

# Recognising Fathers

A national survey of fathers who have children with learning disabilities



# RECOGNISING FATHERS

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**Christine Towers**

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## THE WORDS OF A FATHER

*All of the subjects raised in this questionnaire changed me beyond recognition, having a child that's 'different' sets you apart from other men. It makes you withdraw into yourself and shut out parts of your life to other people. I did not want this role for myself and grew up in a society that was removed from disability and the 'different'. I was so unprepared for the moment (at birth) when I was told my daughter had suffered brain damage. I was shocked, horrified, repulsed and saddened to my core. I was given the cold facts and left to cope with it.*

*Looking back, I know now that I was just about functioning for the first three years of my daughter's life. I had suffered a huge blow (along with my wife) and we spiralled into a very deep depression. All of our friends were pushed away and our families began to distance themselves as we increasingly struggled to cope. My wife had little support and struggled on alone, on many occasions she had to stage dramatic actions to gain the necessary help from various experts. I continued to go to work, it was the only stable thing in my life. But the work I did was low paid and demanded a lot from me. I kept my home life private from my friends and colleagues, unable to join in with the conversations about their kids. I was angry, sad and resentful of their "normal" children they so readily bragged about.*

*I needed someone to talk to but there was nobody. I was never encouraged to attend Makaton, portage, baby clinics or any other health visits, back then (1994) it was very much a female (mum) based society. I hope it's changed. I struggled on at work and home for three years, pretending to everyone, including myself, that we were coping. Finally I went to my GP on a routine visit. I ended up bursting into tears and admitting I couldn't cope. He signed me off work with depression. I refused medication. I was so ashamed. Depression carried such a stigma. First I'd got a disabled child and now I was admitting to my friends, family and work colleagues that I was depressed and somehow mentally weak. This was how I saw it at the time. Male pride is the biggest barrier men face. I thought I'd lost all my dignity.*

*It's only ten years ago, but people's attitudes (including my own) have changed towards disability and depression - thankfully. During my time off work I ...went to London for an assessment with my daughter. This did ...get me accustomed to speaking to people about my daughter's disability. I have always wanted to tell someone about what it is like to be the father of a child with learning difficulties, as I feel fathers are the forgotten people in society. Now I speak to other fathers in a similar situation whenever I can. I have a lot to learn and lot to give. The toughest years, I believe, are behind me. I have been through the shock, the grieving, the letting go and finally the accepting. I've been through my daughter's puberty and teenage years; never again! And I have regained my dignity and pride and made new friends. I have changed for the better and would love to share my experiences and help other fathers in similar situations. Please find my questionnaire of some use and don't hesitate to contact me further. This is the most honest and frank I have ever been about my feelings on this subject and I thank you for the opportunity.*

The comments of a father of a 13 year old daughter with cerebral palsy and learning disabilities in response to an open question when completing the Recognising Fathers questionnaire.

## ACKNOWLEDGEMENTS

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## FOREWORD

Over the last 30 years there has been a huge shift in gender roles – and as mothers have become more present and comfortable in the paid workforce, attention has turned to fathers' increasing involvement at home. Alongside these developments, psychologists, social psychologists and others have explored fathers' influence in families – and are now pointing to the substantial benefits to children (and their mothers) of positive, involved fatherhood.

Public policy is following suit. Government is putting increasing pressure on health, education and other family service providers to “think fathers” in all their approaches to children and families; and services are responding positively, increasingly keen to address the men who were described in 1975 by the great fatherhood researcher, Michael Lamb, as “the forgotten contributors to child development”.

For almost 10 years now, the Fatherhood Institute has been drawing policy makers' attention to lessons from the research; training service providers to engage more effectively with dads, and highlighting the needs of specific groups of fathers. But in all this we were aware of a serious gap: we could see nothing substantial charting the experiences and roles of fathers in families caring for children with disabilities, let alone research that could help us develop in-depth understanding of the factors that support these fathers to be engaged in their children's lives – or that lead to disengagement.

Into that gap leapt, in 2007, Towers and Swift with their first outstanding, and deeply moving, report ‘Recognising Fathers: understanding the issues faced by fathers of children with a learning disability’. At a stroke, this put such fathers onto the agenda. Many of the men, as one might expect, described experiences of shock and a sense of inadequacy; others had managed to find ways (usually with little support) to feel valued and confident in their role. Almost every father, whether living with his child or not, experienced a passionate connection with them and longed to do his best by them. Making public the private lives of these fathers was, in itself, a huge contribution.

This second report, ‘Recognising Fathers: a national survey of fathers who have children with learning disabilities’, goes further. It provides statistical data that validates the previous findings that fathers play a key role and that their needs should be considered and responded to. The report also develops the discussion about these fathers as carers. They show how valuable a resource their care is for their partners and children, that many want to provide more of it, and that this would be enormously beneficial. They identify the barriers these fathers face (some of them internal, many more from employers and social care services) in fulfilling their aspirations; and describe the policy and practice changes that are needed if their contributions in terms of providing both “cash and care” to their families are to be optimised.

It is our sincere hope that this wonderful research will, first, inform national and local policies (for example, the Carers Strategy); second, inform the development of services that will be inclusive towards fathers of children with disabilities; and, third, help create a future in which such fathers are more confident, acknowledged and supported in their nurturing and caring roles, with the ultimate aim of improving the outcomes for children with disabilities, and their families.

Adrienne Burgess  
Research Manager  
THE FATHERHOOD INSTITUTE

## EXECUTIVE SUMMARY

### Introduction

The 'Recognising Fathers' research began in 2005 in response to hearing from mothers and fathers that fathers often felt marginalised in the process of arranging care and support for their children with learning disabilities. At the same time it was apparent that national family policy was indicating a growing recognition of the important contribution fathers make to family life and that strategies need to be developed to support them in this.

The research began with a qualitative study, to better understand the experiences of fathers, which involved a literature review, discussions with organisations and services providing support to families, and in-depth interviews with fathers. This research highlighted significant, yet largely hidden, issues that need to be considered when looking at support for families that include children with learning disabilities.

A national survey was carried out in 2008 to:

- test out and validate the findings from the previous qualitative study
- explore further some of the findings from the previous study: for example, the impact on fathers' paid employment
- capture the experiences of a broader group of fathers than participated in the interviews and to include non resident fathers, stepfathers, foster and adoptive fathers.

The survey was open to fathers in the UK who had one child, or more, with a learning disability aged up to 19 years. Publicity was distributed widely on websites and forums as well as through local and national organisations. Considerable effort was made to recruit fathers from a wide variety of social, economic, ethnic, cultural and geographical backgrounds. A total of 251 fathers who met the criteria completed the survey.

### Key findings

#### Involvement of fathers

- Fathers in the survey had a strong sense of involvement in providing care and support for their child and also in supporting their partner: for those who were in employment, their main involvement was in the evenings and at weekends but some were rearranging their working hours in order to be more involved in care arrangements.
- Almost half felt they would like to be able to spend more time with their child with learning disabilities and the main factor preventing this was the time they spent at work.
- 60% of fathers in the survey felt they made more effort to spend time with their child because of their disabilities.
- Fathers said their main motivation for spending time with their child was that they enjoyed their company. They also felt that their involvement had a positive impact on their child's life and that it was important to take their share of the additional responsibilities.

## Impact on relationships with family and friends

- Having a child with a learning disability can place additional pressures on relationships: these can be exacerbated by the fact that partners have little time to spend together as a couple.
- Almost half of the fathers who also had non-disabled children felt they had not been able to give them enough support: this was described as leading to feelings of pressure, guilt and inadequacy.
- Over half of fathers felt that members of their extended family had found it hard to accept their child with disabilities.
- For a few fathers, having a child with learning disabilities had had a negative impact on their relationships with their partner, their extended family and friends. This is likely to affect a father's ability to cope and family support services may need to find appropriate support.

## Support from family and friends

- Fathers see their partners as an important source of support with over 75% seeing them as their main source of support.
- Over 50% of fathers felt they did not receive emotional or practical support from their extended families.
- Almost 40% of fathers did not have a good friend they could talk to about their situation.
- Over 50% of fathers felt they would like more support from their relatives or friends.
- Services have a role to play in providing fathers with more opportunities to meet other fathers and families.
- The personalisation agenda provides opportunities to develop families' natural support networks and involve relatives and friends in providing care and support.

## Contact with services

- Services appear to be making progress in developing more opportunities for fathers to attend and participate in meetings about their child and fathers welcome this. However, arrangements for some meetings are preventing fathers from being as involved as they would like to be.
- There are limited opportunities for fathers to have informal contact with practitioners supporting their child: informal contact leads fathers to feel included and can give them confidence and skills in providing care and support.
- Fathers experience a lack of support and poor involvement at the time of diagnosis: this involvement right from the start may help to form longer term bonds and commitment to their child.
- Fathers emphasised the importance of being recognised and respected by practitioners for what they contribute and being included in discussions and decision-making.

