."
- "I don't know whether it has affected us a great deal more than with the other kids. He has to fit into the rest of the family."

The father of a boy with Down's syndrome whom the family had fostered for six years commented, "He's been treated as one of the family since he come (sic)."

One father remarked that the only effect was a plus, in that the family got extra money for his daughter with

Down's syndrome. Another father commented that there were no effects except that people stared at his daughter on the street and all the family made a fuss of her.

Normal: 22 fathers (24%) mentioned that the child with Down's syndrome had been treated as normal, or the same as his or her siblings. For example:

- "We treat him as an ordinary child."
- "We treat her in a normal way."
- "All three kids are treated the same."
- "She's treated just like any other member of the family".
- "She has been brought up just like an ordinary child would be."
- "We've always treated her the same as the others."

Siblings: 15 fathers (17%) expressed concern over possible negative effects on their other children due to them being siblings of the child with Down's syndrome. For example:

- "Its restricted what the other kids can do. They've found it frustrating."
- "I feel that her sister is being protective and occasionally wonder whether it is a hindrance to her."
- "Maybe we neglected him and he was a bit resentful."
- "She has taken more time than would be helpful to everyone. The other kids seem to raise their

voices."

- "We've spent a lot of time with him so the others must have felt a bit neglected. Our youngest daughter has probably suffered the most."

Several fathers suggested that some of their children had been negatively affected while others hadn't. Most often the worst effects on siblings were considered to be in the child with Down's syndrome's early years. Also, several fathers commented that they had made changes within the family in order to counteract negative effects on the siblings.

Stress: 15 fathers (17%) referred to the stress on family members due to the child with Down's syndrome. For example:

- "The constant demands put a lot of stress on my wife and myself."
- "She has put a strain on the family unit."
- "The sleep problems do put us under stress."
- "There is tension and anxiety over going places."
- "It puts a lot of stress on you. You can't relax."
- "Its been very hard work. Its taken its toll of me and the wife."
- "For the husband it's a strain, but it isn't half as much for the father as the mother, cause I get out to work....Having a Down's syndrome child puts more

strain on you at work. Its at the back of my mind all the time."

One father explained how his son was hard to control. He would cooperate for some of the time but needed to be constantly held when they were out, and had to be watched inside the house in case he ran away. He said that it was harder for his wife because she couldn't physically manhandle him. He commented, "It's hard work. Its made the wife ill twice."

Initial Trauma: 38 fathers (42%) mentioned that, initially, they experienced difficulty in adjusting to the fact that their child had Down's syndrome. The intensity and length of the period of difficulty experienced varied considerably from relatively mild and brief reactions through to profound and lasting ones. For example:

- "When he was first born I cried my eyes out for two days - got over it in three days - the wife was more worried about me than the baby."
- "The wife had a nervous breakdown when she was born. I just said, 'Bloody Hell!', and then carried on."
- "You try to adapt but its hard."
- "At first I was very confused."
- "Initially, I wouldn't accept it."
- "It was a shock at first and took two or three years before we could talk about it."

- "For the first twelve months I felt a physical ache."
- "The outset was a heartbreaking, traumatic period."
- " I was given the job of telling the wife. I was stunned. She just took it in her stride. I was very sad, took it very hard."
- "He was 7 months old when I found out. It was the first time I'd cried for a long while."
- "We were stunned cold by the birth."
- "When he was born I rejected him. Sometimes I still can't believe he's my son."
- "I was very upset at first. Wouldn't do without him now
- "The wife took it badly initially. I wouldn't accept it, but in time we had to."
- "At first, when she was born, for two or three weeks I was in a quiet mood, but it took the wife two years to fully accept."
- "I wept when I heard. I told all the family. My mother said, 'Why has God done this to us?' For a few months I kept asking, 'Why?'."
- "When he was born it was very upsetting. Both our families were great, they helped us a lot. The first few months it was hard work coming to terms with it.
- "When he was first born it was a great shock. Now we couldn't love him more. He has brought a great deal of enjoyment into our lives."

One father said that he had lost a lot of weight a couple of years ago and the doctor had said that it was a reaction to the birth of his son with Down's syndrome.

Another father talked of the initial shock being followed by feelings of inadequacy. He remembered thinking, "...is that the best I could do?"

Another father explained that when they were told that their daughter had Down's syndrome his wife wanted her adopted, but he insisted on taking her home. He said that while his wife experienced feelings of rejection, he felt only disappointment.

Several fathers said how much they had appreciated the help given, by staff from the Hester Adrian Research Centre Early Intervention Programme, especially in the first few months of the child's life when they felt very isolated.

Restrictions: 39 fathers (43%) commented on the restrictions placed on family life due to the child with Down's syndrome. For example:

- "We are restricted in shopping and holidays."
- "It restricts us a lot socially. Everything has to be planned."
- "We have to watch him all the time."

- "We're limited in being able to go out and do things."
- "Supervising her does restrict us."
- "Sometimes we wish we could socialize more."
- "I don't have as much time for myself as I had."
- "It restricts communication between the wife and me, we can't talk when he's there."
- "Its placed a lot of restrictions on our lives. He can't be left to his own resources, we are always supervising him. I find that taxing. We have to organise him and ferry him about."

One father, with a very severely handicapped child, explained that the house was organised with his son's epilepsy in mind, that is there could be no sharp edges in case he fell over when having a fit. Also, in order to help them care for the child his wife's parents had moved into the house next door. Because of this the father believed that it would be very difficult for them to move house.

Another father explained that he was limited in being able to go out and do things with his wife, but going out as a family was no problem. However, he could see that in the future, "...we aren't going to be independent, in her twenty's we will still have her."

One father described a whole list of restrictions which had been placed on the lives of family members due to the presence of his son with Down's syndrome. They would like to move house but are reluctant to move away from the quiet cul-de-sac where they are because it is safe for his son to play out. They were only going to have two children but decided to have a third because they didn't want one child to be brought up with only a handicapped brother. He would probably have changed jobs, but this may have meant moving house so he had not considered it. He commented on the constant supervision - "always having to watch him", and on being restricted in the choice of holidays and what the other children can do, which he said they found frustrating.

Schooling: 18 fathers (20%) expressed concern about the education of their child with Down's syndrome. For example:

- "We're not sure the special school is the best place for him."
- "What happens after primary education!?"
- "We seem to have to fight for what is best for her schooling."
- "We had hassle over getting her into a normal school."
- "They're teaching him Megaton (sic) at school, which I don't agree with."

- "I'd like to see more emphasis on reading and writing."

Several of the fathers were attempting to get their children moved from special schools into ordinary schools but were experiencing difficulties with this.

Employment: 20 fathers (22%) expressed concern over either losing, or not getting, a job. Some of these fathers referred to the associated financial problems. For example:

- "I'm afraid of losing my job."
- "My only concern is being out of work."
- "I might not be in work in two years time!"
- "The insecurity of not having a proper job concerns me."
- "In the last four years I've been in and out of work."
- "The last twelve months have been very difficult financially."

For several fathers being out of work, either at that time or in the future, was a major concern.

Daddy's child: 9 fathers (10%) perceived that the child with Down's syndrome had a closer relationship with them than with their wife. For example:

- "She's Daddy's girl."
- "She's closer to me than her mother."
- "I'm very close to him. It's always, 'Dad?'"
- "He favours me more than the wife, and I favour him too over his sister."
- "He's more for me than the rest of the family."

Mummy's child: 10 fathers (11%) perceived their wives to have a closer relationship than themselves with their child with Down's syndrome. For example:

- "He gravitates toward his mother."
- "She leans towards her mother."
- "The wife has more of a relationship with her."
- "She's closer to the wife than me."
- "He's a mummy's boy."

Outlook: 13 fathers (14%) considered that having a child with Down's syndrome had given them or the family a better or broadened outlook on life; or, had brought something special into their lives. For example:

- "I like to think I'm a better person, I'm more sympathetic towards people's problems."
- "She's had a good effect all round; made me a better person."
- "He's taught me a lot; made me more compassionate."
- "She's changed our outlook; widened our scope."
- "Having her has been possibly the best thing that's

ever happened to us. It's given us greater awareness of life in general."

- "We're a better family, its brought something into our lives that just wasn't there before."

One father explained that having his son with Down's syndrome had given a lot to the family, including lots of friends and "fighting qualities." He commented that it had made them value the important things in life, and that, "Life would be boring without him."

Several fathers commented that having a child with Down's syndrome had made them much more aware and understanding of handicapped people generally or of mentally handicapped people in particular.

Closer to wife : 11 fathers (12%) noted that the child with Down's syndrome had brought husband and wife closer together. For example:

- "It's brought us closer together."
- "Having him got us together at home instead of going out all the time."
- "It's brought the wife and I closer together."
- "He binded us together a bit more."
- "He's held the family together - we were having a shaky patch - he kept me here."

One father said he thought that having his daughter with Down's syndrome had brought him and his wife closer together, to the extent that without her the marriage may not have survived.

Closer family: 11 fathers (12%) considered that having the child with Down's syndrome had brought family members closer together. For example:

- "It's got us closer together as a family."
- "Having such a child draws everybody closer together."
- "The family is tighter knit."
- "She has perhaps influenced some of the closeness in the family."

Marital difficulties 1: 7 fathers (8%) mentioned marital difficulties which they considered to have been caused mainly by the child with Down's syndrome. For example:

- "It restricts communication between my wife and I."
- "He's brought us close to separation once."
- "He causes disagreements between the wife and me."
- "He has come between me and the wife."
- "My wife has suggested, perhaps it would be better if she hadn't been born. Whereas I'm glad she's my daughter."

One father explained that his son caused tension between him and his wife regarding the different ways that they deal with him. He commented, "She goes on and on, I prefer to smack".

Marital difficulties 2: 3 fathers (3%) mentioned marital difficulties which they considered were not related to the child with Down's syndrome. For example:

- "The marriage break-up wasn't caused by her; we just grew apart."
- "Our marriage may not have survived without her, but it's still very delicate."

One father explained that his wife's heavy involvement with one of the major political parties was causing problems in their marriage.

Extended family problems: 8 fathers (9%) mentioned that there had been conflict with, or difficulties experienced by, some members of their extended families due to the child with Down's syndrome. For example:

- "My parents couldn't accept him. We don't see much of them now."
- "My sister said, 'Could you not have her put away?' It was very hurtful."
- "We don't get much help from the in-laws."
- "It has had a distancing effect between family and

friends."

- "My family haven't volunteered to babysit, which is hurtful."
- "Still my parents don't understand about him, they don't seem to be interested."

One father explained how, when his own father had refused to take his son with Down's syndrome on a trip with the two of them but was willing to take his younger son, there had been an argument, following which he had not seen his father for three years.

Another father told how his parents had been obvious about discriminating between his son with Down's syndrome and their other grandchildren, which had hurt him and put distance between them. He said he felt ashamed of them, and for a long time refused to see them.

Long-term provision: 32 fathers (36%) expressed concern about providing for the child with Down's syndrome after school age or when parents become old, ill or dead. For example:

- "The main problem is the long term future. What will happen when we're no longer here."
- "We worry about what will happen to him if either of us is seriously ill."
- "Where will she go when she leaves school?"

- "What does the future hold for her when we're no longer around?"
- "Who will care for her when we're older?"
- "How will we cope with her in her later years?"
- "I worry more for the future."
- "What would happen to him if something happened to me or the wife!?"
- "What's going to happen to him in time? The wife and I won't live forever."
- "When we're old we wouldn't like to see him in a home."

One father commented that he was not sure what he wanted for his daughter with Down's syndrome as she got older. His wife wanted her to go into a Home-Farm Trust scheme, but he wasn't sure about it.

Several fathers commented that they wanted their son or daughter to be independent or self-sufficient when they were older.

Adolescence: 6 fathers (7%) expressed concern over present or future adolescent problems of their child with Down's syndrome, such as coping with puberty or sexuality. For example:

- "Coping with puberty worries me."
- "Our problems will start when he's in his teens."

- "How will she cope in her teenage years, with menstrual problems etc.?"

One father, who said his 12 year old daughter with Down's syndrome, showed too much affection to everyone, was clearly worried about the sexual overtones.

Another father was worried that his son might get difficult to handle when he got bigger. He said, "Our problems haven't really started yet. They'll start when he's in his teens."

Sleep problems: 9 fathers (10%) mentioned the sleep problems exhibited by their child with Down's syndrome.

For example:

- "He did get up two to three times a night over several years. In the last five years I've only had about ten undisturbed nights sleep."
- "She doesn't sleep at night very well. It's probably the wife's fault, the way she handles it."
- "He wakes up early - he used to bang his head against the wall, now he bangs his back against the wall."
- "Until about a year ago he used to be up five or six times a night."
- "We have a lot of disturbed nights. Until he was five he woke every night without fail."

One father bemoaned his lack of sleep because his ten year old son still woke during the night and asked to come into his parents' bed.

Speech: 13 fathers (14%) expressed concern over speech or communication difficulties of their child with Down's syndrome. For example:

- "He can't communicate as well as we'd like."
- "Her biggest fault is not speaking."
- "I worry about his speech. It's at the back of my mind all the time."
- "There's frustrations on both sides on the communication front."
- "I'd feel much happier if he could say more."

One father talked about the frustration he felt in not being able to communicate in any meaningful way with his son, who was very severely handicapped, and was his only child.

Child's health: 16 fathers (18%) expressed concern about health or physiological problems of the child with Down's syndrome. For example

- "She's prone to illness and has been in and out of hospital umpteen times."
- "He has heart problems. We wonder about it all the time."

- "Her main problem is control of her bowels, she has accidents."
- "We worry about her being small for her age."
- "He dribbles from his penis and it's a nuisance."
- "We are going to get her hearing problem sorted out."
- "She has a heart problem so we live day to day."

Own health: 6 fathers (7%) expressed concern about their own health or illnesses. For example:

- "Three months ago I had an operation. I've been in a lot of pain."
- "I had a fortnight off work with a nervous do."
- "I was treated a couple of years for depression."

When asked what concerns he had at the moment, one father replied, "Getting my nerves right."

Four fathers mentioned having health problems over the last year, such as having a broken arm or back problems, but did not express any concern about these, so were not included in the count of six fathers in this category.

Other findings which emerged from the interview data.

