



# RECOGNISING FATHERS

Understanding the issues faced by fathers of children with a learning disability



Foundation for People  
with Learning Disabilities



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This report is dedicated to Tom Cross whose picture, with his father Gav, appears on the front cover of this report. We were privileged that Gavin shared with us the joy he had in his relationship with his son.

*Cover photo: Chris Thomond*

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## FOREWORD

Patterns of fatherhood have varied throughout history. When men were weavers, farmers or craftsmen and worked at home, they were involved with their babies. Industry changed all that, sending them into factories and keeping them apart from their children. Now things are changing again as more men work from home and have regular coincidental contact with their children (Carpenter, 2002).

Today's media frequently publish photographs of fathers carrying their babies, pushing prams, playing with their children. Prominent political figures (such as Tony Blair, David Cameron) are depicted as proactive fathers, alongside a whole host of celebrity fathers from footballers to pop stars. By the end of the 20th century the acceptable father figure was 'softer', more liberal and one who acknowledged the need to 'get in touch with his feminine side' (Lamb, 2004).

As a father of a child with a learning disability myself, I know that the emotions we experience are full of paradox. Yet the need to protect and 'hold it all together' means that we rarely get the opportunity to share our emotional needs.

However, I do believe that society's attitudes to men as carers generally, and towards fathers of children with disabilities specifically, are changing. Our services need to become more 'father-friendly', respecting the unique contribution fathers have to make towards rearing their children with learning disabilities. The stories we heard from fathers during this project certainly illuminated the male parenting role - commonly known as Dad - in poignant and purposeful ways.

This report consolidates the key messages from fathers of children with disabilities, and re-contextualises them in a 21st century agenda for development. The platform provided by this report is a sound basis from which professionals and services can re-orientate their practice and service delivery to ensure that fathers are heard, and listened to, their needs embraced and their contribution valued. Once the 'Recommendations' of this report have been read, no-one (from Government department to local family support worker) should be left in any doubt as to their role in ensuring that fathers play a key role, recognising the significant support they give to their children with disabilities and families.

Fatherhood needs to be offered status and equality and the fathers of children with disabilities warrant respect and support. For the sake of those children we need to ensure that we are 'Recognising Fathers'.

I would particularly like to acknowledge the contribution of the Advisory Group for this project, who have been supportive and enthusiastic throughout. Most of all I would like to express profound appreciation to those fathers who have shared their insights with us. They have been a major source of inspiration and we hope that this report celebrates their fatherhood, and that of all fathers of children with disabilities.

Professor Barry Carpenter OBE  
Chair of the Recognising Fathers Advisory Committee

## 1. INTRODUCTION

This chapter sets out the context in which the Recognising Fathers project was carried out, with a brief outline of recent changes in policy and practice aimed at promoting the involvement of fathers and the issues faced by families of disabled children. It describes the background to the commissioning of Recognising Fathers and sets out its aims and objectives. The chapter then describes the methodology of the research, including how participants were selected and interviewed and the process of data analysis. It concludes with an outline of the report's structure

Throughout this report the word 'fathers' means 'fathers of children with learning disabilities' unless a wider meaning is specified.

### Fathers in policy and practice

There is a growing recognition in national family policy of the important contribution fathers make to family life and that strategies need to be developed to promote their involvement. The Green Paper 'Every child matters' (Department for Education and Skills, 2003) advocates a stronger focus on parenting and families, including a recognition of 'the vital role played by fathers as well as mothers'. Yet it is still the case that support services for families focus primarily on the needs of mothers and are predominantly provided by women. In order to change this situation the Government has introduced, over the past decade, a number of initiatives aimed at engaging fathers in public services. The Department for Education and Skills (DfES) developed guidance for schools on 'Engaging Fathers' in their children's education (DfES, 2004) and some of the SureStart Local Programmes focused on involving fathers in early years settings. The developing Children's Centres have been given a remit by the DfES to increase the involvement of fathers. The Government has also introduced initiatives to improve work-life balance and, in 2003, introduced paid paternity leave.

This growing interest in fatherhood has been mirrored in the charitable sector. A national information centre on fatherhood, Fathers Direct, was set up in 1999 and other organisations have developed specific programmes on fatherhood, such as Children North East, who work for the inclusion of men in policy and practice through their Fatherhood Centre and Fathers Plus programme. Contact a Family, a national organisation providing support to families of disabled children, established a post to develop support for fathers resulting in a 'Dads' zone' on their website and father specific activities carried out in some of their regions. Similarly, the National Deaf Children's Society ran a project on fathers resulting in a report in 2006, 'Did anyone think to include me?'

### Disabled children and their families

Most disabled children live at home with their families (estimates vary between 85% - 98%) with parents being the main providers of care. Previous research has identified factors faced by families bringing up disabled children including inadequate housing, poverty and diminished employment opportunities (Joseph Rowntree Foundation, 1999). There were additional problems affecting families resulting from the way services are delivered, including the lack of short breaks, the exclusion of children from play and leisure services and the lack of co-ordinated assessments and services. There is also a large body of research describing the huge emotional and physical strain that accompanies the task of caring for a disabled child.

A growing recognition of the role family carers play in delivering support was reflected in legislation to provide support to carers, namely the Carers (Recognition and Services) Act 1995, the Carers and Disabled Children Act 2000 and the Carers (Equal Opportunities) Act 2004. The importance of involving parents of disabled children has also been recognised in initiatives such as Early Support.



## Background to Recognising Fathers

In 2004 the Foundation for People with Learning Disabilities carried out a project, First Impressions, which looked at the needs of families during the first five years of life following a baby or young child being diagnosed with a learning disability. The findings from the project suggested that men were often marginalised in the process of arranging care and support for their children. Compared to mothers, fathers' support needs were overlooked. A mother taking part in the project said of her partner's experience following the birth of their child with Down's syndrome:

*"He is not a talker and he would have been overwhelmed by me wanting to talk about it. He was fearful ... of having to say things at work and I feel there isn't much support"*

Other research has also highlighted how fathers of disabled children have been marginalised (Soult, 1998; West, 2000).

Recognising Fathers was commissioned to address the issues identified by First Impressions and other studies, as well as to reflect the emergence of fathers in the public policy arena. In carrying out this study, it is important to acknowledge that some of the issues faced by fathers of children with a learning disability will be particular to their roles, their views of themselves and the ways in which society views men as carers. However, their issues will also overlap those experienced by mothers and by fathers of non disabled children (albeit perhaps to a different degree). It is also important to note that many of the men participating in this study saw themselves firstly as a father and only secondly as the father of a disabled child.

## Aims and objectives of Recognising Fathers

The study aimed to identify:

- the ways in which fathers of a child with a learning disability contribute to family life
- the problems fathers have experienced in using services or in receiving help in their caring role
- the needs and wishes of fathers in relation to developing 'father friendly' support.

The outcomes we identified for the study were:

- greater recognition of the important role that fathers play in caring for children with a learning disability and reflection of this in the policy and practice of support to families
- understanding of practical approaches that promote the involvement of and support for fathers
- greater awareness of the needs of parents supporting a child with a learning disability amongst research and policy organisations that address issues of fathering and parenting.

The focus of the research has been on gaining an understanding of the experiences of fathers of children with a learning disability. It did not specifically set out to look at the difficulties faced by fathers, but to look more generally at what they contribute to family life, what supports or hinders them in this and what has been the impact on their lives. This emphasis on the contributions of fathers rather than on their deficits or needs was influenced by an approach expressed in the article, 'Ask not what the country can do for fathers, but what fathers can do for children' (O'Sullivan, 2005). This proposed that the public debate on fatherhood should focus away from fathers' rights to the role that men can play in meeting children's needs:

*"It means looking at fatherhood as a national resource... fatherhood is there for children's benefit, and for women's too - if only we can make it accessible. The debate becomes more about releasing and harnessing social capital rather than about meeting individual male needs and 'rights'."*

### Research on fathers of children with a learning disability

There is currently little research that specifically looks at the issues faced by fathers of children with a learning disability. Research into families often refers to parents but usually the number of male participants is fairly small or non-existent. This may reflect a lack of opportunities to participate or a lack of willingness. A recent survey carried out by the Down's Syndrome Association (2006) to examine the pregnancy and birth experiences of parents who have had a child with Down's syndrome, specifically invited fathers to participate. Despite this, only 8% of respondents were male. Where research has focused on fathers, it shows a picture of fathers being seen as secondary carers whose needs are often ignored by health and social care services (West, 2000). The literature also shows that there are differences and similarities between the responses and coping strategies of mothers and fathers. This research aimed to look at this further and explore whether practitioners supporting fathers take this into account.

### Designing the study

The study was designed to take place over a period of approximately 18 months. The main method of data collection was to be in-depth interviews with fathers of children up to the age of 11. This age was chosen as it would capture experiences in the early years, through primary school and include preparing for transfer to secondary school. An Advisory Committee was established with members drawn from a range of professional and academic backgrounds. Four members of the Committee were also fathers of children with a learning disability. Ethical approval for the project was provided by the University of Plymouth, which supplied an external academic adviser to the project in the person of Dr Heather Skirton, Reader in Health Genetics at the School of Nursing and Community Studies. The research was carried out by a principal researcher who developed the research tools and carried out 18 of the interviews. She was supported in the research by the Research Fellow at the Foundation for People with Learning Disabilities who carried out three interviews. The fact that two researchers were involved in the interview process provided an opportunity to discuss the interview process and share learning. At the start of the project a literature search was carried out to identify peer reviewed literature, 'grey' literature and projects that had developed good practice in working with fathers. This information was used to inform the scope of the research and was added to as the study progressed.

### Participants

A combination of approaches was used in order to recruit participants with a range of experiences and characteristics (the design and selection of the sample is set out in Appendix 2). At the start of the project publicity about the study was produced and disseminated using the website of the Foundation for People with Learning Disabilities. A leaflet was distributed via learning disability services and national organisations and information was placed on various forums and in newsletters. Direct contact was also made with a number of existing fathers' groups.

Fathers were recruited in three ways. First, a number of fathers contacted the Foundation and expressed interest in being interviewed. In addition, practitioners working in a variety of organisations interested in the project offered to identify possible participants known to them or their colleagues. Finally, fathers were engaged at father-

specific events, namely a 'fathers' fun day' organised by a regional Contact a Family group and a club for fathers of children with autism.

All of the participants had a child whose main disability was a learning disability and some of the children had additional physical and sensory disabilities. However, as the study progressed it became apparent that certain fathers were under-represented amongst the participants: those under the age of 30, those with children under the age of three and fathers from black and minority ethnic groups. Therefore specific approaches were made to a voluntary organisation, a Special Educational Needs Co-ordinator (SENCO) and a service provider to identify suitable participants. Following the recruitment of additional fathers through this process it was decided that the study had reached a satisfactory point in meeting the selection criteria.

It is not possible to claim that the sample was representative of fathers of children with a learning disability: the fact that they contacted the Foundation, were present at a fathers' event or were suggested by a practitioner indicates that they were fathers who were involved in their children's lives. However, considerable effort was made to meet the various criteria and ensure that participants had a wide range of life experiences and fitted with the aims and objectives of finding out about the experience of men involved in the care of their children with a learning disability.

Through these various avenues potential participants were contacted and given further information verbally and in writing about the study and what the interview would involve. Apart from one father, for whom English was not his first language, all the participants spoke to the researcher before agreeing to arrange an interview. No father decided, at this point, against participating.

## Developing the interview guide

The interview guide was designed to encourage discussion through the use of semi-structured questions. Questions were developed with reference to the literature relating to parenting of children with learning disabilities, the limited literature specifically about fathers of disabled children and the generic literature on fathering. The next chapter provides a brief review of the literature that helped frame the study. The developments in policy and practice relating to fathers generally (mentioned above) influenced a change in emphasis of the project, from looking at the emotional and practical needs of fathers to looking more broadly at the roles played by fathers in raising a child with a learning disability and their resulting support needs.

This provided a framework addressing four areas of fathers' lives: the roles that they take on to support their family, their employment, their networks of support and experiences of support services. Within these broad areas a number of sub-areas had been identified and these were used as prompts during the interview. The draft guide was refined with the assistance of two fathers' support groups and the project Advisory Committee, which included four fathers of children with a learning disability who also worked professionally in related areas. Further minor amendments to the content and design of the interview guide were made as the interviews progressed: questions were added about how men negotiated roles and responsibilities within their families, their health, whether their GP knew about their caring responsibilities, and their feelings about the future. The interview guide is reproduced at Appendix 3.

## Interviewing fathers

Two researchers interviewed a total of 21 fathers (for details see Appendix 4). Participants were given the option of the researcher going to their home or meeting at another place that would provide privacy and would be convenient for them. Ten men were interviewed at home and the others were interviewed at their work, at their

child's school, in meeting rooms belonging to a service provider and one in a pub. Interviews were arranged at times that were convenient for the participants, including evenings and weekends. The interview guide was used to ensure that all the relevant areas were covered in each interview, but was used as flexibly as possible to ensure fathers could talk about their experiences as they saw them. In the interview fathers were able to be expansive in areas that were pertinent to them or add topics that they felt were specific to their situation. At the end of the interview participants were asked to comment on their experience of the interview and these contributed to developing and improving future interviews.

The interviews were recorded and usually lasted between 60 to 100 minutes. In addition fathers were asked background questions, which were completed on a form. Where interviewees provided relevant material informally either before or after the interview, this was noted with their consent. Participants were offered a voucher in recognition of their contribution and provided with information about Contact a Family should they wish to follow up any issues arising from the interview.

### **Analysing the data**

All the interview tapes were transcribed and the transcriptions checked against the original recordings. After approximately half the interviews had been carried out, initial analysis of the interviews began. This involved selecting three of the interviews, covering a range of the original selection criteria, and noting all the interesting points and from this identifying the emerging themes. These were then used to develop a framework to code the ideas. Further interviews were analysed using this framework and the framework was further developed as additional interviews were carried out and new codes identified. Some of these concepts emerged from areas that had been introduced through the interview schedule (such as support at the time of diagnosis), whilst others were ones that were introduced by the participants (such as fathers' awareness of other men who decide not to be involved in their child's upbringing). After approximately two-thirds of the interviews had been coded, the framework had developed into five main areas which were then used to present the findings.

Various checks were made to ensure accuracy and consistency. The academic adviser independently coded two of the initial interviews and these were crosschecked with those of the principal researcher and codings were added to the framework accordingly. Codings were also crosschecked with those of the second researcher who had independently coded an interview.

### **Structure of the report**

The following chapter sets out the results of the literature review. Descriptive accounts of the findings are laid out in Chapters 3 to 7 under the five main areas that emerged from the analysis:

- the emotional impact of having a child with a learning disability
- roles and responsibilities of fathers
- paid employment
- support for fathers
- interaction with practitioners.

Chapter 8 discusses the findings within the wider context of established knowledge about fathers of disabled children and current policy and practice around fathers and families.

A number of key recommendations have emerged during the course of the study and these are listed in the concluding chapter.

## 2. LITERATURE REVIEW

### Introduction

Men are an important resource for families, providing one third of all child-care in the UK, and fathers report wanting to spend more time with their children (O'Brien, 2005). The involvement of fathers has also been shown to help children adjust socially when going to nursery, enhance their educational attainment and reduce the risk of offending behaviour, yet services are primarily aimed at supporting mothers (Ivens and Clements, 2005). The importance of the role played by fathers is magnified by the extra demands placed upon the families of disabled children. Such families are more likely to experience financial hardship, strained emotional relationships within the family, modifications to family activities and goals, a restricted social life, time restrictions caused by care demands, contact with professionals, mourning and depression, and higher stress levels (Olsson and Hwang, 2003).

The emotional reactions of fathers to the birth of a disabled child may vary (Rendall, 1997) and differ from those of mothers (Fidalgo and Pimental, 2004), but the birth is invariably a life-transforming experience (Meyer, 1995) that causes stress, disorientation, and anxiety about the future (Bray *et al.*, 1995). While family members may look to the father for support at this time, his own needs often go unrecognised (Social Care Institute for Excellence, 2005) or are focused on the child and mother (West, 2000). The most dramatic response to the pressures endured by fathers is for them to leave the family, while the level of participation in raising the child by those who stay is strongly associated with their satisfaction with family life (Lamb and Billings, 1997). Other studies have shown that improved support, information and the opportunity to access services would enable fathers to be more involved with their children (West, 2000).

Research on the needs of fathers of disabled children has been infrequent (Gavidia-Payne and Stoneman, 2004), not least because fathers have been said to be 'hard to reach' (McConkey, 1994). They have been variously described as 'the invisible parent' (Ballard, 1994), the 'peripheral parent' (Herbert and Carpenter, 1994) and 'just a shadow' (West, 2000). Evidence about the experience of fathering disabled children has therefore been in short supply. Hornby's analysis (1992) of the written accounts of eight fathers of disabled children has, despite its small evidential base, been influential in developing themes about fatherhood. He identified seven themes from the fathers' accounts:

- 1) the intensity of fathers' reactions to the initial diagnosis of their child's disability
- 2) the process of adapting to the fact of their child's disability and the existential conflicts and questions thrown up by it
- 3) their largely negative reactions to potentially supportive professionals and their relative lack of direct contact with them
- 4) the stress of caring and the negative effect that this can have upon the fathers' lives and their relationships
- 5) their concerns about their child's future, especially their needs for care
- 6) the intensity of the positive and negative emotions experienced by the fathers
- 7) the 'personal growth' for fathers arising from their experience of fathering a disabled child.

In the mid 1990s more was being written about the isolation experienced by fathers of disabled children and the loss to their families of a potential care-giving resource (Herbert and Carpenter, 1994; May, 1996). Carpenter and Herbert (1997) observed that fathers found it difficult to assert their involvement. Neither health and education

professionals nor employers recognised the need of the father for inclusion in the family situation. While this coincided with a continuing emphasis upon the negative effects of stress experienced by parents of disabled children, research also reported the positive aspects of parenting a child with a learning disability as well as focusing upon the role of fathers (Blacher and Hatton, 2001).

To this was added a cultural context to the debate about fathers in which some commonalities could be identified. First, the role of fatherhood is recognised in all cultures. Second, there is a lack of evidence to suggest that men and women differ in their respective capacities to nurture and show affection for their children. Third, a father's active role increases with the age of his child. Thus, whatever the cultural context, 'focusing on mothers to the exclusion of fathers in parent training and other child-centred activities (e.g. social and school activities, parent-teacher communication), produces inconsistencies and may have deleterious consequences, particularly on the progress of children with autism and related disorders' (Elder *et al.*, 2003).

The remainder of this review seeks to examine what has been written about the most prominent dimensions of the experience of being the father of a child with a learning disability. A search of social sciences and psychological databases was carried out to identify literature that:

- 1) had been published in the past 15 years
- 2) made discrete reference to fathers
- 3) related to children with learning disabilities (who were identifiable as a sub-group within a wider definition of disabilities)
- 4) was based upon the findings of research.

Texts were categorised by subject matter and are presented here under four headings that relate to the most prominent issues addressed by the literature: the stress experienced by fathers and strategies they use to cope with stress; the impact of work and employment upon fathers' roles within the family; sources of support for fathers, and professional interventions that affect fathers.

### Stress coping strategies

While an increasing body of literature seeks to represent a spectrum of emotional reactions to parenting a child with a learning disability, 'between joy and sorrow' (Kearney and Griffin, 2001), the balance is heavily skewed towards consideration of their experiences of stress. Parents of disabled children are known to experience higher levels of child- and child-care-related stress compared to the parents of children without disabilities (Trute, 1995; Simmerman *et al.*, 2001). A number of studies identify chronic parental stressors such as behaviour problems, ill health and broken sleep patterns amongst disabled children (McConachie, 1994), while the number of children within families is also a good predictor of the level of stress amongst parents (Warfield, 2005).

It is not clear whether the experiences of stress are different for mothers and fathers, although many studies have reported raised stress levels for both compared to parents of children who do not have a disability (Esdaile and Greenwood, 2003). Some authors have noted the 'numerous studies' that report higher levels of stress amongst mothers of disabled children compared to fathers (Hastings *et al.*, 2005) and a higher incidence of depression (Veisson, 1999). Others point to specific family configurations where the level of stress experienced by fathers is higher, for example where the disabled child is a boy with poor communication skills (McConachie, 1994). Stress may also be part of a cocktail of mental ill health for fathers of disabled children that includes depression and low self-esteem (Dale, 1996).

Levels of stress reported by fathers may be influenced by their own educational attainment and the personality, age, gender and behaviour of their children, as well as their child's specific disability (Ricci and Hodapp, 2003). Men and women may also react differently to stressful situations, with fathers masking their stress with stoicism (Dale, 1996) while mothers of disabled children may be more attuned than fathers to difficulties being experienced by themselves and other members of their families (Little, 2002). Hastings (2003) looked at the inter-relationship between the mental well-being of mothers and fathers of children with autism and behavioural problems. He concluded that the correlation between stress in mothers and the problems experienced by other family members (a correlation not replicated in fathers) may reflect the fact that fathers are less involved in care-giving than their spouses.

There is strong evidence that reduced levels of both maternal and paternal stress are associated with spousal support in care giving (Willoughby and Glidden, 1995; Button *et al.*, 2001), improved marital satisfaction (Simmerman *et al.*, 2001), and good mental health (Trute, 1995). Simmerman *et al.* (2001) found that mothers' satisfaction with their partners' care-giving was not related to the type or actual amount of care-giving that fathers provided, suggesting that this aspect of the father's role is something that needs to be negotiated within individual families. Good spousal support is a key factor in parents adapting positively to the birth of a disabled child (McConachie, 1994), while marital stress has been shown to adversely affect the way fathers in particular interact with their disabled children (Pelchat, Bisson *et al.*, 2003).

There may be some differentiation in the factors that account for stress. For example, Hastings *et al.* (2005) pointed to some evidence for the adoption of different coping strategies by mothers and fathers: mothers being more likely than fathers to opt for 'active avoidance', a strategy associated with higher levels of stress and mental health problems amongst parents, and 'problem-focused' approaches to their child's disability. Other studies suggest that it is fathers who are more likely to adopt avoidance strategies as a way of coping with stress by taking opportunities to withdraw or escape from their families. Withdrawal invariably prompts a downward spiral of diminishing spousal support and an increased burden of care for the parent who remains (Dale, 1996). McConachie (1994) pointed out that parents of disabled children who use problem-focused strategies and who possess problem-solving skills to negotiate support for themselves and their families tend to fare better than those who practise avoidance.

The study by Saloviita *et al.* (2003) of the stress experienced by 116 mothers and 120 fathers of a child with a learning disability found that the most important predictor of parental stress was a definition of their own situation as 'catastrophic'. Their study suggested that for mothers this was most likely to relate to behavioural problems exhibited by their child, while for fathers it was their perceptions of the social acceptance of their child. Mothers in the study were more likely to seek support from outside the family than fathers, who tended to rely on their spouses for support. This echoes Little's (2002) finding that mothers of children with Asperger's syndrome and nonverbal learning disorders were almost twice as likely to use medication than their partners and were more likely to seek professional help.

Warfield (2005) found a correlation between paternal stress and the availability of reliable child-care, suggesting that this might be accounted for by the pressure placed upon fathers to fill shortfalls in child-care where paid support cannot be found. She pointed out that, while there is evidence that increased participation in caring roles can produce positive benefits for fathers, the fathers of disabled children contribute significantly less than fathers of non-disabled children. Elder *et al.* (2003) observed an association between the active involvement of fathers and a general reduction in stress within families, suggesting that raising fathers' confidence to become more involved in the life of their families may be a way to address the issue of stress for families.