## Impact on health

- Fathers are experiencing high levels of stress, with 41% saying they experienced stress most of the time and an additional 52% saying they sometimes experienced stress.
- Their child's future was a major cause of concern: enabling fathers to have a proactive involvement in planning for their child's future may help to alleviate this stress and be beneficial to the long-term outcomes for children.
- Half of the fathers felt their physical health had been affected: there was a strong interplay between stress, mental ill-health and physical ill-health.
- Fathers were receiving very little help with looking after their health, whilst almost half said they needed more help to look after their health, especially those on lower incomes.
- A number of suggestions were made by fathers to improve their health, including having a break from caring and being given regular health checks.
- The Carers Strategy (DH, 2008) provides an opportunity to ensure fathers' health needs are responded to.

## Impact on paid employment

- Fathers are making significant changes to their work because of the needs of their children with learning disabilities: some are making a variety of changes during their working life.
- The need to have flexibility at work in order to be involved in their child's care often results in a loss of career opportunities and income.
- This loss of income can leave families struggling financially: it can also have a cumulative effect over fathers' working lives and into retirement.
- Fathers need to receive information and advice from employers and advisory services in order to make employment decisions that enable them to stay in employment or move on in their career in order to maximise their income and achieve the balance they want and need between paid work and providing care and support to their child.
- Financial support for families with children with disabilities needs to compensate them for their loss of income as a result of providing care.

## Support with paid employment

- Most fathers felt that they can be at least fairly open with their employer about their caring responsibilities. However, a number felt they could not discuss this with their employer.
- Half of the respondents had either a regular or occasional arrangement to give them additional flexibility but a third had never had such an arrangement.



- Over half of the fathers were not aware that they were entitled to request flexible working: only 37 of the fathers completing the survey had used it to gain flexible working arrangements.
- 75% of fathers were not aware that they were entitled to unpaid parental leave: only 14 fathers had taken advantage of this entitlement.
- Employers, employment advisory agencies and family support services need to have a greater role in providing information and guidance on employment or signposting fathers to it. The implementation of the employment strands within the Carers Strategy needs to promote support for fathers who are combining paid work with involvement in the care of their child with disabilities.

## Recommendations

The following recommendations aim to achieve:

- the involvement and inclusion of fathers in discussions and decisions about all aspects of their child's life in order to improve outcomes for children with disabilities, for their siblings, and for both parents
- improved information, advice and support to fathers so that they can combine employment with active involvement in providing care and support to their child with learning disabilities
- improved support to fathers to maintain their own health and well-being
- improved support to families through including fathers.

In all the recommendations it needs to be ensured that the additional support proposed for fathers reaches, in particular, those who are more disadvantaged in terms of their financial, social and information resources. It also needs to be recognised that, in some cases, the father may live separately from the mother and their child: in this situation, every effort must be made to enable both parents to have a valued and continuing role in supporting their child.

Although these recommendations are specific to policies and programmes in England, they should be considered and adapted as necessary to suit the circumstances in Scotland, Wales and Northern Ireland.

### 1. Health

1.1 We recommend that an alert is made from child health services to the GP practices of both parents, with their consent, following the birth or diagnosis of a child with learning disabilities, with the purpose of ensuring that GPs and other health practitioners are aware of parents' caring responsibilities.

#### **Action to be taken by Children's Trusts**

1.2 The Carers Strategy identifies the need for GPs to have a better understanding of carers' needs and that GP training programmes should be piloted in order to achieve this. This training needs to encourage GPs to recognise fathers as carers, even when the father's partner is the main carer, and to understand the health needs of fathers and approaches that work for them. Fathers identified approaches that would improve their health and well-being and these should be routinely available to fathers with an assessed need:

- learning stress management skills
- referrals to talking therapies
- gym referrals on prescription
- screening for high blood pressure
- help with leading a healthy lifestyle (diet, alcohol consumption, exercise)
- help with sleep problems.

#### **Action to be taken by the Carers Strategy implementation team**

1.3 The Carers Strategy also identifies the need for carers to receive annual health checks. The evidence from this research suggests that both mothers and fathers should receive these health checks, which should cover mental, as well as physical, health and that these should not be dependent on the father being identified as the main carer. Fathers are likely to need encouragement to prioritise the time to do this and GP practices may need incentives to ensure the necessary time is allocated to ensure uptake is high amongst fathers.

**Action to be taken by the Carers Strategy implementation team through the health checks demonstrator sites**

1.4 Fathers who take on caring roles for their children with disabilities should be provided with skills and knowledge in maintaining their health and well-being. PCTs should pilot the use of peer group training to enable fathers to support other fathers to look after their health.

**Action to be taken by DH through the implementation plans for the Carers' Strategy**

## 2. Employment

2.1 The Carers Strategy makes a number of proposals to provide better support to carers to move into and maintain their employment as well as to develop their careers: the implementation of these proposals needs to ensure that Jobcentre Plus, human resource departments and employers in SMEs (Small and Medium Enterprises) recognise fathers of children with disabilities as carers with specific needs around combining employment and caring responsibilities.

**Action to be taken by the Carers Strategy implementation team, human resource departments and employers in SMEs**

2.2 Fathers, as well as mothers, should be informed of their own rights to a carer's assessment. This assessment should have regard to their wishes in relation to: access to education or training; entering, retaining or re-entering paid employment, and access to any benefits or tax credits that might assist with the additional costs of having a child with disabilities.

**Action to be taken by DCSF, adult social care (fathers or mothers may be themselves disabled or requiring additional support in their parenting role), DWP and child health services through Children's Trusts**

2.3 The Government's 'Health at Work' agenda across the DH, DWP and the Health and Safety Executive, which aims to improve the health of people of working age, should specifically consider the needs of fathers who have children with additional needs. Good practice in occupational health support for these fathers needs to be disseminated so that employers, human resource managers, unions, other employees and health care professionals respond appropriately.

**Action to be taken by DH, DWP and HSE**

2.4 The use of paternity leave, parental leave and flexible working should be audited to gather information about the use of these regulations by mothers and fathers of children with disabilities. The data gathered should be used to identify how appropriate uptake could be increased, including any improvements to the regulations to make them more effective for families with disabled children.

**Action to be taken by DWP**

2.5 A guidance leaflet for employers should be produced on the implications of the Coleman judgement<sup>1</sup>, with particular relevance for enforcing fathers' rights in light of the 'Recognising Fathers' research.

**Action to be taken by DWP**

<sup>1</sup> Judgement of the Court of Justice in Case C- 303/06, July 2008.

### 3. Informing and involving fathers

3.1 Good practice in relation to involving and supporting fathers should be collated and the results disseminated to Children's Trusts to develop the knowledge and skills of practitioners in working with fathers. This knowledge should also be used by DCSF to inform future policy related to children with disabilities.

**Action to be taken by DCSF**

3.2 Practitioners in education, health and social care should be provided with good practice guidance about arranging meetings, appointments, reviews and home visits in such a way as to maximise the opportunities for both parents to be involved. Fathers as well as mothers need good information to understand fully the treatments or therapies arranged for their child. Appendix 3 contains good practice guidelines to involve fathers in reviews and appointments for their children.

**Action to be taken by DCSF**

3.3 Practitioners in education, health and social care should be provided with good practice guidance to involve fathers in meetings that are concerned with planning for their child's future, such as person centred planning and transition planning. Fathers should be offered appropriate training and support to be actively involved.

**Action to be taken by DCSF and adult social care services**

3.4 The development work to establish the Parents' Forums that are being set up through 'Aiming High for Disabled Children' should seek to ensure that fathers, as well as mothers, are actively involved.

**Action to be taken by the DCSF through the Aiming High for Disabled Children programme**

3.5 Children's Trusts should identify indicators by which the work of practitioners in education, health and social care can be audited in relation to involving and supporting fathers to ensure improvements are made and sustained.

**Action to be taken by Children's Trusts**

### 4. Family support

4.1 Carers' assessments, as referred to above, should be offered and carried out separately for fathers and mothers, to identify their needs for support: to help maintain emotional and physical well-being; caring for their other children without disabilities and for having a life outside of caring.

**Action to be taken by DCSF, adult social care, DWP and child health services through Children's Trusts**

4.2 Assessments and planning around the needs of a child with a learning disability should take account holistically of the wishes, feelings and capabilities of both the father and mother and any other involved relatives such as siblings or grandparents. The delivery of personalised support and individual budgets should be used to work for all the family and improve their life chances.