Besides the above 28 categories, each of which reflected the perspectives of several fathers, other findings

emerged from interviews with between one and three fathers. Although these findings may represent minority viewpoints, it was considered important to include them in order to present the broadest possible picture of the reactions and perspectives of such fathers. These findings will now be discussed.

Three fathers commented on how badly the diagnosis of Down's syndrome had been communicated to them. One of these fathers remarking that the paediatrician had been as "subtle as an air raid." A further two fathers bemoaned the way it was done: one having been told in the corridor; and, the other having been told first, was then expected to tell his wife.

One father, explained that there had been no sexual relations with his wife since the birth of his son with Down's syndrome. He thought this was mainly because of her fear of becoming pregnant and thereby producing another handicapped child. He and his wife slept in different rooms.

There were quite different reactions from three fathers who had step-children in addition to their children with Down's syndrome. One father was very negative about his step-daughter, the second father commented on how much his step-daughter had helped look after the child, and the

third father told how his daughter with Down's syndrome had brought him closer to his grown-up step-children.

Two fathers, who had foster children in addition to their children with Down's syndrome, were concerned about the possible negative effects of the fostering on their own children.

Three fathers mentioned that their wife's parents lived next door and commented on the support they received from them.

One father, whose wife's parents lived next door, when asked the question about important events over the last year, casually remarked that his son with Down's syndrome had "burned the house down." Apparently, he had been in the house by himself, but with his grandparents next door, and had been playing with matches.

For three fathers other disabilities were more handicapping than the Down's syndrome. One said that their son with epilepsy was more physically and emotionally demanding than their daughter with Down's syndrome. Another made a similar comment about his son with cerebral palsy. The third said of his son with Down's syndrome, "The Down's syndrome isn't a handicap, the profound deafness is."

One father explained that his brother had been put off getting married out of fear of having a handicapped child himself.

Two fathers were concerned that their children with Down's syndrome found it difficult to find playmates when they were at home.

One father explained that, when he learned of the diagnosis, at first he had felt a sense of condemnation, but that, "as time passed we saw her as a special gift from God."

Another father (with a son with Down's syndrome) said that he had, "always had a feeling that somebody up there has got it in for me." He went on to explain that he was, "frightened to death of anything happening to my daughter."

One father expressed concern about his wife's health because of the stress due to caring for their child with Down's syndrome. Another commented that his wife, "sometimes gets dragged down by it all."

Two fathers commented on how their lives had changed considerably since the birth of their children with Down's syndrome. One of them had become very involved with MENCAP

on a voluntary basis and the other was then working as director of the local branch of MENCAP.

One father explained that the greatest impact, on the family, of having a child with Down's syndrome, had been on him. "It has made me far more rigid and controlled and far less willing to take chances."

Another father described how he didn't talk about his son at work. His workmates would talk about their sons' achievements but they would appear to get bored when he talked about his son with Down's syndrome. The same father talked about the problems they had with the neighbours in accepting his son. The neighbours' children would lean over the garden fence and shout abuse at his son. When he spoke to the neighbours about this he received further abuse. As a result of this they had decided to move house.

A father of a seven year old boy with Down's syndrome said that he found it very depressing that his son couldn't fulfil any of his ambitions. He said that he had been very disappointed but was coming to terms with it now that his second son had been born.

Two fathers expressed concern about the safety of their children (with and without Down's syndrome), because of all the violence in society.

Another father said of his adopted daughter with Down's syndrome, "It's the best thing we ever did. I love her more than the others, I really enjoy her."

One father spoke of his pride in his twelve year old son with Down's syndrome. "We thought that there would be a lot of situations in which he'd be an embarrassment, but there's not. He takes communion at church and serves at the altar."

Two fathers commented on how their children with Down's syndrome create a positive atmosphere in the family. One commented, "If you're down he cheers you up." The other said, "We have some good laughs." Another father, quite a humourist himself, in describing his son with Down's syndrome, commented, "He's got a face that only a mother could love."

Several fathers made very positive statements about having a child with Down's syndrome. These included,

- "She's the nicest child I've ever known."
- "He's the best kid in the world, I love him."
- "Its the best thing we ever did. I love her more than the others, I really enjoy her."
- "There's a thousand and one pluses."
- "He's the best thing thats ever happened to me."

Findings regarding the seven assertions about fathers of children with disabilities which emerged from the literature review

This section addresses the seven assertions about fathers of children with disabilities, which emerged from the literature review discussed in Chapter Two. The analyses of both questionnaire and interview data relevant to each assertion are considered in turn.

Statistical analyses.

Statistical analyses were carried out using the Amstat statistical packages (Morris, 1987) on an Amstrad PCW 9512 computer. The programmes used by the Amstat packages are based on statistical procedures outlined in texts by Greene and D'Oliveira (1982) and (Siegel and Castellan, 1988).

Both parametric and non-parametric tests were employed in the analysis of the data. The data involved were either total scores or sub-scale scores from questionnaires, such as the Eysenck Personality Inventory, or total scores from instruments including rating scales, such as the Judson Self-Rating Scale. Therefore the level of measurement involved was considered to be interval. Also, most of the data used in the analyses was from large samples (that is,

greater than 80), so it was therefore considered that it could be assumed that the scores were normally distributed. Thus, for most analyses the assumptions required for the use of parametric tests were met and parametric statistics, such as t tests and Pearson's Product Moment Correlation, were used. However, when the samples involved were small (that is, below 20) non-parametric statistics, such as the Mann-Whitney test were used for the analyses.

Findings regarding the assertions: from questionnaire data.

Assertion 1: Fathers' adaptation to sons with disabilities is not as good as that with disabled daughters. This assertion was tested by comparing the total scores, on the Judson Self-Rating Scale, obtained by fathers of daughters with Down's syndrome, with the total scores obtained by fathers of sons with Down's syndrome. The t test was used to investigate differences between the means of the two sets of scores on the Judson scale.

From the analysis it was found that fathers' adaptation to daughters with Down's syndrome (n=31) was, on average, at a slightly higher level than fathers' adaptation to sons with Down's syndrome (n=56). However, this difference was only significant at the 10% level of statistical

significance ($t=1.99$, $df=85$, $p<0.1$). The 10% level is usually regarded, in the social sciences, as indicating that the probability of a difference occurring by chance is too great for confidence to be sustained in its validity. Therefore, it is considered that this finding does not provide convincing support for the assertion that fathers' adaptation to sons with Down's syndrome is not as good as that with daughters.

Assertion 2: Fathers' adaptation is related to the severity of their children's handicapping conditions. For the purpose of this analysis the severity, or level, of the children's mental handicap was taken to be an indicator of the severity of their handicapping conditions. Level of mental handicap was measured in terms of IQ estimates obtained from assessments on the McCarthy Scales. Fathers' adaptation was measured using their total scores on the Judson Self-Rating Scale. The assertion was tested by investigating the relationship of fathers' adaptation scores to their children's IQ scores, using the Pearson Product Moment Correlation coefficient.

Results indicated that there was no statistically significant correlation between fathers' scores on the Judson scale and children's IQ scores ($r= 0.0499$, $df=84$, $p>0.05$). This indicates that fathers' adaptation to their children with Down's syndrome was not related to the

children's level of mental handicap. Therefore, this finding does not support the assertion that adaptation of fathers is related to the severity of their children's handicapping condition.

Assertion 3: The stress experienced by fathers of children with disabilities is related to the age of their children.

This assertion was tested by investigating the relationship of fathers' stress, as measured by their total scores on the Malaise Inventory, to the ages (in months) of their children with Down's syndrome, using the Pearson Product Moment Correlation Coefficient.

No significant correlation was found between fathers' stress scores and their children's ages ($r=0.06$, $df=84$, $p>0.05$), which indicates that the stress experienced by fathers is not related to the ages of their children with Down's syndrome.

However, it was noted that fathers' stress scores on the Malaise Inventory were found to be correlated with their scores on the Neuroticism scale of the Eysenck Personality Inventory at the 0.1% level of significance ($r=0.78$, $df=82$, $p<0.001$). Also, the stress scores of fathers who were unemployed ($n=19$) were significantly higher than those of employed fathers ($n=68$) at the 1% level ($t=2.804$, $df=84$, $p<0.01$). This suggests that the

stress experienced by fathers is related to personality variables and to their employment status.

Assertion 4a: The adaptation of fathers to their disabled children is related to their level of social support. This assertion was tested by investigating the relationship between fathers' adaptation scores, as measured by the Judson Self-Rating Scale, and their scores on the Social Support questionnaire, using the Pearson Product Moment Correlation Coefficient. Separate analyses were conducted for the two aspects of social support included in the questionnaire: fathers' perceptions of the amount of social support they received; and, their satisfaction with this support.

The adaptation of fathers, as measured by the Judson scale, was not found to be significantly correlated with the amount of social support which fathers reported receiving ($r=0.1205$, $df=85$, $p>0.05$). However, fathers' adaptation was correlated with their satisfaction with the social support they received, at the 0.1% level of significance ($r=0.4318$, $df=80$, $p<0.001$). This suggests that fathers' adaptation is related to their satisfaction with the social support they receive rather than to the amount of this support.

Assertion 4b: The adaptation of fathers to their disabled children is related to their personality characteristics.

This assertion was tested by investigating the relationship between fathers' scores on the Judson Self-Rating scale and their scores on the Eysenck Personality Inventory (EPI), using the Pearson Product Moment Correlation Coefficient. Separate analyses were conducted for each of the three scales of the EPI: neuroticism; extraversion; and, lie (or social desirability) scale.

The adaptation of fathers was found to be negatively correlated with their scores on the neuroticism scale of the EPI at the 0.1% level of significance ($r=-0.4599$, $df=83$, $p<0.001$).

The adaptation of fathers was not found to be significantly correlated with their scores on the extraversion scale of the EPI ($r=0.0948$, $df=83$, $p>0.05$).

The adaptation of fathers was found to be positively correlated with their scores on the lie scale of the EPI at the 1% level of significance ($r=0.3230$, $df=83$, $p<0.01$).

Thus, fathers' adaptation scores on the Judson scale were found to be correlated with their scores on the neuroticism and lie scales of the Eysenck Personality Inventory, but not on the extraversion scale. This

suggests that the adaptation of fathers to their children with Down's syndrome is related to some aspects of their personality characteristics, such as neuroticism and social desirability, but not to other aspects such as extraversion.

Assertion 5: Social class, educational level and income are inversely related to the stress experienced by fathers of disabled children. This assertion was tested by investigating the relationship between fathers' stress, as measured by their scores on the Malaise Inventory, and ratings of fathers' social class, educational level and perceived level of financial adequacy, obtained from the Demographic Questionnaire, using Pearson's Product Moment Correlation Coefficient.

The stress experienced by fathers was not found to be significantly correlated with their social class level ($r=0.1757$, $df=84$, $p>0.05$).

The stress experienced by fathers was found to be negatively correlated with their educational level at the 1% level of statistical significance ($r=-0.3092$, $df=82$, $p<0.01$).

The stress experienced by fathers was found to be negatively correlated with their perceived level of

financial adequacy, at the 5% level of statistical significance ($r=-0.2435$, $df=84$, $p<0.05$).

This suggests that the stress experienced by fathers of children with Down's syndrome is inversely related to their educational level and perceived financial adequacy but is not related to their social class levels. The finding regarding fathers' social class was obtained despite significant correlations of social class with financial adequacy ($r=0.5090$, $df=84$, $p<0.001$) and with educational level ($r=0.4726$, $df=84$, $p<0.001$).

Assertion 6: Many fathers of children with disabilities experience depression and/or personality difficulties.

This assertion was tested by comparing fathers' scores, on the measures of personality and depression administered, with published scores on these measures from normal and abnormal populations. Data from fathers' scores on the Eysenck Personality Inventory were used as measures of personality difficulties. As in previous studies of parents with handicapped children (Burden, 1980), scores on the Malaise Inventory were used as indicators of depression (in addition to measures of stress, as discussed earlier in this chapter).

Results showed that, the mean score of the 86 fathers who completed the Malaise Inventory was 3.76, with a

standard deviation of 3.67. In comparison, a recent British study has reported a mean score on the Malaise Inventory for a sample of 200 parents of severely mentally handicapped children to be 5.83, with a standard deviation of 4.1 (Quine and Pahl, 1985). Using the critical ratio procedure (Bartz, 1988) it was found that the mean score of fathers in the current study was significantly lower than that of the parents in the Quine and Pahl study, at the 0.1% level of significance ($t=4.024$, $df=100$, $p<0.001$).

The mean scores on the Malaise Inventory obtained for normal populations by Rutter et al. (1970) was 3.22 on the Isle of Wight, and 4.15 in London. Since the authors did not report the standard deviations of these scores it was not possible to test the significance of their relationships with the scores obtained in the current study. However, since the mean, of 3.76, obtained in the current study, falls between the two means, of 3.22 and 4.15, obtained from normal populations it appears reasonable to infer that the mean of fathers' scores on the Malaise Inventory does not differ substantially from those of normal populations.

Thus, it is considered that fathers' scores on the Malaise Inventory are more closely comparable to the scores from a normal population than scores from a sample of parents of mentally handicapped children. Therefore,

overall results on the Malaise Inventory suggest that, as a group, these fathers show no greater degree of depression than is present in the general population.

However, 21 fathers (24%) obtained a score of 6 or above on the Malaise Inventory, which Rutter et al. suggest is an indication of a high level of emotional disturbance, and Burden suggests is an indication of depression. Whereas, 65 fathers (76%) obtained a score of below 6 which is reported to be an indicator of good mental health. So, while the overall mean depression scores are average, and the majority (76%) of the fathers' scores do not indicate depression, a substantial minority of fathers (24%) do show signs of depression.

Results on the Eysenck Personality Inventory were presented in Table 14 (above) along with scores from a normal population (Table 15) and abnormal populations (Table 16). As discussed earlier in this chapter, these results indicate that the majority (69%) of fathers' scores on the neuroticism scale fell within the range of the normal population, and outside the range of the abnormal populations. However, 26 fathers (31%) obtained neuroticism scores of within approximately one standard deviation of the mean score of the abnormal population. This suggests that a substantial minority of fathers do show signs of experiencing personality difficulties.