## Work

Work appears to be an important factor in the role that fathers can and do play in families that contain a disabled child. Childhood disability is strongly associated with reduced family income levels for a number of reasons: mothers are often forced to abandon employment to care for the child, fathers' choice of employment and career prospects may be restricted, as well as the extra costs of home adaptations, specialised diets and equipment (Kelly, 2002a; Monteith *et al.*, 2002, both cited in McConkey *et al.*, 2004).

The literature suggests that, while the expectations of mothers are focused on the internal dynamics of their family, fathers are more likely to focus their expectations on the wider world, primarily through their work (Pelchat, Lefebvre and Perreault, 2003). Ricci and Hodapp (2003) pondered why fathers in their study who attributed positive characteristics to their disabled child (mostly children with Down's syndrome) did not spend more time in care-giving activity than fathers who reported negative attributes. They surmised that external influences, but most notably their work commitments and scheduling (Quinn, 1999), are barriers to greater involvement in primary care-giving.

An Australian study compared the motivations for seeking paid employment amongst fathers of disabled children compared to fathers of children without disabilities. The primary motivation for both groups was the need to earn money, but a far smaller proportion of fathers of disabled children said they felt a responsibility to provide for their family (Cuskelly *et al.*, 1998). Another study discovered a bi-modal distribution in the working hours of fathers, with some working many more hours than normal and some working considerably fewer (Einam and Cuskelly, 2002). The researchers surmised that having a disabled child leads at least some fathers to re-evaluate the traditional role of fathers as provider/protector as they attempt to reconcile their need and desire to become more involved in care-giving.

In another study income was correlated with marital satisfaction for fathers of disabled children, but not for their spouses (Willoughby and Glidden, 1995). This is reflected in the employment profile of mothers and fathers of disabled children: fathers are more likely to work full-time and work as much as 18 hours per week longer than mothers. They also report a greater level of interest in their work compared to mothers (Warfield, 2005).

Some studies suggest that fathers of disabled children and fathers of non-disabled children devote the same proportion of their time to primary care-giving, but for both groups it amounts to approximately 35% of the time devoted to the role by their spouses (Young and Roopnarine, 1994). Satisfaction with spousal support has been found to be higher in families where both mother and father are in employment (Warfield, 2005), yet the growth in the proportion of women being employed over the last 30 years has not been reflected in the experience of mothers of children with learning disabilities, who have often been hindered by a lack of child-care services (Shearn and Todd, 2000; Einam and Cuskelly, 2002). This is barely offset by the fact that fathers tend to take greater responsibility for primary care-giving in households where the mother works longer hours or where she earns the larger share of the household income (Simmerman *et al.*, 2001).

## Sources of support

Although men are less likely than women to seek help with emotional problems or to attend therapy, a proportion of fathers may be willing to engage in support group activity. The fathers of children with Down's syndrome attending a pilot therapy group facilitated through the health service explored issues of anger, anxiety and grief; they appreciated the openness, honesty and warmth of their fellow group members (West, 1998). Dale (1996) saw positive outcomes for fathers using groups that provided social support, including reductions in their reported levels of stress and depression.



Counselling may help fathers to understand their role as a parent better (Prachee, 2004) and bringing fathers together to discuss their concerns in 'a safe space to show emotions and brag about their children' can help them adjust to the distance between the ideal and actual experience of fatherhood (Quinn, 1999). Counselling provided to mothers can also be beneficial to fathers. Shechtman and Gilat (2005) reported a comparative study of the impact of group counselling and didactic forms of support for mothers. The counselling included sessions on how to involve fathers in educating their children and how to get advice and support from friends and family. The researchers were able to demonstrate that the group counselling intervention had a positive effect upon fathers' feelings of stress and coping. They suggested that 'perhaps the opportunity to address her own emotional needs improves the mother's interaction with both child and spouse' and that 'it is more important to address parents' emotional needs than to provide them with information about their child's problems' (Shechtman and Gilat, 2005).

Simmerman *et al.* (2001) identified some implications for counselling strategies from their study, most importantly that they should explore how couples negotiate their respective responsibilities for care-giving and satisfaction with these arrangements, especially the role that fathers play. In this sense counselling seeks to bolster what the literature suggests is the most important source of support for parents: their partners. In most instances men will play a subsidiary role to mothers in the direct care provided to a disabled child, yet their presence and support has been shown to maintain mothers' mental well-being (Dale, 1996).

A review of research evidence from the early 1990s concluded that social support from friends, relatives and parental organisations was more likely to promote parental well-being and had proved more effective in helping parents adapt to their situation than contact with professional services. However, it noted that, while poor services have been a source of stress for parents of disabled children, conversely good quality professional interventions could be of considerable benefit (McConachie, 1994). The role of the extended family can be a mixed blessing, with reports that contacts between the fathers and the grandparents of disabled children are experienced as both supportive and a source of stress (Hastings *et al.*, 2002).

## Professional interventions

What of the relationship between fathers and the professionals employed to support the families of disabled children? Consultations carried out in advance of the publication of *Valuing People* revealed that the parents of disabled children want better advice and information, an integrated approach from the professionals and greater access to support services (Department of Health, 2001), but made no specific mention of the needs of fathers.

The literature suggests that the relationship between fathers and professionals is moulded around key events: the diagnosis of a child's condition and decision-making about the child's subsequent support needs. The accounts of health care professionals providing a diagnosis focus on the differential reaction between mothers, who tend to regard it as an expressive crisis (what will be the emotional impact on the child and the family?), and fathers, who may regard it as an instrumental crisis (what are the practical implications for the child and the family?) (Lamb and Billings, 1997). The direct testimony of fathers not only furnishes a more subtle range of responses from fathers (Hornby, 1992), but also illuminates 'the mishandling and insensitivity of professionals when 'breaking the news' to them, with no recognition of their emotional needs' (Carpenter, 2002).

By marginalising fathers, professionals supposedly practising in a 'family-centred' way are failing to make the most of a major resource for families. Fathers in one study were more likely to participate in support activities if their role was acknowledged by professionals (Lillie, 1993), specifically by inviting them to attend, and by scheduling the activities at times and places that took account of other demands upon their time (Turbiville and Marquis, 2001). It is suggested that part of the reason for this neglect lies in fathers' inability to recognise their own needs when compared to mothers (Bailey *et al.*, 1992), or at asking for help with their needs. Professionals have therefore usually regarded mothers as the natural conduit to support services for families (Lillie, 1993).

An American study of fathers' participation in early education programmes found that fathers were more likely to participate in activities that also included their spouses as opposed to those open to men only, including informational programmes and support groups. This confirmed a gender trait: men rated strategies for involving them that were outcome-oriented (generally ones that emphasised full family involvement) more highly than those that were process-oriented (such as the provision of food, having child-care available or restricting participation to men only). In other words, the decision to participate was determined by what the programmes offered fathers rather than how the programmes were organised (Turbiville and Marquis, 2001). Lamb and Billings (1997) explained the likelihood of participation more straightforwardly as reflecting fathers' level of satisfaction with their family life.

Quinn (1999) emphasised the importance of interventions that help fathers to develop their role as parents and suggests a role for mothers to support their partners to adapt to the needs of the family, whilst also finding a place for fathers to share their experiences.

### Summary

The research literature on the issues confronting fathers of disabled children is limited, although interest in the experience of fathers has grown since the publication of Hornby's seminal work (1992) in the early 1990s. This review found that the subsequent literature on fathers can be grouped under four categories:

- the stress experienced by fathers and the strategies they use to cope with it
- the impact of work and employment upon their role within the family
- the sources of support that are available for fathers
- how professional interventions affect them.

Stress is a complex phenomenon and research evidence sometimes offers a confused picture about the stress experienced by parents. However, there is some clarity around two aspects of stress: that the parents of disabled children suffer greater levels of stress than parents of non-disabled children and that the mothers and fathers of disabled children experience stress in different ways and sometimes for different reasons. Men and women may seek different ways of coping with stress and stress can have serious implications for marital relationships. Fathers report wanting to spend more time with their disabled children, but they are still much more likely to remain in employment after the birth of a child than are mothers. Working fathers are presented with a dilemma about their role within the family: the need to provide the family with an income must be balanced with the need to provide direct care and support to both mother and child.

Men are less likely than women to seek help with emotional problems or to attend therapy, although some fathers are willing to engage in support activity and have found that counselling can help them to cope with their situation, especially where it helps to resolve respective caring roles with their partners. It is also suggested that 'natural' support from friends, family and others who share similar experiences is more likely to be effective than professional support.

Although there is a relatively small literature on professional interventions for fathers, it does contain some significant messages. Fathers' experiences in the early years of a child's life are often coloured by the insensitivity of professionals, especially at the time of birth or of diagnosis. There is some evidence that men have not been good at expressing their own needs and that these have therefore gone unrecognised. However, some successful strategies for engaging men have been identified: through interventions that are outcomes-focused and by considering when it is best to engage fathers and mothers in a joint enterprise.

### 3. FINDINGS: EMOTIONAL IMPACT OF HAVING A CHILD WITH A LEARNING DISABILITY

*Note: in the chapters that follow quotes from interviewees are identified by a number that matches the interviewee's description in Appendix 4.*

#### Introduction

Having a child has an impact on the life of any man, but if the child also has a disability then the man is entering not only the world of fatherhood but also of disability. The semi-structured interview questions used in this study did not particularly focus on the emotional impact of the situation for fathers, so the fact that they spontaneously mentioned those issues seems to indicate a willingness to talk about the emotional aspects of their experience. Towards the end of the interview fathers were asked a general question about how they would describe the experience of being the father of their child and the impact it had had on their life. This provided an opportunity for fathers to reflect back over years, and most fathers talked about a mixture of joy and rewards that were coupled with struggle and worries. These reflections provided very moving descriptions and some fathers found it difficult to talk as they were overcome with emotion.

There are many variables that influence the emotional impact of having a disabled child, which range from the personal outlook of the father to the level of support they have in their lives from their partner, extended family, friends and support services for their child and themselves. The nature and severity of their child's disability may also have an impact - especially where a child has severe autism or challenging behaviour. All of the fathers interviewed were men who remained living in the same house as their child.

#### Acceptance and decision to stay

During the interviews a number of fathers made reference to those men who are not able to cope with having a disabled child and decide either to opt out and leave responsibility to their partners or to leave their family. Interviewees were not specifically asked about their commitment, but their comments reflected their awareness of themselves as fathers who are committed to their children:

*"I don't want to do the, you know, Reggie Perrin, throw your clothes in the sea sort of thing, I want to be there, I want to be absolutely involved." (19)*

*"You get to hear the different stories and you hear some fathers walked out and to me, I can't understand why but obviously they have their reasons. When they have a child with a disability they just can't cope and go. So, you have kids with Down's who are up for adoption 'cause their parents don't want them and to me that... I just couldn't do that." (8)*

Fathers emphasised that their commitment was even stronger because their child had a disability:

*"I think dads just take a little bit of a backward step with it, in certain aspects of it. I'm not saying they don't love their child more or less. But you hear of people leaving them you know and different things. But it's just made my feelings for [my son] 100% like." (11)*

*"People keep saying that he's fortunate that he is with us, and we always think, 'well anybody would have done that', but sometimes you find some people wouldn't, that some people put their kids up for adoption and that. And in fact we know of people who won't have anything to do with a disabled child but he's totally helpless, he needs us and I could never, I could never not be there for him." (14)*

None of the participants mentioned having had thoughts about leaving their children, even though some were finding it a constant struggle to provide care. One described feelings of rejection towards his son when he was first diagnosed with autism, but at the same time described the strong bond they now have:

*"But it took me a while to get used to how I cope and I know it's a bad thing what I'm saying, but when I first found out I wish he'd died, passed away or whatever but I'm glad he didn't because he gives me a fight in life now to make sure I've got something to look after because he's going to need it." (5)*

From the sample it is not possible to say what motivates fathers to make this commitment to their disabled child. Some described themselves as having a positive attitude, enjoying challenges or being problem solvers, whilst others described themselves as family men who gave a high priority to their children. Around half talked about the huge adjustment that was required to accept the situation and to look at the situation positively. This was often described alongside the decision to overcome negative feelings and take a positive approach:

*"You sort of adjust to the situation and you just get to a point where you say well, I accept it and start doing something to make things better or you just curl up and die. So obviously I went down the first path, so that was more or less where I was coming from."(8)*

For fathers whose children were on the autistic spectrum there was an indication that the adjustment was harder:

*"Oh I think it is very difficult when you think of your child as something and then you find something wrong with them. I think it's a very, very, very difficult thing to go through and I think it really depends on the people, how they cope with it you know? If you're not really strong and everything you might want to just totally forget and say 'Ah this is not happening'; ignore it or you might just feel so depressed and that you can't get anywhere." (16)*

*"..you look at your child and you think oh it's a blip, but then you try to deny that there's anything wrong and... you get angry, and then as things go on and on I guess you begin to accept the enormity of it really." (9)*

## Impact of diagnosis

For some of the interviewees this acceptance of their children had begun fairly soon after realising that 'something was wrong' or after receiving a diagnosis. For others it had been a more a difficult process that occurred in stages as they understood more about their child's disability or gradually received a more complex diagnosis.

Across the interviews there were many differences in the diagnosis that had been received, in the timing in relation to the birth of the child, and in the way in which it was delivered. Three fathers had received a prenatal diagnosis for their child, while for nine the diagnosis had been made at the time of birth. A further six fathers became aware of their child's diagnosis in the early years and children of three fathers were still awaiting a specific diagnosis. Some fathers were informed their child had a disability in the early years but this was not specifically diagnosed until later. Three fathers, including two from the Bengali community, had not yet received a specific diagnosis for their children and this caused them some concern.

Of the three men who had received a prenatal diagnosis, two talked about their decision as a couple to continue with the pregnancy, having been offered a termination. Both already had older children. One of them said that he found it helpful to have this time to prepare, although his wife had felt differently and would have preferred not to know. He also described the impact of a prenatal diagnosis on his relationship with his child in that the diagnosis of Down's syndrome became more significant than the unborn child:

*"It was all very abstract... you've got a diagnosis and a medical condition but you haven't got the child yet and it was in a way a relief when he finally turned up and you found he was in many ways just like any other baby for the first few months at least, apart from having a lot more medical check-ups and whatever, but he cried and slept and poed and weed like any other baby. I think we actually forgot he would do all of that, we just sort of thought that this sort of whole set of medical symptoms will appear rather than actually being a child."* (4)

In addition, he found out that his child would have a learning disability before he knew that he would have a son:

*"So he's never been the son who I was going to play football with and was going to follow in my footsteps at work and we were going to go off to the pub drinking and that, because there's never been that father/son thing, which again is perhaps different from a lot of other fathers who've found out first of all that they have a son and then secondly that they have a son with disabilities."* (4)

The third father who had a prenatal diagnosis described his joy at being told that one of the twins they were expecting might have Down's syndrome, as he and his wife had previously been told the baby might have Edward's syndrome. They had been hoping for a family for fifteen years and, as Edward's syndrome would have resulted in their child having a limited life expectancy, this diagnosis had been devastating:

*"So we looked in books for Edward's and I remember [my wife] reading it and said, 'I don't think I should tell you this' and I said, 'Well I've got to know.' So when she told me I was shocked. So after a couple of months . . . then they said, 'It's not Edward's' and we went, 'Oh brilliant it's not' . . . So they said 'But there is definitely a problem. We think it's Down's syndrome' and they said 'What do you think about that?' Well we were doing cartwheels, going, 'Oh it's only Down's syndrome, it's only Down's syndrome' you know, 'At least we've got a little baby like, innit?' Oh 'cause we were over the moon."* (10)

Over half the interviewees talked about feelings of shock, bewilderment and 'facing the unknown'. These feelings seemed predominant amongst those who received the diagnosis soon after the birth, as one expressed it: *"It's such a shock because it's basically the unknown."*(8)

For some the impact manifested itself in a physical reaction and prompted what one regarded as a symbolic act of rejection:

*"I think, like I'd kind of almost sort of fainted and I just put [my son] down in his cot, which was sort of symbolic of me like, giving up on him, which is rubbish I know but I did feel really bad about doing it, but I didn't know what I was going to do really."* (19)

This same father talked in some detail about the traumatic effects of having not only a disabled son, but also one with significant health problems. His testimony is littered with a simmering sense of injustice that his middle years should be disrupted by the demands of caring for his son, combined with impatience for those 'well-meaning people' who suggested that they were well equipped to deal with the situation:

*"We wanted two normal children, we didn't one to almost die in hospital, we just wanted to get on with our lives."* (21)

Another father talked about the difficulty of knowing something was 'wrong' and having to deal with this on his own as his wife was recovering from a Caesarean operation:

*"The first day he was born was, you know, the worst day of my life, and I'll never, ever forget it, because. . . . [my son] was rushed to the special baby care. So I was dealing with all that. [My wife] didn't know anything about it, she didn't have a clue, I didn't tell her till the next day, but that first night. . . . I cried myself to sleep." (14)*

For a father whose son was diagnosed with autism during his early years the need to adjust his expectations happened more gradually:

*"I picked up that something was wrong with [my son] from quite an early age really. You know he was diagnosed from around 2 or 3 years old but you know it really does change your life round completely . . . . because obviously I had different expectations as to how things were going to be and I've had to readjust to that." (9)*

### Changes in social values and personal attributes

A number of interviewees talked about changes in their social values and personal attributes since the birth of their child. Some talked about how they had previously been completely unaware of issues about disability and that they felt they had entered a previously unknown world:

*"And once you have a child with a disability it's like all these hidden places that you've never noticed in your life before, yet they're actually in front of your eyes all the time." (6)*

This echoes the sense of bewilderment that some had mentioned experiencing at the time of diagnosis, yet they now saw this greater awareness of disability as a positive experience:

*"I've done things and accepted things that I thought I might never have done." (8)*

One father had grown up with negative feelings about 'handicap' as a result of his experience of being sent to hospital as a child:

*"There would be all types of people there and I used to hate it. I run away from that school quite a few times. But all through life I hated it. I can never face anybody who is disabled." (5)*

After some initial difficulty, he had accepted his son and was now interested in training to work with children with autism. He had also been brought up with a mistrust for social workers and taught to 'keep family business within the family'. He had to make another huge adjustment to ask people for help and let them into his life.

A small number of participants mentioned that they had become better people or better fathers since having a disabled child: they were spending more time with their family, were less focused on their work and had developed personal attributes that they saw as being beneficial for their family:

*"Well it's probably made me better actually. I spend more time with the family, which is a good thing, I do less work." (1)*

*"I think it is different and I think I've been a different dad, probably been more patient and spent more time with them really, and more with [my daughter]. . . it was about just making sure [my daughter] was treated no differently than anyone else." (8)*

A number of fathers mentioned that, through their experience, they had developed positive qualities such as patience, tolerance, thoughtfulness and becoming more settled in life. A few fathers felt their experiences had led them to be more assertive, as this was needed for their children:

*"To be honest I am quite shy really... not since [my daughter]. I have got more confident because I have to be otherwise things don't get done, and if you don't speak up, she wouldn't have half of what she's got now." (1)*

But their experiences had also led to less positive changes. One father said that, although his determination had grown, he had also lost confidence and self-esteem because of leaving work to become a full-time carer.

## Impact on relationships

### Relationship with child

Most fathers described a range of emotions in their relationships with their children; where fathers felt under pressure, there was a strong sense of tension between having a rewarding and a difficult relationship. The predominant emotions reflected a strong commitment to their children and the descriptions they gave conveyed a genuine sense of closeness and pleasure in their child's company:

*"I haven't been able to put her down since then, she's been wonderful... the relationship I've had with her and she's been so close and kind really and always pleased to see me... and you know I find that fantastic, to actually be able to share your time with somebody like that." (6)*

Many talked about the stresses and the pleasures in the same sentence, conveying a sense of how the two emotions are tied in together:

*"Ah, made everything, at the beginning very stressful, right, very joyous, very joyous, hard work, mind. It is very hard work especially when he's smearing and all, that it is really hard work then but when he's his own little self then it's joyous it is, really, really nice." (10)*

*"Joyful! Yeah. Only special people get children like [my son]! Yeah really good... a tie on our lives but he's a delightful little kid." (11)*

The tension between the rewards and the difficulties was even greater for a father whose son was on the autistic spectrum and whose behaviour meant that he needed constant support:

*"It does have its rewards but probably fewer than most fathers would expect. You know I find it is a struggle, you know to the extent that sometimes I feel I can't live with him any more. There you go, I mean that really says it all, doesn't it, but it is a struggle but I find that once he's been away, for instance, overnight on respite, I find myself laying the place for him for dinner and then when he comes back it's great to have him back again. Yeah, a lot of conflict, that's all I can say." (9)*

Some men described a two-way giving and taking relationship, where the fathers provided protection and support and in return appreciated the love and achievements of their children:

*"You're always going to have a strong bond with your kids anyway, but it's something that's a bit more special and stronger with him because he can't do a thing, you know that, you know, he totally relies on you. And when you do get one little smile or something out of him, you know, it's worth every minute of it." (14)*

*"The [daughter] that we have got is the only [daughter] there will ever be and that is good enough for me because she is a fantastic kid and you know she really does give back everything you give to her. So it is just not a problem." (6)*

Indeed several fathers had come to the realisation that having a disabled child validated their parental role as their children were very dependent on them to provide opportunities, as described by a father whose daughter had complex needs including visual impairment:

*"When [my daughter] was first diagnosed, I think for the first four years ... I threw myself into work, so there was a sort of slight running away... But since then, since I now know there's a real need and there's a defined... there's a defined role really. I make a difference to [my daughter]." (3)*

The experience for fathers of children with autism appeared more strained as this two-way relationship was more difficult to achieve. Two of the fathers described the sense of loss they felt through having a child who was difficult to get close to and who they were struggling to understand:

*"I mean first and foremost I think [my son] is our child, not our disabled child, but not far behind that he has a certain set of needs and conditions that make him different from other children. I suppose partly because of his condition it's a bit strange being his father... he's not at all demonstrative and we sort of feel a bit cheated in some ways because... I mean he's pleased by interaction if you sit down and physically sort of engage him in a game or an activity... he enjoys it but the, you know, the idea of a smile or running to greet you when you walk in the door just isn't really there. But I mean that's part of, I suppose, the mix of things that is having [my son] in the family." (4)*

*"I mean, [my son] being autistic, it's difficult to have a close rapport with him. I'm his dad and it's hard to get too close to him, you know, I think one of the real striking things about the condition and I think other parents have spoken about this before is that very rarely you get a glimpse of the child underneath it all and you see it, does that make sense, and then it's gone again... and I wish I could get there, I wish I could get under that surface and get to him there because that's who he really is, I'm sure that's the child he is." (9)*

Other fathers described a sense of anguish that, although they did what they could to improve their children's situation, they could not overcome the dependency and difficulties they faced:

*"With him being disabled, it's hard to describe how much you do love him, and you know, want to be there to help him, but obviously you can't make anything right, but you can just try and make life as good, give him as good a life as you can." (14)*

*"Yes, it is quite a bit of a struggle, because he's saying that he feels for him, because he can't go out on his own, he can't be independent, because he needs someone to overlook what he's doing." (Interpreter translating for 18)*



## Relationship with partner

Most of the interviewees were living with their partner, although one had been widowed, another was at the point of separating and a third was leading a fairly separate lifestyle even though still living with his partner.