**Action to be taken by Children's Trusts**

4.3 The Children's Plan identified the need to 'introduce new ways to support parents at times when their relationships come under strain': the support needs of parents with disabled children should be given specific consideration due to the higher levels of relationship breakdown in the first eight years after a child with disabilities is born. A good practice review should be carried out and guidance provided to practitioners in universal and specialist services.

**Action to be taken by DCSF**

4.4 'Aiming High for Disabled Children' and the Children's Plan identify the need to expand the provision of short breaks for children with disabilities and their families. Development work on short breaks should include discussions with fathers as well as mothers about the kind of short breaks that would be most effective for them as a family or as sole carers. This should be used to inform commissioning strategies on short breaks.

***Action to be taken by the DCSF, through Local Authorities and other delivery partners involved with the Aiming High for Disabled Children programme***

4.5 Models of family support should be developed that include attention to the support networks of fathers, including providing opportunities for fathers to link with one another. Commissioning strategies should reflect the fact that fathers particularly identified that they would like more opportunities to participate in events and activities that were for fathers with their children.

***Action to be taken by DCSF***

4.6 'Aiming High for Disabled Children' and the Carers Strategy emphasise the role of parents and family carers as partners in care and as experts. Fathers should have opportunities to participate in programmes that use their expertise to support other fathers or to train professionals in involving and supporting fathers.

***Action to be taken by DCSF and the Carers Strategy implementation team***

## 1. INTRODUCTION

### Background to 'Recognising Fathers'

In 2004 the Foundation for People with Learning Disabilities (the Foundation) carried out a project, 'First Impressions', to assess the needs of families during the first five years of life after a baby or young child was diagnosed with a learning disability. The findings from the project suggested that the fathers of these children 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 study 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."*

'Recognising Fathers' was originally commissioned in 2005 to explore the issues identified in 'First Impressions' and other studies (Hornby, 1992; West, 2000).

The project should also be viewed in the context of the growing recognition in national family policy of the important contribution that fathers generally make to family life and that strategies need to be developed to promote their involvement in family services. 'The Children's Plan: Building Brighter Futures' (DCSF, 2007) stressed the *'need for public services to engage with both father and mother except where there is a clear risk to the child to do so'*. It also acknowledged that parents should be involved in all policy affecting their children and *'that we need to improve how Government and services involve all family members, including fathers.'*

In addition there is a growing body of research that has looked at the influences of fathers generally on their child's development (Fatherhood Institute, 2008). A systematic review of studies (Pleck and Masciadrelli, 2004, cited in Fatherhood Institute, 2008) found that 'positive' father involvement was associated with a range of desirable outcomes for children and young people. These positive outcomes included better peer relationships, fewer behaviour problems, lower criminality and substance misuse, increased capacity for empathy and higher self esteem and life-satisfaction. On the other hand, absent fatherhood has been shown to negatively affect children directly by contributing to their difficulties with peer relationships, including bullying (Parke et al. 2004; Berdondini and Smith, 1996, cited in Fatherhood Institute, 2008). It has also been shown to negatively affect children indirectly through increased maternal stress and reduced income (McLanahan, 1997; McLanahan and Teitler, 1999, cited in Fatherhood Institute, 2008).

### Families with disabled children

The experiences of fathers whose children have learning disabilities are shaped by the changing nature of families with children with disabilities and of the services that provide support. Most disabled children live at home with their families throughout their childhood years (estimates vary between 85% to 98%) with parents being the main providers of care. An increasing number of children with more severe disabilities are surviving and being supported at home within their families (Chesney and Champion, 2008). Some families are receiving co-ordinated and innovative service delivery but this is not the case for others: levels and standards of support are variable, depending on the Local Authority in which they live. It is acknowledged that those most in need are not always the ones who receive support (HM Treasury and DFES, 2007).

Research has shown a complex inter-relationship between poverty and childhood disability: household finances are likely to be reduced as a result of having a child with disabilities as well as the risk of disability being increased by the financial circumstances of a family (Emerson and Hatton, 2005). There have been many studies that have identified factors faced by families bringing up disabled children, including inadequate housing, poverty and diminished employment opportunities (Joseph Rowntree Foundation, 1999; Emerson and Hatton, 2004).

A recent report published by the Department for Work and Pensions (Clarke and McKay, 2008) indicates that couples who have children with disabilities experience an increased risk of separation particularly during the very early stages of parenting a disabled child. This risk is greatest when the child is between the ages of 0-2, and continues to rise slightly until the age of eight at which time it flattens off. This contributes to the fact that a third of children with disabilities live with a lone parent, overwhelmingly a lone mother, compared with around a quarter of other children.

### **Background to the survey: first stage of the research**

An Advisory Group was set up at the beginning of the work to inform and shape the research. Members included fathers of children with learning disabilities, some of whom also had a professional interest in the area, and there were also representatives from national charities and research institutes. The Group contributed to the first and second stages of the research that are described below.

The 'Recognising Fathers' project began with a qualitative study of the experiences of fathers with children with learning disabilities that was completed in 2006. That study was undertaken in three parts: a review of relevant literature, discussions with organisations and services providing support to families, and in-depth interviews with fathers. The interviews were the main method of data collection and were carried out with 21 fathers who had children with a learning disability aged 11 and under.

The findings from those interviews highlighted the key messages from fathers of children with learning disabilities and identified issues that needed to be addressed within policy and practice. The key messages were that fathers of children with learning disabilities are often very involved in their children's lives and felt a stronger bond with their child because of their disabilities. This was often combined with many struggles and difficulties especially in relation to getting the right support for their children and to combine their employment with caring responsibilities. Fathers' roles help to sustain and strengthen families who have a child with learning disabilities yet this role and the specific support that fathers need to carry it out are rarely recognised by children's and family support services or by employers. Recognition of the support fathers can and, in many cases, do provide to families is an effective way of supporting families and improving the life chances of children with learning disabilities.

The findings from this research were reported under five main themes: the emotional impact of having a child with a disability, the roles and responsibilities of fathers, the impact on paid employment, sources of support for fathers and the interactions fathers have with practitioners.

Recommendations were written for Government departments, children's services and trusts, health services, and the voluntary sector that aimed to ensure that in the development of initiatives (such as the Gender Equality Duty, the Common Assessment Framework and carers' assessments) the needs of fathers were addressed. There were also recommendations for practitioners in health and social care settings, education and family support services, which included good practice guidance for including fathers in discussions, reviews and appointments concerning their children.

The Foundation, along with the project's Advisory Group, felt that the research had highlighted significant, yet largely hidden, issues that needed to be considered when looking at outcomes for families with children with disabilities. In order to get these issues onto the public agenda, and responded to, it was agreed that the findings needed to be verified with a greater number of fathers than had participated in the interviews. This led to funding being sought to carry out a national survey in order to collect data from a larger, and more diverse, sample of fathers.

## Aims and objectives of the survey

The overall aim of the survey was to investigate the experiences of fathers of children with disabilities in order to inform the development of policies and practices that recognised and encouraged the potential contribution of fathers to the well-being of families with children with learning disabilities.

The objectives were to:

- test out and validate the findings from the previous qualitative study;
- explore further some of the findings from the previous study, for example, the impact on fathers' paid employment;
- capture the experiences of a broader group of fathers (for example, to extend the age range to include fathers with disabled children up to the age of 19, to include non resident fathers, stepfathers, foster and adoptive fathers and to have responses from fathers from a wider range of black and minority ethnic communities).

## 2. DESIGNING AND ANALYSING THE SURVEY

### Developing the questionnaire

The findings from the previous study were central in identifying the areas to be explored and the level of importance attributed to potential areas of interest. These were discussed with the Advisory Group before moving on to the next stage to design the questions.

A draft questionnaire was reviewed by members of the Advisory Committee and an adapted version was piloted. Five fathers with a range of experiences completed the pilot questionnaire and were given a prompt sheet to aid their feedback. The questionnaire was amended following verbal and written feedback.

The main topic areas of the questionnaire were:

- fathers' type and level of involvement with their children
- the impact on their relationships with family and friends
- their support from family and friends
- the impact on their health
- fathers' contact with services for their children
- the impact on their employment
- support to balance employment and care responsibilities.

The questions were a combination of multiple choice and closed questions, with a small number of open questions in order to gain a better understanding of fathers' reasoning or motivation for certain actions. The final questionnaire can be viewed at the Foundation for People with Learning Disabilities website: [www.learningdisabilities.org.uk](http://www.learningdisabilities.org.uk)

### Ethical approval

Ethical approval was gained from the University of Plymouth Faculty of Health and Social Work Ethics Committee and from the NHS National Research Ethics Service Joint UCL/UCLH Committees.

Consent to be involved in the study was obtained from participants. The questionnaires were completed anonymously by fathers and, at any point, participants could choose to stop completing the questionnaire.