Fathers' scores on the neuroticism scale of the Eysenck Personality Inventory (EPI) were found to correlate with their scores on the Malaise Inventory (MI) at the 0.1% level of significance ($r=0.8073$, $df=82$, $p<0.001$). In fact, 18 of the 21 fathers who obtained a score of 6 or over on the MI were also counted in the 26 fathers who fell within the abnormal range on the neuroticism scale of the EPI.

Fathers' scores on the extraversion scale of the EPI did not correlate significantly with their scores on the MI ($r=-0.1083$, $df=82$, $p>0.05$). As reported earlier, fathers' scores on the extraversion scale were closely comparable to those of the normal population reported by Eysenck and Eysenck.

Fathers' scores on the lie scale of the EPI were found to correlate negatively with their scores on the MI at the 1% level of significance ($r=-0.3552$, $df=82$, $p<0.01$). Thus, fathers with higher scores on the lie scale tended to have lower scores on the Malaise Inventory. As discussed earlier, fathers' scores on the lie scale of the EPI were significantly higher than those reported by Eysenck and Eysenck for their normal population. Eysenck and Eysenck (1964) suggest that a score of 5 or over on the lie scale "shows that faking good is likely to have occurred (p.14)." In fact, 21 (25%) of the fathers obtained a score of 5 or over on the lie scale. This suggests that

for 25% of fathers' their responses may have been influenced by a tendency towards presenting themselves in socially desirable ways. It also suggests that for 75% of the fathers this was not the case.

Overall results suggest that, on the whole, these fathers do not experience greater personality difficulties, or depression, than other fathers. However, a substantial minority of fathers do appear to experience personality difficulties and depression to some extent.

Assertion 7: Fathers of disabled children tend to experience considerable marital distress and desert the family more frequently than the average. The first part of this assertion was tested by comparing fathers' scores on a measure of marital distress with those of a normal population of fathers, and with those of fathers for whom a high level of marital distress was indicated by the occurrence of marriage breakdown. The questionnaire used to assess marital distress was the Measure of Marital Satisfaction (Kelso et al., 1984). Fathers' scores on the Measure of Marital Satisfaction (MMS), and scores on this instrument obtained by Kelso et al. from a group of married men, and a group of divorced men, are presented in Table 17.

Table 17: Comparison of fathers' scores on the MMS with those obtained by Kelso et al.(1984).

<u>Group</u>	<u>Scores on the MMS</u>
83 study fathers	mean = 1.58, s.d. = 0.36
47 married men (Kelso et al.)	mean = 1.68, s.d. = 0.24
48 divorced men (Kelso et al.)	mean = 2.38, s.d. = 0.33

The MMS scores obtained by fathers in this study were not found to differ significantly from those obtained by Kelso et al. in their sample of 47 married men ($t=1.69$, $df=100$, $p>0.05$). However, fathers' scores were found to be significantly lower ($t=12.55$, $df=100$, $p<0.001$) than those obtained by Kelso et al. with their sample of divorced men, indicating that study fathers had significantly higher levels of marital satisfaction. This suggests that fathers of children with Down's syndrome do not experience high levels of marital distress.

The second part of this assertion, that fathers of children with disabilities desert their families more often than the average, was assessed by comparing the divorce rate of the cohort with the divorce rate for the population as a whole. Information on the marital status

of the parents of children in the cohort was available for all 127 families from the time when they first participated in the early intervention programme, operated by the centre responsible for the current research, up to the time of the current study.

At the time of the study, in the 127 families in the cohort, 11 divorces had occurred, and in one family the child's parents were separated. One of the families consisted of a single mother (who had never been married) and her child with Down's syndrome. Therefore, the divorce rate at the time of the study was 11 out of 126 marriages, which is a rate of 8.7%. This compares with a national divorce rate of 8% for the same period (OPCS, 1987). This does not indicate a high level of marriage breakdown for fathers of children with Down's syndrome. Therefore, this finding does not support the assertion that fathers of children with disabilities desert their families more often than the average.

Findings regarding the assertions: from the interview data.

The qualitative analysis and descriptive statistics used in the analysis of interview data were discussed earlier in this chapter. As discussed in the method chapter, the semi-structured interviews and the qualitative analysis of

taped interviews were included in the study in order to investigate fathers' perspectives of their experiences of parenting children with disabilities. These procedures were not included in order to address the assertions discussed above. Of the open-ended questions asked, none was directly relevant to any of the seven assertions. This was carried out in order to avoid a narrow focus on the assertions which emerged from the literature review, and to ensure a broader description of fathers' perspectives. However, although it was not intended for the qualitative analysis of interview data to provide evidence to support or refute any of the assertions, it was considered possible that some aspects of the analysis may be of relevance to some of the assertions.

Inspection of the results of the qualitative analysis suggests that several of the categories which emerged from the analysis may be relevant to the assertions about fathers which were drawn from the literature review. Each of these will now be considered in turn.

Assertion 1: Fathers' adaptation to sons with disabilities is not as good as that with disabled daughters. It is considered that 2 of the 28 categories which emerged from the qualitative analysis may be relevant to this assertion, which concerns fathers' adaptation to their sons and daughters with Down's syndrome. The categories

from the qualitative analysis which are considered to be possibly relevant to this assertion are those concerned with whether fathers considered the child to be closer to them or to their wives. These are the categories of "daddy's child" and "mummy's child". It is suggested that, if fathers of daughters are better adapted than fathers of sons, then daughters with Down's syndrome are more likely to have been described as "daddy's child", and sons as "mummy's child".

In fact, 5 fathers (14%) referred to their daughters as "daddy's child", and 4 fathers (8%) referred to their sons in this way. Also, 4 fathers (11%) referred to their daughters as "mummy's child" and 6 fathers (11%) referred to their sons in the same way. Thus, there does not appear to be a trend in favour of better adaptation for fathers of daughters. However, the numbers of fathers involved is too small for statistical analysis to be used to determine whether differences are statistically significant or not.

Assertion 2: Fathers' adaptation is related to the severity of their children's handicapping conditions. One category which emerged from the qualitative analysis was considered to have possible relevance to whether fathers' adaptation is related to the severity of their children's handicapping conditions. This is the category of Down's syndrome health problems. It was considered that the

health problems experienced by the children with Down's syndrome could be an indicator of the severity of their handicapping conditions. Thus, if fathers' adaptation is related to the severity of their children's handicapping conditions one would expect a higher level of adaptation for fathers of children with less severe health problems.

From the qualitative analysis of the taped interviews it was found that 16 fathers expressed concern about the health problems of their child with Down's syndrome. A comparison of these fathers' adaptation scores (on the Judson scale) with the adaptation scores of fathers who did not express such concern was carried out using the Mann-Whitney test. It was found that fathers who had expressed concern about their children's health problems had, on average, lower adaptation scores than the other fathers ($U=365$, $p=0.0875$). However, this difference was only significant at the 10% level of statistical significance. Therefore, it is considered that this finding does not provide convincing evidence in support of the this assertion.

Assertion 3: The stress experienced by fathers of children with disabilities is related to the age of their children.

None of the categories, which emerged from the qualitative analysis, was considered to be of relevance to this assertion.

Assertion 4 (a): The adaptation of fathers is related to their level of social support. One of the categories which emerged from the qualitative analysis was considered to be of possible relevance to this assertion. This is the category in which 8 fathers (9%) referred to conflict with members of their extended families. It was postulated that these fathers would be less satisfied with the social support they received because of this conflict and therefore would have lower levels of adaptation. In order to test this assumption, adaptation scores (on the Judson scale) of fathers who referred to such problems were compared with those of the other fathers, using the Mann-Whitney test.

It was found that fathers who, in the interview, referred to conflict with members of their extended families, had, on average, a lower level of adaptation than the remaining fathers. This difference was significant at the 5% level of statistical significance ($U=147$, $p=0.0357$). Therefore, this finding provides some support for the assertion that the adaptation of fathers is related to their satisfaction with the social support they receive.

Assertion 4 (b): The adaptation of fathers is related to their personality characteristics. None of the categories,

which emerged from the qualitative analysis, was considered to be of relevance to this assertion.

Assertion 5: Social class, educational level and income are inversely related to the stress experienced by fathers of disabled children. None of the categories, which emerged from the qualitative analysis, was considered to be of relevance to this assertion.

Assertion 6: Many fathers of children with disabilities experience depression and/or personality difficulties. One of the categories which emerged from the qualitative analysis was considered to be relevant to this assertion, which is concerned with the extent to which depression or personality difficulties are experienced by fathers. This is the category of "own health problems". From the analysis of taped interviews it was found that 6 fathers (7%) referred to their own health problems. This included problems of both physical and mental health. Thus, 93 per cent of the fathers did not refer to such problems. Therefore, this finding does not support the assertion that many fathers experience depression.

A comparison was made, of fathers' scores on the Malaise Inventory, of fathers who had referred to health problems and the remaining fathers, using the Mann-Whitney test. It was found that there was a difference at the 0.1%

level of significance ($U=40$, $p=0.0008$), with the fathers who referred to health problems having higher scores on the Malaise Inventory, indicating higher levels of depression or severe emotional problems. So the 6 fathers (7%) who referred to their own health problems in the interview also had high scores on the questionnaire measure of stress and depression. However, the questionnaire data suggested that a higher number of fathers (21, 24%) experienced depression.

Assertion 7: Fathers of disabled children tend to experience considerable marital distress and desert the family more frequently than the average. Four of the categories which emerged from the qualitative analysis were considered to be relevant to the first part of this assertion, which concerns the marital distress experienced by fathers of disabled children. Two of the categories were concerned with marital difficulties, and two with closer relationships in the family.

From the analysis of interview data it was found that 7 fathers (8%) reported marital difficulties caused by the child with Down's syndrome, and 3 (3%) reported marital difficulties not related to the child. This suggests that the majority of these fathers do not experience undue marital distress.

A comparison was made, of scores on the Measure of Marital Satisfaction, of fathers who had referred to marital difficulties (of both types) in the interviews and those who didn't, using the Mann-Whitney test. It was found that there was a difference at the 10% level of significance ($U=231.5$, $p=0.0509$), with the fathers who referred to marital differences in the interviews having higher scores (less marital satisfaction) on the MMS, than other fathers. However, this level of significance does not provide convincing evidence of a relationship between fathers' reports of marital difficulties and their scores on the MMS. This casts doubt on the level of marital difficulties suggested by the interview data.

Another finding from the qualitative analysis was that 11 fathers (12%) commented that the child with Down's syndrome had brought husband and wife closer together. This suggests that some of these fathers experience closer marital relationships following the birth of the child with Down's syndrome. However, a comparison of scores, on the Measure of Marital Satisfaction, for those fathers who commented on closer marital relationships, and those that didn't, revealed no significant differences ($n=83$, $U=231.5$, $p=0.2868$). Therefore, the finding on closer marital relationships, which emerged from the qualitative analysis, may not be of relevance to the level of marital distress experienced by these fathers.

A discussion of the results reported in this chapter, in relation to the existing literature on fathers of children with disabilities, is presented in the following chapter.

CHAPTER FIVE

DISCUSSION

The negative effects have been overstated, the positive aspects have been ignored and many other family variables have been neglected from study (Lyon and Lyon, 1991, p.253).

This quotation is taken from these authors' review of the research literature on families with disabled children. It is considered to provide a fitting introduction to a discussion of the findings of the current study.

In this chapter findings from the current study are discussed in the light of previous research with fathers of children with disabilities. Firstly, the assertions about such fathers, which emerged from the existing literature, are addressed. This is followed by a discussion of the findings from the analysis of the interviews. Then, the implications for practitioners who work with disabled children and their families are considered. Finally, the weaknesses of the current study and recommendations for future research are discussed.

Findings regarding assertions about fathers

Assertion 1: Fathers' adaptation to sons with disabilities is not as good as that with disabled daughters.

In the current study it was found, from the analysis of questionnaire measures, that fathers' adaptation to daughters with Down's syndrome was, on average, slightly better than their adaptation to sons. However, this difference was only found at the 10% level of statistical significance. The results of the current study therefore provide tentative support for this assertion.

All eight previous reviews of the literature included the above assertion (Bristol and Gallagher, 1986; Brotherson, Turnbull, Summers and Turnbull, 1986; Lamb, 1983; McConachie, 1982; Meyer, 1986a and b; Meyer, Vadasy, Fewell and Schell, 1982; Price-Bonham and Addison, 1978). However, only two of the studies cited in the reviews reported findings which supported this assertion. These were the studies by Farber, Jenne and Toigo (1960) and Tallman (1965). In addition, recent studies by Frey and her colleagues (Frey, Greenberg and Fewell, 1989; Frey, Fewell and Vadasy, 1989) also reported that fathers are better adjusted to daughters with disabilities than to sons with disabilities.

Further evidence regarding this assertion came from the analysis of taped interviews. It was found that the proportions of fathers who referred to their children with Down's syndrome as "daddy's child" or "mummy's child" did not show any discernable differential effect in favour of daughters, or sons.

Given the findings from both questionnaire and interview measures, the effect found in the current study is considered to be a weak one, which does not provide convincing support for this assertion. Also, it is noteworthy that, over a period of 30 years, only the three research projects cited above, have reported such a finding, and the two earlier reports, by Farber et al. and Tallman, are now quite dated. Also, in the most recent of the three projects (in which Frey and her colleagues report on the same cohort of families at different times), it was reported in both papers that mothers were also found to be better adjusted to their daughters with disabilities than to their disabled sons. In fact, in the paper by Frey, Fewell and Vadasy (1989), in which levels of statistical significance are reported, this sex difference was found to be significant at the 5% level for fathers and at the 1% level for mothers, which provides stronger evidence for this effect with mothers than with fathers.

A possible reason why the findings obtained by Frey et al. were obtained at higher levels of statistical significance than in the current study is because different measures of parent adjustment to disabled children were used. The measure of parent adjustment used by Frey et al. was not a single instrument like the Judson Self-Rating Scale used in the current study. It was a combination of scores from a scale assessing parental responses to daily events (Crnic and Greenberg, 1984) and three scales from the Questionnaire on Resources and Stress (Friedrich, Greenberg and Crnic, 1983). Thus, the instruments used in the current study and that by Frey et al. may have been measuring somewhat different aspects of fathers' reactions. This is highlighted by the use of different terms to refer to the phenomenon in question. Most of the American literature uses the term adjustment, whereas the British literature uses adaptation. Both terms are used to describe the extent to which fathers have come to terms with their child having a disability. However, because this is not operationally defined in any of the studies conducted to date, it is possible that, where different instruments are used to measure adjustment, or adaptation, they will be measuring somewhat different aspects of the same phenomenon. Therefore, this may to some extent account for the difference in the findings from the current research and the studies conducted by Frey et al.