Almost all commented on the impact having a disabled child had on their relationship, covering aspects such as having strengthened their relationship, the pressures it placed on maintaining a relationship and the ways in which they had to work things out together. Ten fathers reported that it had put significant pressures on their relationship, sometimes to the point of struggling to continue living together:

*"At one stage you know things were so low I thought that our marriage was going down the tubes you know and I didn't want that and I really wanted to keep the marriage together and to keep us together as a family." (9)*

*"In terms of us and our needs they don't exist because so much time and energy and effort goes into [my son], there's almost nothing left. That's how we got through the last two and a half years. A couple of months ago we did almost split up." (20)*

Both of these men also described how closely they worked as a team with their partner to provide complex care to their children, and how they and their partners supported each other to maintain their morale.

One father described how the situation with his child had led to the breakdown of his marriage. He and his wife each had a different response to the birth of their daughter and had not found a way of resolving this in the way they cared for her. The change in their relationship was now an added difficulty in the dynamics of supporting his daughter. Another described how his son had come between himself and his wife, as he was spending much of his time supporting his son, who had become the main focus of his life. However, he was prepared to lose his relationship to care for his son:

*"But if it costs me my marriage, it costs me." (5)*

Another participant felt that the birth of their child had had a detrimental impact on his relationship with his wife because he had not understood her reaction to the situation:

*"I was probably too hard on my wife for a long, long time, saying 'Come on, I've got over it, you can', sort of thing. She was off work with depression... I think I let her down badly because I kind of didn't understand at the time; it was kind of 'Who's this about, is it about you or is it about [our son]?' (19)*

Two fathers mentioned how their relationship with their partners had improved through spending more time with each other and sorting out problems together. One of these said that, although it had made their relationship stronger, it had also led them to have more arguments:

*"I think it probably has made it stronger...I mean we argue quite a lot really and seriously sometimes but as I say it's not about him but it's about things that happen... it's usually the hassles we've had with all the authorities and everything with him and we end up arguing about that." (15)*

There was a sense that the relationship between the men and their partners had become focused on working things out together to support their child. Twelve fathers talked about how they worked closely with their partner. On the whole, relationships had become about supporting their children rather than having time together independently. Some saw this as a loss, with one describing the importance of having a support service to care for their twins in order to have time to go out with his wife:

*"There were times when it was just 24/7, just constant caring. Me and [my wife] hadn't been out since the babies had been born. We hadn't been out together at all and then we were put onto an organisation called Crossroads. And we're allowed one Tuesday a month now and one Saturday a month, so in a month we can go out twice... and that is the best hours!" (10)*

On the other hand, another man described how giving up on a social life as a couple made sense for themselves and their children:

*"And I think we probably have missed out about going out together just as a couple ...we very rarely do it to be honest... but that's a decision we made on the basis of what is best for [our daughter], what's best for the family." (6)*

## Impact on health and well-being

During the course of the interview almost two-thirds of interviewees talked about experiencing stress, depression or lack of sleep. Some of these felt under constant stress:

*"Sometimes you can believe anything. I must have a virus or something. I'm so tired and it's like a tiredness that comes over you that you could just go to sleep straight away and it's probably just all the stress that goes on. And as I say small problems turn into large problems, even though they are just small and you worry about all sorts." (1)*

*"[You] get a sustained period where we're not getting much sleep or you feel as though you're on the edge and you feel as though you can't deal with your son any more." (9)*

Eleven men reported a lack of sleep, with one having to get up every night. Factors other than the struggle to provide care also caused stress: problems in relationships, inadequate housing and employment difficulties. One father described having a breakdown resulting from the impact of various stressful factors. A few had additional health problems that added to their stress: for example, one father had recently been treated for cancer.

Although fathers experienced these high levels of stress, very few were talking to their GP or other potential sources of support, and most did not see that this was something for which they could receive help (see Chapter 6, Support for Fathers p.49). One father catalogued the 'considerable amount of time' both he and his wife had taken off work since the birth of their son, who still required periods of hospitalisation for associated health problems. Another, whose son had recently been diagnosed, did not feel that he had time to think about his health and take measures to reduce his stress, even though he recognised this was something he should be doing as he was aware of hereditary illnesses in his family.

On the other hand, a few fathers felt that their children's disability had not affected their health, with two fathers mentioning that their main cause of stress was their work rather than their children. Another father described how caring for his daughter, who was very dependent, made him realise the need to look after his own health and lead a healthier lifestyle:

*"It makes you think well, we'll look after our health, let's cut that down a bit, let's make sure we do plenty of bike rides and exercise and eat well. So there's a real benefit there." (3)*

## Views about the future

About half the participants mentioned that they were worried about the future and for some it was a constant worry:

*"Always worrying about the future, I suppose. And probably in one way it has made me grow up quicker, I suppose. ... Not really how it affects me, but how it's going to affect them, basically." (2)*

One respondent found it hard not having a diagnosis for his two-year old son, yet recognised that having one would confirm the permanent nature of the disability and cause more anxiety about the future:

*"You don't want to have a diagnosis or a label because you know then what to expect and you can research it and you can look at the law of averages and say this is what he's going to be able to do or can't do, this is how long he can live for, and these are support needs that he might need... in future. And you go through your head every day, what is it going to be like in five years' time, when he's 18, perhaps when he's 25." (20)*

There were concerns about the short-term future as their children's care needs changed as they grew older:

*"As [my daughter] gets older I can see that I will have to start doing more because she's getting bigger and you know [my wife] won't be able to cope with it." (1)*

*"The care side of it does worry me, that she is going to get older and her intimate personal care at some point ... you know probably daddy is not the best placed person to be delivering this and that'll need planning for, we'll need to cross that bridge." (6)*

There were also concerns about changes in services such as the transition from primary to secondary school and from children's to adults' services:

*"I think things are easier to deal with you know when [my son] is a child. I think there's more acceptance when he's a child and you know my own concerns are around the period of transition, you know when he goes from children's services into adult services." (9)*

Over half mentioned concerns about the long-term future, including the quality of their children's adult lives, the level of independence they would be able to have and who would support them when they, as parents, were no longer able to do so:

*"I love him to bits, he's my son, I want the best for him. I fear for the future for him. I wonder who's going to support him and love him in the future." (9)*

Concern about the long-term future was a strong theme in most of the interviews, but fathers from black and minority ethnic communities seemed to have particular concerns about their sons growing up with a disability:

*"So that was my concern, is my son going to be dependent on me and his mother for the rest of his life or can he progress? Is there anything we could do to help and that sort of thing." (16)*

*"He's saying what happens if they do die. ... what's going to happen, who's going to look after him." (Interpreter translating for 18)*

Some expressed concern about the prospect of remaining the primary carer for their child well into adulthood, although they also recognised that support services for adults with learning disabilities had improved. One described how a nephew with Down's syndrome still lived with his parents at the age of 22; the interviewee and his wife had to convince themselves that their son would have better life opportunities than their nephew because of the support that is available now. This formed part of a coping strategy that allowed him:

*"... to lie on that bed and think right, well I did the best that I could and [my son] in particular is in this sheltered accommodation with this job with this level of protection so that I don't have to worry that he's going to be, you know, abused or thrown in a home or Christ knows what." (19).*

Similarly, another talked about how he and his wife had begun to plan for the future for their son:

*"Well, our aspirations for the future, we'd like to see [my son] settled in sheltered accommodation, you know probably towards his early twenties." (12)*

Although most fathers were concerned about their children's continuing dependence, one felt positive about his continuing close relationship with his daughter after the time when most children would have left home:

*"And one of the benefits is to think well, I'm needed for that forever. It's like you know you have a...son or... daughter, and you know at some point something's going to change, he's going to go off and he's going to do something, but with [my daughter] that's not going to happen. And in a funny sort of way it's quite reassuring and it makes you want to carry on." (3)*

## Key points

- The experience of becoming the father of a child with a learning disability was described by many of the men in the study as 'life-changing', leading them to reassess their values and priorities.
- Immediately after receiving a diagnosis fathers generally reacted with shock, bewilderment and a sense of 'entering an unknown world of disability'.
- After the initial impact of the diagnosis, fathers often described how they picked themselves up and 'got on with it'.
- Most fathers described a close emotional bond with their child and described the joy they got from their relationship with their child. However, the pleasure they expressed was often tinged with a sense of struggle.
- Fathers of children with autism often expressed frustration at the difficulty in having a two-way relationship with their child.
- Most fathers were affected by a lack of sleep and by depression or stress; some felt under constant stress.
- Couples were often under a lot of pressure: sometimes this had strengthened their relationships, yet for others it had led to separation.
- Fathers were concerned both about their child's short-term future (often relating to their health or access to educational services) and about their prospects in the longer-term (often about the quality of their lives and their ability to live independently).

## 4. FINDINGS: ROLES AND RESPONSIBILITIES

### Introduction

The men in the study came to fatherhood with a variety of expectations, many of them fashioned by their relationships with their own fathers. Most hoped to play a more active role in their children's lives than their fathers had during their own childhood:

*"I think he used to sort of come home from work and go to the pub and then, I don't think it was every night, but you know, he used to sort of arrive home and see me for ten minutes and then it was kind of over, if you like." (19)*

Some struggled to reconcile their situation with their expectations for fatherhood. For example, one man traced his passion for cricket back to his father pushing his pram round the boundary of the local club: *"That sort of like give me goose bumps thinking oh one day I'll be able to push my son in his pram around the cricket ground and say right you'll be playing on there soon."* The birth of his son would enable him to do this, but he was finding it difficult to accept the fact of his daughter's disability and what that might mean for his role.

Whatever their hopes and expectations of fatherhood, the men in the study realised that raising a disabled child would require them to play many roles.

Most of the fathers who were interviewed were in paid employment and therefore one of their key roles was as a breadwinner for the family. Fathers were asked about the roles they took on to support their disabled children, their other children and their partners. They were asked whether these roles differed from their partner's roles and how these had been negotiated. Many, apart from talking about specific tasks they were involved in, also talked about the reasons for doing them. These indicated their commitment to their children having opportunities now and in the future.

A few felt that their roles and responsibilities had not been significantly influenced by having a disabled child, whilst others felt it had had an enormous impact on their types and level of involvement.

### Fathers' involvement

#### Level of involvement

Of the 21 fathers interviewed, only one described himself as having a low level of involvement in family life. Another father's work commitments meant that he was often away from home during the week and therefore his involvement was chiefly at the weekends. All the other fathers described considerable day-to-day engagement with their children, although the intensity and type of involvement varied. Some fathers described how they saw themselves as a father, using terms like: 'hands-on dad', 'family man' and 'a second mum' to indicate their commitment to being involved in the upbringing of their children.

Three of the fathers were clearly the main carers for their children. The reasons for this varied: one was a single father following the death of his partner, the wife of another was housebound due to ill health and the other had developed an extremely close bond with his son and had taken on the main responsibility for his care and development. The single father described how he was the only person available for his son:

*"[I do] everything you know. Bath him, wash him, dress him, cook for him, clean after him, play with him, put his videos on, put his DVDs on, read to him, sit down and do his homework with letters, numbers, that type of thing; you name it, I do it. So you know it's seven days a week, twenty-four hours a day." (13)*

The father whose wife was unwell described a busy daily routine that allowed him very little free time in between getting children ready for school, taking children to school and nursery, doing housework, shopping and collecting children. With three disabled children he also had frequent appointments to fit in.

Ten fathers talked about having similar levels of involvement to their partners, although the nature of their involvement varied. Most of these men either had a partner who worked or they themselves were not working. A Bengali father took responsibility outside the home because his wife did not speak English:

*"My wife, she is unable to read in English, and she doesn't speak in English, most of the time I have to do myself." (17)*

The partners of three fathers had all either given up work or not looked for work following the birth of their child. These men acknowledged that their partners had considerably more responsibility for providing care:

*"Hers is the main role because she's with him constantly, she's the one who deserves the medal." (14)*

*"I wouldn't say I care for [my daughter] like [my wife] does because she's here all the time, but I do take a lot of time off to take [my daughter] to different places, and go to the appointments. And maybe if she's not very well, I stay off." (1)*

## Sharing responsibilities and supporting each other

The roles and responsibilities that fathers took on were described not just in relation to their disabled child but also to their partner and other children. Fourteen fathers talked about how they worked closely with their partners to provide care for their children. Sharing the work was described in different ways: some couples shared responsibility for 'whatever needed doing', others had more clearly defined roles about who did what and a few men took the lead from their wife and fitted in around the care they were providing.

The couples that shared responsibility for 'whatever needed doing' tended to be both working and therefore had significant pressure on their time:

*"I think the roles within our family, they have to be shared and you know we tend to work as a team, my wife and I... my wife doesn't do the bulk of the child-care for instance or the domestic work. It's very much shared and we're so used to it now that you know when we come into the home or certainly when I come into the home I look at things which need to be done and just get on with it really and I think that's essential to make things work." (9)*

Some couples worked out different roles by being aware of who was good at what and dividing tasks along these lines:

*"My wife has got her strengths, I have mine, I pay attention more to details than she does so I would rather go [to meetings] myself and then try to help her. I would say that she would give him more emotional support - although I'm not a very reserved person, but she is better at it than me. I will support her in other aspects, yes." (16)*

*"I think I'm the more fun one. I'm the more 'playey' one. [My wife]'s the more serious one amongst us then, I'm the one who likes to have a laugh and I'm always on the floor and I'm always rolling around with them, where [my wife] is not that type. ... So, that's the difference between us then, she's the straight one, she does all the cooking and the business and all that." (10)*

Two fathers, whose partners were not working, recognised how difficult it was for their partners who were at home all day with their young children. They described how they tried to support their partners by fitting in around them and both seemed comfortable with taking the lead from them:

*"And because it is very sort of stressful for [my wife], I try and sort things out to make [my wife]'s life easier caring for [our daughter]. So, in a knock-on thing, I am helping [my daughter] by helping [my wife] and just trying to keep everything as normal." (1)*

*"She's here constantly so she knows the routine... I learn from her because... she's with him all day." (14)*

Another way in which fathers spoke of how they supported their partner, and sometimes other children, was by providing them with a break by taking their disabled child out:

*"I'm there for an hour, but it gets me out of the house for two hours if I'm taking and bringing him back, so that gives [my wife] and the girls a bit of time where they don't have to think about what [my son] is doing." (4)*

Another father had a reciprocal arrangement with his wife whereby he took the children out on a Saturday morning to give her a break and he had a lie-in on a Sunday:

*"On Saturday mornings then I do leave her have a lie in and I go up my mother's 'til 12 o'clock. You know - I do give her time like to have a bit of peace." (10)*

Providing respite also entailed staying in to allow their partners to have a night out; one recalled how his wife had been reluctant to leave their son, even with him, but with his support and encouragement she had begun to enjoy girls' nights out as she had in the past.

Whilst fathers did talk about some of the things they did with their other children, the immediate care needs of their disabled child often prevented them from doing this. Their comments were tinged with guilt about this:

*"We try to do 50/50 to be fair on them but of course if [my wife] is doing dinner and I've got [my son] on my lap and [my other child] wants attention, I feel like I'm neglecting him. So I find that a bit hard." (10)*

*"You need to know what he's up to and you need to know that he's engaged in a productive activity otherwise you'll end up with problems, so that takes away some of the attention from [my daughter]... I think sometimes she finds that difficult because she will go and seek out your attention you know and I'm conscious sometimes you get a bit short, you get a bit tired or frustrated and you get a bit short." (9)*

One father described the pull between thinking about what his son needed whilst also being mindful of the development of his younger child:

*"I'm thinking what he needs yes, yes, yes. And also trying not to deprive his little sister from the support that she needs too." (16)*

Another father, who had a young child with complex health needs, described how he and his wife tried to keep their elder daughter's life as normal as possible:

*"We do try you know ... try our best to keep it as normal as possible for her." (1)*

## Day to day living

### Domestic and household tasks

Approximately half of the fathers mentioned that they carried out some domestic and household tasks, although their involvement in this seemed far less than in the daily care of their children. A few fathers implied that the care of the home was chiefly their partner's responsibility. However, for some the birth of their disabled child had necessitated them taking on more of a role in maintaining the household than previously:

*"I would never do that beforehand and I do all the hoovering and that. Sometimes I come home from work and I think, 'Oh I better do the hoovering for [my wife]'; especially if she's had a really hard day, because [our daughter] can be up all night and then she would be crying all through the day. So I suppose I've taken on a bit of a 'house husband' type role, as well as doing my work and that. So that role has changed you know like, I definitely do more around the house." (1)*

Two fathers, whose partners were also working, took an equal responsibility for domestic tasks:

*"With the ironing and the washing and all of the other stuff, that goes into making the house work, it is just whoever has got the time, whoever can do it, or sometimes, whoever has got the energy to actually do it at that particular moment." (9)*

For some fathers the division of labour within the household was determined by what they felt they were able to contribute. The father of twins, one of whom has a learning disability, cheerfully admitted that he was an unreconstructed man lacking any domestic skills. However, he believed that he compensated for this by 'doing as much as is physically possible' to care for his children once he gets home from work.

### Daily caring tasks

Almost all the fathers were involved in providing personal and practical support to their children. This involved activities such as getting them up in the morning, washing, bathing, showering, dressing, getting ready for school, preparing meals, feeding, bath-time in the evening and putting to bed. The type of tasks fathers were involved in did not appear to vary depending on whether or not they were at home or at work during the day, although not surprisingly it affected the amount they did. A father who was studying and working part-time described his involvement:

*"Generally I do practically everything; I change nappies, I play with him, cuddle him, I think the only thing that my wife does more than me is actually feeding him... I don't go out a lot and I like to stay around my children so I really do quite a lot. Yeah, I think my wife if she was here she would say the same thing." (16)*

When fathers were working more regular hours they would be involved in morning routine and again after school:

*"During the week, I'm at work every day so I get him up in the morning and give him his shower. He comes in the shower with me. Get him washed and ready and dressed and give him his breakfast and then off to school... Then I get home between half five and six, so we just really have a play around for a while because he's usually quite tired after school... He goes to bed at 7 o'clock so I just give him his bath, put him to bed and usually stay with him until he's gone to sleep because he won't go to sleep on his own." (15)*



Fathers also seemed to take their share of getting up at night and, where necessary, sleeping with their child to get them back to sleep:

*"We do it in relays. We do one night on. I have a good night's sleep and [my wife] has got her ear out and it's vice versa. So we've got to do it that way, just got to." (10)*

## Providing routine

Two fathers whose children were autistic mentioned the importance of routine, but both found it stressful to combine their work commitments with providing the necessary structure:

*"Because [my son] has got to be in a routine, i.e. up at half past seven, breakfast, drink, dressed for school, it has got to be all... you have got to synchronise, it's got to be, the bus driver comes at ten past eight in the morning, if it is ten minutes late, he is getting bored, he starts kicking off so for those ten minutes I like to be there but sometimes I can't be there because I am on mornings." (5)*

*"So I have to go straight into that [from work] and he's a very demanding child and I find that really hard sometimes because all I want to do is go in and sit down and have a cup of tea but I can't do that, I've just got to go straight in and that carries on really throughout the evening... but we try to keep it as structured with as much routine as we can up to bedtime and then I'm able to relax." (9)*

## Supporting their children's development

### Interaction with their child

Most of the fathers attributed a good deal of importance to interaction with their children. They described a range of activities such as play, sitting with their child, listening to them, having cuddles and kisses. Some described more traditional interactions between fathers and children based on rough play and sharing interests such as football:

*"I tend to be the fun department where like we'll have the rough play and the chasing round the house. I'll chase around the garden and that and she tends to be the ... when he scrapes his knee he goes to Mum for a cuddle sort of thing. But that tends to be what we do and he's always liked reading books with [my wife] but not with me... he'd rather just sit and have a talk, but then he'll sit and watch the football on the telly with me and he won't with her." (15)*

A number of fathers described the pleasure they got from developing a deep understanding of their children:

*"I love every minute of it because as I say I have him on my lap all the time and he has a go at doing his signs and he talks to me in his own little way and if you put him on somebody else's lap and he says them words, babbling, they won't understand him but because I'm with him all the time I know his words." (10)*

Another father described intensive interaction with his daughter around a shared interest in music:

*"In fact I'm ever so close to [my daughter], particularly in terms of music, and that to me is brilliant, we can have conversations about music in her language for hours ... I play guitar as well so if I'm playing the guitar she'll sing and then she'll play the keyboard, then I'll say 'you're solo' she'll say 'solo' and she's actually interacting at an advanced level through music and it's wonderful you know." (3)*

This father had consciously used problem-solving techniques to find ways of connecting with his daughter and giving her a variety of opportunities: he felt that his wife had not managed to connect in this way and because of this she responded to their daughter with a lot more frustration.

### Learning and development

About two-thirds of the fathers mentioned involvement in their children's learning and development. Some were supporting their children's learning at home through reading, providing learning activities and help with homework:

*"So coaching him, right, is my reward in life and ...I think it's great. It is learning him and I am learning as well. Because the more you do it, coaching, the more for his standard in life when he is older. I think that is a good way of putting it." (5)*

This father had spent time with his autistic son at the pre-school assessment centre he attended and through this experience he had learnt from the teachers how to support his son at home and felt this had helped him to understand his son and be more patient towards him.

Two Bengali fathers, whose children had been assessed as having learning disabilities during their primary school years, were very committed to their children getting the support they needed for them to overcome their disability as much as possible. One father described how he was concerned that his son would criticise him in later life for not fighting hard enough for educational support:

*"He may say, 'My Daddy he is not trying, he's not trying in which way I can be better now,' so this blame I do not want to accept. So this is why I go to every agency and I have got very helpful and all things his school arrange for it. I don't know where to go, how to go what other agency, often the school arrange for things, the school is very helpful." (17)*

Other fathers were accompanying, or had accompanied, their children to an early years centre or pre-school learning setting. A number of children were also pursuing developmental programmes that relied upon parental participation such as Portage or Picture Exchange Communication System (PECS). A number of fathers placed a lot of importance on the development of communication skills and two had attended a course for parents on communication development so that they were able to help their child at home. One father described how he used shopping trips to develop his son's signing ability, despite the fact that it makes trips last much longer than normal.