### Sample

The inclusion criteria for the survey were:

- fathers of one child, or more, with a learning disability aged up to 19 years
- fathers aged 18 or over
- biological fathers, foster or adoptive fathers, step fathers
- fathers living in the UK.

Fathers under the age of 18 were not included, as the provision and complexity of the available support would be different if someone aged 16 or 17 had a child with a learning disability, for example they may receive support through Children and Family Services rather than Adult Social Services. Using the age of 18 meant that we could receive questionnaires from fathers who had had their child under the age of 18 but were older at the time of completing the questionnaire and able to comment on their experience. In practice, we did not receive completed questionnaires from anyone under the age of 25.



In the questionnaire a learning disability was defined as ‘someone with an impaired intellectual and social functioning that starts before the age of 18 and is life long’. The definition included children with autism if they had also been assessed as having a learning disability. However, the returned questionnaires included a number of fathers (28) who described at least one of their children as having Asperger syndrome and a decision was taken to include these fathers in the data. Some of the analysis was carried out without including the fathers of children with Asperger Syndrome to see whether this significantly changed the results and this did not seem to be the case.

It was stated that the questionnaire was not appropriate for fathers who had a child with a specific learning difficulty such as dyslexia. In practice a few fathers completed the questionnaire whose child appeared to solely have a specific learning difficulty and these were removed from the data set.

Although we were mainly reliant on participants’ judgement as to whether their child had a learning disability, as defined above, there were a few questions within the questionnaire that helped to verify this information. A small number of questionnaires were removed where it was not possible to verify this.

### **Recruiting participants**

A combination of approaches was used to recruit fathers to complete the questionnaire. A publicity flyer (see Appendix 2) was produced which explained the research, what fathers’ participation would involve and how the information would be used. It also gave the options for accessing the questionnaire on-line or contacting the Foundation for a paper copy. This publicity sheet was available as a PDF or printed sheet and was sent to a wide variety of organisations that fathers might contact.

Short information articles were placed on websites and in newsletters, magazines and forums. Flyers and questionnaires were taken to conferences and events where professionals or parents were present and might be willing to pass these on to fathers. The researcher spoke to a small number of parents’ groups, especially to generate interest from fathers from black and ethnic minority communities. Information, usually with an electronic link to the website, was sent to national and local organisations and services to place on their websites or distribute to families.

Considerable effort was made to recruit fathers from a wide variety of social, economic, ethnic, cultural and geographical backgrounds. Questionnaire returns were monitored to identify criteria where there was a low rate of return and to identify further places to publicise the research in order to try to overcome this. Particular effort was made to contact fathers who it was thought may be less likely to hear about the survey, for example, fathers from black and ethnic minority communities, single fathers and those not living with their children. This was done by contacting organisations representing these groups and looking at ways to target publicity.

When contacting individuals and organisations and in the publicity sheet, we offered support to complete questionnaires. This was particularly so that fathers for whom English was an additional language or who had language, literacy or learning difficulties would not be prevented from participating. The budget included money for interpreters. Some organisations that had direct contact with fathers offered to provide support to complete the questionnaire and one organisation used an interpreter to explain and complete the questionnaire with a small group of Turkish fathers.

### Accessing the questionnaire

The questionnaire was available for completion in hard copy and on-line. The on-line version (as well as information about the research) was accessed by a link from the Foundation's website. Participants were able to complete their questionnaire over the period of time they needed, as they could use the link to return to their questionnaire where their answers had been saved. Although the majority of fathers completed it in one session, a number used this facility and some commented on how useful that had been.

The paper version was sent out with an information sheet and a pre-paid envelope for returning to the Foundation.

The survey was open from September 2007 until January 2008.

### Analysing the data

Data were entered onto a spreadsheet using SPSS (Miller et al., 2002) and analysed using descriptive statistics and cross tabulations. It was not always possible to say whether findings were significant as the numbers of fathers in some categories were too small.

The qualitative data was analysed using content analysis (Weber, 1990). Each participant was given a code number, which appears next to any quotes from open questions.

### 3. SURVEY PARTICIPANTS

A total of 251 fathers who met the inclusion criteria completed the survey; 173 online and 78 using hard copies. The final number of participants included those fathers whose children had Asperger syndrome mentioned above. The total number of children was 283.

#### Demographic profile of participants

Relationship to child (n=251)	%	Frequency
Biological father	93.6	235
Adoptive father	3.6	9
Foster father	0.8	2
Stepfather	2.0	5

Marital status (n=249)	%	Frequency
Married/with partner	90	226
Separated/divorced	8.4	21
Single	0.4	1
Widowed	0.4	1

Age (n=250)	%	Frequency
18-24	0	0
25-34	12.4	31
35-44	42.4	106
45-54	33.2	83
55-64	10	25
65 and over	5	

Ethnic background (n=251)	%	Frequency
White British	82.1	206
White other	4.4	11
Turkish	0.8	3
Mixed	0.8	3
Asian	3.6	9
Not specified	8.4	19

Location in the UK (n=249)	%	Frequency
Northern Ireland	4.4	11
Scotland	9.6	24
Wales	7.6	19
NE England	11.2	28
NW England	6	15
Midlands	12.4	31
East Anglia	8.8	22
SE England (excluding London)	20.5	51
SW England	6.4	16
London	12.9	32

### **Fathers' employment and that of their partner**

Employment status (n=249)	%	Frequency
Employed full-time	62.3	154
Employed part-time	8.1	20
Self employed	10.5	28
Unemployed	3.2	8
Not working due to health problems	5.7	14
Not working, as main carer for child(ren)	7.7	19
Retired	2.4	6

Employer type (n=200)	%	Frequency
Small private firm	22.5	46
Multi national company	21.6	44
National company	12.7	26
Local authority	12.3	25
Voluntary sector/NGO	9.3	19
Government	8.3	17
Health service	5.9	12
Higher education	2	4
Other	3.4	7

Partner's employment status (n=247)	%	Frequency
Full-time paid work	12.1	30
Part-time paid work	31.6	78
Not in paid work	51.4	127
Not applicable	4.9	12

**Education, occupation and income**

<b>Highest level of education completed</b> (n=249)	<b>%</b>	<b>Frequency</b>
Completed primary school	0.8	2
Completed secondary school	7.6	19
Passes at GCSE or equivalent	13.7	34
Passes at A level or equivalent	8.8	22
Vocational training	15.3	38
Degree or equivalent	33.3	83
Post graduate qualification	16.1	40
Other	4.4	11

<b>Standard occupational classification</b> (n=230)	<b>%</b>	<b>Frequency</b>
Not working	15.7	38
Elementary occupations	5.2	12
Plant and machine operatives	2.2	5
Sales and customer service	10	23
Personal service	15.2	35
Skilled traders	6.5	15
Admin and secretarial	10	23
Associate professional and technical	16.5	38
Professional occupations	3.5	8
Managers and senior officials	14.3	33

<b>Income in £</b> (n=218)	<b>%</b>	<b>Frequency</b>
Under 10,000	13.3	29
10,000 - 19,999	17.9	39
20,000 - 29,999	23.4	51
30,000 - 39,999	19.7	43
40,000 - 49,999	10.1	22
50,000 and over	15.6	34

**Father's children with learning disabilities**

<b>Number of children with learning disabilities</b> (n=251)	<b>%</b>	<b>Frequency</b>
1	87.3	219
2	11.6	29
3	1.2	3

<b>Categorisation of children's learning disabilities</b> (n=283)	<b>%</b>	<b>Frequency</b>
Learning disability	30.4	86
Learning disability and/or additional physical or sensory disability	14.8	42
Multiple disabilities/complex support needs	16.3	46
ASD	28.6	81
Asperger syndrome	9.9	28

<b>Age of children with learning disabilities</b> (n=282)	<b>%</b>	<b>Frequency</b>
0-2	3.9	11
3-5	16.7	47
6-10	33.3	94
11-19	45.6	129

<b>Gender of children</b> (n=283)	<b>%</b>	<b>Frequency</b>
Male	69.3	196
Female	30.7	87

<b>Where children live</b> (n=283)	<b>%</b>	<b>Frequency</b>
At home with father and partner	83.4	236
With their father	3.2	9
With their mother	3.5	10
Shared arrangement between father and mother	2.5	7
With a foster carer	0.7	2
Residential placement	6.7	19
52 week provision	4.5	13
Term time	0.4	1
Weekly	1.4	4
Unknown	0.4	1

It is not possible to say how representative the survey participants are of the general population of fathers who have children with learning disabilities. The fathers predominantly lived with their partner, although a small number of separated, divorced, single and widowed fathers responded. A questionnaire of this nature is more likely to be completed by fathers who are engaged with their child with learning disabilities, although this does not necessarily mean that they need to live in the same household. There were no respondents who were not in touch with their children, although there were a few who did not live with their children or whose relationship had broken down and they were struggling to maintain their contact with their children. There was a low response from fathers from black and ethnic minority communities and no respondents from black African or black Caribbean backgrounds despite substantial efforts to reach these groups.