Another factor to be considered, in addressing this issue, is whether fathers of non-handicapped children (and possibly mothers) also exhibit higher levels of adaptation to daughters than sons. None of the above studies included a control group of fathers of non-handicapped children. Therefore, it is not possible to say whether this sex difference is one which tends to occur with fathers in general, and therefore is of limited relevance when considering the effects of disability on family members.

Because of the weak effect found in the current study, the limited amount of recent supportive research evidence, and the possibility that this effect is not limited to fathers of disabled children, it is considered that the confidence in the validity and salience of this assertion, suggested by the fact that all eight previous reviews of the literature have cited it, is difficult to justify.

Assertion 2: Fathers' adaptation is related to the severity of their children's handicapping conditions.

From the quantitative measures employed in the current study, it was found that fathers' adaptation was not related to the level of mental handicap of their children. From an analysis of interview and questionnaire data it was found that fathers who expressed concern about the

health problems of their children with Down's syndrome had lower levels of adaptation than other fathers. However, this effect was only significant at the 10% level of statistical significance, and therefore cannot be regarded as providing convincing support for the assertion. Therefore, the overall results of the current study are considered to provide little support for this assertion.

Three of the previous reviews of the literature make this assertion (Bristol and Gallagher, 1986; McConachie, 1982; Meyer, 1986a). However, apart from the research by Frey and her colleagues (Frey, Greenberg and Fewell, 1989; Frey, Fewell and Vadasy, 1989) the current review of the literature on this topic provided little support for the assertion. It is important, therefore, to consider what may account for the differences between the results of the current study and those obtained in the studies conducted by Frey et al.

In both papers by Frey et al. the authors report that the adjustment of fathers (and mothers) to their disabled children is related to the children's "ability levels." Scores were reported for the subjects' children on the Vineland Adaptive Behavior Scale (Sparrow, Balla and Cicchetti, 1985), which consists of four subscales measuring: communication; daily living skills; socialization; and motor skills. However, the

relationships between Vineland Scales and the parents' adjustment which were reported to be statistically significant were those between mothers' and fathers' adjustment to their disabled children and their scores on the Vineland Communication Scale only. It appears therefore, from the information presented in the papers, that parents' adjustment scores were not significantly related to their children's overall scores on the Vineland Scales.

It seems, therefore, that Frey et al. did not find that fathers' adjustment was related to their children's overall ability levels but to their competence with communication. Although it can be argued that communication competence is related to severity of handicap it is clearly not synonymous with it. Therefore, it is considered that the findings of Frey et al.'s studies do not provide convincing evidence in support of the assertion that fathers' adaptation is related to the severity of their children's handicapping conditions.

Thus, given the paucity of research evidence, obtained in the current study and in previous studies, in support of the assertion that fathers' adaptation is related to the severity of their children's handicapping conditions, it is considered that the validity of this assertion is open to doubt.

Assertion 3: The stress experienced by fathers of children with disabilities is related to the age of their children.

In the current study it was found, from an analysis of questionnaire measures, that the stress experienced by fathers was not related to the ages of their children. Therefore, the results of the study do not support this assertion.

Although this assertion was discussed in the three of the previous reviews of the literature (Meyer 1986a and b; Price-Bonham and Addison, 1978), the research studies cited in these reviews reported contradictory findings regarding the relationship between fathers' stress and the ages of their children. Some of the sources report that fathers of older children have lower levels of stress than fathers of younger children (eg. Cummings, 1976); others report that the opposite is the case (eg. Gallagher, Beckman and Cross, 1983).

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In a recent study of the effects of children with disabilities on their mothers and fathers it was found that the children's ages were not significantly associated with the levels of stress reported by either mothers or fathers (Beckman, 1991). The children in this study were aged from 18 months to six years, and the author made the

point that perhaps this age range was too small to detect any effect in their parents' stress scores.

The age range of the subjects' children in the current study was from six years eleven months to fourteen years. Although this is a broader age range than that in the Beckman study it is somewhat restricted in that no pre-school children and few adolescents were included. Also, it could be argued that the pre-school period and adolescence are the times when most parents are under more stress than the period of middle childhood. If this were in fact the case then the relationship between the stress experienced by fathers and the ages of their disabled children would be curvilinear. However, this would only be detected by studies which included fathers of disabled children with a wide range of ages, or by longitudinal studies of fathers. To date no such study could be located in the literature.

Notwithstanding this possibility, given the lack of research evidence in support of this assertion, both in the current study and in previous research, the validity of the assertion, that the stress experienced by fathers is related to the ages of their children, is considered to be open to doubt.

However, what did emerge from an investigation of the relationship of fathers' stress scores to other measures were the findings that stress scores were significantly related to their employment status and to personality variables. Thus, the stress levels of fathers who were unemployed were found to be higher than those of employed fathers. Also, fathers with higher stress scores exhibited higher levels of neuroticism on the Eysenck Personality Inventory.

Taken together the above findings suggest that the stress experienced by fathers is related to their personalities and current life situation and not to the ages of their disabled children.

Assertion 4a: The adaptation of fathers to their disabled children is related to their level of social support.

From the analysis of questionnaire measures employed in the current study, it was found that fathers' adaptation was not related to the level of social support which they received. However, fathers' adaptation was found to be related to their satisfaction with the social support they received. That is, the more satisfied fathers were with their social support, the better adapted they were to their disabled child.

From an analysis of interview and questionnaire data, it was found (at the 5% significance level) that fathers who referred to conflict with members of their extended family had lower levels of adaptation than other fathers. It is considered that this provides tentative support for the finding that the adaptation of fathers is related to their satisfaction with the social support they receive.

Therefore, although the results of the current study do not directly support the above assertion, they do support an amendment to it. These findings suggest that it is fathers' satisfaction with the social support they receive which is related to their adaptation to their disabled children, rather than the level of this support.

The two previous reviews of the literature which make this assertion (Brotherson et al., 1986; Meyer, 1986a) do not cite any research studies in support of it. However, a recent study has investigated this topic (Frey, Fewell and Vadasy, 1989).

The study conducted by Frey et al. used as the measure of social support, a questionnaire which, like the instrument used in the current study, was adapted from the Inventory of Parents' Experiences (Crnic, Greenberg, Ragozin and Robinson, 1982). Frey et al. reported that satisfaction with social support was significantly related

to fathers' adjustment, but that amount of social support was not. This is a similar finding to that obtained in the current study.

It should be noted from fathers' responses to the additional items on the social support questionnaire (see Table 12) that, in the current study, 63% of fathers reported that they were satisfied with the amount of practical support they received, while 23% were dissatisfied. Also, 65% of fathers reported that they were satisfied with the amount of emotional support they received, while 13% were dissatisfied. This does not support the suggestion that fathers of children with disabilities tend to become cut off from sources of social support, which has been reported in the literature (Cummings, 1976; Lamb, 1983; Price-Bonham and Addison, 1978).

Also, 93% of fathers report that they mainly receive emotional support from immediate family members and 95% report that most practical support also comes from immediate family members. This supports the suggestion that their wives are a major source of support for these fathers (Brotherson et al., 1986). In fact, there is some evidence to suggest that the quality of the marital relationship is a key variable in the adaptation of

parents to their disabled children (Friedrich, 1979; Minnes, 1988).

Assertion 4b: The adaptation of fathers to their disabled children is related to their personality characteristics.

In the current study it was found that fathers' adaptation was significantly related to some aspects of their personality characteristics (as measured by the Eysenck Personality Inventory), such as neuroticism and social desirability, but not to others, such as extraversion. Thus, fathers with high levels of adaptation to their disabled children demonstrated high levels of social desirability and low levels of neuroticism. This finding was obtained despite the fact that both previous reviews of the literature which made this assertion (Brotherson, et al., 1986; Meyer, 1986a) provided little convincing research evidence in its support.

However, notwithstanding the lack of existing research evidence, the findings of this study provide support for the assertion that the adaptation of fathers to their disabled children is related to their personality characteristics.

Assertion 5: Social class, educational level and income are inversely related to the stress experienced by fathers of disabled children.

In the current study the stress experienced by fathers was found to be significantly negatively correlated with their educational level and perceived financial adequacy but was not related to their social class level. That is, fathers with lower levels of stress had better educational qualifications and perceived their financial position as being more adequate than fathers with higher levels of stress. However, the stress experienced by fathers was unrelated to their social class level.

It is noteworthy that, despite the lack of significant correlation between social class and stress, correlations were found between social class and educational level, and social class and perceived financial adequacy, both at the 0.1% level of statistical significance. This suggests that social class, educational level and perceived financial adequacy are all significantly related. This raises the question of why two of these should be related to fathers' stress and not the third, or alternatively, why one of them should not be significantly related while the other two are. Given the uncertainty which the foregoing discussion implies, it is therefore considered that the significant correlations obtained in this study, between

fathers' stress and both educational level and financial adequacy, must be viewed with a degree of caution.

Three of the previous reviews of the literature have made this assertion, about the relationship of social class, educational level and income to the stress experienced by fathers (Lamb, 1983; Meyer, 1986a and b). However, the small number of studies cited in support of the assertion are equivocal in their findings and do not demonstrate convincing support for any of the three relationships included in the assertion.

Despite the lack of existing research evidence, the results of the current study do provide some support for the assertion that educational level and perceived financial adequacy are inversely related to the stress experienced by fathers of disabled children. However, the results of this study do not support the assertion that fathers' stress is related to their social class level. However, further research evidence is necessary before these findings can be accepted with confidence.

Assertion 6: Many fathers of children with disabilities experience depression and/or personality difficulties.

In the current study it was found that fathers' scores on the questionnaires included to measure depression and

personality difficulties were closely comparable to those of normal populations and significantly different from those of abnormal populations. However, approximately a quarter of the fathers obtained scores on these measures which are considered to be outside the normal range, and therefore perhaps of clinical concern. Overall, these results suggest that, while the majority of fathers of children with disabilities do not experience depression and/or personality difficulties, a substantial minority of such fathers do experience these difficulties, possibly to the extent that some form of intervention would be helpful.

Six of the previous reviews of the literature made this assertion ((Bristol and Gallagher, 1986; Brotherson et al., 1986; McConachie, 1982; Meyer, 1986a and b; Meyer, et al., 1982). These reviews cite only two studies as providing evidence for the assertion. In one of these studies the findings were based on clinical impressions only (Eisenberg, 1957). The other study used more rigorous methodology including control and comparison groups of fathers, and a range of questionnaire measures (Cummings, 1976). However, the author appeared to go beyond his data in making interpretations such as, "...many fathers of mentally retarded children undergo long-term personality changes which resemble a pattern of neurotic-like constriction (p.252)." In addition, similar findings have

not been reported in subsequent studies with such fathers. In fact, a recent study on fathers of disabled children has reported contrary findings. Bristol, Gallagher and Schopler (1988) found that there were no significant differences between such fathers and fathers of non-disabled children on a test of depression. It is therefore considered that support for this assertion, from the existing literature on fathers of disabled children, is quite limited.

Therefore, if one takes the usual dictionary definition of the word 'many' included in this assertion to be 'more', 'most', or 'numerous', then it is clear that there is a lack of research evidence in support of the assertion, both from the current study and from previous research. For while it can be concluded that some fathers do appear to experience depression and personality difficulties, it is clear that this does not apply to the majority of fathers, and that the overall levels of such difficulties are comparable to those of normal populations of fathers.

Thus, it is considered that the validity of the assertion, that many fathers of children with disabilities experience depression and/or personality difficulties, is open to doubt.

Assertion 7: Fathers of disabled children tend to experience considerable marital distress and desert the family more frequently than the average.

In the current study it was found that, on the questionnaire measure of marital distress, fathers' scores did not differ significantly from those of a normal sample of married men, and were at a significantly higher level of marital satisfaction than a sample of divorced men. In addition, information on the marital status of the whole cohort of parents involved in the study indicated that the divorce rate of these parents was closely comparable to the national divorce rate for the period of the study. Therefore, the results of the current study do not support this assertion.

All eight previous reviews of the literature included this assertion. While some research evidence in support of it was provided by the studies cited in the reviews, more recent studies by Bristol, Gallagher and Schopler (1988), Gath and Gumley (1984) and Roesel and Lawlis (1983) (which were discussed in Chapter Two) have tended to find levels of marital distress and divorce rates which were comparable to normal samples.

Therefore, given the equivocal nature of the research evidence in support of this assertion in previous studies,

and the contrary results obtained in the current study, it is considered that the validity of this assertion is open to doubt.

Summary of findings regarding assertions about fathers.

Findings from the current study provided little support for most of the assertions about fathers which emerged from a review of the literature. Convincing evidence was obtained only in support of assertion 4b: that the adaptation of fathers is related to their personality characteristics. This was obtained despite of the apparent lack of previous research evidence for the assertion.

Some support was also obtained for parts of assertion 5: that the stress experienced by fathers is related their educational level and perceived financial adequacy, but this was not altogether convincing.

Limited support was found for assertion 1: that fathers' adaptation to sons with disabilities is not as good as that with disabled daughters, but this was not at all convincing.

A limited amount of support was found for assertion 2: that fathers' adaptation is related to the severity of

their children's handicapping conditions, but this was even less convincing than that for assertion 1.

No support was found for assertion 3: that the stress experienced by fathers is related to the age of their children with disabilities. In fact, fathers' stress was found to be related to their employment status and personality characteristics.

No support was found for assertion 4a: that the adaptation of fathers to their disabled children is related to the level of social support they receive. However, fathers' adaptation was found to be related to their satisfaction with this social support.

No support was found for assertion 6: that many fathers of disabled children experience depression and personality difficulties.

No support was obtained for assertion 7: that fathers of disabled children tend to experience considerable distress and desert the family more frequently than the average.

It appears, therefore, that little is reliably known about fathers of children with disabilities. However, it is possible to state some tentative conclusions. One can

be confident that their adaptation to their disabled children tends to be related to their satisfaction with the social support they receive and their personality characteristics, rather than to the characteristics of their disabled children.