### Inclusion and providing opportunities

Most of the fathers talked in some way about wanting their children to have opportunities - whether this was to take part in normal day to day activities, being included in group and community activities, or looking to the future and wanting them to grow up to have an ordinary life:

*"If you boil it down to its logical conclusion, it's just you want to give your child the best opportunity you can and with whatever's available I suppose." (3)*

Fathers seemed to have quite an important role in taking their children out of the house, including visiting family and friends, going to the mosque, trips to the park, shopping together, swimming pool, restaurants. This provided both challenging and rewarding experiences:

*"Generally I mean the most time I get with him is at weekends, so Saturday I spend basically all day with him really. We go out shopping in the morning, he likes going to the supermarket and chucking things around, getting things off shelves." (15)*

*"I'll try and take her to the supermarket, which... which in the early days was absolute hell, it really was and I... I still do it because I thought, 'well if you don't do it you're never going to make any progress.'" (3)*

A few fathers mentioned that they were more comfortable than their partner was when taking their children out to public places, as they did not worry as much about other people's reactions to their children's behaviour:

*"Now there is the issue of people looking at you as well, but for some reason it doesn't really affect me... it doesn't because there's no practical use to it if you see what I mean. I can't see the point of thinking, 'Oh everyone's looking'... whereas my wife will say, 'Is everybody looking?'" (3)*

Fathers seemed to take a lead in making sure their child was included. A number of fathers had supported their children when they started at nursery or primary school or at activities out of school to facilitate their inclusion:

*"You know, I spent an awful lot of time at the school, giving him one to one support, trying to help him to integrate into that setting." (9)*

*"As I say, it was about just making sure [my daughter] was treated no differently than anyone else." (8)*

## Strategies for now and for the future

### Problem-solving

A number of fathers talked about the rewards they gained from taking on a problem-solving role to improve their children's lives:

*"As I say, if you do come up against a problem and you do sort it out, it's another achievement and you do feel better that you've actually done something to improve the quality of their life." (8)*

*"Strategies, exactly, all the 'does this work – no, does that work – let's try it', you know. It's quite challenging actually and if I can see just a modicum of improvement in her, whether it's down to me or anybody else it doesn't matter, but it's... it's just opening up the world for her really you know." (3)*

### Advocacy and identifying resources

Over half the participants talked about arguing or fighting for resources for their children and some had put considerable energy into this. One explained how he had fought to get special equipment without which his daughter's posture would have deteriorated and through this process had also managed to change the local system of equipment funding:

*"I've done a lot to get her equipment because funding in [local area] was terrible.. it took over six months to get her special chairs, and I think it was a year to get her a special buggy." (1)*

Many of the fathers were very assertive in this role and were willing to contact people at senior levels such as MPs and the Children's Commissioner in Wales in order to get the support they wanted for their children:

*“Well I’ve been really involved in that – from speech and language to OT services. I’ve gone to the Trust manager and I’ve had an advocacy organisation involved to get [son] ‘stated’. I’ve had appointments with the bottom to the top... Because I find if you just sit back and wait for things to come to you, they just don’t happen. You speak to people on the phone, and then you’re just forgotten. So it’s a case of getting up and knocking on doors.” (11).*

*“No, I had to fight for that, I rung people up, I treated it like a business exercise actually and I’m quite persuasive when I want to be. So just making a phone... I spoke to [MP] and loads of people and I got it done so that’s in place.” (3)*

This role of arguing for services was very central in some of the interviews: fathers were angry that their children were not being offered the support they felt they needed and they often regarded this as a race against time in terms of improving the support their child received. However, a small number of interviewees felt their partners took a leading role in this area as they had better skills in negotiating for services.

### Finding information

A number of fathers had taken a role in finding information, often through the internet. Often this was viewed as part of a coping strategy, something proactive and positive to be done in response to the shock of receiving a diagnosis. One father’s experience was typical. He spoke of ‘devouring’ information on Down’s syndrome once he and his wife realised that they needed to become the experts on what is best for their son. For him this was all about being a good parent, that gathering information is a manifestation of him ‘doing his best’ for his son because the information offered by services was ‘absolutely terrible’. He went on, *“what you then do, if you’ve got a computer, is you go onto Google, you get onto a website in America and say ‘hi, I’m new’ and you get [information] from other parents” (19).*

### Attending meetings and appointments

All the fathers interviewed attended some appointments and meetings concerning their children, with some fathers attending most or all of them. This commitment to being involved in assessments, discussions and decision making about their children fits with many of the other roles mentioned such as supporting their partner, improving opportunities and fighting for resources (see Chapter 7, Interaction with Practitioners, p.53)

#### Key points

- Fathers in the study had a high level of involvement in their children’s lives.
- Many fathers felt having a child with a learning disability had led them to be more involved.
- Most shared responsibility for care with their partners. This was worked out through a process of negotiation around other commitments, such as work or the need for a break, and their respective skills.
- Those in paid employment tried to be involved in the daily care of their children before and after work, including tending to them during the night.
- They were conscious of not always being able to provide other children in the family with the attention they deserved
- Fathers appreciated opportunities to participate in developmental activities with their disabled children.
- Fathers wanted to ‘do their best’ for their children, including fighting for appropriate services.
- Fathers regarded themselves as having an important role in facilitating their inclusion in the local community through trips outside the home.

## 5. FINDINGS: PAID EMPLOYMENT

### Introduction

One of the main ways in which fathers support their families is through paid employment. Of the 21 men interviewed, 17 were in paid employment. Of the four who had ceased working, two were past retirement age, one had done so because of ill health prior to having children and the other because of his caring responsibilities for three children with a learning disability. One of the working fathers was studying part-time for a degree and did part-time work around his studying and care commitments. Approximately half of the men had partners who were also working, mostly part-time.

The interviewees had a range of occupations with different levels of skills, training and job security. They also differed in the work patterns associated with the job and the degree of control that the individual had over how they carried out their work. There was also variation in the significance of work in their lives and the degree to which they were developing a career or simply taking on work that was available. About half of the working fathers were in predominantly male environments. This section describes the experience of those men whose main daytime activity was paid work.

### Work/care balance

The need to balance paid work with the provision of care for their children seemed to be one of the main concerns. Almost all of the fathers described how they enjoyed spending time with their children, whilst only one expressed how much satisfaction and enjoyment he gained from his work. The overall sense was that work was a means to earn money and that most would have liked more time or more flexibility to be at home with their children:

*"But I would like a job what I could to do nothing at all, get paid for just to be at home with [son], that is what I'd like to do."(5)*

One father described the pull between earning and being with his son:

*"I'd like to spend more time with him but that's not practical really. You know, either I work or I don't work and I work because we need the money to do what we do so you know I've accepted that I'm not going to get the time ... I'd like to spend every day with him but it's not going to happen. That's life. So I enjoy the weekends; I enjoy the time we get in the morning and the evening but if I was self-employed or part-time or something..." (11)*

Besides the satisfaction that fathers clearly gained from spending time with their children, the interviews also conveyed the transformative effect of becoming a father of a disabled child. This involved reflecting upon their priorities in life, which one man, with a job at management level, described when he suggested that:

*"The job's the artificial thing, this is the real world and this is what actually matters in life: this little family unit here." (6)*

Balancing employment and home life became a logistical exercise with a number of fathers rushing home from work to step straight into caring roles either because they were the only parent at home or to support their partner with after school tasks:

*"I work till half past two and I'm home by the time he's dropped off. I mean I work forty miles away... so it's a mad dash up the motorway to be here before he's dropped off." (13)*

This lone father described how he came home from his paid employment 'merely to start another day's job'. The interviewee who had given up work to care full-time for his children recalled that there had come a point when he could no longer cope with the two roles and had chosen to prioritise caring for his family:

*"I enjoyed the work, don't get me wrong, I enjoyed it, but at the end of the day it was a choice of my daughter's health or work and obviously family come first." (7)*

For three fathers, work had initially been a place where they could hide from their situation, but this had changed over time as they had become more accepting of their children's disability. Two of these fathers had since changed their work pattern in order to have more flexibility to spend time at home. The third was still *"really struggling to find time to mix family life with work and stuff like that"*. His own assessment was that he could *"probably make a 50% improvement on being a better dad"*, but found it difficult to adapt to the needs of his family. The interview prompted him to reflect upon the year since his daughter (and her twin brother) had been born. Work colleagues had expressed surprise at how well he was coping with his situation. His apparent stoicism fitted with his notions of how a 'traditional dad' might have reacted to his situation, but now he was not so sure:

*"Last year I spent 95% of my time in work when I'd perhaps, in hindsight, I should have got signed off from the doctor, I shouldn't have been able to cope with my little girl in hospital at the end of the day... I should have been signed off for like four weeks or something like that and say 'well devote all your time to your daughter.'" (21)*

The desire to achieve a realistic balance between work and care is apparent in the following sections that describe the decisions fathers are making in relation to work and the extent to which their employers support them to achieve this.

It may be the case that this tension between work and family life is apparent in many men's lives, whether or not they have a child with additional needs. One of the interviewees, who worked in an employment setting that was chiefly male, commented that home-life balance was an issue for many men he worked with and he viewed having a disabled child as an extra pressure within this struggle:

*"And I think that's the same for all the fathers I speak to at work, they're under pressure, they should be spending more time at home and but then they're saying we need to come to work to pay for the day-to-day. So that sort of experience is no different, I don't think, to most of the others. But I've had extra responsibilities, like running about and taking [daughter] to hospital appointments." (8)*

## Work choices

A number of fathers described how their choice of occupation and job had been influenced by the fact that they had a disabled child. For some this meant remaining in their employment, as they were not sure whether they would receive the understanding and support they required should they move elsewhere. Indeed, one father felt constrained to remain working for an employer who had shown these qualities:

*"I wanted to do a lot of things in my life; I wanted to change career and I couldn't because I can't afford to because I've got to have a stable life for [my son] and the rest of the family because his priority is being stable." (5)*

In contrast, an interviewee had left a job because his employer did not provide the flexibility he needed:

*"The second one, they were just totally and utterly inflexible about it, which was why I left." (15)*

Two men mentioned the attraction of working in sectors that understood about the needs of carers - namely, the voluntary sector and health sector:

*"As I say, working for a Trust with these policies in place and their outlook really helps me because the wheels would definitely come off to be honest if that weren't the case." (9)*

Self-employment had provided two fathers with the flexibility they needed to cope. One of them had originally found it difficult at work with long travelling hours and had set up a new franchise business. Another, who was already self-employed, took more control over his hours by organising them himself rather than working through a contractor. He felt this was the only way in which he could cope with work:

*"If I wasn't self-employed, then I wouldn't... I wouldn't have a job." (1)*

Men with higher skill levels or in areas of economic prosperity seemed to feel they had more options to choose work that offered them the flexibility to have the involvement they wanted with their child:

*"So that's been good, working from home and you can work on evenings and stuff and fit it around stuff. One thing that definitely wouldn't work in terms of health, I couldn't work nine till five in an office and do that because it just wouldn't work with the way the children are and that would be really, really stressful, I think for both of us. So to some extent we have to choose the work that will allow us to be flexible."(6)*

## Loss of career opportunities/income

Some of the choices that fathers made had led to a reduction in career opportunities or a loss of income. Two interviewees talked about lost opportunities in developing their career because they could not make the changes in their work pattern required to gain promotion or because they did not want to take on additional responsibility:

*"I would say, if there was any promotions going where I was working at, I didn't have the flexibility they were looking for... somebody who could work till later of a night, to cover teams and so, you know, I couldn't offer any kind of flexibility... I was asked quite a few times would I like to cover the team, and all that as a progression. But the fact that I had managed to get the seven till quarter to three (shift) was beneficial to us. I'd get out of a morning, get my work done, and then I was here. I was getting there just in time to pick [non-disabled child] up from school if need be." (14)*

*"It was just after, a couple of months maybe three or four months after [son] was born, I did consciously say at work that... because I knew I was coming up to my annual review, and I did consciously say 'look if you're thinking about giving me a bigger job or promoting me... I just don't want to think about it at the moment.'" (4)*

A single father had arranged to work part-time following a particularly stressful period. In order for this change to be sanctioned he had agreed to downgrade his post. He felt he had not received any advice from his employer about the options available to him before making this decision. This had resulted in him feeling that he had ruined his career and had no prospect of moving back to a higher grade without returning to full-time work.

*"Well my career opportunities are dead in the water, well and truly." (13)*

Six interviewees mentioned that they earned less as a result of choices they had made in order to be able to provide more support to their family: working less than a full week, not doing overtime, not doing shift work and taking on work that paid less favourably in order to have a supportive employer:

*"I find now my earning capacity is reduced because I feel the time that I'm not working I need to spend with [my son], where there's always overtime there, and ... I know we could all do with the extra money, but I feel I need to be there with [my son]. So it's reduced my earning capacity I would say." (11)*

*"I could have earned a lot more money if I were more flexible in my working hours. But I have consciously not done that because I need to be at home. So I would be working flexible hours and having a lot of time off, but there's no point in me having time off if [my son] is in school. I need to be home when [my son] is home." (12)*

Against this, fathers from dual income households and those with well-paid jobs appreciated the choice and flexibility that their relative wealth afforded them. One father felt able to spend more time with his family after the birth of their second child because of a higher household income once his wife had returned to work. This also allowed them to buy in additional care support, freeing time to spend with each other. Another marvelled at an older father he had met who was in a position to take a lot of time off work to spend with his disabled daughter:

*"You know his attitude is 'I can spend lots of time with my child'. It's almost like the opposite situation to me: I'm trying to work around so we can survive but also get a work/life balance!" (20)*

## Job performance and job satisfaction

The project did not set out to gauge the impact that men's caring responsibilities had upon their ability to perform their jobs, but several volunteered that it had, albeit to varying degrees. Mostly the effects were marginal though cumulative:

*"It's just little things like, you know, I was late for work this morning because I had to, no because I wanted to go into the nursery and show his care assistant how to put his hearing aids on because I don't really want to do that on Monday because I'm busy and I'm the only person who can do it. That constantly makes you late for work, you know extra stuff that you need to do." (19)*

Two fathers felt that there had been a significant negative impact:

*"The minuses, it impinges upon work. It makes concentration on work very, very difficult." (3)*

*"I've just got to prioritise and I've just got to do what I can as best I can but there's a part of me which says, 'You could be doing a hell of a lot better here if you had more time and more flexibility'; so I do feel a little bit constrained in that respect." (9)*

Significantly, this father had not told his manager about his care commitments, as he felt this would constitute asking for favours (see section Disclosure to employers and colleagues, p.37). This echoed other interviewees, some of whose employers were aware of their situations. One expressed clearly that he did not want to have concessions made about his performance, although he needed concessions about how he managed his work:

*"I have always drawn a line with what ... this entitles me to and what it doesn't entitle me to because as far as I'm concerned I get paid the money and I do the job for them exactly the same as anybody else without a child with disabilities does and I get judged on performance in exactly the same way. It's just that at times I may need to do things that other people may not need to do and as long as they understand that, that's fine."(6)*

The issue of job performance was subtly different for the self-employed fathers in the study. One who often had to step in to care for his daughter, was aware that this led him to let down his customers, which worried him, even though he tried to pretend that it did not.



## Disclosure to employers and colleagues

In order to achieve this work/care balance fathers need to feel that they can inform their employer about their situation. All but one of the men interviewed had made their current employer aware that they had a disabled child, although they had not always said very much about the impact this had on their life. One father, who tried to attend all of the meetings concerning his son's welfare, was very clear that he wanted his employers to know so that they would understand why he needed time off from work:

*"Because I don't want them thinking I'm just taking loads of hours off here and hours off there, I want them to know there's a reason for it." (15)*

Some fathers were reticent about their situation because they did not want to be treated in ways that might be resented by colleagues. One had only just completed his probationary period with the police when he felt compelled to take time off with stress following the birth of his son. Initially he did not tell anyone at work about the problems he was experiencing for fear of being labelled one of those people

*"... on special dispensations for this, that and the other, they can't work nights because their doctors says they can't. So there's a lot of issues about part-timers in the police and demanding what hours to work and there's a lot of resentment with that because you know it puts a lot of pressure on other staff being able to take time off. So it was a concern me doing it but at the end of the day I thought the only people that are important is my family and it doesn't really matter to me what anyone at work thinks of me. I've been fortunate enough to not really have any comeback from that."(20)*

Another father gave credence to such concerns by admitting that he had been reluctant to take time off work when his daughter was in hospital because,

*"I'm probably the first to sort of moan and groan if people are off sick in work you know and then we've had a few women off with stress you know and I think well why, why is she stressed?" (21).*

The fact that both he and his wife worked for the same company meant that it would have been difficult to stop colleagues from hearing about their situation even if they had wanted to. As it was, both his employer and his colleagues had been 'absolutely fantastic' and 'brilliant'.

The father who had not discussed his son with his manager (see section on Job performance, p.36), thought the manager was unaware of the high level of care this father provided at home:

*"I don't think he does to be honest. I think he knows that I have caring responsibilities at home, he knows I have children but as to the nature I don't think he knows." (9)*

This father was sharing the care responsibilities with his wife and returned from work to provide constant support as his wife worked evening shifts. He said that he would like his manager to know, but was worried that he would be seen as looking for concessions. In comparison, he said his wife talked about their son at work and that she had taken him in to meet her colleagues. Talking about this within the interview situation led him to realise that he would like his employer to know. The line manager of one interviewee also had a child with the same disability but although they were both aware of this, they did not talk about it with each other. On the other hand, one of the self-employed fathers (see section on Job performance, p.36) described how he sometimes told his customers about his daughter as he felt this gained him some understanding in relation to his unreliability.

Six men mentioned how they talked to colleagues about their disabled child; a few of these mentioned specific support they received through work colleagues (see the section on Support from colleagues in Chapter 6, Support for Fathers, p.46).

## Employer co-operation

All the fathers in paid employment talked about the importance of having an understanding employer or line manager. This need seemed to be greater amongst those who had jobs with routine and fixed working patterns such as on a production line or shift working. One father, who had left his employment and become self-employed, described what he needed from an employer:

*"More flexible working, the ability to work from home... more understanding if you needed to have time off and stuff."(2)*

There were two main ways in which fathers defined an understanding employer: their willingness to give time off, either in an emergency or to attend appointments, and their agreement to have flexible work arrangements that enabled fathers to adapt their work to fit in with providing care. All 14 fathers who were employed, rather than self-employed, had been given one or more of the above arrangements. However, very few fathers talked about their employer as having written policies that actively supported carers.

## Flexibility

Fathers talked about a number of flexible working patterns that they had used in either current or past employment: term-time working, home working, flexible starting and finishing times, and compressed working hours. As mentioned in the section on work choices, some men had the flexibility they required through jobs enabling them to manage own time:

*"And likewise with my current job, it's flexitime and you know they recognise that as a carer you do need sometimes to be flexible in the way you can work."(6)*

Other interviewees had negotiated flexibility with their employer. Several fathers had arranged to reduce their hours. A policeman had come off shifts to work his own unique pattern of four long days with the flexibility to take time off when required. There was no procedure for this and he had to negotiate it himself:

*"I think a lot's changed, a lot of people have said to me 'Ooh that wouldn't have happened five years ago or 10 years ago', and you know that's probably exactly right. But anyway they had to change their views and attitudes and they're much more accommodating." (20)*

A single father had been given a term-time contract to support him through the holidays, although this arrangement did not include the summer holidays, when he was expected to find child-care for his son. However, in order to have this arrangement he had to work Fridays, which had previously been a day off:

*"The only thing is I've got to work on a Friday... I hate working on a Friday because it was my one day to myself. And nowadays I've got no day to myself. But it means come the holidays - apart from the summer holidays, which they will not give me, they refused point blank - I can have every half term I want." (13)*

One interviewee had been given time off for appointments, but in return he regularly worked through lunch breaks. Another had arranged to work through a lunch break so that he could leave work earlier in order to collect his daughter from school:

*"So you would have a half-hour break at ten o'clock and then another one at half one, something like that. So I asked if I could drop one of those half hour breaks. So I was still working exactly the same hours and just having a half-hour unpaid lunch rather than an hour, and put down that I had a disabled child and losing that half hour would enable us to finish in time to pick [non disabled daughter] up from school if need be. And there was some 'umming' and 'ahing', but I eventually got that." (14)*

Flexibility was also mentioned in relation to being 'on call' by a father who wanted to be available in an emergency for his son but whose work had a policy that mobile phones had to be switched off during working hours.

*"Well they said there are no phones in the warehouse at all because they distract you from work. So I had to go to them and got HR involved, saying 'I have got to have my phone on because of [my son] being autistic, if there is problems in school, he's kicking off, I have got to rush out and calm him down and things like that'. Because my wife, at the time, could not cope." (5)*

This man did shift work, but his company was very flexible about allowing him to change shifts to accommodate appointments and other care responsibilities:

*"They only let me change shifts. If I have got an appointment at [my son]'s school, I have got to take the paperwork in and show them I have got an appointment and they will let me change shifts anytime. An hour's notice or a week's notice or a month's notice they'll change, they don't need to, they don't have to, but they will!" (5)*

## Time off for emergencies and appointments

All of the interviewees had been able to take time off work to attend appointments through flexible working patterns, swapping shifts or being given special leave. Gaining flexibility from employers was easier for men with responsibility for managing their own work:

*"I've had very understanding managers who have basically... because they recognise to a certain extent, the level of job you're doing, if the work's done, it doesn't matter whether you do it on the train, on the bus or sat in the bath at home, they have allowed you to be as flexible as possible around things like medical appointments for [my daughter]." (6)*

For most fathers obtaining leave or time off seemed to be based on ad hoc arrangements where they needed to make a case for leave as and when appointments arose. A father who worked in the public sector said that he was usually given time off and that his employer was more sympathetic than his wife's:

*"Meetings are usually in the day times so I've had to take time off work. But I don't have a problem with my employer. They're fairly flexible. So I haven't experienced trouble in getting time off." (12)*

He felt his employer had been especially supportive when his son was in hospital. Another father, who worked factory shifts, had to find a colleague with whom he could swap shifts or else take a day's annual leave. Because of the nature of his work, he was not able to take a few hours off and he therefore had to take annual leave or lose pay:

*"Like because I say if I get a hospital appointment that will take me say two to three hours, I would take a 12-hour shift off, because when I'm off, because there's only forty of us working there, somebody needs to cover you. And nobody's going to come in and sort of cover me for two hours so I've got to take a day's holiday." (11)*

A number of interviewees had responsibility for being available in an emergency when their child was in nursery or school. Two fathers had experienced a lack of sympathy with one being asked why his wife could not collect their child:

*"School rang once and they wouldn't let us go and pick him up from school when he'd fallen and I said, 'look, I'm going, that's it. Sack us if you want because you know, I mean, he's fallen over at school. He's got to come home' but, 'Oh why can't your wife go and get him?' was the attitude, so that's why I left there." (15)*

## Change over time

A small number of fathers mentioned that they felt their employer was more sympathetic to them when their child was first born, at the time of diagnosis or when their child required surgery. They felt that, as their child got older, their employer had become less willing to accommodate their requests for time off and flexibility:

*"Initially when he was born you know there was a... 'Oh take as much time as you like', but now he's getting older, if I go in now and say, 'Look, I do need a day off for an appointment tomorrow.' 'Don't we all, but there's no running off home. That's what I get now, like.'" (11)*

For some there was a sense that employers became blasé or neglectful of their situation, as though the need for support and consideration should naturally diminish over time. For one father this led to a confrontation with his manager:

*"I had a big bust-up with one of my bosses once over work and I went to see the big boss and broke down in tears in his office because basically it all came out. I realised I was extremely resentful to them for not asking how I was, you know." (19)*

## Rights at work

Interviewees were asked whether they were provided with information about their rights at work as a parent of a disabled child and none seemed to have been given written or formal verbal information. A number of fathers were unaware that they had rights as the parent of a disabled child:

*"Nobody has said to me what my rights are... looking after a disabled child. Am I allowed time off with payment, certain amounts of time to go to these appointments or different things like that, where now I sort of struggle to fit the appointments in with holidays? And then I find I haven't got holidays to go on holiday with [my son]." (11)*

Others had found out about their entitlements through sources such as the internet. One man had printed off information about his entitlements and given them to his manager so that he could argue on his behalf with senior managers:

*"I had them all printed off, and I kept giving them to my manager. Because they were trying to say I... wasn't entitled to special leave like when [my son] was in hospital having operations... But it was set in stone, you're entitled to up to two weeks at any one time if one of your children is in hospital or anything like that, or a dependant requires your help." (14)*

Another father threatened his employer with his rights when his employer wanted to change his daily hours:

*"I threatened them with it because he wanted to change my hours and I said, no, I wasn't prepared to change*

*the hours I was working because he had a choice of 8 till 5 or 9 till 6 and I was doing 8 till 5 so I could get home in the evening.... He says, 'Well, you've got to.' I says, 'No, I don't have to.' So we had an argument about it and I said, 'Well you do realise that as the father of a child with Disability Living Allowance I am entitled to ask for my hours to be changed to work the hours that I want.'" (15)*

Similarly, a single father had threatened to get legal advice in order to be granted a term-time contract. But not all fathers felt confident about using the legislation, as described by a father who felt it was wiser to negotiate than to assert his rights:

*"Neither of us has ever had to go and insist on having the time off, which we know we have a statutory right to do. But we've never had to use that, and I don't think that's a wise thing to do. That has always got to be the last resort, and we've never had to go that far." (12)*

### Key points

- Fathers in paid employment found it difficult to balance their paid work with providing support at home.
- Many men had to alter work patterns or status, in order to carry out their responsibilities as carers. This included flexible starting and finishing hours, compressed working hours, term-time working and becoming self-employed.
- Fathers felt that having a child with a disability had reduced their earning capacity and career opportunities.
- Most fathers had talked to their employers about their family situation, but the support they received through work was variable.
- Fathers valued employers that were able to accommodate flexibility in work patterns, reacted positively to requests for emergency leave and gave time off to attend appointments.
- Few fathers were aware of their statutory entitlements to request flexible working, special leave and parental leave.