## 4. RESULTS AND DISCUSSION:

### 4.1 INVOLVEMENT OF FATHERS

#### Introduction

The results and discussion are presented in seven sections that follow the structure of the questionnaire:

- involvement of fathers
- impact on relationships with family and friends
- support from family and friends
- contact with services
- impact on health
- impact on paid employment
- support with paid employment.

At the beginning of each section there is a summary of relevant points from the previous study, 'Recognising Fathers: understanding the issues faced by fathers of children with a learning disability' (Towers and Swift, 2006).

In the text, the use of the term 'fathers' usually refers to fathers of children with learning disabilities unless it is specified that it refers to fathers generally.

#### Involvement of fathers

In the interviews in the previous study, we discovered that most fathers had found that having a child with disabilities had changed, often significantly, the roles and responsibilities they had with their child and the amount of time they spent with them. Some interviewees had changed their work patterns or left work in order to have more involvement with their child. However, most of the fathers remained the main breadwinner and one of the key themes that the interviews explored was the kind of activities fathers got involved in and how this was negotiated with their partner and worked around their employment.

Participants' involvement was explored in more depth in the survey through looking at the

- types of activities that fathers were involved in
- level of involvement they had
- motivation for their involvement.

There were also supplementary questions as to whether they were satisfied with their type and level of involvement and, if they were not, this was explored through open questions to find out why they were not able to have the level of involvement that they would like.

The data collected about involvement of fathers in all these areas of activity is obviously based on their own perceptions: we might well have received a different picture if we had asked their female partners for their views. However, men's perceptions of their involvement and their motivation for being involved are an important part of the picture. Understanding this will, for example, enable practitioners and services to engage better with fathers and value them for what they contribute.

First, we asked fathers to choose the description that was closest to their situation in order to gain an overall picture of each respondent's relationship to their child in terms of providing care. In response 60% of fathers described themselves as sharing the care of their disabled child with their wife or partner, whilst 29% described their wife or partner as the main carer. Nearly 10% described themselves as the main carer and just under 1% as the sole carer. From the interviews in the previous study we were aware that sharing the care does not necessarily imply equal time spent providing care and support, but a shared sense of responsibility.

One of the key factors that will affect the involvement that fathers are able to have is their employment status and that of their partners. Over 80% of participants were employed full-time, part-time or self employed and 19% were not working for a variety of reasons. Just over 50% of respondents' partners were not working and a further 31% were working part-time. There were 26 families where neither the father nor mother were working and three fathers, living without their partner, who were not working. These different patterns of employment within families will influence the involvement fathers need, or are able, to take on.

## Involvement in activities

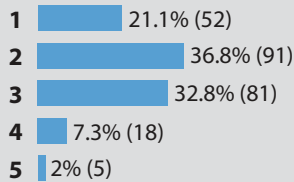
There is general acceptance that fathers in the population at large in the UK are looking for, and sometimes achieving, greater involvement with their children than in previous decades (EOC, 2006). The questions in the survey were designed to find out about fathers' involvement in the sense of direct contact with their children through providing care and sharing activities. Involvement in different activities was broadly grouped into three areas: daily routines, specific care tasks and activities with their child. Fathers were asked to rank their level of responsibility for the activities or to note that their child did not require that kind of support.

### Daily routines

Fathers were asked about their involvement in the morning, evening and bedtime routines.

#### **Which of the following best describes your situation: involvement in daily routines**

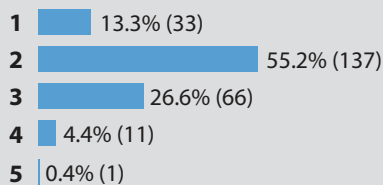
##### Morning routine (e.g. dressing, breakfast) (n=247)



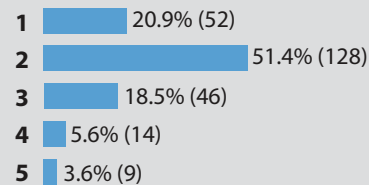
##### KEY

- 1 Main responsibility
- 2 Equal share
- 3 Partner has main responsibility
- 4 Rare or never
- 5 Child doesn't need this support

##### Evening routine (n=248)



##### Bedtime routine (n=249)



The main response, for all these areas of daily routines, was that fathers saw themselves as having a fairly equal share with their partners. However, fathers are indicating greater involvement, either taking the main or shared responsibility, for evening and bedtime routines than for those in the morning. This fits with fathers' descriptions, both in the interviews and in the open questions in the survey, of trying to start work early so that they could get home and participate in evening routines. Involvement in routines before the start of school is generally not compatible with going to work at the usual start times and it may well be less acceptable for men, compared with women, to negotiate later start times. These findings appear to indicate that the main factor for fathers to be involved in daily routines is their availability which is restricted by the fact that they are often at work during key times when childcare tasks take place.



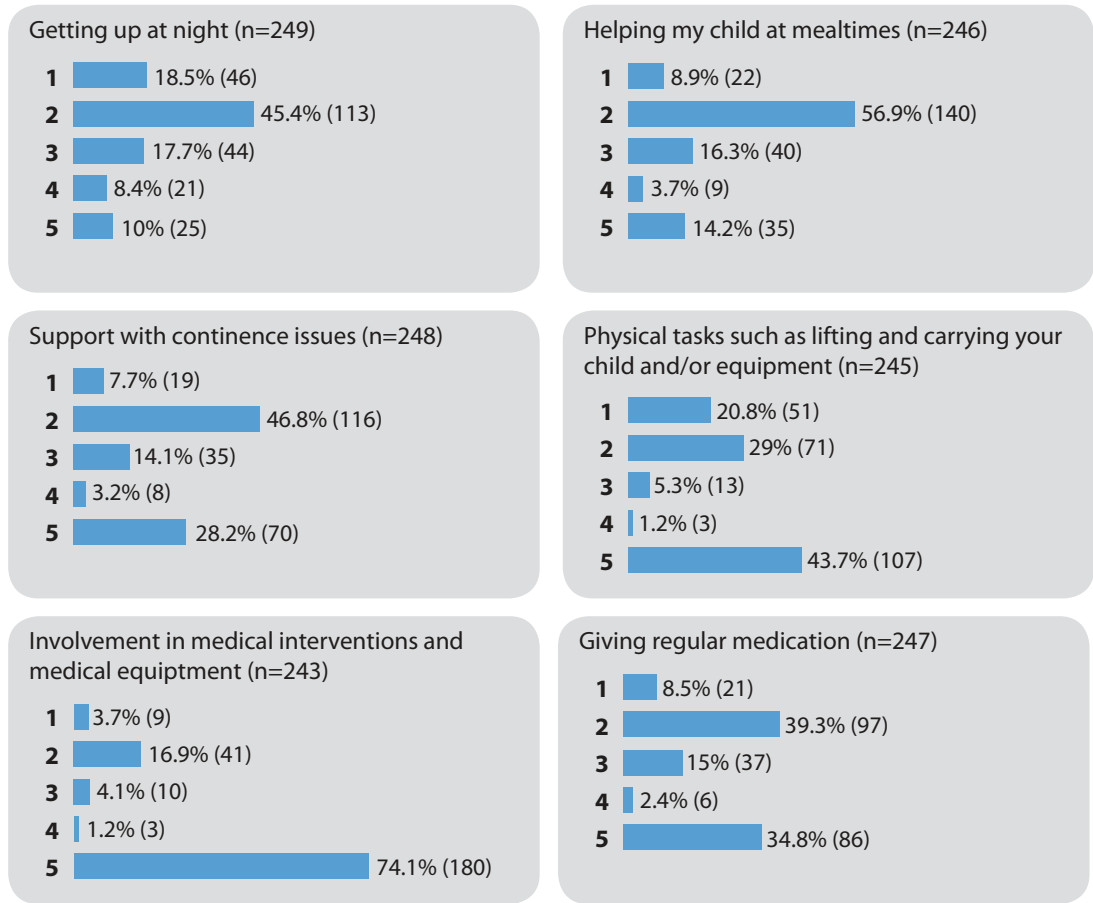
### Specific care tasks

We then asked fathers about their involvement in specific care tasks, such as support with continence issues and physical tasks such as lifting and carrying, to identify whether men were likely to get involved in certain kinds of care tasks.