One can also be confident that such fathers do not experience greater levels of depression, personality difficulties, marital difficulties, or divorce, than fathers of non-handicapped children.

Also, it seems more likely that the stress experienced by fathers is related to their educational level and perceived financial adequacy, rather than to the ages of their disabled children.

It is clear, then, that these conclusions provide quite a different view of the effects on fathers of parenting children with disabilities than has been discussed in the literature to date. The findings from this study are less pathological regarding fathers' experiences of parenting disabled children than has been presented in the existing literature. Therefore, it is considered that the assertions about these fathers, on which there was a consensus in the previous reviews of the literature, provide a mostly erroneous view of the experiences of such fathers.

Findings from the analysis of taped interviews

In Chapter Four the results of the qualitative analysis of taped interviews with fathers were presented in the form of categories of fathers' comments and the number of fathers whose comments were coded into each category. The following section addresses phase four of Hyatt's (1986) model for the analysis of qualitative data, which involves interpretation of the patterns which emerge from the data in the light of the existing literature on fathers of children with disabilities.

The categories described in Chapter Four can be grouped into five clusters relating to the focus of the comments in each category (see Appendix I for a summary). The five clusters are: description of the child with Down's syndrome; concerns about the child with Down's syndrome; family organisation; effects on the family; and, effects specifically focussing on fathers. These clusters are now discussed in turn.

Description of child with Down's syndrome. There were five categories of fathers' comments which focussed on descriptions of their children with Down's syndrome. These were the categories of: bright disposition; lovable; active; sociable; and naughty.

The most frequent comment, made by 46% of fathers, in describing their children with Down's syndrome, was that they had a bright disposition. In contrast, only 9% of the 67 fathers who had children at home, in addition to their disabled child, described their other children in this way. In fact, the most frequent comment made by these fathers, about their other children, referred to their high level of intelligence. Twenty-one percent of fathers who had other children referred to them as intelligent, whereas only 4% of fathers referred to their children with Down's syndrome in this way. This suggests that fathers tend to view the major characteristic of their children with Down's syndrome to be their bright disposition, while the major characteristic of their other children is seen as their high level of intelligence.

Other comments made frequently by fathers were that their children with Down's syndrome were lovable (32%), sociable (21%), active (23%), and naughty (27%). For each of these categories a greater proportion of fathers made such comments about their disabled children than about their other children.

So it appears that fathers view their disabled and non-disabled children quite differently. In fact, fathers' descriptions of their children with Down's syndrome are closely comparable to the descriptions to be found in the

literature regarding these children. For example, "In general, they are cheerful, friendly, outgoing and active (even boisterous at times), though many may have a stubborn streak." (Smith and Wilson, 1973, p.39). In addition, although Cunningham (1982) cautions against accepting stereotypes regarding common behavioural characteristics of children with Down's syndrome, he notes that several studies have, "...classified the majority of persons as being pleasant, out-ward going, active, affectionate and sociable with a sense of humour (p.127)." He adds that some recent studies have found that, "... the majority of children are cheerful and lively (p.127)." So it appears that the overall pattern of fathers' perceptions of their children with Down's syndrome is very much in line with descriptions found in the literature. Also, it is noteworthy that the overall tenor of fathers' comments about their children with Down's syndrome was mainly positive, suggesting that they tended to view these children in a positive rather than a negative manner.

Concerns about the child with Down's syndrome.

The most frequent concern, expressed by 36% of fathers, regarding their children with Down's syndrome, was about providing for their children after school-age or when parents became old or ill, or when they died. That fathers experience a high level of concern over the future care of

their children with disabilities is widely reported in the literature. This concern figures in the personal account by Hannam (1975), in three of the studies conducted with such fathers (Erickson, 1974; Linder and Chitwood, 1984; McNeil and Chabassol, 1984), and in seven of the previous reviews of the literature (Bristol and Gallagher, 1986; Brotherson et al., 1986; Lamb, 1983; Meyer, 1986a and b; Meyer, et al., 1982; Price-Bonham and Addison, 1978). Thus, this finding, from the current study, supports those reported in the existing literature, which suggests that concern over the long term provision for, or future care of, their disabled children, is an important issue for these fathers. However, it is notable that this concern did not emerge from any of the studies on fathers of non-disabled children, discussed in Chapter One, which suggests that it may only be an important issue for fathers of children with disabilities.

The second most frequent concern, expressed by 20% of fathers, was about their children's schooling. This was a prominent issue in the personal accounts by Greenfield (1972, 1978). The importance of this issue to fathers is also supported by the findings of three of the studies which focussed on fathers' involvement in early intervention programmes (Linder and Chitwood, 1984; Markowitz, 1984; McNeil and Chabassol, 1984). These

studies found that the majority of fathers were interested in their children's education programmes.

The above findings, that the two concerns most frequently expressed by fathers were related to the future care of their disabled children and their education, reinforce the importance of using the ecological model of family functioning, when considering the effects on family members of having a child with a disability (Bronfenbrenner (1977, 1979); Mitchell (1985)). This model, discussed in Chapter One, suggests that factors additional to those operating at the level of the nuclear family (microsystem level), will have an impact on the family and its members. For example, the availability of appropriate residential facilities (exosystem level), and the effectiveness of educational personnel in working closely with parents (mesosystem level), will have an impact on the experiences and concerns of family members, such as fathers.

Other less frequently mentioned concerns about their children with Down's syndrome, which were expressed by fathers were: concern over the child's health or physiological problems, such as hearing difficulties or heart defects (18%); concern over present or future adolescent difficulties, such as coping with sexuality (7%); concern over the child's difficulties with speech

or communication (14%); and, concern over the sleep problems exhibited by the child (10%). Each of these concerns is related to difficulties which are reported in the literature to be often associated with children with Down's syndrome (Cunningham, 1982; Smith and Wilson, 1973). Therefore, these findings support the existing literature in reinforcing the impact on fathers of these child related problems, but suggest that they have less impact on fathers than concerns regarding the education and future care of their children.

Family organisation.

In this cluster of categories, the most frequent comment, expressed by 30% of fathers, was about how well the child with Down's syndrome had fitted into family life and had minimal or no effects on family functioning. In contrast, only 8% of fathers commented that family life revolved around the child with Down's syndrome.

It was noted in Chapter One, that one of the developmental tasks of parents, in adapting to a young disabled child, is considered to be the establishment of a balanced family life (Mitchell, 1985). Also noted was the definition of parents' reactions when they have reached the final phase of the stage model of the adaptation process, as described in Chapter One (Hornby, 1982). This

is one in which the disabled child is treated as 'just another member of the family which does not revolve around him or her.'

Considering the above findings in the light of these comments from the literature, it appears that a larger proportion of fathers had achieved a high level of adaptation to their child with Down's syndrome, whereas a smaller proportion of fathers were still caught up in the adaptation process and were not fully able to come to terms with the situation.

This view is reinforced by the finding that the second most frequent category in the family organisation cluster, was that involving comments, expressed by 24% of fathers, to the effect that they treated their child with Down's syndrome as if he or she were normal.

It is interesting to note that similar proportions of fathers considered their children with Down's syndrome to be either a "daddy's child" (10%) or a "mummy's child" (11%). This suggests that close relationships can exist between either parent and the disabled child. In contrast, several of the previous reviews of the literature have suggested that fathers in such families tend to play mainly an instrumental role, as opposed to an expressive role, with respect to their disabled children, to the

extent that traditional parental roles are intensified in such families (Brotherson, et al., 1986; McConachie, 1982, Meyer, 1986a and b; Price-Bonham and Addison, 1978). However, while two of the studies conducted with fathers of children with disabilities reported results which supported this suggestion (Gallagher, et al., 1981; Gleason, 1989), another two studies found contrary results (McNeil and Chabassol, 1984; Shannon, 1979). Findings from the current study suggest that, as many fathers perceive themselves to have close relationships with their disabled children as perceive their wives to have such relationships. Therefore, these findings are considered to suggest that the intensification of traditional roles in such families, with fathers playing mainly an instrumental role, may not necessarily be the case for families with disabled children.

Effects on the family.

In this cluster of categories, the most frequent comment, expressed by 43% of fathers, was about how the child with Down's syndrome had placed restrictions on family life. There is considerable consensus, in the literature, that having a child with a disability places additional restrictions on family life, such as limited opportunities for leisure activities and economic difficulties, as discussed in Chapter One (Gallagher, et al., 1983;

Lonsdale, 1978; McAndrew, 1976; Murphy, 1982; Philip and Duckworth, 1982). The results of the current study therefore add further support to this finding. However, it is noteworthy that Lewis (1986), in his study of fathers of non-disabled children (discussed in Chapter One), found that 23% of fathers referred to similar restrictions on family life, which suggests that this phenomenon is not peculiar to fathers of disabled children.

Another category of comments, expressed by 17% of fathers, was that of concern about the stress placed on family members due to the demands of the child with Down's syndrome. There is considerable support in the literature for the finding of increased levels of stress on the members of families who have disabled children. The personal accounts by Greenfeld (1972, 1978) and Hannam (1980) highlighted the stress placed on family members, particularly their wives, by caring for their disabled children. Also, the study conducted by Gallagher, et al. (1981) found that 48% of fathers reported experiencing mild to severe levels of stress. In addition, a recent study by Dyson (1991) has found that parents of children with handicapping conditions experienced substantially higher levels of stress than parents of non-handicapped children, and that this increased stress was related to the care of their handicapped children. The finding that 17% of fathers expressed concern about the stress on

family members provides some support for the concern about increased levels of stress in such families. However, it is noteworthy that an even greater proportion of fathers did not express this concern, perhaps reflecting the generally lower level of negative effects found in the current study compared with previous research.

Another concern, expressed by 17% of fathers, was regarding the possible negative effects, on the disabled child's siblings, of living in a family with a disabled child. There is considerable support in the literature, which was discussed in Chapter One, for the possibility of negative effects on siblings (Crnic and Leconte, 1986; Seligman and Darling, 1989; Simeonsson and McHale, 1981). Thus, the finding of the current study, that 17% of fathers are concerned about such negative effects, provides support for the possibility of negative effects on siblings.

A further finding, in the cluster of categories regarding effects on families, was that 8% of fathers commented on marital difficulties they considered to be caused mainly by the child with Down's syndrome, and a further 3% of fathers reported marital difficulties they considered had not been caused by this child. As discussed in Chapter Two, the existing literature is equivocal on the subject of whether there are higher levels of marital

difficulties in families with disabled children. However, as discussed earlier in this chapter, findings from the questionnaire measures used in the current study suggest that these fathers do not experience higher than average rates of marital difficulties. The fact that only 11% of fathers commented on such difficulties in the interviews therefore provides further support for this finding.

Another finding regarding effects on the family was that 12% of fathers reported that the child with Down's syndrome had brought husband and wife closer together. Also, a further 12% of fathers commented that the child with Down's syndrome had brought family members closer together. Although some of this second group of fathers were referring to members of the extended family, the majority appeared to be commenting mainly on their relationships with their wives. Thus, it is considered that around 20% of fathers believed that having the child with Down's syndrome had brought about closer marital relationships.

Five of the previous reviews of the literature have suggested that many fathers consider that parenting their disabled children has brought them and their wives closer together (Brotherson, et al., 1986; Lamb, 1983; McConachie, 1982; Meyer, 1986a and b). Also, three studies have reported this finding (Burton, 1975; Gath, 1977;

Kramm, 1963, cited in Lamb, 1983). Burton (1975) found that 53% of fathers of children with cystic fibrosis believed that raising their disabled child had brought them closer to their wives. Gath (1977), in her study of 30 mothers and fathers of infants with Down's Syndrome, found that almost half of the parents felt closer to their partner and considered their marriage to have been strengthened by parenting their disabled child. Kramm (1963) reported that the majority of fathers of children with Down's syndrome commented that the birth of their children had drawn them closer to their wives.

Thus, this finding from the current study provides further support for the suggestion that many fathers of disabled children consider that having such children has brought them closer to their wives. However, it is noteworthy that the study conducted by Lewis (1986), which was discussed in Chapter One, found that many fathers of non-disabled children considered that being parents had brought husband and wife closer together. So it seems that this may not be an effect which is limited to families with disabled children.

A small number of fathers (9%) commented on problems in relationships with members of their extended families, which in most cases were their own parents. Although there is only a limited amount of existing literature on this

topic (discussed in Chapter One), there is some evidence for the potential negative effects of disabled children on the relationships between their parents and their grandparents (George, 1988; Pieper, 1976; Seligman and Darling, 1989). This finding, from the current study, therefore provides further evidence for such negative effects.

Finally, one of the effects on the family, reported by 14% of fathers, was that having the child with Down's syndrome had brought about a different outlook on life for themselves, or for members of the family including themselves. This finding provides support for such an effect which has been reported in three of the personal accounts of parenting disabled children, which were discussed in Chapter Two (Biondello, 1988; Roos, 1978; Turnbull, 1978, 1985). However, it must be noted that such effects have also been reported in research conducted with fathers of non-disabled children (Lewis, 1986; Simms and Smith, 1982) which suggests that it may be at least partly due to the experience of parenting itself.

Effects specifically focussing on fathers

The most frequent comment, made by 42% of fathers, about the effects on themselves of having children with Down's syndrome, was about the initial trauma they experienced in

adjusting to the diagnosis of the disability. It is notable that this was also a major issue addressed in nearly all of the personal accounts of fathers discussed in Chapter Two.

The overall impression gained from the comments made by fathers in the current study is one of an initial shock followed by a period of adaptation to their disabled child. This apparently lasted from a few days to a few years, with a small minority of fathers still not having come to terms with the situation at the time of the interview. Thus, the process which it is considered fathers' comments exemplify, is most similar to the stage model of parental adaptation, as discussed in Chapter One (Bicknell, 1988; Hornby, 1982; Seligman, 1979). Therefore, this finding from the current study provides some tentative support for the notion of a stage model of adaptation, and emphasises the importance of recognising the considerable impact on fathers of coming to terms with their child's disability.

The other two categories, which were grouped into this cluster, included comments which concerned effects on fathers which were not related to their disabled children. Firstly, 22% of fathers expressed concern about being unemployed, or losing their job, and/or about the financial problems related to each of these situations.

Secondly, 7% of fathers expressed concern about their own health problems. Both of these findings are considered to reinforce the importance of taking a broader view of such fathers' experiences than simply considering effects resulting directly from their children with disabilities.