## 6. FINDINGS: SUPPORT FOR FATHERS

### Introduction

Much has been written about the support needs of parents of disabled children, both emotionally and practically, and the factors that reduce stress and help them to cope. In order to identify the sources and types of support that were helpful to fathers, they were asked about the relationships they had with their immediate family, extended family, friends and within their local community. They were also asked about their contacts with other families with a disabled child and, in particular, with other fathers.

In order to get a picture of whether they found services supportive, they were asked about their contact with services and organisations in both the voluntary and statutory sectors that were delivering a service to their child or offering parental support. Some of the issues related to the effectiveness of services at supporting fathers are covered in the next chapter, which looks at the interactions between practitioners and fathers.

Support can mean many different things, but ultimately it is about helping a family to function with the added responsibilities of having a disabled child. There was a wide variation in fathers' perceptions of the support needed: some felt that they did not need much support, whilst others felt they were under constant pressure. These perceptions sometimes reflected the nature of their child's disability or the support package that was in place, but they also reflected the wider support networks that existed within their family and friendship circle. There was also a wide variation in the types of support that were useful; for many fathers the main source of support was a partner, but where this was not available men had tended to find alternative sources of support. Generally, it seemed that support was most useful from people who had an empathic understanding through sharing the same situation:

*"I think you've got to be in the same situation, because unless you are...they can't understand where you're coming from." (13)*

### Support from their partner and immediate family

For many fathers the main source of support was from their partner, which was expressed as mutual support gained from sharing experiences and working things out together. Some of these fathers broadened this to include the other members of their family unit, including other children, as a central source of support. One father saw this support coming from the relationship between the family members, whilst another saw it in more practical terms of providing support to their son:

*"I've been away from probably a lot of available support out there, but I have tended to find all the support I've needed within the family environment, particularly in the relationship between us [wife, daughter and son]."*  
(6)

*"He said, no, they don't ask anybody for support, they feel they get it from themselves and they work as a family unit to provide the support they do for him rather than ask people to do it, they don't get it from anyone, they just meet his needs whenever it's required." (Interpreter translating for 18)*

A father who said he and his wife had struggled to keep their relationship together also described how they supported each other emotionally and practically in the care of their son. This appears to reflect the extent to which parents prioritise their children's needs over their own. This father described how he tried to appear strong in order to support his wife in her caring roles. In comparison, another man, who worked closely with his wife, said he was more comfortable talking to her (about his problems coping) than looking for outside support:

*"You know it's difficult because they might think that I'm not coping with [daughter] herself or you know whatever, even though you are. ... so normally I just speak to [wife] about it." (1)*

The need to appear strong for their partner and hide the fact that they were struggling was mentioned by several other fathers. However, this was chiefly around the time of diagnosis. It appeared that over time couples developed strategies for working things out together – perhaps as they developed an in-depth understanding of their child or had experienced inadequacies within service provision. Two men talked about living with a partner with whom they felt unable to share problems and anxieties and how they would have liked more support from them:

*"I'd like to be able to talk to my wife about the... all the issues and have a discussion - a two-way discussion: 'I think this - what do you think?'" (3)*

A single father, who was experiencing high levels of stress, made regular references during the interview to the fact that he was on his own without anyone to share things with emotionally and practically:

*"If you go shopping you take him with you; if you go to the doctor's you take him with you; if you go to the library you take him with you. There is literally ... well apart from work I don't think there's anywhere that I go that he doesn't come with me you know, because there are a lot of people who know me and they say he's like a little shadow. Of course he's a shadow. There isn't anyone else to look after him." (13)*

## Extended family

Less than half of the fathers received support from their extended families. Those that did received either direct practical (and often regular) help with caring tasks or support over the phone in the form of a listening ear or giving advice. Regular practical help from extended family, such as collecting the children from school, was appreciated, but was often coupled with anxiety about asking too much of them:

*"My mother-in-law helps out from time to time. But of course we don't particularly want to burden her with the care of [our son] because obviously you know she's getting older, and we see it as unfair to burden her." (12)*

*"But everybody just helps out when we need them. We try and do as much as we can ourselves, we don't like asking people. You know, if we can do it ourselves." (14)*

Other fathers described how they and their children went to visit their parents each weekend, one for Saturday breakfast and one for Sunday lunch. This appeared to have a dual function of giving the father a break and for the children to have a close relationship with their grandparents:

*"I take them up and they do the breakfast, where I always do the breakfast. My father gives them toast and tea or they have Weetabix and my father does all that and my mother sits on a chair and feeds [son] and it just gives me a break; then I can sit down and read the newspaper. I don't know what it's like to read a newspaper back home!" (10)*

Similarly, a father whose parents lived many miles away found that holidays with them enabled him to cope with three disabled children:

*"Three times a year we usually go up and visit my parents and once again because my wife suffers from agoraphobia she's not much good at long journeys so I usually just throw all the kids in the car and then we go up and we usually spend anything from a weekend up to four weeks at a time up there." (7)*

Two fathers, who were the main carers for their children, received some practical support from their parents-in-law who lived nearby. In contrast to these fathers who felt supported by their extended families, there were others

who received limited or no support. There were a number of reasons for this, but the two main themes were the attitudes of family members and ageing of parents. Four fathers described how their families did not understand the nature of their child's disability:

*"I'd talk to my mother more than my dad. I mean my dad, ... don't get us wrong, my dad loves him to bits but he just can't understand him at all. He's a bit, it's a horrible thing to say, but he's a bit alien to my dad." (15)*

Two of these fathers found their family's lack of acceptance difficult to cope with and it had affected their willingness to have a relationship with them:

*"...a bit of me says that it's involvement on their terms and I don't really want that. You know I want them to accept [son] for how he is." (9)*

Different cultural understandings of disability were also a reason for limited family support. A father who was raised in a north African country but who had lived in England for eighteen years explained how his family did not understand about his son's autism. His family, who still lived in his country of birth, thought that 'this problem does not exist' and saw his son's behaviour as 'bad habits'. His brother, who lived nearby, only partly understood, as he felt that living in a different culture might have caused his son's problems:

*"Yeah I mean my brother has accepted what I've explained to him, yes, but he still says that he has not accepted it, maybe we should go to [home country] a little bit more often and let him play and stuff there and everything because in a way here, he's a little bit more restricted obviously than the way we live there, with free mixing and stuff with a neighbour where he's got to know where he's come from; that might help. And maybe, he might have a point there, but I understand that he's got a problem, that's my understanding." (16)*

In a number of cases, the fathers' parents had died, sometimes since the birth of their child, whilst other parents had become more frail and unable to offer help:

*"We've got no relatives because we're a bit older than most so we've got no relatives that can look after him. So really the only people he'll stay with is my, well mum and dad, but they are nearly 80 now so they just can't cope with him." (15)*

Another father described how his mother, who initially had been seen as a source of support, became someone he also supported. Since she had a stroke, he had been making weekly visits to her in a nursing home and was responsible for her affairs:

*"And at the time I was visiting my mother in hospital every day because she had a stroke six weeks after [son] was born and went from being a potential carer to being somebody that we also had to look after." (4)*

There was only a limited amount of support from siblings, who were sometimes described as being busy with their own children, although a few fathers made positive references to talking on the phone for advice or having someone to listen. Not surprisingly, the fathers who received most practical support from their family tended to be those who had remained living in the area they were raised and still had family living nearby. This physical proximity may have helped extended families to understand the implications of caring for a disabled child and thereby encouraged them to offer help.



## Support from friends

There was also a varied picture about the extent to which fathers received support from friends. There were only a few fathers for whom friends were an important source of either practical support (through reciprocal caring arrangements, for example) or moral support. One father described friends as his main source of moral support and viewed going out for a walk or cycle ride with his friends as an important part of his coping strategy. This was especially significant, as he felt unable to get this type of support from his wife. Similarly, two other fathers who were the main carers found support through friends, and each had a close friend who also had a disabled child:

*"It would be the wife that will usually support or I wait until the kids have gone to bed and then I'll pop round to a friend's house... and then I'll just chill out there." (7)*

A frustration for some fathers was the inability of people they had regarded as best friends to identify with their situation:

*"... he will listen, but he's so far removed, his world is so completely different to mine that I can talk to him but I don't feel it's a sort of an outlet really, the release I need. Obviously I try and talk to [my wife] about things, but generally other than that I don't talk to anyone about it at all." (20)*

Many fathers preferred not to talk about their problems with friends, as they wanted a break from their worries:

*"Sometimes you get lumbered with their problems as well so it's a two-way thing. So we tend not to go too deeply into it, we just go to the match and have a pint, you know... and just forget about it for a while rather than go to the match and have a few pints and get all down about it, you know." (15)*

Often this 'downtime' centred on either playing or watching sport. One explained how he played football on Friday nights to 'let off steam'. Team-mates used to ask about his son, and he appreciated that, but now Friday nights are his 'time off' and he is happy not to be asked any more.

However, one father appreciated the opportunity to listen to friends' problems with their own children:

*"I remember ringing one of them once, and him saying 'Oh I'm having a problem with my wife's daughter, but I can't talk to you about that, can I, because of what you're going through'. And I said 'no, talk to me about it please'. It was great to offer them advice then because, you know, people would treat us with kid gloves." (19)*

But more generally fathers did not seem to look to friends either for support or as a way of having a break. A number of men commented on their wives' ability to maintain friendship networks either for themselves or for the family:

*"We've friends who are very supportive, sort of family friends I would say rather than sort of specifically my friends, but ...we thought ...when he was first diagnosed... we wouldn't be able to go away for weekends with people any more like we used to and all the rest of it and we'd sort of be condemned to this sort of purdah of being locked up in our own home with this strange child to look after. And they've all been incredibly supportive and we don't even think about it, we just carry on doing all the same things that we used to do." (4)*

This contrasted with those men who felt they had lost contact with friends, either because they lacked time or because friends did not know how to react to other disabled children:

*"Most of the friends we had before [son] was born, we've just lost touch with them. I mean you haven't got time for friends a lot of the time." (15)*

*"Yeah, we do tend to do a lot of things with the children, I mean, friends, uh, that's difficult because what we've found is, we used to have a lot more contact with friends, particularly my wife's friends." (9)*

*"Before we had the children I used to have a couple of mates that come down here on Fridays when [wife] went out and we used to get the DVD on and watch a film but since I've had [twin sons] they don't seem to come down no more now. So friends don't talk about it much, my mates then, the boys like. They don't talk about [sons], nothing like that. We usually just talk about rugby." (10)*

## Support from colleagues

Six fathers talked about having informal conversations about their situation with their colleagues (see section on Disclosure in Chapter 5, Paid employment, p.38) and two of these mentioned how this had led to colleagues offering specific help:

*"I talk to my colleagues in work. They would ask about [son], but they always ask because they know the issues I'm going through, and there's one or two always get interested in it... when [son] had his first heart surgery they made a collection in work for me... which helped us for the time we were up there." (11)*

*"I've got a very good friend from work who's a personal assistant to a manager and she used to do teaching of autism and she brought me a lot of paperwork in and you know I read all through it." (5)*

## Neighbours/local community

Some of the fathers talked positively about support from neighbours, the local community or community groups, but this was limited and served to reinforce the impression that many of the families experienced varying degrees of social isolation, depending instead on their own families and friends for support. A few fathers mentioned places they went with their children where they felt welcomed and included. For some this came from belonging to a faith community:

*"We were already involved [in church] before [son] was born so it's not something that's come about since [son] has been with us. And yes, we have a lot of strength and support from that." (12)*

Two fathers attended a mosque and, while both men felt their sons were welcomed there, they did not feel that it was somewhere they personally received support in relation to their sons.

A few fathers described the areas where they lived as having a sense of local community, reflected in neighbours stopping to chat with their children and taking an interest in them. One father played cricket and felt very comfortable taking his son, along with other members of his family, to matches. But others saw the local community as being unsupportive, especially when they took their children out to public places:

*"In the outside... I'd say it does feel very taboo towards you and in a way segregated. I wouldn't say ridiculed - how can I put it, that you're looked on as if you're imperfect in a way, yeah." (7)*

*"You feel penned in, you're so restricted and you're just looking for occasionally a little bit of understanding and tolerance, which to my mind isn't there." (9)*

## Support from other parents

This section looks at the contact fathers have with other parents who have a disabled child. This contact may occur informally through friendships or through organised groups and events. Fathers talked about a number of opportunities to meet other parents with a disabled child, such as attending events or outings organised by voluntary groups, meeting informally through attending an early years service, attending courses for parents or through their partners. Around half of the fathers welcomed this contact with other parents and some felt it was more valuable than contact with professionals:

*"Whereas the other parents, they will tell you what happened to them and what it is like and so you feel more in-tune. ... I think the support of other family and people who have been through the experience is more valuable. That's my personal opinion." (16)*

But other fathers described how they did not particularly want to have contact with other parents for a variety of reasons: they did not see it as a good use of their time, the variation in experience between parents meant that it was not helpful or they did not like other parents knowing their business:

*"So, it's just time, it's just finding the time to do everything. I mean it would be nice to have the support, but again I can see why people don't take it if it's offered, because you want the time with your child as well." (15)*

*"I chose not to [go to parent groups]. The reason was because I don't like people knowing my business and that's the truth." (5)*

Two fathers talked about how contact with other parents can feel destructive:

*"And that's what I find sometimes about groups for parents with disability ... it's not relaxed and it's all fraught and a lot of the time, sadly in my experience of this is you're covering old ground which ... it can't be reclaimed. There are people who are still in denial about the fact that their children have disabilities and there are people who are still angry about it 15 years after their kids have been born." (6)*

One of these fathers talked about how his son's behaviour was not always accepted by other parents at events for children with the same disability and how this made him feel angry towards them:

*"Because you know, he had to wait in queues to go on the trampoline and he can't do that and some of the parents, to be honest, shall we say they weren't very positive about his presence, you know." (9)*

A few fathers mentioned that it was mothers who got to meet each other and develop close relationships:

*"It tends to be the mums who would know each other." (4)*

*"Because I mean [wife], she's got friends who have ... she's come in contact with friends now who have disabled children." (1)*

A single father had met other parents through his local Gingerbread group, where he was the only parent of a disabled child, and he had found helpful support there. At other groups, he had found that mothers assumed he was giving his wife a break:

*"They were just taken aback, you know, that you walk in and you're a bloke ... and it was 'Oh you giving your missus a break?'" (13)*

## Support from other fathers

Most of the fathers were not involved in situations where they would receive father-specific support, although four fathers had been to groups or events specifically arranged for fathers. Two had attended meetings for fathers of children with autistic spectrum disorders, and both had found this very helpful, with one saying it was his main source of support:

*"It wasn't until the fathers' club started up a couple of years ago that I realised I wasn't coping very well." (2)*

This father wondered why people were sceptical about the need for fathers' groups when the need for support groups for mothers is accepted:

*"And you think, hang on, we do need support. So... it is about time the fathers were recognised because I think... when they were first diagnosed there were some support groups for the girls but there was nothing for the dads." (2)*

But he also pointed out that there is a downside as well as an upside to attending the group:

*"Sometimes I come home feeling a bit depressed because you are actually there because you have got two children who have got problems. But it is good because you can talk about... you listen to what other people have to say... their problems." (2)*

Two other fathers had been to a 'fun day' organised for fathers and their children by a voluntary organisation and they both felt this had been enjoyable and supportive. Both these fathers had strong views about the benefit of fathers supporting other fathers:

*"I've said loads and loads of times that there should be a sort of like a father support. Not necessarily a group for fathers, how can I put it, where it's an excuse for fathers to go out and be merry and everything, but somewhere where dads can just drop in and have a chat... So yeah, I really, really feel that there should be some sort of fathers' groups." (7)*

One of them noted that men need support from each other but they take longer to develop supportive relationships:

*"That's what it's about: passing information on. I think men, once they break the ice and get to know it all, then yeah, the information starts flowing – it just takes a bit longer, really." (8)*

Two other fathers had had the opportunity to attend a fathers' group in the voluntary organisation where their wives were already involved in a parent and child group. However, they decided not to get involved. The fact that most fathers were not involved in support specifically targeted at men appears to be due to a conscious decision (as above), but also in many cases a lack of awareness of opportunities. Two fathers who had not come across support groups for men became interested in the idea through the process of being interviewed:

*"No, no, I wasn't aware that there was anything specifically for fathers, but then equally I haven't gone out to look for anything specifically for fathers... I mean I'm genuinely interested now you've said it; I just wonder what they talk about." (4)*

Another father, who was attending a course run by his local speech and language therapy department, described how he made a point of talking to other fathers and that other fathers did the same. He did not mind that there

were more women than men on the course and said he would happily talk to mothers and fathers, but that he valued hearing about other men's experiences:

*"One of the dads there I got close to, and he was telling me about his experience, I mean I wouldn't get that from a mother because he's taken his son to play football and everything, and how he's getting him to join in rather than grab the ball and run with it, which my son exactly does the same thing. So obviously that sort of thing probably I would not get from a mum, I would get from a dad, yes so it is, it is a pity that there are not many, as many dads there as women." (16)*

## Support with health and well-being

There generally seemed to be little support for fathers related to their health, even though a number of them were experiencing constant stress and some were the primary carer for the family.

Fathers were asked whether their GP was aware that they had a child with a disability and whether they had ever received acknowledgement of this or support from their GP. The overwhelming picture was of fathers not being recognised as carers and not being asked about their well-being. Fourteen fathers expressed negative comments about their GPs' lack of knowledge or interest. Two fathers, one of whom had serious health problems for which he had been receiving treatment, said their GPs were not aware that they had disabled children. Even the father caring for three children said he felt the GPs in his practice regarded him as a 'hindrance' and had not offered support when he was physically unwell.

Of the 13 fathers who mentioned that they experienced stress (see also Chapter 3, Emotional impact, p.22), none said they were receiving treatment for it from their GP. Two of these men had talked to their GPs about the stress they were experiencing, but neither had received specific support. However, a few said that they did not see it as the GP's role to consider their health as a carer, even though their caring role was having a serious impact:

*"Well I don't think there's much a GP can really do to be honest with you. I mean, 2003 I think it finally caught up with me, the enormity of everything, and I'd six months on the sick with depression." (13)*

Some fathers had found counselling a useful way of dealing with the problem of stress. Three had used a counselling service at some time since the birth of their child: two of these had gone with their partner and one had gone alone. Through such counselling with Relate a father had realised that it would have been helpful to have had bereavement counselling to cope with various experiences of loss around his children, although he felt this would have been a *"frightening experience, as it would have opened up a huge sense of loss"* (3).

One father suggested more counselling, of the type that he had received through his work's occupational health schemes, be made available through local health and social services. He particularly appreciated this counselling for being dispassionate and removed from his close circle of support:

*"I will talk to [my wife] or talk to my friend, but in some ways it is easier talking to a third person, who's not got any connections or involvement with you in any way. I could... really, really miss out on, and really could have benefited from but it always seems so difficult to get anything." (20)*

## Support around the time of the diagnosis

Around half the fathers said they had not been offered any support around the time of diagnosis. Two fathers who had received pre-birth diagnosis said they had not received support even though, with their partner, they

were faced with a decision whether or not to terminate the pregnancy. Two fathers commented that additional support had been offered to their partner. One of them, who was the main carer, described how practical support following the diagnosis was offered to his wife rather than to himself:

*"They were more informative and more helpful towards the wife. I mean the wife kept saying, 'Well look, you know, speak to my husband, he's the one that takes them out.' And they'd be like, 'Er, well what we'll do is we'll send you a brochure or we'll send you some letters out, you know.'" (7)*

The birth of their children was recalled as a time of confusion, when joy at the birth of a child was tinged with bewilderment and anxiety. One father described his conflicting emotions and the different reactions he experienced at breaking the news to others:

*"And of course other people we know, really those people were kind and said you know, 'Congratulations! You've got a new son.' There were a few people who said, 'Oh, I'm so sorry,' and I said, 'Well don't feel sorry for me because I've got a new son.'" (12)*

Unlike other interviewees, he had been offered counselling, yet had opted to turn it down, preferring, if necessary, to seek support from family and friends:

*"I was obviously upset. I was greatly upset at the time and they did say then that perhaps I needed some counselling. And I said no that I didn't want it. And I really came to terms with it on my own really." (12)*

Another father recalled how, shortly after his son was born, he was asked to take him to get a blood sample taken. They couldn't draw the blood and the father was "all over the place"; it was a time when he needed support, but none was available.