#### Which of the following best describes your situation: specific care tasks

**KEY**

- 1 Main responsibility
- 2 Equal share
- 3 Partner has main responsibility
- 4 Rare or never
- 5 Child doesn't need this support

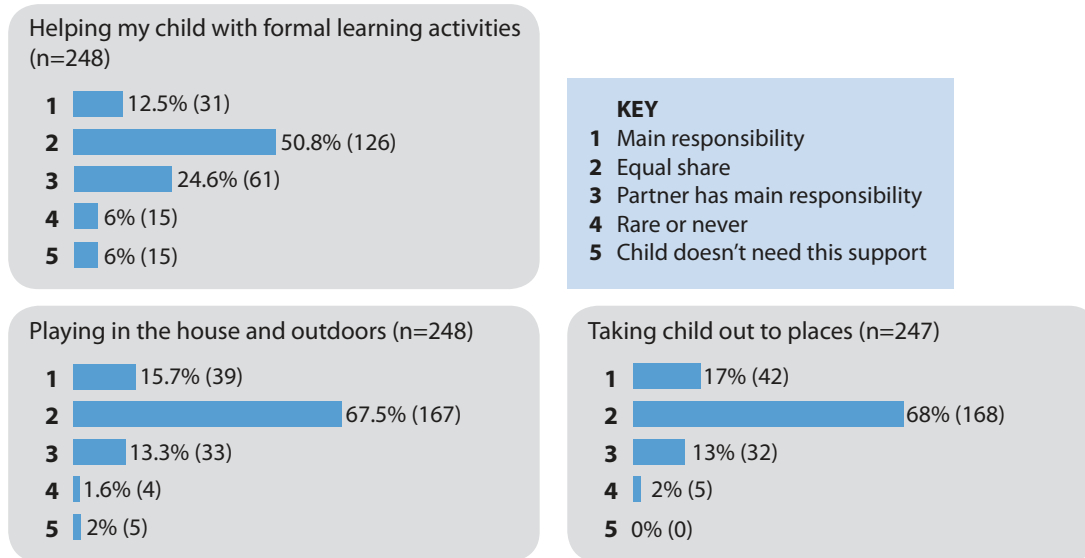


Again, where their child needed the support, fathers were most likely to see these tasks as a shared responsibility.

A significant number of children did not need support with specific care tasks and so further analysis was carried out after excluding the participants whose children did not need the support. This showed the high level of responsibility men had for physical tasks with 37% having the main responsibility and 51% having an equal share. Providing physical care has a detrimental impact on parents' health and this may be one of the factors that is having an impact on men's health and well-being, as identified in section 4.5.

### Activities with your child

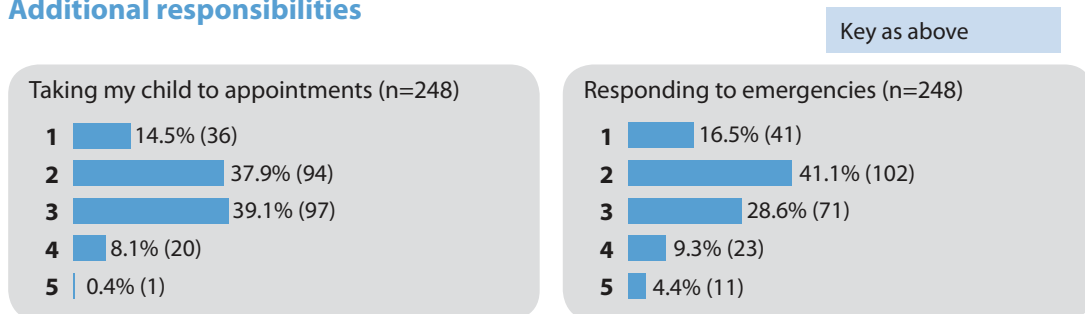
#### Which of the following best describes your situation: activities with your child



These questions looked at specific activities with their child rather than carrying out care tasks. In the interviews fathers had described a high level of commitment to their children's learning, playing and taking them out to places. In the survey the most common response was to share responsibility with their partner. Fathers were indicating only a slightly higher level of responsibility than their partners for playing and for taking their child to places. However, data from later questions indicate that fathers may spend more time at the weekends doing these activities and their partners may have greater responsibility on week days.

In addition fathers were asked about their involvement in attending meetings and appointments for their child and responding to emergencies.

### Additional responsibilities

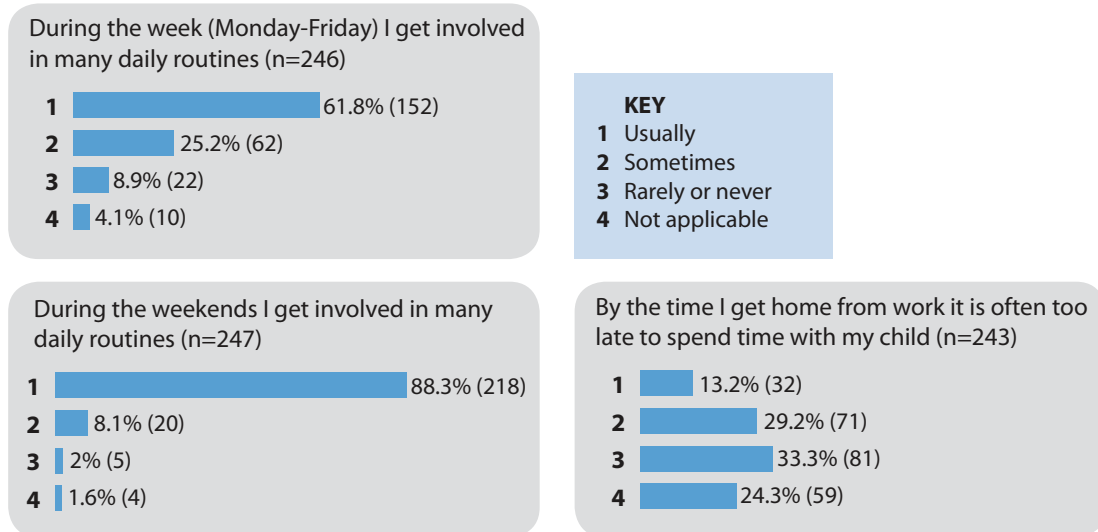


A slightly higher number of fathers saw their partners as having the main responsibility for taking their child to appointments rather than as a shared activity, which implies that even though fathers want to be involved in appointments (Towers and Swift, 2006) their partners are taking a higher level of responsibility for these. This is possibly because appointments occur when fathers are at work

### Level of involvement

In this section of the questionnaire we explored the amount of time that fathers spend with their child with learning disabilities. However, it is difficult to explore fathers' level of involvement in any detail as timings will vary depending on the needs of their children and on the employment status of the father and of their partner. Therefore, the information we gathered provides an indication of trends rather than detailed examination of how fathers spend their time.

**Please tell us the amount of time you spend with your child with a learning disability in the kind of activities described below:**



These findings indicate that many fathers are managing to spend regular time with their children during the week, and that most are involved in providing support at weekends. It is not clear how this compares with fathers of non disabled children but a study carried out by the Equal Opportunities Commission (EOC, 2003) identified that fathers in two-parent families carry out an average of 25% of the family's childcare related activities during the week and one-third at weekends: these levels were higher where both parents were working full time. We asked fathers whether they made more effort to spend time with their child because of their disabilities and found that 60% (147) felt they did make more effort, 31% (77) felt they did not, whilst 9% (22) did not know whether the child's disability affected their involvement.

## Satisfaction with their involvement

Most fathers (77%, 194) were satisfied with the type of activities they were involved in: only 12% (30) said they were not and 9.6% (24) said they did not know. However, the picture was different when fathers were asked whether they were satisfied with the amount of time they spent with their child. A slightly higher number of fathers (48.6%, 120) were not satisfied with the amount of time they spent with their child than those who were satisfied (46.6%, 114) and 5.3% (13) said they did not know. Dissatisfaction with the amount of time covered both fathers who would like to spend more time with their child (n=116) and those who would like to spend less time (n=7) plus seven fathers who did not know.

There were also six open questions about the satisfaction fathers felt about their involvement.

### **Which activities would you like to be more involved in?**

This question was answered by 98 fathers. The most common response was activities connected with education and learning (25) whilst daily care tasks/routines (20), leisure activities and play (20) and appointments and meetings (17) also received a high response. Sixteen fathers said they would like to be more involved in all activities: half of these described working long hours and another four described working shifts as barriers to achieving this.