That such factors as fathers' concerns about their health and employment status would have a significant impact on fathers' experiences is predicted by the Family Systems Conceptual Framework (Turnbull, et al., 1984), which was discussed in Chapter One. Thus, these findings, from the current study, provide support for the value of using such a model when considering the effects on family members of having a child with a disability

Overall summary of fathers' perspectives.

Fathers' comments in describing their children with Down's syndrome were overwhelmingly positive and supported descriptions of the behavioural characteristics of such children found in the literature. Fathers expressed a number of concerns about their disabled children, the main ones of which were the education and future care of the children, which were in agreement with the existing literature. While a minority of fathers considered that the family revolved around the child with Down's syndrome, many more fathers commented on the normality of family

organisation. Both positive and negative effects on families were reported by fathers. Although more fathers reported negative effects, such as the restrictions placed on family life, positive effects on family members were reported by a substantial number of fathers. Fathers' comments indicated that the main effect on them was in coming to terms with their child's disability. Other effects were unrelated to their disabled children but were more to do with their current life situation, such as their employment status.

Thus, a conclusion which can be drawn from consideration of findings from the analysis of taped interviews with fathers, in relation to the existing literature discussed in Chapter Two, is that these findings provide further support for the quotation which introduced this chapter, that is:

The negative effects have been overstated, the positive aspects have been ignored and many other family variables have been neglected from study (Lyon and Lyon, 1991, p.253).

Possible explanations for positive tenor of results

It is clear from the discussion so far in this chapter that the overall findings of the current study provide a

more positive view of the experiences of fathers, of parenting children with Down's syndrome, than is gained from a review of the related literature. There are several possible reasons for this.

Firstly, as concluded in Chapter Two, there is limited hard research evidence available to support the assertions regarding such fathers which emerge from a review of the existing literature. It may well be that this literature paints a more negative picture of the effects on such fathers than is in fact the case. Therefore, the findings of the current study may provide a more accurate perspective of the experiences of these fathers.

Secondly, there is some evidence to suggest that the experiences of parents may differ depending on the type of disability which their children have (Donovan, 1988; Seligman, 1991). Thus, the effects on fathers of parenting children with Down's syndrome may differ from the effects on fathers of children with other disabilities. Morgan (1990) has suggested that parents of children who have a definite diagnosis of the disability generally find it easier to deal with the situation than parents of children who have not been given a diagnosis. The personal accounts by Greenfeld (1972, 1978) and Roos (1978), which were discussed in Chapter Two, are testimony to the difficulties fathers experience when a diagnosis is not

easily forthcoming. Also, Down's syndrome is one of the few disabilities for which a diagnosis can be gained very early in the child's life, which again may facilitate the adaptation of fathers. In addition, Goldberg et al. (1986) have reported on a series of studies in which families of children with Down's syndrome were found to experience less negative effects than families of children with other developmental disabilities.

Therefore, the effects on fathers of parenting children with Down's syndrome may be less negative than for fathers of children with other disabilities. Although more studies have been conducted with parents of mentally handicapped children than any other type of disability, the literature reviewed is based on research with fathers of children with a wide range of disabilities. Therefore, this may at least partly account for the less pathological results found in the current study than are generally reported in the literature to date.

Thirdly, the fathers involved in the current study had children with Down's syndrome whose ages ranged from 6 years 11 months to 14 years. Thus, none of the children were of pre-school age and there were few adolescents in the sample. Since children in these two stages of development may present more difficulties to parents, than children of the ages involved in the study, it is possible

that the negative effects on fathers may have been somewhat reduced, particularly since most studies to date have involved fathers of younger disabled children.

Fourthly, there is some evidence to suggest that, in recent years, there has been increased awareness of the needs of parents of children with disabilities (Carr and Hewett, 1982, cited in Gath and Gumley, 1984; Seligman, 1991). This has led to greater availability of practical and emotional support and professional services aimed at helping parents with their disabled children (Fewell and Vadasy, 1986; Hornby, 1991; Seligman, 1991). In fact, during the interviews, several fathers commented on their appreciation of the help they received from members of the early intervention team attached to the research centre at which the current study was based. This improvement in awareness, support and services available could, at least partly, explain the lower level of negative effects, such as marital difficulties and depression, found in this study, than has been reported in the existing literature.

Finally, as stated in Chapter Four, 25% of fathers obtained a score on the Lie Scale of the Eysenck Personality Inventory which suggests that their responses on questionnaire measures may have been influenced by a tendency to present themselves in socially desirable ways. If this was in fact the case, then the results obtained on

questionnaires, measuring such variables as marital difficulties and depression, may be more positive than was the case.

Implications for practitioners

The findings of the current research project have thrown into doubt most of the assertions about fathers of children with disabilities which are found in the existing literature. It appears that published perceptions of the experiences of such fathers may be considerably more negative than is in fact the case. It also appears that, for many of these fathers, other aspects of their life situation, such as their employment status and the quality of their marital relationship, may have greater impact on their lives than the fact that they have a child with Down's syndrome. Therefore, it is important for practitioners not to project onto these fathers the sort of negative expectations which are found in the existing literature.

However, most fathers experience some negative effects resulting from parenting their disabled children, although only a minority of fathers experience difficulties so great that some form of intervention would appear to be needed. However, it is considered that, because there are some fathers who would benefit from such intervention it

should be made available to all of them from the time that the disability is first diagnosed or strongly suspected. For example, since so many fathers referred to the difficulties they experienced in coming to terms with the child's disability, it is considered that supportive counselling should be made available to them from the time of diagnosis onwards. Therefore, practitioners should make fathers aware of opportunities for individual counselling (Laborde and Seligman, 1991), group counselling (Hornby and Singh, 1982), parent workshops (Hornby and Murray, 1983) and self-help groups for parents, such as parent-to-parent schemes (Hornby, 1988). Then, the fathers who would benefit from such help could avail themselves of it, at the times when they need it and in the form which is most acceptable to them.

It was clear from the analysis of the interviews that two major concerns for fathers were their children's education and their future care. Also, the studies of fathers' involvement in their children's educational programmes, which were discussed in Chapter Two, found that most fathers want to be involved in their children's education, and that, in general, they prefer to be involved along with their wives. It is therefore important for practitioners working with disabled children to ensure that there are opportunities for their fathers, as well as their mothers, to become involved. This may necessitate

scheduling opportunities for parent involvement at times when fathers are more likely to be able to attend, such as on evenings and weekends.

Ideally, practitioners should make available a wide range of types of parent involvement, most of which would encourage fathers to participate along with their wives (Hornby, 1989). However, it may be helpful to have some forms of parent involvement which are specifically designed for fathers. Meyer (1986b) describes several programmes which are available to fathers in various parts of the U.S.A. He considers the main benefits of such programmes are in providing fathers with information, about such things as services available to them, and in providing social support through contact with other fathers of disabled children.

In the interviews fathers expressed concern about the siblings of their disabled children and about the stress placed on other members of the nuclear family. They also talked of problems experienced by members of the extended family, particularly the children's grandparents. Therefore, in working with such families the whole family system should be considered and the needs of all family members should be taken into account when practitioners plan an intervention ostensibly focussed on the disabled child.

In order for any of the above suggestions to be successfully implemented it is necessary for practitioners who work with disabled children to be provided with training in the appropriate skills and knowledge for developing productive working relationships with the children's mothers and their fathers (Hornby, 1990). Practitioners will then be able to assist in facilitating the adaptation of fathers to their disabled children, and in ensuring that any negative effects on fathers are minimized, instead of creating further problems, like those described in the personal accounts of fathers which were discussed in Chapter Two.

Recommendations for future research

Weaknesses of current study.

A major weakness of this study is that it was not feasible to include a comparison group of fathers of children without disabilities. Thus, particularly with the interview data, it is difficult to evaluate the extent to which similar results would be found for fathers of non-disabled children on the measures employed.

Another weakness is that the representativeness of the sample of fathers was reduced by fathers who declined to participate and those who failed to complete questionnaire

booklets. Thus, the validity of the findings, regarding fathers of children with Down's syndrome, may have been somewhat reduced.

Also, since this study was restricted to fathers of children with Down's syndrome, the ability to generalise these findings may be limited, and their applicability to fathers of children with other disabilities must be considered with caution.

In addition, the age range of the children with Down's syndrome whose fathers were involved in the study was somewhat restricted which further limits the ability to generalize these findings.

Finally, another limitation was related to the level of sophistication of the statistical analyses employed in the study. Because a large number of univariate analyses were carried out, and the 5% level was used as a guideline for statistical significance, it could be expected that some differences and relationships would be found to be significant purely by chance (Ottenbacher, 1991).

Also, since the results are reported in terms of their levels of statistical significance and not effect size (Lunt and Livingstone, 1989) or substantive significance (Oakes, 1986), it is not possible to estimate the extent

to which they are clinically significant. For example, the relationship between fathers' stress levels and their educational qualifications was found to be statistically significant but may not be of sufficient effect size, or clinical significance, for practitioners to need to take it into account when planning interventions.

Areas for future research.

Further research is needed in order to replicate the current study before the findings can be accepted with confidence.

In future studies with fathers of disabled children it would be valuable to include a control or comparison group of fathers with non-disabled children. It would then be possible to determine which findings were true for fathers in general and which were due to the specific effects of parenting children with disabilities.

In such studies it would be useful to develop operational definitions of terms such as adjustment or adaptation, which are somewhat ambiguous, in order to be able to select or design the most appropriate measure. It would also be useful to ensure the anonymity of participants in order to minimise socially desirable responses. However, the procedures employed to ensure

anonymity would need to be carefully designed in order to produce high participation rates and thereby obtain representative samples of fathers.

Longitudinal studies would be particularly useful, in order to investigate the experiences of fathers at different stages of their disabled children's development, and at different stages of their own development.

Future studies should employ a wide range of measures to investigate the effects on fathers of various individual and family variables (as discussed in Chapter One) in order to ensure that the most comprehensive perspectives of fathers' experiences are obtained.

Also, a wide range of research methods should be employed in future research with such fathers, including designs which enable the use of multivariable data analysis.

Finally, it would be valuable to conduct separate studies with fathers of children with various disabilities in order to determine what similarities and differences exist in the experiences of such fathers.

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Appendix A: Demographic Questionnaire

1. Your name..... Date of birth

PLEASE CIRCLE THE NUMBER BESIDE THE APPROPRIATE RESPONSE TO EACH QUESTION.

2. Your relationship to the child with Down's syndrome.

- 1. Natural father
- 2. Father by legal adoption
- 3. Foster father
- 4. Step-father

HOUSING

3. Are your housing conditions adequate for you and your family's needs?

- 1. Adequate
- 2. Slightly inadequate
- 3. Markedly inadequate
- 4. Severely inadequate

WORK

4. Are you working at present? 1. No 2. Yes

If YES, do you work part-time or full-time? 1. Part-time 2. Full-time

Do you work days only, nights or shifts? 1. Days only 2. Night work
3. Shift work

5. If working, what is your occupation?
.....

6. Are you self-employed?

- 1. No
- 2. Yes

7. If not working, what was your last occupation?
.....

Appendix A: Demographic Questionnaire (continued)

FINANCE

10. Is the money coming in adequate for you and your family's needs.

- | | | | |
|-------------|---------------------------|---------------------------|---------------------------|
| 1. Adequate | 2. Slightly
inadequate | 3. Markedly
inadequate | 4. Severely
inadequate |
|-------------|---------------------------|---------------------------|---------------------------|

Do you have any difficulties in meeting bills and other financial commitments?

- | | | | |
|-----------------------|---------------------------|---------------------------|---------------------------|
| 1. No
difficulties | 2. Slight
difficulties | 3. Marked
difficulties | 4. Severe
difficulties |
|-----------------------|---------------------------|---------------------------|---------------------------|

How satisfied are you with your financial position?

- | | | | |
|--------------|-----------------------------|-----------------------------|-----------------------------|
| 1. Satisfied | 2. Slightly
dissatisfied | 3. Markedly
dissatisfied | 4. Severely
dissatisfied |
|--------------|-----------------------------|-----------------------------|-----------------------------|

Appendix B: Judson Self-Rating Scale

JUDSON SELF-RATING SCALE

Here is a list of descriptions of feelings - about yourself, your relationship with your child and your relationships with experts or professionals. For each description, the opposite is given on the other side of a line with 7 spaces on it.

Please mark in one of the spaces along each line how you feel at the moment about each item on the scale.

- | | | |
|--|-------------------------------|---|
| 1. In control of things | : _ : _ : _ : _ : _ : _ : _ : | Helpless |
| 2. My child and I have lots of fun together | : _ : _ : _ : _ : _ : _ : _ : | My child and I don't have any fun together |
| 3. Relaxed | : _ : _ : _ : _ : _ : _ : _ : | Anxious |
| 4. Nobody is interested | : _ : _ : _ : _ : _ : _ : _ : | Lots of people are interested |
| 5. Enjoying my child | : _ : _ : _ : _ : _ : _ : _ : | Not enjoying my child |
| 6. Confident in asking questions about my child | : _ : _ : _ : _ : _ : _ : _ : | Afraid to ask questions about my child |
| 7. Wary of what 'experts' tell me | : _ : _ : _ : _ : _ : _ : _ : | Trust what 'experts' tell me |
| 8. Find it hard to show affection towards my child | : _ : _ : _ : _ : _ : _ : _ : | Find it easy to show affection towards my child |
| 9. Proud of my child | : _ : _ : _ : _ : _ : _ : _ : | Ashamed of my child |

Appendix B: Judson Self-Rating Scale (continued)

- | | | | |
|-----|---|------------------------|--|
| 10. | Comfortable
with my
child | :__:__:__:__:__:__:__: | Ill at ease
with my
child |
| 11. | Cold | :__:__:__:__:__:__:__: | Warm |
| 12. | Active | :__:__:__:__:__:__:__: | Passive |
| 13. | My child
seems an
unhappy
child | :__:__:__:__:__:__:__: | My child
seems a
happy
child |
| 14. | Calm | :__:__:__:__:__:__:__: | Worried |
| 15. | Indulgent
with my
child | :__:__:__:__:__:__:__: | Firm with
my child |
| 16. | Not noticing
any progress
in my child | :__:__:__:__:__:__:__: | Noticing
great progress
in my child |
| 17. | Confident | :__:__:__:__:__:__:__: | Unsure of myself |
| 18. | Know how
much to
expect of
my child | :__:__:__:__:__:__:__: | Don't know how
much to expect
of my child |
| 19. | Comfortable
with medical
people | :__:__:__:__:__:__:__: | Ill at ease
with medical
people |
| 20. | Depressed
about my
child | :__:__:__:__:__:__:__: | Happy about
my child |
| 21. | Alone with
my worries
about my
child | :__:__:__:__:__:__:__: | Able to share
my worries
about my
child |
| 22. | Pessimistic
about my
child's
future | :__:__:__:__:__:__:__: | Optimistic
about my
child's
future |

Appendix C: Measure of Marital Satisfaction

MARITAL RELATIONSHIP

While a child's environment has a great effect on his/her personality and behaviour, this influence is not a one-way process. How your child behaves affects your outlook and your behaviour as well. The following questions concern two aspects of your home environment - your general mood and your marriage relationship.