## Support from services

When asked about the support they received from services, most fathers talked about the support that was provided for their child, with most finding it difficult to think about their own support needs. On the whole they appeared to feel supported when they felt their children were getting the help they needed. As one put it, "as long as he's healthy, or as long as he's happy and not in pain, then we can carry on with life as it is" (14). Another mentioned the benefits to him from his son having a dedicated care assistant at his nursery:

*"I found it a very liberating experience not going in the nursery with him. You know, it's not that I didn't want to be in a nursery with him, but he's in a nursery, they're looking after him and I came out and I started talking to the other parents and I've never spoken to the other parents in the nursery because I've always been in there with him and now I'm outside and they're looking after him and it's like it's much, much, much more normal." (19)*

Around half said that they had not been asked about their support needs. Two of these fathers, who were the main carers, said they needed more support, and did not feel that their situation had been taken into account when the support needs of their children were being assessed. On the other hand, another father felt that he did not want people to be asking him about his support needs and would prefer to ask when he needed help:

*"I would rather people just ... I don't like people fussing all the time, you know. I would rather, if I need help I'll ask for it and if I don't need help I don't want people, you know, thrusting it on us." (12)*

Whether fathers felt they needed support from services was influenced by the support package that their child had, the complexity of their child's needs and the support they had from family and friends. A father, whose child's behaviour meant that he required constant supervision, was pleased with his son's support package but still felt that they were really struggling to cope at home:

*"I think we would appreciate a bit more help for the family basically. I think [son] has good input but, as I say, for the family, I think there probably could be a bit more out there. As to what that is, I'm not too sure, I mean I guess respite's always welcome and also ...I think someone to talk to sometimes, you need that, particularly somebody who has some idea what you're talking about basically. Yeah, so some kind of emotional support as well." (9)*

He also pointed out that professionals did not offer help or advice whenever he mentioned that he was finding it hard to cope:

*"My impression is that when you go to meetings, it is focused on my son's needs, which is right but you know when you talk about how things are as a parent, what I've found is usually you get the kind of affirmation ...where people say to you, 'Oh well that must be really hard, that must be terrible'. They don't say, 'Can we do this?' or 'Have you heard of this?' ... So you know, perhaps a little bit more help directed towards the needs of the parents and me as a father, would have been more appreciated: personalised help." (9)*

A father who felt that support services did not recognise the importance of supporting the whole family made a similar point. He felt that a more holistic approach that considered the parents' well-being and recognised the importance of their own support network would have a positive impact on the child:

*"One of the things about the whole way that disabled kids are looked after is the family are generally going to be the primary carers for them. And probably the most significant effect you can have on that child's well-being and their own health, is to make sure the carers are kept in good health and not going completely off their heads with stuff. ... I think there needs to be a lot more of that, actually looking beyond [daughter] as the patient, which to my mind. ... she is just a little girl who has particular needs. And to look at the whole family unit as being the support structure there, that sometimes needs a bit of help to get it along." (6)*

A number of participants felt services had not been helpful when they were trying to find specific information they needed for their child, such as advice about benefits or practical help with adaptations and equipment:

*"When she goes in the bath, it takes two of us to bath her. You know, you ask someone, and no one seems to, to know a practical way of dealing with something like that." (1)*

However, some fathers had found support through a variety of services and organisations. One, who had a limited support network amongst family friends, was involved in decision making and supported in his caring role by staff at the early years centre. Initially, he had been reluctant to look for help but then realised he needed to in order to cope, and he ended up working closely with staff:

*"It is a lot easier if you've got somebody to ... if I have a problem, I could phone [teacher] up any time and she will talk you through and I can do it that way, so I've got no problems there." (5)*

This father clearly preferred one to one situations and found it easier to have one person to go through to access support; the early years service had responded. Another father felt supported by a SureStart local programme that provided group activities that his children attended and, in addition, made him feel valued through his involvement in developing a play area for the centre:

*"The manageress at SureStart, every time I see her she's like, 'Oh, it's our star dad... he's going to get the ball rolling.'" (7)*

Fathers also felt supported by carers' organisations and family support organisations within the voluntary sector. A father who had serious health problems described the supportive nature of outings arranged by a carers' organisation when all the family could go along:

*"You know it's nice, relaxing and jolly like, there's no stress involved so it's like an unwinding period for us and the children really, because it's an exciting trip for them as well. It's somewhere that they had never been before. So that's what we think of them."* (10)

Some of the fathers with older children pointed out that support needs changed over the years as the family and the children were faced with changing issues. A number of fathers had found the earlier years more difficult, but felt that with time they had got to know more about service systems and had become more confident about their ability to understand the needs of their children.

The interview with a man struggling to define his role as the father of a daughter with Down's syndrome encapsulated many of the issues raised in this chapter. Asked what the purpose of support might be, he simply replied that he was conscious of his failings and wanted guidance on how to be a better dad, but was not sure how to seek it out. He tended to suppress difficult emotions, not just because he felt discomfort at the idea of disclosing them to anyone other than his wife, but because he simply did not have anyone else he could turn to; he remains reluctant to talk to his family about problems, even though he lived with his parents until the age of 30, and the focus of his small circle of friends was sporting activities. In comparison, his wife has a wide circle of friends - he noted wryly, *"it is not often the phone rings for me"*. However, joining the Down's Syndrome Association had at least brought him and his wife into contact with the parents of another young girl with Down's syndrome who live close by.

### Key points

- Fathers find it hard to think of themselves having support needs.
- The main source of support for fathers is their partners. Lone fathers, those whose partners are unwell or where a relationship has broken down are likely to experience additional stress without this support.
- Support from extended family was variable. Some grandparents gave practical support to allow fathers respite from caring, but others did not understand their grandchildren's disability.
- Compared to mothers, fathers found it harder to sustain existing friendships or develop new networks with other parents following their child's birth.
- Fathers who had experienced support designed specifically for fathers usually found it to be beneficial.
- GPs were often unaware of fathers' caring responsibilities and the implications for their health.
- Some fathers thought the option of counselling at the point of diagnosis and at birth might be a helpful way of dealing with stress.
- Support services are generally designed to support children. Most fathers agree that this should be a priority and that good support for their child indirectly helps them fulfil their own role within the family. However, some fathers believe that services should have a greater sensitivity to mothers and fathers providing care.
- Fathers value most the support that is borne out of a shared experience: from their partners, from other parents or from fathers.



## 7. FINDINGS: INTERACTION WITH PRACTITIONERS

### Introduction

During the interview fathers were asked about their experiences of receiving services either for themselves or for their children. They were also asked about their experiences of attending meetings and appointments. The services and practitioners that fathers had encountered ranged across health, social services, education and the voluntary sector. The term 'practitioners' has been used in a very broad sense to cover all the people in paid roles in these sectors, including health practitioners, social workers, teachers, school support workers and family support workers. When interviewees talked about practitioners it was often not clear to what sector or what level of responsibility they were referring.

The level of involvement with services varied considerably - often depending on the age and the complexity of the support needs of their children. Interaction with practitioners took place in formal settings such as meetings and appointments or in more informal situations such as dropping children off at school or going along to group situations such as playgroups and clinics. The issues that arose focused around the opportunity to have contact with practitioners, the environment in which fathers were likely to come into contact with them and the quality of any interactions that took place.

### Opportunities to interact

A number of fathers commented on the lack of opportunities to meet workers from different services, as most services operate within normal working hours when they themselves are at work:

*"She [Portage worker] did the Portage with him for a while but again that was during the day so I didn't see that much of her." (15)*

The main opportunities fathers had to interact with practitioners appeared to be at meetings and appointments concerning their child rather than informal settings. However, for fathers who were not working, or who had flexibility within their work, there was the opportunity to have informal day to day contact with services supporting their children, such as at dropping off times at playgroups and school.

All the interviewees attended meetings or appointments, with 16 of them going to all, or trying to go to all, meetings. Most attended with their partner, but four attended on their own, two of whom were Bengali. One of these shared the care with his wife, but as she did not speak English he went on his own. The other needed an interpreter to talk to non-Bengali speaking staff, but he had taken on the responsibility for liaising with the school:

*"Well, his wife hasn't really dropped in, it's always been him." (Interpreter translating for 18)*

In addition, another father chose to attend some meetings on his own within his local health trust, as he felt this was the only way to get professionals to interact with him rather than his wife:

*"I mean one of the things that we did do about that is I started taking [my daughter] to meetings by myself so they had to talk to me and ask me issues about how she was getting on and is she constipated and other stuff because all the care needs stuff is just like looking at [my wife]." (6)*

The difficulty of attending appointments was frequently mentioned (see Chapter 5, Paid employment, p.39) and only a few said that they were consulted about their preferences for times of meetings:

*"Nothing is ever arranged round me. [My wife] will come home and say, 'Oh I've got an appointment at so-and-so', and I say, 'Right, well I'll have to take that off', and I have to juggle my stuff about to do that." (1)*

Most men did not think it was reasonable to ask for meetings to be held outside nine-to-five but thought it would be good to have a choice of days and of times that fitted within their working pattern:

*"People should have some sort of input into it. I'm not saying they can accommodate everybody, but you know what I mean if their diary's free on that day, to them perhaps a morning or afternoon is neither here nor there, but to me it means a day's pay." (11)*

*"We've had one or two which have been home visits where people have come around at 5 o'clock or something and I've been able to work the afternoon and then come home, which has been helpful." (4)*

Fathers said that the high number of meetings, particularly in the early years, made it difficult for them and their partner to attend them all. Some pointed out that, after a while, they realised that some meetings and appointments were important to attend as issues would be discussed and decisions made, whereas others were routine or screening. They therefore worked it out with their partner whether they were needed or, if they were both working, who could attend:

*"You know the bits that are very important that sort of float to the top when I obviously get involved with. But there is an awful lot more of just regular assessment visits that happen every month or every quarter or whatever, people who can come around to see how he's doing and spend time with him and such like that I just don't participate in." (4)*

But not all fathers may want to have contact with practitioners. One interviewee pointed out that he encouraged practitioners to have more contact with his wife when they phoned, as he felt she was more competent in this area:

*"They would speak to me I've got to be honest they would speak to me, but when it comes to dates and all that I'm terrible, I go, 'Hang on a minute'; and I give them to [my wife] so she can take the dates down because I am terrible, I go, 'Yeah okay.' Then I put the phone down and I go, 'What did they say?'" (10)*

## Under-representation of men

About half of the fathers commented on the fact that, when they went to meetings or went along to support services, they were most likely to come into contact with women. This is because the practitioners working with children are predominantly female and it is more usual for mothers to attend than fathers. One father described how he was the only man in the room when he went to meetings:

*"I'm the only man there, and they're talking, and they do talk a lot more to [my wife] than to me because I suppose [my wife] does more than what I do. But you know... sometimes I do feel a bit out of it then." (1)*

This father took his daughter each week to an early years service where his experience was also of only seeing women:

*"It's not like a dad's place. It's more a mum's place and when I go there I don't think I've seen another dad there." (1)*

Others commented on support groups being attended predominantly by women:

*"I mean, I must admit most of the places that I go and then I see more mums than dads, there are very few dads there." (16)*

Another man clearly described why he chose not to go to groups run by a local voluntary organisation:

*"So, again that was sort of mothers; I can't just take an afternoon off and I don't want to just sit with a load of mothers anyway." (15)*

## Involvement in meetings

Eight interviewees felt that practitioners included them in meetings, with a number saying they felt treated the same as their partner:

*"Whenever there was hospital appointments for [our daughter], and we had to go and see the doctor or the specialist in the early years, I always went along and I did feel that from my point of view anyway, that they were speaking to the both of us. So that was a bit better. That wasn't too bad." (8)*

*"I think they like to have both parents going to them and you know obviously I took as much interest as I could in it. There was times I couldn't go as well, but generally I would go whenever I could and I didn't feel excluded at all, no." (15)*

Some men were assertive about their right to have their say at meetings, as they saw themselves as an equal caregiver:

*"I think it's true to say that we take a joint effort in as much that we both care for the child and we both have a point of view to put." (12)*

Others talked about a variety of negative experiences or a mixture of positive and negative experiences with different services. Three fathers, even though they were very involved in the care of their children, talked strongly about how practitioners focused on their wives at meetings:

*"I think it's seeing her really more as the expert...she's quite confident and she has the knowledge. They tend to look at her...as the focus of the consultation if you like, which is fine you know. Which is not to say that they won't ask me how I am, but I sense that I'm a little bit secondary and does that bruise my ego, I suppose if I was to be honest with you I suppose it does a little bit." (9)*

This man felt that he was carried along in discussions and not given enough information to be fully involved in the decision-making.

Another felt there was a significant difference between the way he was treated by health services and social services, with staff working in the former showing traditional attitudes about carers and gender:

*"There is a very big difference in the way that services treat men and women in [local area]...it is almost like you're...excluded from this caring relationship that you have with [daughter] and I find that really quite annoying because as I say we have done it 50:50 from the beginning and we've all played an equal part in looking after [daughter] and her development. We share 50 per cent of the anxiety of that." (6)*

Another interviewee, who had given up work to care full-time for his children and attended meetings on his own because his wife was not able to leave the house through illness, said he felt pushed out of meetings:

*"That's what they usually turn round and say, 'Well it would be nice for you to get her in, you know, and get her involved.' And I'm like, 'Yes, but it's not that easy to get her in. You're more than welcome to come to the house. 'Oh well, we don't make home visits.' So I say, 'Ah, well that's the only way you're going to get to see her.'" And they're like, 'Oh well blah, blah, blah, blah' and it's the usual bits and bobs of them trying to fob you off... and they sort of push you out of the way at the meeting and conduct their meeting as if... you're not there." (7)*

This man sensed that fathers have to work harder to be included than mothers and that practitioners were unable to understand or appreciate his level of involvement.

## Practitioners' attitudes to fathers

A number of themes emerged about how fathers saw practitioners relating to them. These fall broadly into two areas: recognition and respect for fathers as carers, and partnership between fathers and practitioners. These themes are closely related to each other and generally convey the extent to which practitioners recognise and value the role that fathers play.

### Recognition and respect for fathers

Interviewees had had differing experiences about how much they were recognised and respected in their role as a male caregiver. A few men thought that practitioners did not seem to expect them to turn up at meetings. This was sometimes experienced as surprise, whilst others felt unwelcome:

*"Yeah, I mean they're almost surprised sometimes to see me I suppose." (4)*

*"I think they are surprised because I always try to go; I always try to go to these things and I think they were surprised the number of times I went." (15)*

*"And it was almost like 'What are you doing at the appointment, get out and earn some money.' It's bizarre the way that happened, I found that quite difficult sometimes." (6)*

In comparison, two men mentioned that practitioners said they were pleased to have them present when attending a course for parents run by a speech and language therapist and an early years service respectively:

*"I think she was chuffed that I was there. You know what I mean? At least I made the effort then." (11)*

*"Everybody says they don't see many dads and that and they say, 'It's good that you're here.'" (1)*

One father, who was the main carer for three children who have a learning disability, expressed anger that he was spoken to 'like an idiot'; instead of having respect for the care he provided, he was left feeling that it was 'taboo' for a man to be so involved with his kids. Similarly, a single father, who lived in a rural area, felt that local practitioners were not comfortable with his role as the main carer because it was less common than it might be in a city. Despite having a limited support network and caring for his son on his own, education and social services had offered him minimal assistance.

Sometimes a father felt a lack of respect from one service but felt respected by another. Two of the fathers above, who had negative experiences with some services, also described experiences of feeling recognised as carers when they took their children to school, where they were included in the informal banter that usually happens between teachers and mothers:

*"And the school's been very supportive. I mean they're fun because they take the mickey out of me when [my wife] is away and [daughter] goes in and she's got plaits in and they go 'Have you been plaiting her hair, dad, have you?' and 'Oh well, you can come and do our kids tomorrow' and they will have a joke like that with me. But it's fun because they are sort of recognising that actually I can do my daughter's hair on a morning and I can dress her and get her to school and stuff. And so they have been supportive." (6)*

*"I mean, all the ladies at school they regard me as 'one of the girls' so to speak... I was getting involved in all the little chit-chats and the gossip." (7)*

One man mentioned how practitioners recognised him as the main carer when his wife had a breakdown. Another talked about his experience of an early years service that had always been welcoming to him and helped him when he needed advice or support. This had given him a feeling of being respected in his role as the main carer and had developed his confidence in supporting his son. He appreciated that one teacher in particular was able to combine professionalism with a friendly manner:

*"She'll always help me. To tell the truth, she's a very good professional in her job. [My son] is over the age of her group, but she's still a friend; she's a friend to me and the wife and especially to [son] she's a very good friend." (5)*

The strength of this relationship may be gauged by the fact that his son's teacher had contacted the research project to suggest his inclusion, as the school recognised him as a father with a very high level of commitment (see section on Support from services in Chapter 6, Support for fathers, p.51).

## Working in partnership

Fathers made a number of comments that reflected their sense of partnership, or lack of it, with practitioners in sorting things out for their child. The father mentioned above described his relationship with the early years service that reflected his sense of working in partnership:

*"No, I've always been included and [head of early years support unit] knows that, if there's any problems, include me because I would like to be there for him... They've got to bond between teacher, father and child... They talk about it... if they could help each other out, for the child's sake, this is great." (5)*

One father described how he had worked closely with the physiotherapist to support his daughter to walk, which made him feel *"like an equal partner"* (6).

Other fathers talked about the opportunity to work together or learn from a worker. Portage workers were mentioned a few times for the way in which they worked closely with a family and became like a friend. Only one of the families had a key-worker to co-ordinate their child's care. Although the father felt included, the relationship did not lead to a sense of working in partnership:

*"The only one I can say really had my interest would be the key worker, I suppose, because .....she always does try and involve me." (1)*

On the other hand, some interviewees felt that practitioners did not work in partnership with them and they had to fight for help or resources, were not recognised as an expert on their child, and did not trust practitioners to act in their or their child's best interest. Two men said they did not have enough trust in practitioners to mention that they were experiencing stress.

One saw this as an absolute last resort:

*"You know, it's difficult, because they might think that I'm not coping with [daughter] herself." (1)*

This father also expressed strongly how he felt practitioners do what is in their own interest, whereas he had his daughter's interests at heart.

Some fathers felt there was a lack of faith in parents as experts about their own children. One father described how practitioners carried out a hearing test and argued that his daughter had a hearing problem, even though he had explained that he knew his daughter was not deaf as he spent a lot of time caring for her and knew that she responded to sound:

*"It is just the complete lack of faith that is placed in you as somebody who's looking after her as being the expert in her condition. And knowing about these things, it just doesn't seem to be given any credence at all!" (6)*

Similarly, another father described his experience at an accident and emergency unit, when the doctor failed to realise that he was a full-time carer and understood about his daughter's epilepsy:

*"One particular weekend she was really, really bad and she had five fits in a day. She was rushed into the hospital and it was usual and I suppose I shouldn't have been angry but the doctor that we saw was so intimidating, you know... I think he got the impression that I was... a normal dad... found out that his daughter was ill and you know took her in and not had any... background and history. When I was trying to tell him something... he was talking over me and I just couldn't get a word in and in the end I just said to him, 'Look, no disrespect to yourself... you know what you're doing but at the end of the day this is my daughter. I'm with her 24/7, I know what's wrong... I can tell you the reason why she had that fit, what brought the fit on, what needs doing', and yeah, very, very intimidating." (7)*

## What supports good interaction

Fathers identified factors that they felt helped them in their interactions with practitioners and ways of working by practitioners that would be more inclusive of fathers. The main factors that fathers identified as being of benefit with practitioners were having assertiveness, negotiation skills and organisational skills. Three fathers talked about how they brought these skills from work: two were used to business meetings and one was a shop steward and was therefore used to negotiating on behalf of his union members.

*"I mean I go to a lot of meetings [at work] where [wife] doesn't, so quite often she's said to me afterwards that it was really useful having you there to be able to ask them something in a way that perhaps clarified where there was a bit of an inconsistency or discrepancy between what they were saying." (4)*

*"Because I'm used to sitting face-to-face with managers and putting an argument across, I was able to do that and then transfer it over... So that sort of experience built up at work has been useful. Again, one or two of the times, you've had to do it at the school...and it's like when you're at work, you need to back up your argument with evidence and facts." (8)*

One interviewee suggested that when practitioners first came into contact with a family they should find out about the family and who is involved in caring for the child. This might help them to appreciate the role played by fathers within families and ensure they are involved from the start:

*"So I think the big step would be for everybody, if they are looking at a series of meetings, first contacts, whatever, to find out the background of who is actually looking after the children, what the families... and make sure that people are involved equally from the beginning." (6)*

Another father felt that practitioners did not understand the amount of stress that parents experienced and that their relationship with carers should be supportive and caring rather than adversarial:

*"You know it is stressful. It can be upsetting, particularly when you have to fight, you have to fight every inch of the way as it were. It's not been easy, many families that care for a child with a disability think that the professionals . . . should be more caring towards the carer." (12)*

### Key points

- Fathers wanted to be respected and valued for the role they play in caring for their children with a learning disability.
- Practitioners tended to maintain gender stereotypes around the respective roles of mothers and fathers.
- Fathers felt it was important to attend all meetings where decisions were being made, yet a lack of flexibility and choice in the arrangements for meetings sometimes made it difficult for them to do so.
- Some fathers felt excluded in meetings and felt they had to push to be as involved as they would like. Others felt welcomed and efforts were made to include them.
- Fathers were often the only man when they went to meetings, clinics or support groups and some men found this difficult.
- Fathers want to feel as though they are working in partnership with practitioners who support their children. They think this should be built upon a foundation of mutual trust and respect for one another's role.
- Fathers felt better able to work with practitioners if they themselves possessed assertiveness, negotiation and organisational skills.
- Fathers wanted practitioners to spend more time establishing how families organise care for their children, the role played by fathers and the pressures involved in parenting.

## 8. DISCUSSION

This chapter considers some of the key themes to emerge from the findings and how these can be interpreted in relation to ideas within the literature review and in relation to developments within policy and practice. It identifies areas for future research and highlights some of the issues addressed in the recommendations in the following chapter.

### Emotional impact

Fathers are often portrayed as needing to be strong and as unwilling to express their emotions and reluctant to talk, yet the men in the study appeared to talk openly about their experiences of being the father of a child with a learning disability. Many said they welcomed the chance to talk, referring to the interview as *“enjoyable”*, *“therapeutic”* or *“the first opportunity to reflect”*, echoing the findings of previous researchers (Carpenter and Herbert, 1997). Their willingness to talk indicates a need for them to be provided with more opportunities for this by their partners, family and friends and by practitioners.

### Expressing feelings

The participants used the opportunity to describe their feelings and emotional responses to different stages of their journey into fatherhood, including receiving a diagnosis and the process of acceptance, their changing relationship with their child and partner, their day-to-day reality and their concerns for the future. The interviews revealed the huge emotional impact of being the father of a disabled child and the combination of positive and negative experiences. A complex interplay of factors relating to the internal world of the men and their families and to the external world, such as the support they receive and society’s response to disability, determined the nature and extent of this impact..

Parenting a disabled child has previously been described as a journey ‘between joy and sorrow’ (Kearney and Griffin, 2001) in which families took a constructive approach to their situation and, although experiencing pain, found ways of dealing with it. The findings from the study corroborate this picture, with fathers often expressing conflicting emotions about their parenting experiences. This tension appeared to be greater for fathers whose children were on the autistic spectrum and with whom it was more difficult to have a close emotional relationship. This sense of conflicting emotions may be a potential source of stress in itself and needs to be recognised by practitioners supporting families, as fathers appear to have fewer sources of informal and formal support than mothers to discuss these emotions. Such situations are especially hard for men who are lone parents or do not have a supportive relationship with their partner.

Having a disabled child made a fundamental transformation to most of the men’s lives, leading them to reassess their values and priorities. Many described how they had developed attributes and skills through their experience and preferred to focus on such personal growth, rather than the limitations that having a disabled child had imposed on their lives. Hornby (1992) also found that fathers acknowledged a sense of personal growth, yet the fathers he spoke to seemed to give greater emphasis to the stress of caring and the negative impact on their lives than the fathers in this study. This may be the result of the growing acceptance, albeit gradual, of fathers being more involved in, and consequently more satisfied with, their family life (Elder *et al.*, 2003). The men in this study made references to moving away from values associated with a ‘male’ world (such as achievement, competitiveness and focusing on the bigger picture) towards more ‘female’ attributes, such as tolerance, patience and appreciating the smaller achievements of their children.



## Emotions at time of diagnosis

There is often an assumption that men are slower to pick themselves up after receiving a diagnosis. However, the ability of men in this study to move on fairly rapidly from the initial shock was more in line with the findings of Pelchat *et al.* (1999), who found that mothers have more difficulty adapting. There are two key implications for practitioners involved with parents around the time of diagnosis. First, they need to understand that mothers and fathers are likely to have different responses to the diagnosis, over different timescales. They may therefore need to be offered support individually as well as (or instead of) together. Second, they should be aware that fathers may have 'come to terms' with the diagnosis before their partners and can therefore play an invaluable role in supporting them. On the other hand, if fathers are struggling to 'accept' a diagnosis, then it would be important for practitioners to find ways to ensure they are involved in what is happening rather than simply to focus on the mother. Good practice at the time of diagnosis has been shown to have a positive effect in the longer term on parental adaptation (Hatton *et al.*, 2003). The experience of having a central role at this stage is likely to give men confidence in their fathering role and create an expectation to remain involved in the future.