### **Which activities would you like to be less involved in?**

Only a small number of fathers (21) responded to this question, with a variety of responses such as continence issues, getting up at night, going out and attending meetings. Four fathers mentioned negotiating or fighting for resources for their child. One father mentioned physical care tasks saying:

*'All of the physical carrying and handling side - but there is no alternative, although I have developed an arthritic hand that ought to be rested.' (115)*

### **What prevents you from being more involved in these activities?**

This question was answered by 139 fathers, which is a higher number than those who said they were not satisfied with the activities in which they were involved. The most common response was work (95) followed by divorce or separation (12) whilst some fathers mentioned finding it difficult to be with their child either because of their child's disability or behaviour or because of their own problems such as ill-health, tiredness or disabilities:

*'My son does not want me involved unless he wants me to take him somewhere. He is very good at blanking me out.' (123)*

*'I have a diagnosis of ASD myself and find some aspects difficult. My ex supports me to have a good relationship with my children.' (198)*

A father described how his work commitments, combined with the way in which services are delivered, resulted in him being less involved than he would like:

*'My work responsibilities - services run as though all carers are at home during working hours, this has prevented me from learning about my son. My partner has to pass on what she has learnt from her interactions with professionals, and sometimes, it is easier for her to put her own learning into practice rather than pass on her second-hand training to me.' (170)*

**What prevents you from being less involved in these activities?**

The main reason for not being able to be less involved was that there were few alternatives:

*'Lack of resources for outside agencies to take her out on trips or to organise play activities for her when she is not at school.'* (102)

**What are the reasons for not being able to spend more time with your child?**

When asked about the reasons for not being able to spend as much time as they would have liked with their children, 82 of the 113 fathers who responded cited work. Other factors mentioned were an overall lack of time (8), divorce or separation (7), child at a residential school (8), tiredness or ill-health (4):

*'I work away from home as a long-distance lorry driver. I am away from home Monday-Friday.'* (86)

*'One of us needs to earn the money... my wife gave up teaching to be a carer, I gave up senior management.'* (108)

*'My ex wife has the main care and I live 150 miles from them.'* (149)

**What are the reasons for not being able to spend less time with your child?**

Fourteen fathers answered this question. Some gave reasons why they would like to spend less time: the main reasons for this were that they found it difficult to cope with the needs of their child and they wanted to spend more time with their other children:

*'Sometimes I get frustrated with lack of progress and her understanding and need a break from her.'* (185)

*'Would like to spend more time with my other two.'* (141)

Others explained why they could not spend less time: the main reasons were the needs of their child with learning disabilities or to support their partner:

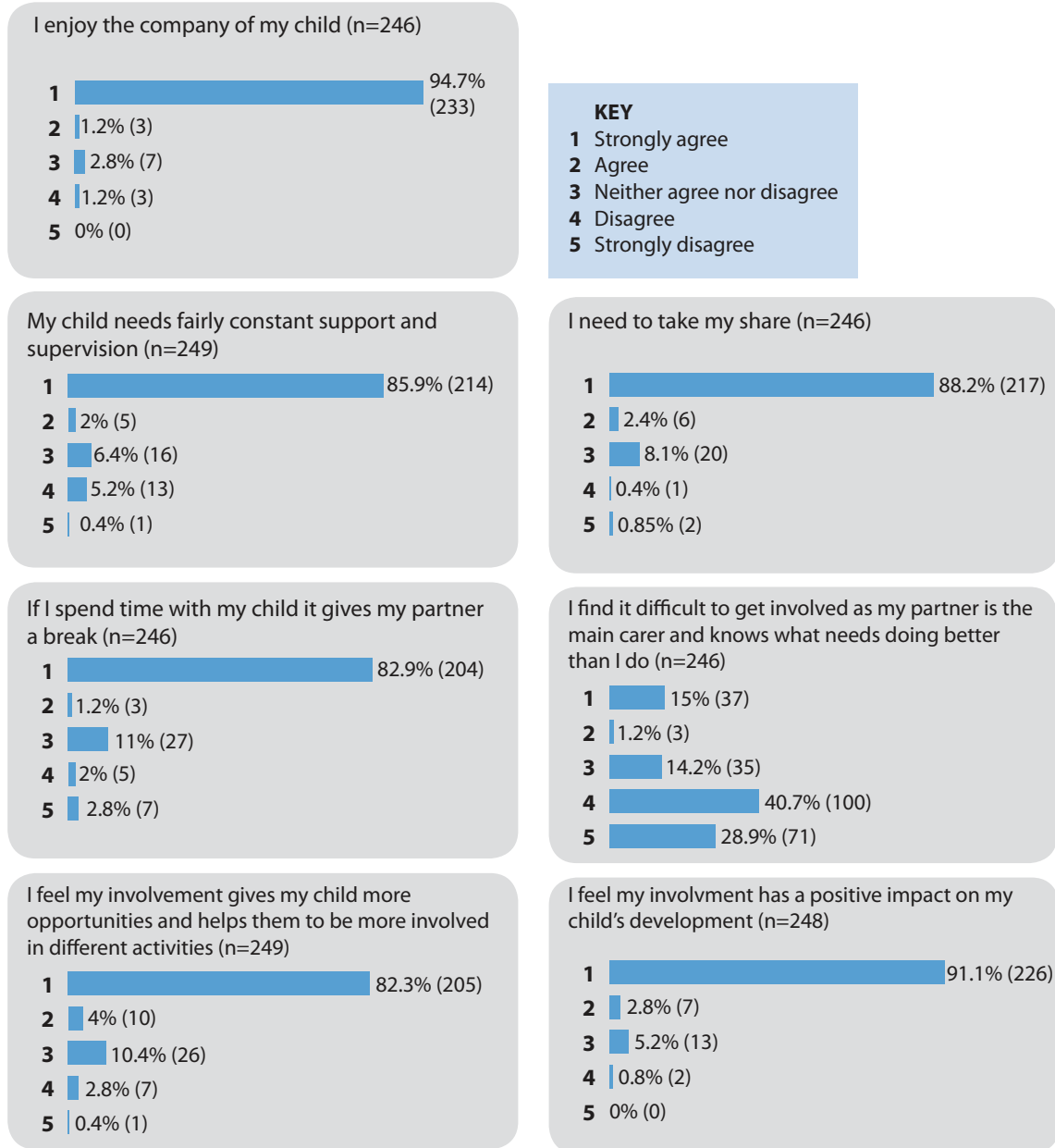
*'I recognise that my daughter needs a great deal of care and someone has to do it. My wife does more than me and I don't think it is fair to expect her to do any more.'* (75)

*'My son is quite reliant on me and is unhappy or uncomfortable when I am not present or when he doesn't know when I will be returning for him.'* (238)

Overall, the answers to these open questions about their involvement indicate that fathers are sometimes struggling to have the involvement they would like to have and the main cause of this is their work commitments.

**Motivation for involvement**

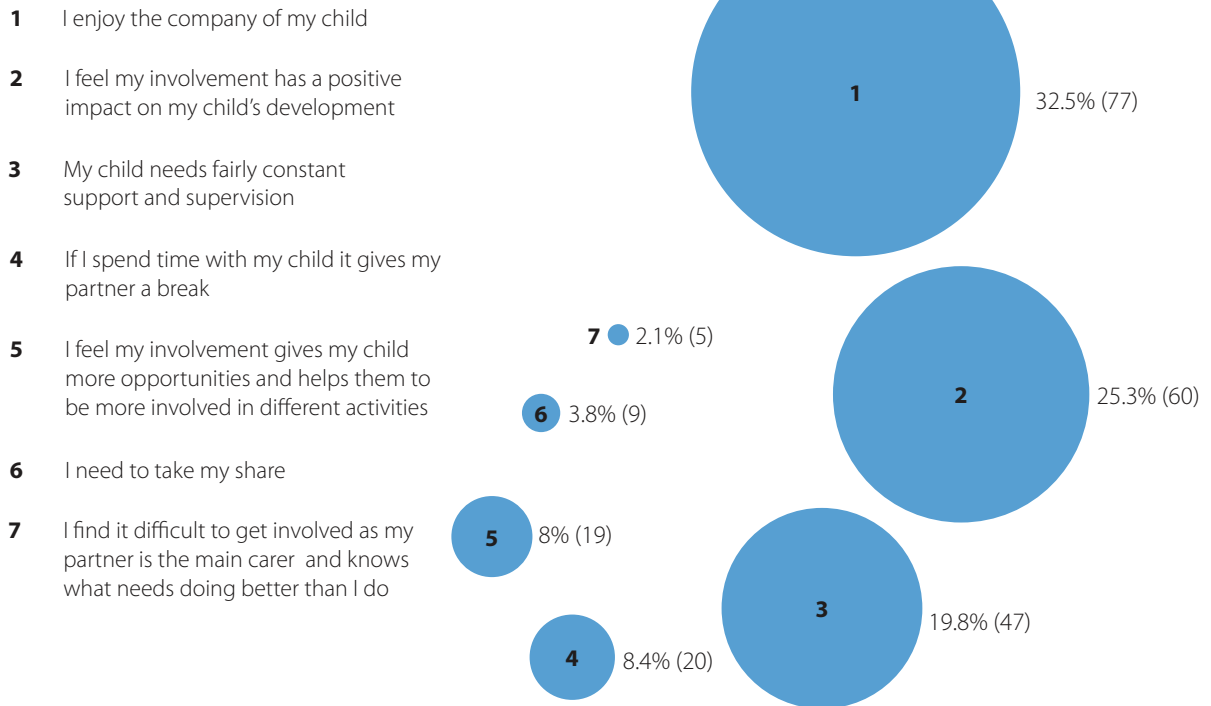
Fathers were asked to rank seven statements on a five point Likert-type scale in order to gain an understanding of the factors that motivated or prevented them from being involved. All of the statements implied involvement apart from one that implied difficulty to be involved. The aim of these statements was to explore whether fathers got involved because: they felt their input had a positive impact on their child's life; a sense of responsibility because of the level of support that was needed, or because they enjoyed spending time with their child.