Please fill out the items by placing a tick next to or under the appropriate answer. If there are any items you prefer not to answer, please leave them blank.

PLEASE DO NOT COMPARE YOUR ANSWERS WITH YOUR SPOUSE

1. In your family, who has made the decisions in each of the following areas?

	<u>Almost always husband</u>	<u>Shared equally</u>	<u>Almost always wife</u>	<u>Does not apply</u>
a) where you live	_____	_____	_____	_____
b) whether wife works	_____	_____	_____	_____
c) how to handle the children	_____	_____	_____	_____
d) when to spend time with relatives and in-laws	_____	_____	_____	_____
e) how to spend money	_____	_____	_____	_____

2. When you and your spouse disagree, does it usually end that:

_____ wife or husband give in

_____ disagreement is avoided or unresolved and decisions are made separately

_____ you reach a compromise that you both like

Appendix C: Measure of Marital Satisfaction (contd.)

3. In the past six months, how often have you and your spouse agreed on ways of handling situations involving your children?

	<u>Always</u>	<u>Usually</u>	<u>Sometimes</u>
a) praising the good things they do	_____	_____	_____
b) what their responsibilities should be	_____	_____	_____
c) when or how to discipline them	_____	_____	_____
d) sharing the responsibility of their care	_____	_____	_____

4. Over the last six months, have you been getting on each other's nerves around the house?

- _____ rarely or never
- _____ occasionally
- _____ often

5. Have there been any problems that have caused serious difficulties in your marriage?

- _____ none
- _____ one or two
- _____ three or more

6. How satisfied are you with your ability as a couple to talk over and resolve your differences?

- _____ very satisfied
- _____ moderately satisfied
- _____ dissatisfied

Appendix C: Measure of Marital Satisfaction (contd.)

7. In the past month, how much tension or quarrelling has there been between you and your spouse?

_____ very little or none

_____ a moderate amount

_____ a great deal

8. Do you tell your spouse about things that are on your mind - like what is worrying you, things that make you feel unsure of yourself or problems your friends have shared with you?

_____ rarely or never

_____ usually

_____ always

9. Do you every wish you had not married your present spouse?

_____ rarely or never

_____ occasionally

_____ frequently

10. In the past two years, have you been separated because of conflict?

_____ no

_____ yes

11. In the past two years, have any of your quarrels led to physical violence and injury to each other?

_____ no

_____ yes

Appendix C: Measure of Marital Satisfaction (contd.)

13. Most couples experience different degrees of happiness at different times in their marriage. The questions below concern your general satisfaction with your marriage as it has been for you in the past year.

	Almost always <u>happy</u>	Happy most of <u>the time</u>	Hardly ever <u>happy</u>
a) everything considered, how happy are you in your marriage?	_____	_____	_____
b) everything considered, how happy do you think your spouse is in your marriage?	_____	_____	_____
c) is time spent with your spouse happy for you?	_____	_____	_____
d) how do you think your spouse feels about time spent with you?	_____	_____	_____

12. How happy are you with the way you and your spouse handle the following aspects of your family life?

	Always happy	Usually happy	Seldom happy	Does not apply
a) talking with each other	_____	_____	_____	_____
b) showing affection	_____	_____	_____	_____
c) trusting each other	_____	_____	_____	_____
d) having sex	_____	_____	_____	_____
e) going out with the children	_____	_____	_____	_____
f) spending time with relatives and in-laws	_____	_____	_____	_____
g) spending time with children	_____	_____	_____	_____
h) managing money	_____	_____	_____	_____
i) sharing the responsibilities of your home	_____	_____	_____	_____

Appendix D: Social Support Scale

SOCIAL LIFE

Please circle the number beside the most appropriate answer to each question.

1. How involved are you in your neighbourhood?
 1. Not at all
 2. Somewhat
 3. Very involved

2. How satisfied are you with this situation?
 1. Very satisfied (I'm really pleased)
 2. Somewhat satisfied (It is alright at present)
 3. Somewhat dissatisfied (I would like some changes)
 4. Very dissatisfied (I wish things were very different)

3. Are there any organised groups that are a source of support for you?
 1. None
 2. Some
 3. Many

4. How satisfied are you with this situation?
 1. Very satisfied (I'm really pleased)
 2. Somewhat satisfied (It is alright at present)
 3. Somewhat dissatisfied (I would like some changes)
 4. Very dissatisfied (I wish things were very different)

5. Think of a typical week. About how many times did you talk on the phone with your friends or family?
 1. No talks
 2. 1 talk
 3. 2 - 3 talks
 4. 4 - 7 talks
 5. More than 7 talks
 7. Other (please explain) _____

Appendix D: Social Support Scale (contd.)

6. How satisfied are you with this.
1. Very satisfied (I'm really pleased)
 2. Somewhat satisfied (It is alright at present)
 3. Somewhat dissatisfied (I would like some changes)
 4. Very dissatisfied (I wish things were very different)
 7. Other please explain _____
7. In the last week, how many times have you visited your friends?
- _____
8. How satisfied are you with this amount of visiting?
1. Very satisfied (I'm really pleased)
 2. Somewhat satisfied (It is alright at present)
 3. Somewhat dissatisfied (I would like some changes)
 4. Very dissatisfied (I wish things were very different)
9. If you were to become upset or angry, would you have someone to talk honestly to, who is not involved? How many people?
1. No people
 2. 1 person
 3. 2 people
 4. 3 - 4 people
 5. More than 4 people
10. How satisfied are you with this?
1. Very satisfied (I'm really pleased)
 2. Somewhat satisfied (It is alright at present)
 3. Somewhat dissatisfied (I would like some changes)
 4. Very dissatisfied (I wish things were very different)
11. When you are happy, is there someone you can share it with - someone who will be happy just because you are?
1. No
 2. Yes
12. How satisfied are you with this situation?
1. Very satisfied (I'm really pleased)
 2. Somewhat satisfied (It is alright at present)
 3. Somewhat dissatisfied (I would like some changes)
 4. Very dissatisfied (I wish things were very different)

Appendix D: Social Support Scale (contd.)

13. At present, do you have someone you can share your most private feelings with?

- 1. No
- 2. Yes

14. How satisfied are you with this situation?

- 1. Very satisfied (I'm really pleased)
- 2. Somewhat satisfied (It is alright at present)
- 3. Somewhat dissatisfied (I would like some changes)
- 4. Very dissatisfied (I wish things were very different)

15. Do you feel you get enough practical support?

- 1. No
- 2. Yes
- 3. Don't know

16. Who are usually the main people who give you this support?
(You may circle more than one category)

- 1. Immediate family (husband, wife, children)
- 2. Other relatives
- 3. Friends
- 4. Professionals
- 5. Other (please describe)
.....
.....

17. Do you feel you get enough emotional support?

- 1. No
- 2. Yes
- 3. Don't know

18. Who are usually the main people who give you this support?
(You may circle more than one category)

- 1. Immediate family (husband, wife, children)
- 2. Other relatives
- 3. Friends
- 4. Professionals
- 5. Other (please describe)
.....
.....

Appendix E: Malaise Inventory

PARENTAL HEALTH QUESTIONNAIRE

Below is a list of general questions about your health. Can you read through these questions and circle either 'Yes' or 'No' for each one

- | | | |
|--|-----|----|
| 1. Do you often have back-ache? | Yes | No |
| 2. Do you feel tired most of the time? | Yes | No |
| 3. Do you often feel miserable or depressed? | Yes | No |
| 4. Do you often have bad headaches? | Yes | No |
| 5. Do you often get worried about things? | Yes | No |
| 6. Do you usually have great difficulty in falling asleep or staying asleep? | Yes | No |
| 7. Do you usually wake unnecessarily early in the morning? | Yes | No |
| 8. Do you wear yourself out worrying about your health? | Yes | No |
| 9. Do you often get into a violent rage? | Yes | No |
| 10. Do people often annoy and irritate you? | Yes | No |
| 11. Have you at times had a twitching of the face, head or shoulders? | Yes | No |
| 12. Do you often suddenly become scared for no good reason? | Yes | No |
| 13. Are you scared to be alone when there are no friends near you? | Yes | No |
| 14. Are you easily upset or irritated? | Yes | No |
| 15. Are you frightened of going out alone or of meeting people? | Yes | No |
| 16. Are you constantly keyed up and jittery? | Yes | No |
| 17. Do you suffer from indigestion? | Yes | No |
| 18. Do you often suffer from an upset stomach? | Yes | No |

Appendix E: Malaise Inventory (contd.)

19. Is your appetite poor?	Yes	No
20. Does every little thing get on your nerves and wear you out?	Yes	No
21. Does your heart often race like mad?	Yes	No
22. Do you often have bad pains in your eyes?	Yes	No
23. Are you troubled with rheumatism or fibrositis?	Yes	No
24. Have you ever had a nervous breakdown?	Yes	No

Appendix F: Eysenck Personality Inventory

PERSONALITY QUESTIONNAIRE

Here are some questions regarding the way you behave, feel and act. After each question is a space for answering "Yes" or "No".

Try to decide whether "Yes" or "No" represents your usual way of acting or feeling. Then tick the space under the column headed "Yes" or "No". Work quickly, and don't spend too much time over any question; we want your first reaction, not a long-drawn out thought process. Be sure not to omit any questions.

There are no right or wrong answers, and this isn't a test of intelligence or ability, but simply a measure of the way you behave.

	<u>YES</u>	<u>NO</u>
1. Do you often long for excitement?	—	—
2. Do you often need understanding friends to cheer you up?	—	—
3. Are you usually carefree?	—	—
4. Do you find it very hard to take no for an answer?	—	—
5. Do you stop and think things over before doing anything?	—	—
6. If you say you will do something do you always keep your promise, no matter how inconvenient it might be to do so?	—	—
7. Does your mood often go up and down?	—	—
8. Do you generally do and say things quickly without stopping to think?	—	—
9. Do you ever feel "just miserable" for no good reason?	—	—
10. Would you do almost anything for a dare?	—	—

Appendix F: Eysenck Personality Inventory (contd.)

	<u>YES</u>	<u>NO</u>
11. Do you suddenly feel shy when you want to talk to an attractive stranger?	—	—
12. Once in a while do you lose your temper and get angry?	—	—
13. Do you often do things on the spur of the moment?	—	—
14. Do you often worry about things you should not have done or said?	—	—
15. Generally, do you prefer reading to meeting people?	—	—
16. Are your feelings rather easily hurt?	—	—
17. Do you like going out a lot?	—	—
18. Do you occasionally have thoughts and ideas that you would not like other people to know about?	—	—
19. Are you sometimes bubbling over with energy and sometimes very sluggish?	—	—
20. Do you prefer to have few but special friends?	—	—
21. Do you daydream a lot?	—	—
22. When people shout at you, do you shout back?	—	—
23. Are you often troubled about feelings of guilt?	—	—
24. Are all your habits good and desirable ones?	—	—
25. Can you usually let yourself go and enjoy yourself a lot at a lively party?	—	—
26. Would you call yourself tense or "highly strung"?	—	—
27. Do other people think of you as being very lively?	—	—
28. After you have done something important, do you often come away feeling you could have done better?	—	—

Appendix F: Eysenck Personality Inventory (contd.)

	<u>YES</u>	<u>NO</u>
29. Are you mostly quiet when you are with other people?	—	—
30. Do you sometimes gossip?	—	—
31. Do ideas run through your head so that you cannot sleep?	—	—
32. If there is something you want to know about, would you rather look it up in a book, than talk to someone about it?	—	—
33. Do you get palpitations or thumping in your heart?	—	—
34. Do you like the kind of work that you need to pay close attention to?	—	—
35. Do you get attacks of shaking or trembling?	—	—
36. Would you always declare everything at customs, even if you knew that you could never be found out?	—	—
37. Do you hate being with a crowd who play jokes on one another?	—	—
38. Are you an irritable person?	—	—
39. Do you like doing things in which you have to act quickly?	—	—
40. Do you worry about awful things that might happen?	—	—
41. Are you slow and unhurried in the way you move?	—	—
42. Have you ever been late for an appointment or work?	—	—
43. Do you have many nightmares?	—	—
44. Do you like talking to people so much that you never miss a chance of talking to a stranger?	—	—
45. Are you troubled by aches and pains?	—	—
46. Would you be very unhappy if you could not see lots of people most of the time?	—	—

Appendix F: Eysenck Personality Inventory (contd.)

	<u>YES</u>	<u>NO</u>
47. Would you call yourself a nervous person?	—	—
48. Of all the people you know, are there some whom you definitely do not like?	—	—
49. Would you say that you were fairly self-confident?	—	—
50. Are you easily hurt when people find fault with you or your work?	—	—
51. Do you find it hard to really enjoy yourself at a lively party?	—	—
52. Are you troubled with feelings of inferiority?	—	—
53. Can you easily get some life into a rather dull party?	—	—
54. Do you sometimes talk about things you know nothing about?	—	—
55. Do you worry about your health?	—	—
56. Do you like playing pranks on others?	—	—
57. Do you suffer from sleeplessness?	—	—

Appendix G: Interview Protocol

Interview Protocol

A. NEGOTIATE TIME, PLACE, USE OF TAPE-RECORDER.

B. Can I tell you what we would like to do in this interview? We want to begin by talking about N and the family. After that we would like to find out what you think of the booklet of questionnaires, and any problems you had with it. Then lastly we would like to discuss with you the results of the assessment on N at school, and any other things you want to talk about. The reason we have chosen this order is because first and foremost we want to hear your views about N, the family, and how things are, without us influencing what you say. One of the things about questionnaires is that you can only answer the questions that you are asked. We want to hear your own views on what you think is important. Is that O.K.? Agreeable to you? Is it O.K. for me to jot down a few points as we go?