## Emotions in relationships

The interviews convey the huge emotional commitment that men have made to their children. This appears to begin at the point when fathers make an initial acceptance of the situation after receiving the diagnosis. Their commitment was expressed in terms of day-to-day involvement and concerns about the bigger picture of their child's development and long-term future. Fathers worried about their children's future, particularly in terms of the sense of uncertainty and of their children's loss of opportunity. It is therefore important that fathers are engaged in helping to plan for the future.

Previous research has highlighted the strain that having a disabled child can place upon the relationship between partners. This study suggests that there are two sides to this: the strain caused by the provision of constant care, allowing parents little time for themselves, may sit alongside a bond between partners developed through a desire to work together to 'make things right' for their child. This is explored later in this chapter under the heading 'Support for fathers'.

It was interesting that a number of fathers interviewed referred spontaneously to men who, having been unable to accept their child's disability, had decided to leave. Although none sought explicitly to compare this with their own decision to stay with their family, it would imply that they were aware that this is an option open to men. As previously acknowledged, the sample for this study was men who were committed to their children: it would be interesting to explore further what motivates men to stay and what causes some to leave.

## Roles and responsibilities

One of the key areas for the study was to gain an understanding of how men saw their roles and responsibilities as the father of a disabled child. Mothers are usually seen as being central to children's well-being as the primary caregiver, whereas fathers' roles are regarded as more peripheral to day-to-day life.

## Engagement, accessibility and responsibility

Research on fatherhood has used the model developed by Lamb *et al.* (1987), which identified three types of involvement: engagement, accessibility and responsibility. Engagement refers to direct contact through providing care and shared activities; accessibility to being present or available, and responsibility refers to making sure a

child is taken care of and arranging resources. This model is helpful when analysing the involvement of fathers in this study.

As described in the findings, fathers had a high level of 'engagement' over a range of care and support activities. Some described enjoying the playful relationship emphasised in previous research (Pleck, 1997), but along with this they also described their involvement in their child's development and in their daily routines. Indicative findings from this study show that men are providing a significant amount of daily personal care for their disabled children and make huge adjustments to their work patterns to achieve this.

The men in the study appeared not only to spend a lot of time with their children, but also to take on a wide variety of roles inside and outside the home. A number of fathers mentioned that they were more confident than their partners about taking their children out into public places, although this study is unable to show why this might be so. However, discussion of the findings with other fathers yielded a number of suggestions: that men are generally less self-conscious, they are more concerned with the outcomes for their children than the opinions of others, or that public attitudes are more understanding towards fathers than mothers when they are struggling to cope with children in public.

The idea of fathers being 'accessible' in the sense of being called upon if needed, was less relevant to fathers in the study, who emphasised the need to be at home to be actively involved. While this might reflect the need for parents of disabled children to be much more 'hands on' than simply adopting a supervisory role, it also seems to reflect the high level of commitment fathers had to be engaged with their disabled children.

Asked about their roles in relation to employment, support at home and child-care, interviewees tended to emphasise their care role over their economic role. However, following Lamb's typology, they described a high level of 'responsibility' - not only in terms of being breadwinners, but also in relation to advocating and arguing for a broad range of resources and services, including statements of special educational need, speech and language therapy and specialist equipment, and concerning themselves in meetings concerning their children.

## Sharing the care

Most of the interviewees were sharing care responsibilities with a partner, which meant either taking an equal share in care arrangements or contributing to the provision of care. This was worked out through a process of negotiation around other commitments, such as work or the need for a break, and was based on a realistic assessment of who was best at achieving the outcomes they wanted for their children, irrespective of traditional gender roles. The one area of work that did appear to have a gender divide, and to which men did not appear to attribute much importance, was housework. However, this was more likely to be shared when both partners were working, especially if they were both in full-time employment.

Fathers in the study attributed a good deal of importance to supporting their partner; where women were the primary carers, their ability to cope might be dependent on the input of their partner. The study did not involve talking to women to find out the value they attached to their partner's input, but a previous study (Simmernan *et al.*, 2001) found that there was a high level of agreement between mothers and fathers about the extent of fathers' help. The current study identified a dual benefit whereby men sharing the care not only eased the burden of care on mothers but also developed a sense of a supportive relationship. In situations where fathers are taking a share of care responsibilities and supporting their partners but are not so visible because they are at work they may not be recognised as involved parents by practitioners. It may help to sustain fathers in these roles, as well as couples in their relationships, if practitioners acknowledge their contributions when fathers turn up at meetings and appointments, treating them as an equal partner.

## Economic, social and cultural influences

Recent research by the Equal Opportunities Commission (2006) showed that fathers of all children generally want more involvement with their children and that this is particularly true of men on low incomes, in manual jobs and from black and minority ethnic communities. This would suggest that men from higher socio-economic groups have been more able to accommodate greater involvement with their children by virtue of their higher incomes, employment flexibility and lack of social inhibitions about carrying out the role. It should not therefore be assumed by practitioners that less involved fathers do not want a greater level of involvement and adaptations in practice may be required to support this, such as flexible meeting times. The introduction of paid paternity leave in April 2003 was viewed as a means to encourage fathers to become involved in the early weeks of their children's lives, but the current rate is generally acknowledged to be too low to enable families on low incomes to be able to take advantage of this entitlement (O'Brien, 2005).

All the minority ethnic fathers interviewed for this study were from an Islamic background and all had a high level of involvement both within the home and in the external world. This needs to be placed within the context that little is known about forms of fathers' involvement with their children among minority ethnic families in Britain (O'Brien, 2005). Factors affecting the involvement of fathers generally may differ for those from minority ethnic communities: they may have different employment patterns, a higher number of children and live in a local area with a strong minority ethnic community. These, and other factors, may lead to a different balance between paid work and care and to different responsibilities. Fathers from black and minority ethnic communities may also have difficulties accessing support services either for themselves or for their children, which may lead to them needing to play a greater role. These factors will also vary between minority ethnic fathers and is an area that requires more detailed study.

## Men's changing roles

While there is clarity in society about the role of mothers in caring for children (not specifically disabled children), the debate about the role of fathers is still evolving. However, fathers in the study seemed to have a clarity and sense of purpose about their own role. This sense of purpose may result from the many extra tasks that need to be carried out, coupled with the limited sources of support available to families with disabled children. It may also be a natural outcome of their involvement with their children, and the attendant pleasures of being central to their lives, which fathers of non-disabled children often miss.

## Paid employment

There has previously been considerably more focus on the impact on women's employment patterns when they have a disabled child, rather than on men's. The extra caring responsibilities and the lack of suitable child-care are both factors that make it difficult for women to return to work. However, findings from this study indicate that having a disabled child also has an enormous impact on men's working lives in terms of the choices of work they make, the loss of opportunities and earnings, and the struggle to get the flexibility they need.

## Motivation

Most of the fathers in this study were playing a key role in bringing income into their household, even though the birth of a disabled child had led to a reappraisal of their priorities. However, an interesting finding was the relative lack of importance that they attributed to work. Although two men mentioned that initially they had used

work as a place to hide from their child's disability, it was not generally described as a place to gain relief from providing daily care or achieving self-fulfilment outside the home. Men in this study were more likely to say that they would like to be able to spend more time at home with their children, corroborating the earlier finding that men were taking on increasing levels of responsibility with their children. It also supports Einam and Cuskelly's contention (2002) that fathers who reduce their work commitments so that they can be more involved in care-giving demonstrate the value that they place on this role over that of 'provider/protector'. This seems to indicate that men saw employment as having an economic, rather than a personal, benefit (contrasting with the findings of Hautamaki (1997), that maternal employment was linked to well-being rather than financial reward).

## Entitlements

The growing awareness of the need for parents to achieve a balance of work and home life has prompted the Government to introduce various measures to help parents achieve this, with parents of disabled children being given slightly more generous entitlements. All parents have the right to take time off work to deal with an emergency involving someone who depends on them, although there is no statutory right to be paid during this time. Parents of non-disabled children have the right to take up to 13 weeks unpaid parental leave during the first five years of their child's life. This entitlement is extended for parents of disabled children (defined as children who receive Disability Living Allowance), who can take up to eighteen weeks until their child is 18. Parents also have the right to request flexible working, with parents of disabled children having the right to request this throughout their son's or daughter's childhood.

What was apparent from the interviews was that fathers were not using these entitlements to their best advantage. The picture that emerges is of fathers trying to create their own solutions to balancing their paid employment and their care responsibilities. Few had received advice on how to achieve this from an employer, support services or advice agencies. Fathers generally had a low level of knowledge about their rights and were also reluctant to assert these rights when they were known. However, a small number of men knew their rights, talked about them clearly and were happy to use them when necessary.

The interviews identified some possible reasons why men were not given the formal support they required to combine employment and support to their family. Employers appeared to have limited perceptions of carers: respondents in this study believed their employers regarded women as the main carers within families and men's involvement as more peripheral. Employers seemed to be more sympathetic to granting leave for short-term intensive care, such as hospital admissions for heart surgery, than for long-term care. There may also be limited understanding amongst employers and human resource departments that fathers' needs for flexibility are different from mothers': men tend to continue working full-time (as they need to maintain their salary), but need flexibility in how they arrange this, whereas women are more likely to arrange part-time work. There needs to be further discussion about this to raise awareness amongst employers that flexibility at work is an issue for men as well as for women. However, there are signs that this situation is changing. A number of major employers, such as BT and PricewaterhouseCoopers have signed up to the Action for Carers Project set up by Carers UK to improve employers' support to carers.

This study indicates that the ability to maintain paid work and to balance employment and care responsibilities are central to fathers, yet they are receiving little formal support to work this out. Certain factors, such as having more than one disabled child, are likely to make this even more difficult. The two participants in the study who had more than one disabled child had both left paid employment; one to run a franchised business from home and the other to become a full-time carer. Information and support around balancing paid work and care roles need to be part of the package of support for families. Practitioners should be aware of sources of specialist support about employment and be able to signpost fathers to it. Working Families have produced a comprehensive booklet called 'Making it Work for You' (2006), which would provide parents with a comprehensive guide to the choices available to them.

## Poverty

It is generally accepted that families with a disabled child are more likely to experience poverty: for example, one study found that the cost of raising a disabled child was at least three times more than a child without a disability (Dobson and Middleton, 1998). These figures emphasise the importance of maintaining earning capacity within a family and the impact resulting from a loss of earnings or career progression. From the study it would appear that men from higher socio-economic groups are more able to gain the flexibility they want without experiencing a loss of income.

Further work needs to be carried out to consider how men in lower paid and less skilled jobs can achieve the involvement they want without struggling to cope financially. The government has set a target of halving child poverty by 2010, but families with a disabled child (and especially those with more than one disabled child) will continue to experience financial hardship unless extra support is targeted on them.

## Support for fathers

### Perceived needs

Fathers in the study appeared to have had little opportunity to talk about their support needs or to consider what their support needs might be. They were unlikely to recognise their own needs; when asked about what support they received, they were most likely to mention the support needs of their children rather than their own. This corroborates the findings of Bailey *et al.* (1992). Giving priority to their children's needs over their own, and ensuring those needs are met is itself a source of comfort and support to fathers. However, their response also indicates the lack of expectation that many men have of receiving support, given the lack of acknowledgement of their caring role by service providers, employers and more generally by society.

### Sources of support

The support networks that were described by fathers were fairly limited. Most had a family member or friend they could talk to, but not many described a supportive network of relationships. Those that had, talked less about the stress they experienced, although it is not possible to say whether this was because the network of support reduced stress or whether they were able to maintain their network because they experienced less stress. The findings do indicate that women are more effective than men at maintaining contacts made prior to the birth of their child and developing new networks focused around the life of their disabled child.

The main source of support identified by fathers was their partner. This support took the form of talking things through together, sharing concerns and ideas, and trusting one another. From the interviews it is not possible to know whether mothers would also describe their partner as the main source of support, whether they would have a different perception of their relationship, or whether they draw upon a wider range of sources of support. The study by Saloviita *et al.* (2003) suggested that mothers were more likely to look outside the family than fathers, who tended to rely more on their spouses.

This dependency on a partner for emotional support raises two concerns. First, what are the implications for single fathers, for those whose partner is physically or mentally unwell, or for those not coping and where the relationship is breaking down? Second, fathers indicated that they had very little time with their partner away from their children. If they are looking to their partner for support, then opportunities for parents to spend time together would be of value.

Few families in the study were receiving a service that gave them some form of respite and, where they were, the number of hours was usually not seen as adequate. Many fathers expressed reluctance to consider respite services, especially where this involved their children being cared for outside the home. Families who were receiving a service through Crossroads saw this as invaluable. A family caring for twins, one with Down's syndrome, appreciated the fact that the Crossroads' carers also looked after their non-disabled child, giving them the opportunity to go out as a couple. Direct Payments offer an alternative means of receiving additional support. The fact that only one family was receiving them (for their child to be included in 'ordinary' activities, such as the Guides), and that others did not seem to be aware of them as an option, suggests a need for more information to be made available to families about the potential of Direct Payments.

Support from grandparents was variable, with some fathers receiving practical and/or emotional support and others feeling that their own parents had either not accepted their child or were physically not able to provide care. Fathers sometimes expressed a reluctance to ask their parents for assistance, which may indicate wariness about appearing dependent on their own parents to cope. Mirfin-Veitch and Bray (1997) found that the 'relationship history' where 'a long-term closeness had previously existed' between a disabled child's parent and grandparent made it more likely that the latter would provide the type of support appreciated by parents. They suggest that professional assessments should take into account intergenerational relationships and 'encourage a level of involvement that is acceptable and useful to parents'.

The findings from our study indicate that women are more effective at developing new networks focused around the lives of their disabled children. From this it should not be assumed that men would reject support networks if they were geared around their interests and run in a way that worked for them. The fathers in the study who had participated in father-specific activities talked about the benefits that they gained from contact with other fathers. Men who had participated in a group for fathers felt they benefited from sharing experiences and emotions with other men in a similar way to that encountered by West (1998). Men who were involved in activities for fathers where their children were also involved valued these opportunities as it served a number of purposes: it gave them time with their children, gave them opportunities to meet other fathers and share experiences, and gave their children an opportunity for social interaction. This form of activity seemed to be particularly welcome to men who were the sole or main carer.

### Specific support needs

An area where there seemed to be a considerable lack of support for fathers was in looking after their health, despite the evidence of poor health amongst parents of disabled children (Dale, 1996). Not all of the fathers in the study had informed their GP of their caring responsibilities and few GPs had offered support when fathers talked to them about feeling stressed. This implied that not only do GPs often lack awareness of fathers' needs as carers, similar to that noted previously amongst employers, but also a lack of confidence that fathers feel in talking to their GP. Another source of support that is sometimes available through primary care is counselling; indeed, a few of the fathers in the study had used counselling, either on their own or with their partner, and found it helped to talk things through with an independent party. Efforts to raise the profile of family carers in primary care need to be renewed and attention should be drawn to the specific needs of fathers in this context.

In this study the fathers from black and minority ethnic communities did not specifically indicate they were experiencing a lack of support. The Bengali fathers seemed satisfied with the support they were getting for their sons through the school. Their support needs may have been better met because they were living in an area with a high number of Bengali families and services had been developed to meet their needs. One of the fathers was interviewed with a Bengali family link worker, who acted as an interpreter; there was also a strong sense of home/school liaison. This does not reflect the overall picture of a high level of unmet need (Audit Commission, 2003) with issues such as language, communication and information barriers preventing access to services.

## Support from services

Overall, there was little evidence of fathers receiving direct support for their own needs from services. What they seemed to find most helpful was support to be involved with their child and especially around their child's development. Lillie (1993) found that fathers were more likely to participate in support activities if their role was acknowledged by practitioners. Fathers were keen to develop their knowledge and understanding of their child and to do this would attend meetings, events and courses. Fathers talked positively about their contact with Portage workers and speech and language therapists, who had run courses for parents.

Fathers' lack of contact with services reinforces their marginalisation in two ways: having limited contact with people who are working with their children, they do not receive the informal support from service providers that mothers get, while limited contact also reduces the external value placed on their role as carers. Given the evidence that fathers place considerable importance on the development of their child, it seems to follow that both fathers and practitioners would gain from greater contact with each other and this is explored further in the next section.

## Interaction with practitioners

Much has been written about how men are reluctant to engage with practitioners and services, but the findings from this study seem to indicate that fathers are keen to have contact where they feel this leads to improved outcomes for their children. Overall there appeared to be two key issues that either facilitated or hindered men's involvement: having time available to be in contact, and the ways in which practitioners responded to them when they were able to be present.

## Opportunities

Generally, fathers have fewer opportunities than mothers to be in contact with practitioners. This may well be explained by the fact that most services operate during normal working hours and therefore, where men are in paid employment, it can be difficult to have contact without taking time off. In this study, contact was mainly achieved through attending meetings and appointments rather than through direct involvement with services such as playgroups, schools, early intervention services and family support services.

Participants in the study gave a high priority to attending meetings, to the extent that some chose jobs or employment patterns that enabled them to be present. Most of the interviewees would have liked to attend all the meetings, but they were usually faced with prioritising as a result of either the high level of appointments or the lack of flexibility and choice in the arrangement of meetings.

Although this study identifies a high level of commitment by fathers to attend meetings and appointments, this does not seem to be acknowledged in attempts to facilitate their presence. The assumptions that seem to be made are that mothers are not working or work part-time (and are therefore free to attend), that one parent at a meeting is enough, and that fathers do not have valuable contributions to make. This indicates the need for meetings to be arranged with a greater sensitivity to the needs of both fathers and mothers. Part of the initial contact that practitioners have with mothers and fathers should include identifying their work and care commitments. The interviews also indicate that mothers and fathers need to be provided with better information about the nature and purpose of meetings so that they can make informed decisions about who should attend. For example, a family-held record could be used to note what meetings are planned, for what purpose, and who might attend.

## Settings

The findings seem to indicate that the reasons for men giving such a high priority to meetings included wanting to participate in discussions and decision-making around their children's needs, to argue for resources, to receive first-hand information, to support their partner and to receive external validation for their role as a carer. Fathers appeared to have less frequent contact with service providers such as schools or clinics, although a number did prioritise this when they saw it as being of benefit to their children. A few fathers had contact at the start of their children's placements, for example at nursery, with the purpose of supporting their integration in a new setting; another father regularly took his daughter to an early years service for her to be involved in developmental activities.

It may well be the case that fathers are more comfortable in the structured environment that meetings provide, rather than attending services that require less formal interactions. Schools, playgroups and clinics are often seen as a mum's place: the father mentioned above, who had a weekly commitment to take his daughter to an early years service, pointed out that he was usually the only man present and was the only regular male attendee. The staff profile of services is usually predominantly female and female workers may feel less comfortable engaging with fathers than with mothers. Similarly, conversations between staff and mothers and between mothers may feel excluding to fathers.

## Attitudes

Meetings do not always appear to be facilitated in a way that ensures fathers feel valued and respected, so that their involvement is maintained. Some fathers perceived meetings to be uncomfortable due to: the predominance of women; the lack of information to enable full participation and the perception that they were not respected in their caring role. These findings raise questions about how practitioners can affirm the sense fathers often had of themselves as involved, competent and caring parents. This experience of not being valued by practitioners may not be unique to fathers: a previous study (Todd and Jones, 2003) found that mothers felt their encounters with professionals were sometimes based upon conflict and their character and worth as mothers were continually being scrutinised. The father who felt that his role as the primary carer for his three disabled children was 'taboo' appears to be describing just this sense of unfavourable scrutiny.

However, a similar number of fathers felt meetings and appointments were run in a way that gave them a voice and made them feel recognised in their role. In the study mentioned above, Todd and Jones (2003) found that mothers were willing to challenge professional perspectives on their children and their needs. Similarly, in this study, fathers were willing to stand up at meetings for their children and argue for resources. This was often spoken about with pride, giving a sense that these encounters were affirming their identities as fathers.

## Skills

Some of the fathers in the study mentioned they had gained skills at work that gave them confidence in their interactions with practitioners and particularly at meetings. This raises the question how men can have the opportunity to gain these skills when they are not in employment or when they are in jobs that do not involve skills such as negotiation. This is more likely to affect fathers from lower socio-economic groups. Fathers could be given opportunities to gain these skills independently from work, such as through Early Support training and Partners in Policymaking courses.

Practitioners also need to be provided with opportunities to develop their skills in working with whole families, including fathers. Family-centred models of support require practitioners to understand the support networks of a family, respect their way of working and develop support based on those networks. Within this model, the



concept of 'the self-defining family' (Carpenter, 2000) is useful in that it includes 'family members as defined by the family itself', such as fathers, siblings, grandparents and friends. In recent years, generic services such as SureStart have begun to develop their practice in involving fathers and identifying what works. Research has shown that men are more likely to become involved when services employ men, staff are trained on working with fathers and other men are present. Services that support disabled children and their families may be able to benefit from what has been learned in these services.

## Further research

This study has identified a number of areas that require further investigation:

- In the study men talked about some of the factors that motivate and support them to be involved with their children, but looking at this in more depth and with a larger cohort would provide useful data to enable support to be targeted more effectively.
- The findings highlighted the importance of partners working together, sharing responsibilities and balancing employment and the provision of care in a way that worked for their family. Further investigation into the factors that help or hinder this negotiation could yield information that would help couples in future.
- This study focused on fathers of children up to the age of secondary school, but fathers indicated that the transition to secondary school, the teenage years and the transition to adult life were of concern to them. Looking at the issues for fathers throughout these years would develop understanding of how fathers can be supported to maintain and develop their roles as their children move towards adulthood.
- The study identified that some fathers may have extra or different needs for support and a wider study would be needed to explore these in more detail. These include:
  - fathers from black and minority ethnic communities
  - fathers who are primary carers or lone parents
  - fathers of children on the autistic spectrum.

## Conclusion

This study provides considerable evidence of the significant contributions that fathers make and the central roles they play in their children's lives, but there is still a long way to go in terms of these being recognised by service provider organisations, practitioners (in health, social care and education), employers and more generally in society. Fathers mentioned a few examples of excellent family-centred practice, but on the whole services still seem to be geared around the concept of mothers as the carers to whom their efforts should be directed. There still needs to be a significant shift in practice within generic children's services and services for disabled children to involve fathers and treat them as respected partners. There also needs to be a shift in public perceptions of men as carers so that it is more acceptable for men to be the main carer or to be looking for a work-life balance that enables them to combine paid employment and giving the level of support that works for the whole family.

The Gender Equality Duty (in effect from April 2007) may be a stimulus for change, as it places a duty on public organisations to consider whether employment practices and services discriminate against people because of their gender.

The ambition of this report is to raise awareness of fathers' roles – shifting from the common view of them as a 'peripheral parent' to recognition of the significant contributions they can make to the lives of their disabled children and their families.

## 9. RECOMMENDATIONS

### General comments

These recommendations, relating to the policy and practice of supporting fathers of children with learning disabilities, are addressed to those who would be responsible for implementing them. However, they all are underpinned by an understanding that fathers of children with learning disabilities are resources for the whole family and bring unique perspectives and sets of skills to the task of caring for their children. Fathers' roles help to sustain and strengthen families who have a child with a learning disability, yet this role and the specific support that fathers need to carry it out are rarely recognised. Investment in support for fathers as carers must therefore be recognised as an effective way of supporting families and improving the life chances of children with a learning disability.

Fathers are a heterogeneous group and as a result have differing needs. Fathers from black and minority ethnic communities may have different roles from those with white European backgrounds, resulting in different support needs, and may have different issues about accessing services. Similarly, fathers who are 'primary carers', those who have more than one child with a disability or who are lone fathers may have specific or additional support needs. Additionally, some fathers of children with a learning disability may also have a disability themselves. It should also be recognised that these factors, amongst others, may increase the likelihood of families experiencing poverty, which can create additional needs and affect a father's ability to access support.

### Recommendations for Government departments

The Government's Policy Review of Children and Young People, led by HM Treasury and the Department for Education and Skills, should include recognition of the roles of fathers of children with a learning disability and acknowledge the benefits of early support as an effective and efficient way of supporting the whole family.

The Department for Education and Skills should ensure that the development of the lead professional and keyworker role and the development of the Common Assessment Framework tool lead to better understanding and partnership working with fathers as well as mothers.

The Department for Communities and Local Government should ensure that the Gender Equality Duty is effective in tackling discrimination faced by fathers of disabled children.

The Department of Trade and Industry should consider strengthening and extending the employment rights of parents of disabled children, including the introduction of paid time off to attend key appointments. The introduction of recent legislation in relation to the right to request flexible working, emergency leave for dependants and parental leave are moves in the right direction, but fathers who are combining employment and the provision of care need stronger support to maintain their employment.

The Department for Trade and Industry should also consider the introduction of Additional Paternity Leave at a higher rate to take account of the additional responsibilities and financial costs associated with raising a disabled child.

## Recommendations for children's services and trusts

Children's trusts should establish standards for involving fathers of disabled children at key stages in their children's lives. This would include:

- Engagement with fathers through involving them in decision-making, facilitating their attendance at meetings and providing opportunities for them to participate in developmental programmes for their children.
- Lead professionals, who will have responsibility for carrying out the Common Assessment Framework from 2007, having the knowledge and skills to establish successful relationships with fathers.

Children's service directorates, children's trusts and primary care trusts should appoint a local fathers' champion from within their service, the voluntary sector or the community. This role should have the authority to report directly to Children and Young People's Partnership Boards and be able to influence the development of services and the Children and Young People's Plan.

Balancing employment and providing care has greatest impact on fathers whose children have high support needs. Carers' assessments would be a useful tool to identify where additional support is needed. These should be regularly reviewed to respond to changing needs.

Health and social care practitioners need to be aware of the impact that the needs of disabled children in the family have on the care of non-disabled children. Support should be available to enable fathers and mothers to offer appropriate care for all their dependent children.

Given the value placed by fathers on the support they receive from partners, it is important that they have time together away from caring responsibilities to maintain and nurture their relationship, thus sustaining the family in the longer term. Commissioning priorities that require services to provide families with practical support in the home, short breaks and individualised support for their children would support this. Direct Payments can be a useful element in this.

Directly provided and commissioned services should be monitored to ensure they consider and address the particular support needs of fathers from black and minority ethnic communities, lone fathers and fathers who are primary carers.

## Recommendations for health services

Primary care trusts should ensure that they identify fathers who are providing care to a disabled child.

GPs and other primary health workers should have an awareness that providing care to disabled children may lead to physical illness, stress, anxiety or depression in both mothers and fathers.

Midwives and health visitors should include fathers when providing information about the fetus or child during and after pregnancy and ensure that fathers are included in decision-making that affects the future of the child.

## Recommendations for voluntary sector, advice and information services

National organisations for people with learning disabilities should review their work with parents and families to ensure that the role of fathers is acknowledged.

Information produced by national and local organisations should be 'father friendly' and refer to both 'mothers' and 'fathers'. Some information may need to be targeted at fathers.

Local family support organisations and groups should consider how they can involve and support fathers through developing activities that fathers can do with their children or by helping fathers to support one another.

## Recommendations for Early Support

Training packages developed by Early Support, such as Parents' Workshops and the 'Working in Partnership through Early Support' programme, should reflect the specific needs of fathers within their components and ensure that fathers are targeted to participate.

Early Support, children's centres, SureStart local programmes and other UK wide initiatives should produce materials for families and staff that address the needs of fathers. This would raise awareness, signpost fathers to support networks and information, and encourage fathers to establish an involved role in their children's early years.

## Recommendations for practitioners in health and social care settings, education and family support services

Practitioners need to be aware that fathers may have their own support needs in order to fulfil their roles within their families. These need to be addressed in order to support the whole family.

Several points of good practice for arranging meetings, appointments and home visits should be adopted to maximise the opportunities for both parents to be involved:

- Be aware of parents' work commitments, preferences for days and times of meetings and how much advance notice they need to give at work to arrange time off.
- Provide information about the purpose and significance of meetings in advance to help fathers decide what priority they should give to attending.
- Consider whether meetings could be arranged outside normal working hours.
- Take account of other obligations such as prayer times or religious holidays.

When fathers are not able to attend significant meetings, good practice could involve ensuring that they are informed of discussions and decisions through direct contact by telephone or e-mail.

During meetings, appointments, clinics and other discussions practitioners should acknowledge the input and expertise of the father.

Practitioners need to understand that the process of coming to terms with their child's disability may be different for fathers and mothers: post-diagnosis meetings should be offered to them together and/or separately.

Practitioners need to have an awareness of the cultural needs of some fathers who may not be comfortable discussing sensitive topics with female members of staff.

Men should be given opportunities to participate in courses and development programmes that build up their skills to support their child's development. This might include running courses in the evenings, at weekends and considering whether some should be run for men only.

Practitioners such as health visitors and social workers should provide employment-related support by providing written information or directing fathers to specialist organisations such as Working Families.

Practitioners should be aware of practical and emotional support that is available to fathers locally and signpost fathers to this.

### **Recommendations for professional bodies**

Professional training and continuing professional development should promote a holistic approach to supporting families that includes understanding and responding to the needs of fathers.

### **Recommendations for employers, human resource managers and trades unions**

Employee productivity is likely to be enhanced where fathers are able to achieve a balance between their working and home lives. Employers are recommended to review their recruitment practices and terms of employment to enable fathers of children with a learning disability to make reasonable adjustments to their work patterns. Good practice would include the provision of information about entitlements to paternity leave, emergency leave for dependants, parental leave and the right to request flexible working.

Trade union representatives should be aware of the issues for working fathers of disabled children. Trades unions should provide advice and representation for fathers who seek to combine paid work with care for a disabled child.

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## APPENDIX 1: MEMBERSHIP OF THE RECOGNISING FATHERS ADVISORY COMMITTEE JULY 2005 - NOVEMBER 2006

### Advisory Committee Chair

#### **Professor Barry Carpenter OBE**

Father of Kate  
Chief Executive and Principal of Sunfield School

### Members of the Advisory Committee

#### **Ruth Beckman**

Information Officer  
Down's Syndrome Association

#### **Hugo Crombi**

Father of Tom

#### **Gav Cross**

Father of Tom  
Project Manager, Early Support

#### **Matthew Henderson** (served from July 2005 – December 2005)

Senior Parent Advisor  
Contact a Family

#### **Vicki Hill** (served from June 2006 – November 2006)

Strengthening Families Project Manager  
Scope

#### **Tim Kahn** (served from February 2006 – November 2006)

Family Learning Development Officer  
Pre-School Learning Alliance

#### **Rohan Kariyawasam** (served from December 2005 – November 2006)

Father of Sumedho  
Solicitor, FRSA  
Director, Programme in Information Technology, Media and e-Commerce Law  
University of Essex

#### **Gloria O'Flaherty** (served from February 2006 – November 2006)

Carers & Family Members Partnership  
Co-ordinator  
Royal Mencap Society

#### **Prithvi Perepa** (served from February 2006 – November 2006)

Development Officer - BME Project  
National Autistic Society

#### **Dr Heather Skirton** (served from December 2005 – November 2006)

Reader in Health Genetics  
Faculty of Health and Social Work  
University of Plymouth

## **Staff members, Foundation for People with Learning Disabilities**

**Isabel Cooke**

Projects Officer

**Jill Davies**

Research Programme Manager

**Laura Gibson**

Public Relations Officer

**Christine Towers**

Recognising Fathers Research Project Manager

**Paul Swift**

Research Fellow

## APPENDIX 2: DESIGNING AND SELECTING THE SAMPLE FOR 1:1 INTERVIEWS

### Study population

The study population is fathers who have a child with a learning disability aged 11 or under. This will mainly be fathers living with their partners and child(ren) but may also include fathers who are separated from their partners. Fathers will be aged over 18.

### Sample frame

A combination of sampling approaches will be used in order to reach the diversity of fathers set out in the selection criteria. Publicity will be placed on the website of the Foundation for People with Learning Disabilities, a project leaflet will be produced and information will be posted on various disability and carers' forums and newsletters. Organisations will be contacted that provide services or represent particular interests such as the Down's Syndrome Association or National Autistic Society.

These approaches will be used to generate interest from fathers directly and for organisations and services to become interested in the research and inform fathers. It will be important for some organisations to identify fathers who are not using support services in order for the study to cover fathers who are less well informed, outside a support network or feel excluded.

### Selection criteria

Following a search of relevant literature and previous research, criteria have been identified that need to be represented in the study participants. Within fathers there are sub-groups that may be interesting to explore in more depth but which will not be possible at this stage of the study. For example, cultural meanings of fatherhood may be important, but it will only be possible to include a small number of fathers from different black and minority ethnic communities.

Criteria	Justification
Family unit	The number of other children in the family, position in the family of disabled child, having more than one disabled child, being separated from their partner are all likely to affect the fathers' experiences and influence their attitudes
Socio-economic group	To ensure a balanced demographic sample and because this will influence opportunities and choices available to fathers
Employment activity of father	Type of work may influence level of flexibility in working hours and ability to take time off. Self employment may be being used to gain more flexibility
Regional location	Type and levels of support may vary in different parts of the country
Type of area	The type of support networks may vary in rural, urban and inner city communities
Ethnicity of father	Cultural aspects of fatherhood will influence the attitudes of fathers
Age of father	Ensure a balanced demographic sample and because age may affect experience and ability to cope
Age of child(ren)	As children get older the roles for fathers and issues they face will change
Diagnosis of child(ren)	Including a range of diagnoses will enable the study to explore the impact of the diagnosis and complexity of the child's disability
Age of child when diagnosis made	The point at which a father receives the news may affect his responses
Contact with support services	Different levels of contact with support services (e.g. receiving information, talking to other parents) will enable the study to explore the impact of support.

## Prioritising selection criteria

The selection criteria have been divided into primary and secondary criteria: primary criteria are those most relevant to the study population and to the objectives of the study.

Primary	Secondary
Socio-economic status	Type of area <ul style="list-style-type: none"> <li>• urban</li> <li>• rural</li> <li>• inner city</li> </ul>
Employment activity <ul style="list-style-type: none"> <li>• part-time</li> <li>• full-time</li> <li>• self-employed</li> <li>• flexible work patterns</li> <li>• inflexible work patterns</li> </ul>	Ethnicity of father
Regional location <ul style="list-style-type: none"> <li>• England (NW, NE, SE, Midlands)</li> <li>• Wales</li> <li>• Scotland</li> <li>• Northern Ireland</li> </ul>	Age of father <ul style="list-style-type: none"> <li>• 19-29</li> <li>• 30-39</li> <li>• 40+</li> </ul>
Age of child(ren) <ul style="list-style-type: none"> <li>• 1-3</li> <li>• 4-7</li> <li>• 8-11</li> </ul>	Age of child when diagnosis made <ul style="list-style-type: none"> <li>• prior to birth</li> <li>• soon after birth</li> <li>• after first year</li> </ul>
Diagnosis of child(ren) <ul style="list-style-type: none"> <li>• specific diagnosis e.g. Down's syndrome</li> <li>• non-specific diagnosis</li> <li>• complex disability</li> <li>• autism</li> </ul>	
Family unit <ul style="list-style-type: none"> <li>• non-disabled child(ren) in the family</li> <li>• more than one disabled child</li> <li>• father separated from mother</li> </ul>	
Contact with support services <ul style="list-style-type: none"> <li>• well informed/part of support group</li> <li>• not receiving support</li> </ul>	

## **Location of the study**

The research will take place across the UK, so sites in England, Scotland, Wales and Northern Ireland will be identified. These regions will cover a mix of inner city, urban and rural sites, which should cover the selection criteria of regional location and type of area.

## **Sample matrix**

A matrix will be used to identify the criteria that each participant has met; this will be regularly reviewed as the recruitment of further participants takes place. A record will also be kept of fathers as they are recruited.

## **Selecting fathers to be interviewed**

In order to maximise the variety of the fathers who are interviewed, it will be necessary to carry out some kind of screening process. It may be necessary to complete a very brief screening questionnaire with potential participants to ensure that the selection criteria are being covered.



## APPENDIX 3: INTERVIEW GUIDELINES

*Note: prompts are shown in italics*

### Section 1: Ways in which fathers contribute to family life

First, we would like to find out about the things you do for your family - such as caring for children, helping out around the house, being a breadwinner.

*How would you describe the responsibilities you have within your family?*

*What are the main things you do with, or for, your disabled child(ren)?*

*What are the other main things you do ?*

- for other children?

- for partner/the family as a whole?

*Do you think having a child with a learning disability has affected your involvement at home?*

- involvement compared with other children?

*In what ways do you think your roles differ from that of your partner/wife?*

*How do you share responsibilities/work out who does what?*

*In what ways do you think your additional family responsibilities have affected your relationship with your partner?*

*Are there other roles/ responsibilities you would like to have but are not able to ..... why are they difficult? (e.g. health, financial)*

### Section 2: Sources of support for fathers

The next area we want to look at is the sorts of things you might need help with as a father and where you look for this kind of support

What kind of support have you had as a father - who from, what do they help you with (and how useful is it)?

Checklist:

- partner
- extended family
- friends
- other fathers/parents of children with/without a disability
- support organisations (e.g. CaF, Mencap, SureStart)
- GP/other health workers
- work
- school/pre-school groups
- faith-based community
- local community.

*Have you been part of any support group for fathers?  
If yes, in what ways was that helpful or not helpful to you?  
If no, do you think you would have liked contact with other fathers?*

*Where do you look for information that you might need?*

*Have you had any support with thinking about your own health?  
Do people working in services ask how you are?*

*When do you look for support outside the family?*

*Have you always found the support you need?  
What other support do you feel you need?*

### **Section 3: Fathers' experiences of support services for their child**

We would also like to find out about your experience of services from the time of diagnosis to the present such as: how you feel they have included you in discussions and decision making about [your child] and what support they have given you as a father involved in providing care and support to [your child].

*What have been your experiences of being involved/supported by services:*

- At time of receiving [your child]'s diagnosis?
- Have the services/practitioners felt welcoming to you as a father?
- Have you felt included in discussions and decision-making about the support your child receives? Different from wife?
- Have meetings been arranged at times that are convenient to you? If not, what would have been helpful?
- Have you been asked about your support needs as a father or have you been offered any father-specific support by services (e.g. meeting other fathers)?

*What do you think have been the barriers, if any, to you getting support from practitioners/services for your role as a parent/father?*

*Do you think these barriers have affected the support that your child has received?*

*What do you think services, such as early years support or playgroups or schools, could do to improve the involvement of fathers in the way they support your child?*

*What service has been most helpful to you in your role as a father/parent?*

## Section 4: Work

We are keen to look at the impact of having a child with a learning disability on your work arrangements and on earning capacity.

*How do you think having a disabled child has affected the work you do (or your ability to remain in paid employment)?*

*Is your employer aware of your situation?*

*In what ways, if any, does your employer support you?*

*Do you know about legislation to allow flexible working/parental leave/emergency family leave (and have you made use of any of the options)?*

*Are there ways in which you think your work could be more supportive?*

## Section 5: Overall

To finish with there are a few general questions:

*Is there any one thing that you think would have been particularly helpful to you in your role as a father/parent?*

*How do you like to access 'support', e.g. face-to-face contact/phone lines/printed materials/web based?*

*How would you sum up the experience of being [child]'s father?*

*What difference has it made to your life?*

*Do you think that your experiences are typical of fathers with a disabled child?*

## Section 6: Interview questions

Because we are still learning about what is important to fathers, there are a few questions about the interview itself so that we get some feedback.

*Did you feel comfortable with the questions asked?*

*Do you think the questions covered the areas you were interested in talking about that were important to you?*

*Do you think there are areas that are missing?*

## APPENDIX 4: FATHERS TAKING PART IN THE STUDY

	Family unit	Employment status	Regional location	Type of area
1	Wife, 2 daughters aged 10 and 2	Self-employed, skilled crafts man	South East	Urban
2	Wife, triplets aged 9. Two with autism	Self-employed, franchise	South East	Urban
3	About to separate from his wife. 1 child	Insurance broker	South East	Suburban
4	Wife, 2 daughters aged 9 and 7, son aged 4	Scientific adviser to a national company	North East	Urban
5	Wife and 12 children	Stock controller (works shifts)	Midlands	Urban
6	Wife, son aged 5 and daughter aged 10	Voluntary sector manager	North East	Suburban
7	Wife, son aged 8 and daughters aged 6, 5 and 3	Full-time dad and carer (wife unwell)	Midlands	Urban
8	Wife, 2 daughters aged 8 and 9	Machine operator setter (works shifts)	Midlands	Urban
9	Wife, son aged 8 and daughter aged 4	Public sector officer	South East	Urban
10	Wife, 2 sons(twins)	Unemployed due to ill-health	Wales	Rural
11	Wife and son. Grown up children from previous marriage	Machine setter	Wales	Rural
12	Wife, daughter and son aged 7	Engineer for local council	Wales	Rural
13	Single dad, son aged 7	Clerical worker (part-time)	Wales	Rural
14	Wife, daughter 6, son 2 and newborn baby	Telephone engineer	North East	Rural
15	Wife,son	Distribution worker	North East	Urban
16	Wife, daughter aged 2 and son aged 3	Part-time student and part-time employment	London	Inner city
17	Wife, sons aged 16, 9, 2 and daughter aged 10	Retired	London	Inner city
18	Wife, daughters aged 20,12, 7 sons aged 14, 9, 6	Retired	London	Inner city
19	Wife, 2 sons	Flexible work patterns	London	urban
20	Wife, son aged 2	Police officer (flexible work pattern)	South West	Suburban
21	Wife, twins (boy and girl) aged 1	Insurance clerk	South West	Suburban

Ethnic origin of father	Age of father	Disabled child(ren)			
		Age	Gender	Diagnosis	Age at diagnosis
White British	34	2	F	Complex disability	Prior to birth
White British	40+	9, 9	F, M	Autism	After first year
White British	47	8	F	Complex disability (autism, blindness, epilepsy)	Soon after birth
White British	43	4	M	Son with Down's syndrome and ASD	Prior to birth
White British	44	5	M	Autism	Around 2 years
White British	40	10	F	Complex disability, rare chromosome disorder	At time of birth
White British	39	6, 5, 3	F, F, F	Global developmental delay	Around 6 months
White British	38	9	F	Down's syndrome	At time of birth
White British	45	8	M	Autism and epilepsy	Around age of 2
White British	47	5, 5	M, M	Down's syndrome	Pre birth
White British	47	9	M	Rare chromosome disorder	At birth
White British	49	7	M	Down's syndrome	At birth
White British	43	7	M	Autism	Around 3 years
White British	34	2	M	Rare chromosome disorder	Soon after birth
White British	49	9	M	Rare chromosome disorder and autism	Soon after birth (autism at 9 yrs)
Black African	47	3	M	Autism	Around 2.5 years
Bengali	70+	9	M	Global developmental delay	During infant school
Bengali	63	9	M	Non specific	During primary school
White British	40+	3	M	Down's syndrome	Soon after birth
White British	30-35	2	M	Non specific	Soon after birth
White British	35-40	1, 1	F	Down's syndrome	At birth

## APPENDIX 5: USEFUL RESOURCES

### **Carers UK: Action for Carers and Employment project**

Provides information for employers and carers in order to support carers who wish to work.

Tel: 020 7490 8818  
Email: [info@carersuk.org](mailto:info@carersuk.org)  
Website: [www.carersuk.org](http://www.carersuk.org)

### **Contact a Family**

Provides advice, information and support to parents of all disabled children. Developed work on fathers including a 'Dads' zone' on the website, a Fathers' factsheet and father specific activities in regional areas.

Tel: 020 7608 8700  
Helpline: 0808 808 3555 or Text phone: 0808 808 3556  
Free phone for parents and families (10am-4pm Mon-Fri)  
Email: [info@cafamily.org.uk](mailto:info@cafamily.org.uk)  
Website: [www.cafamily.org.uk](http://www.cafamily.org.uk)

### **Early Support**

Early Support aims to improve services for young disabled children and their families in England. Produced training materials for parents and professionals.

Tel: 020 7296 8238 or 020 7296 8307  
Website: [www.earlysupport.org.uk](http://www.earlysupport.org.uk)

### **Fathers Direct**

National information centre on fatherhood. Disseminates information about developments in 'father friendly' policy and practice and events, provides training and developed standards for 'father-friendly' practice (the 'Fatherhood Quality Mark').

Tel: 0845 634 1328  
Email: [mail@fathersdirect.com](mailto:mail@fathersdirect.com)  
Website: [www.fathersdirect.com](http://www.fathersdirect.com)

### **Foundation for People with Learning Disabilities**

First Impressions Project produced information on the emotional and support needs of families during the early years from diagnosis to five years of age. Reports available from website.

Tel: 020 7803 1100  
Email: [fpld@fpld.org.uk](mailto:fpld@fpld.org.uk)  
Website: [www.learningdisabilities.org.uk](http://www.learningdisabilities.org.uk)

**National Autistic Society**

Black and Minority Ethnic (BME) Communities Project provides information about the needs of families belonging to minority communities. Produced a booklet, 'Invisible Families', which is available on website.

Tel: 020 7833 2299  
 Email: nas@nas.org.uk  
 Website: www.nas.org.uk

**National Deaf Children's Society**

Produced a report 'Has anyone thought to include me?' about fathers' perceptions of having a deaf child and the services that support them, available on the website.

Tel: 020 7490 8656  
 Email: ndcs@ndcs.org.uk  
 Website: www.ndcs.org.uk

**National Family and Parenting Institute**

Charity concerned with parenting and families in the 21st century including understanding the role of fathers within families. Produced reports relating to policy and practice.

Tel: 020 7424 3460  
 Email: info@nfpi.org  
 Website: www.nfpi.org.uk

**Pre-school Learning Alliance**

Educational charity specialising in the early years. Carried out research about involving fathers in generic early years settings. Reports available on website.

Tel: 020 7697 2500  
 Email: info@pre-school.org.uk  
 Website: www.pre-school.org.uk

**Partners in Policymaking**

Provides leadership training programmes for parents of children and adults with learning disabilities and self advocates.

Tel: 01254 235913  
 Email: lynne.elwell@yahoo.com

**Working Families**

Supports families to achieve a work-life balance. 'Waving not Drowning' is a specific project for parents of disabled children trying to balance work and care, which provides information, advice and a newsletter.

Tel: 020 7253 7243  
 Email: office@workingfamilies.org.uk  
 Website: www.workingfamilies.org.uk