C. Perhaps we can start with N. What sort of a child is he/she?
(IF QUESTIONED: Children are all different, they all have their own characteristics. What about N?)
(PROMPT: How do you get on together?)

Do you have other children? IF YES, GO ON TO D.

D. How about X (sibling)? What sort of a person is he/she?
(PROBE: How do you get on together?)
REPEAT FOR EACH SIBLING AGE 16 AND UNDER. NOTE AGE AND SEX OF EACH SIBLING.

E. I suppose having any child affects parents and families in all sorts of ways. How has N affected you and your family?
(FOR EACH: How do you feel about that? How important is that to you?)
(PROBE: (IF ALL PAST EFFECTS) And at the moment?)
(PROMPT: Are there any other ways N has affected you, good or bad?)

F. One of the aims of our research is to find out how families with children with Down's syndrome change, what things happen to them, what things are important to them at different times, and how they react to them. So we'd like to find out if any really important things have happened to you or your family in the last year.
(PROMPT: Is there anything else that is really important?)

Can you tell me what concerns you most at the moment?

Appendix H: Categories from Analysis of Interviews

CODES (definitions and examples)

1) REVOLVE: family life revolves around the child with Down's syndrome.

Examples:- "We have to have specific times for everything."
- "He comes first i'th'ouse. He shouldn't but he does"
- "We have to arrange everything around him."
- "The house just revolves around her."
- "Everything has to be organized around him."

2) FITTED IN / NO EFFECT: the child with Down's syndrome has fitted in to family life, or has had minimal, or no, effect on family life.

Examples:- "It doesn't stop us doing anything."
- "It hasn't really affected us."
- "He just fits in."
- "It doesn't affect us at all now."
- "He is one of us."
- "The four of us get on well."
- "Things would be no different."
- "He has been treated as one of the family."
- "We don't do anything special, he goes everywhere with us."

3) NORMAL: the child with Down's syndrome has been treated as normal, or the same as his/her siblings.

Examples:- "We treat him as an ordinary child."
- "We treat her in a normal way."
- "All three kids are treated the same."
- "She's treated just like any other member of the family."

4) SIBLINGS: concern expressed over negative effects on the siblings of the child with Down's syndrome.

Examples:- "His brother was resentful of him."
- "It's a drag on our son. We've tried to change it."
- "Its restricted what the other kids can do. They've found it frustrating."
- "I feel that her sister is being protective and occasionally wonder whether it is a hindrance to her."
- "In the early years it was quite a strain on her sister."
- "She gets upset when her sister gets teased."
- "Her sister has probably suffered the most."
- "Maybe we neglected him and he was a bit resentful."
- "She has taken more time than would be helpful to everyone. The other kids seem to raise their voices."

5) STRESS: referred to stress on family members due to the child with Down's syndrome.

- Examples:
- "The constant demands put a lot of stress on my wife and myself."
 - "She has put a strain on the family unit."
 - "Sometimes my wife gets dragged down by it all."
 - "It has caused more pressure."
 - "The sleep problems do put us under stress."
 - "There is tension and anxiety over going places."
 - "It's hard work. It's made the wife ill twice."
 - "We are always supervising him. I find that taxing."

6) INITIAL TRAUMA: mentioned his initial difficulty in adjusting to the child having Down's syndrome.

- Examples:
- "It was a shock at first and took two or three years before we could talk about it."
 - "We were very upset at first."
 - "At first I was very confused."
 - "Initially, I wouldn't accept it."
 - "For the first twelve months I experienced a physical ache."
 - "When she was born I just said, 'Bloody Hell', and then carried on."
 - "It caused problems at first because it was explained to us very badly."
 - "The outset was a heartbreaking, traumatic period."
 - "I was very sad, took it very hard."
 - "It was the first time I'd cried for a long time."
 - "At first I was in a quiet mood, but it took the wife two years to accept it."
 - "We were stunned cold by the birth."
 - "When he was born I rejected him. Sometimes I still can't believe he's my son."

7) RESTRICTIONS: reported restrictions on family life due to the child with Down's syndrome.

- Examples:
- "We are restricted in shopping and holidays."
 - "We can't move easily."
 - "It restricts us a lot socially."
 - "We have to watch him all the time."
 - "We're limited in being able to go out and do things."
 - "Supervising her does restrict us."
 - "We tend not to do things spontaneously."
 - "I don't have any time to myself."

8) SCHOOLING: concern expressed over the education of the child with Down's syndrome.

- Examples:
- "Mark changing school was a bit of a worry."
 - "We're not sure the special school is the best place for him."
 - "What happens after primary education?"
 - "We seem to have to fight for what is best for her schooling."
 - "We're trying to get him more integrated."
 - "I'm concerned about Stephen's education."
 - "We had hassle over getting her into a normal school."

9) EMPLOYMENT: concern over losing or not getting a job, and/or the associated financial problems.

- Examples:
- "I'm afraid of losing my job."
 - "My only concern is being out of work."
 - "I packed in my job last month."
 - "My job situation is not 100% secure."
 - "I might not be in work in two years time!"
 - "The insecurity of not having a proper job concerns me."
 - "In the last four years I've been in and out of work. The last twelve months have been very difficult financially."

10) DADDY'S CHILD: father perceives that the child with Down's syndrome has closer relationship with him than the mother.

- Examples:
- "She's Daddy's girl."
 - "She's closer to me than her mother."
 - "Joanne has a close bond with me."
 - "I'm very close to him. It's always, 'Dad?' "
 - "He favours me more than the wife, and I favour him too, over his sister."
 - "He's more for me than the rest of the family."

11) MUMMY'S CHILD: father perceives mother has closer relationship with child with Down's syndrome.

- Examples:
- "I'm jealous of the attention he gets from my wife."
 - "He gravitates toward his mother."
 - "She leans towards her mother."
 - "The wife has more of a relationship with her."
 - "She's closer to the wife than me."
 - "He's a mummy's boy."

12) OUTLOOK: having a child with Down's syndrome has given me/us a better/broadened outlook on life; or, has brought something special into our lives.

- Examples:
- "She's had a good effect all round; made me a better person."

- "It makes you more aware of handicapped people."
- "It's made us value the important things in life."
- "It gives you a different outlook."
- "He's taught me a lot; made me more compassionate."
- "She's changed our outlook; widened our scope."
- "Having her has been possibly the best thing that's ever happened to us. It's given us greater awareness of life in general."

13) CLOSER WIFE : the child with Down's syndrome has brought husband and wife closer together.

- Examples:
- "It's brought us closer together."
 - "Having him got us together at home instead of going out all the time."
 - "It's brought the wife and I closer together."
 - "He binded us together a bit more."
 - "He's held the family together - we were having a shakey patch - he kept me here."

14) MARITAL DIFFICULTIES 1: marital difficulties caused mainly by the child with Down's syndrome.

- Examples:
- "We have had no sex since he was born."
 - "It restricts communication between my wife and I."
 - "He's brought us close to separation once."
 - "He causes disagreements between the wife and me."
 - "He has come between me and the wife."

15) MARITAL DIFFICULTIES 2: marital difficulties not related to the child with Down's syndrome.

- Examples:
- "The marriage break-up wasn't caused by her; we just grew apart."
 - "Our marriage may not have survived without her, but its still very delicate."

16) CLOSER FAMILY: having the child with Down's syndrome has brought family members closer together.

- Examples:
- "It's got us closer together as a family."
 - "Having such a child draws everybody closer together."
 - "The family is tighter knit."
 - "She has perhaps influenced some of the closeness in the family."
 - "She helps me get on better with my step-children."

17) EXTENDED FAMILY PROBLEMS: there has been conflict with, and/or difficulties experienced by, extended family members due mainly to the child with Down's syndrome.

- Examples: - "My parents couldn't accept him. We don't see much of them now."
- "My sister said, 'Could you not have her put away?' It was very hurtful."
- "We don't get much help from the in-laws."
- "It has had a distancing effect between family and friends."
- "My brother was put off getting married out of fear of having a handicapped child himself."

18) LONG TERM PROVISION: concern about providing for the child with Down's syndrome after school age or when parents are old, ill or dead.

- Examples: - "We worry about what will happen to him if either of us is seriously ill."
- "Where will she go when she leaves school?"
- "What does the future hold for her when we're no longer around?"
- "Who will care for her when we're older?"
- "I often think of what life will be like when she gets into her twenties or thirties."
- "How will we cope with her in her later years?"
- "I'm not sure what I want for her when she gets older."
- "The problems will come in sorting out long term provision."
- "I worry more for the future."

19) ADOLESCENCE: concern over present or future adolescent problems of the child with Down's syndrome's such as coping with puberty or sexuality.

- Examples: - "She shows too much affection. I worry over the sexual overtones."
- "Coping with puberty worries me."
- "Our problems will start when he's in his teens."
- "How will she cope in her teenage years, with menstrual problems etc."

20) SLEEP PROBLEMS: mention of sleep problems exhibited by the child with Down's syndrome.

- Examples: - "Until about a year ago he used to be up five or six times a night."
- "We have a lot of disturbed nights."
- "She doesn't sleep at night very well."
- "He wakes up early - he used to bang his head against the wall, now he bangs his back against the wall."

21) SPEECH: concern over speech/communication difficulties of the child with Down's syndrome.

- Examples: - "He can't communicate as well as we'd like."
- "Her biggest fault is not speaking."

- "I worry about his speech. It's at the back of my mind all the time."
- "There's frustrations on both sides on the communication front."
- "I'd feel much happier if he could say more."

22) CHILD'S HEALTH: concern about health or physiological problems of the child with Down's syndrome.

- Examples: - "She's prone to illness and has been in and out of hospital umpteen times."
 - "He has heart problems. We wonder about it all the time."
 - "We have tackled her bowel problem with some success."
 - "We worry about her being small for her age."
 - "He dribbles from his pinis and it's a nuisance."
 - "We are going to get her hearing problem sorted out."

23) OWN HEALTH: concern about father's own health or illnesses.

- Examples: - "Three months ago I had an operation. I've been in a lot of pain."
 - "I had a fortnight off work with a nervous do."

24) HAPPY: the child with Down's syndrome is described as being happy or its equivalent.

- Examples: - "jolly"; "content"; "happy-go-lucky";
 "bubbly"; "cheerful."

25) LOVABLE: the child with Down's syndrome is described as being lovable or its equivalent.

- Examples: - "loving"; "affectionate"; "lovely."

26) ACTIVE: the child with Down's syndrome is described as being active or its equivalent.

- Examples: - "lively"; "vibrant"; "energetic";
 "full-of-beans"; "never still"; "full-of-life."

27) SOCIABLE: the child with Down's syndrome is described as being sociable or its equivalent.

- Examples: - "gregarious"; "outgoing"; "extrovert";
 "friendly."

28) NAUGHTY: the child with Down's syndrome is described as being naughty or its equivalent.

- Examples: "mischevous"; "cheeky"; "a handful"; "defiant";
 "difficult to control"; "a little devil";
 obstinate"; "stubborn"; "frustrating";
 "awkward"; "strong-willed"; "aggressive";
 "domineering."

Appendix I: Summary of Qualitative Analysis of Taped Interviews

DESCRIPTION OF CHILD WITH DOWN'S SYNDROME (DS)

<u>%Fs</u>	<u>Categories</u>	<u>Definitions</u>
46	HAPPY	- DS child seen as: happy/cheerful/content
32	LOVEABLE	- DS child seen as: lovable/lovely/loving
23	ACTIVE	- DS child seen as: lively/vibrant/energetic
21	SOCIABLE	- DS child seen as: outgoing/friendly
27	NAUGHTY	- DS child seen as: stubborn/cheeky/defiant

CONCERNS ABOUT CHILD WITH DOWN'S SYNDROME(DS)

<u>%Fs</u>	<u>Categories</u>	<u>Definitions</u>
20	SCHOOLING	- concern over DS child's education
36	LONG TERM PROVISION	- worry about providing for DS child: after school-age; when parents old/ill/dead
7	ADOLESC.	- concern over present/future adolescent problems eg. coping with sexuality
10	SLEEP PROB	- mention of sleep problems of DS child
14	SPEECH	- concern over child's speech/communication
18	DS HEALTH	- concern over child's health/physio. probs

FAMILY ORGANISATION

<u>%Fs</u>	<u>Categories</u>	<u>Definitions</u>
8	REVOLVE	- family life revolves around DS child
30	FITTED IN/NO EFFECT	- DS child has fitted into family life, has had minimal/no effect on family
24	NORMAL	- treated child as normal/same as sibs.
10	DADDY'S CHILD	- father perceives DS child has closer relationship with him than mother
11	MUMMY'S CHILD	- father perceives mother has closer relationship with DS child

EFFECTS SPECIFICALLY FOCUSSED ON FATHERS

<u>%Fs</u>	<u>Categories</u>	<u>Definitions</u>
42	INITIAL TRAUMA	- initial difficulty in adjusting to child being DS (eg. shock, upset)
22	EMPLOYMENT	- concern over losing/not getting a job, plus associated financial problems
7	OWN HEALTH	- concern over own health/illnesses

Appendix I: Summary of Qualitative Analysis of Interviews
(continued)

EFFECTS ON FAMILY

<u>%Fs</u>	<u>Categories</u>	<u>Definitions</u>
17	SIBLINGS	- concern over negative effects on sibs.
17	STRESS	- stress on family members due to demands of DS child
43	RESTRICTION-	restrictions on family life due to DS child (eg. due to constant supervision)
9	EXTENDED FAMILY PROBLEMS	- conflict with, or difficulties experienced by, members of extended family, due mainly to DS child
8	MAR.DIFS.1	- marital difficulties caused mainly by DS child
3	MAR.DIFS.2	- marital difficulties not related to DS child
12	CLOSER(W)	- DS child has brought husband and wife closer together
12	CLOSER(F)	- DS child has brought family closer together
14	OUTLOOK	- having DS child has given me/us better/broadened outlook on life; brought something special into our lives