**How strongly do you agree/disagree with the following statements?**

The responses above show strong agreement (over 80%) for all the statements implying involvement. Only a small number of fathers (16.2%) said they found it 'difficult to get involved' because their partner knew better about what needed doing. Further analysis indicated that work patterns were a significant factor when fathers found it difficult to be involved as over half of these fathers said they worked long hours, sometimes away from home. It did not seem to be related to the complexity of their child's needs, as their children had a range of disabilities.

A follow-up question was asked to identify what fathers saw as their *main* motivation.

**Which statement do you most strongly agree with?** (n=237)



This indicated that the main motivations were the pleasure experienced by fathers in spending time with their child with learning disabilities (statement 1) and also the positive impact that they felt their involvement has on their child's life (statements 2 and 5). Although they attributed importance to taking their share and supporting their partner, as seen in the previous question, this was not their primary motivation for being involved.

### KEY POINTS

- Fathers in the survey had a strong sense of involvement in providing care and support for their child and also in supporting their partner: for those who were in employment, their main involvement was in the evenings and at weekends but some were rearranging their working hours in order to be more involved in care arrangements.
- Almost half felt they would like to be able to spend more time with their child with learning disabilities and the main factor preventing this was the time they spent at work.
- 60% of fathers in the survey felt they made more effort to spend time with their child because of their disabilities.
- Fathers said their main motivation for spending time with their child was that they enjoyed their company. They also felt that their involvement had a positive impact on their child's life and that it was important to take their share of the additional responsibilities.

## 4.2 IMPACT ON RELATIONSHIPS WITH FAMILY AND FRIENDS

In the interviews carried out in the previous study, we found that almost all the fathers commented on the impact that having a disabled child had on their relationship with their partner, 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. Fathers talked less about the impact on their relationship with their extended family, although a few fathers described how their extended family's lack of understanding towards their child had been difficult to cope with. Some fathers also described how they had lost touch with friends because of time pressures or because they found it difficult talking with men who did not share their experience. On the other hand, a few described how important their friends had become to them.

In the questionnaire we asked about the impact on relationships with their partners, other children, extended family and friends.

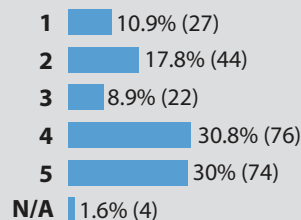
### Relationships with partners

There were four questions that explored the impact on the relationship that fathers had with their partner.

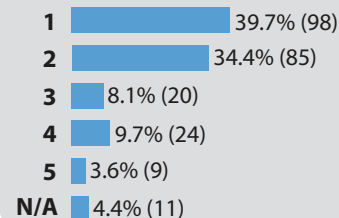
#### KEY

- 1 Strongly agree
- 2 Agree
- 3 Neither agree nor disagree
- 4 Disagree
- 5 Strongly disagree

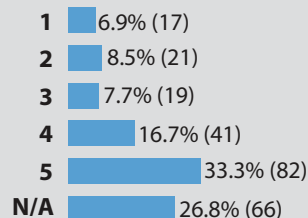
Having a child with a learning disability has NOT affected our relationship/marriage (apart from the usual impact of having a child) (n=246)



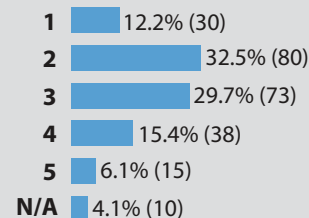
Having a child with a learning disability has meant that my partner/wife and I have less time together as a couple than if our child did not have a learning disability (n=246)



My partner/wife and I have separated or talked about separating as a result of having to care for a child with a learning disability (n=249)



Having a child with a learning disability has made me and my partner/wife closer to each other (n=246)





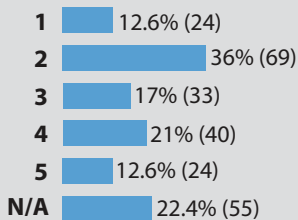
The findings from the four questions above indicate that, although having a child with learning disabilities has an impact on partner relationships, there are both positive and negative effects. Over 60% of respondents felt that it had affected their relationship but the question did not specify positive or negative impact.

The finding that 74% of fathers felt they spent less time with their partner as a couple may be unsurprising, given the additional responsibilities towards their children. However, it would seem to highlight a need for additional support so that couples are able to have time together outside their caring responsibilities. This may be an important factor in sustaining partner relationships. In the report *'No Time For Us'* (Contact a Family, 2003), that looked at the relationships between parents with a child with disabilities, respite or breaks from caring that provided time to be with their partner and/or other children was the most important factor parents identified that supported their relationship.

The number of fathers who said they had separated or talked about separating may be lower than would be expected: it is not possible to say whether this is because of the self selecting nature of the questionnaire or whether there are other reasons such as a greater pressure on couples to make things work. It may also reflect the findings in the question about the situation leading to them being closer, where 44% (110) agreed that it had brought them closer together and only 21% (53) disagreed with this statement. In the interviews in the first stage of the study, a number of fathers described how they felt closer to their partner because of the necessity of communicating and spending time together in order to support their child.

### Relationships with other children

I feel that I have not been able to give my other child(ren) without a disability enough support (n=245)



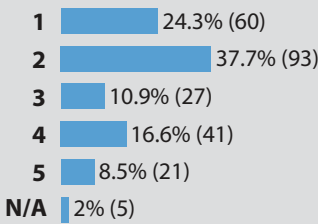
#### KEY

- 1 Strongly agree
- 2 Agree
- 3 Neither agree nor disagree
- 4 Disagree
- 5 Strongly disagree

Almost 50% of fathers who also had children without a learning disability felt they had not been able to give enough support to these children. This in itself, as a number of fathers described in the interviews in the previous study, can lead to feelings of pressure, guilt and inadequacy. This finding highlights the need for family support services to take into account the needs of all members of the family: breaks from caring can also provide opportunities for parents to have dedicated time with their other children. This, in turn, has the potential to improve outcomes for all the family.

### Relationships with extended family

Some members of my wider family (e.g. parents, parents in law, siblings) have found it difficult to cope with my child's disability (n=247)



**KEY**

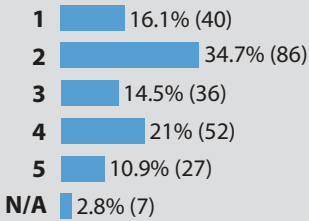
- 1 Strongly agree
- 2 Agree
- 3 Neither agree nor disagree
- 4 Disagree
- 5 Strongly disagree

Over 60% of fathers felt that some members of their family had found it difficult to cope with their child's disability. This lack of acceptance was identified by some fathers in the interviews in the first stage of the research as causing them to cut off or reduce their contact with their parents, thus leading to a reduced support network for themselves and their family.

### Impact on friendships

The questions about the impact on friendships were designed to find out the extent to which fathers had lost their social contacts and friendships or developed new networks and friends.

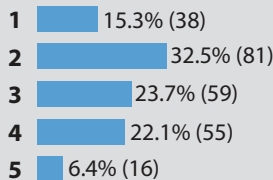
I have lost touch with friends I used to have since having a child with a disability (n=248)



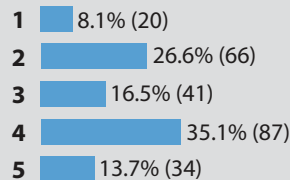
**KEY**

- 1 Strongly agree
- 2 Agree
- 3 Neither agree nor disagree
- 4 Disagree
- 5 Strongly disagree

Having a child with a learning disability has given me new friends and/or social networks (n=249)



I have got to know, or made friends with, other fathers who have a child with a disability (n=248)



Just over 50% (126) of fathers had lost touch with existing friends since having a child with a learning disability. This may not, in itself, be a problem if new friendships are made and the survey findings indicate that some fathers were finding new networks of support amongst families and other fathers who had children with learning disabilities. However, 46 fathers who had lost touch with existing friends had not made new friends or social networks, nor established friendships with other fathers with a child with learning disabilities. This group of 46 fathers, who had experienced a significant reduction in their social network, were fairly evenly spread across the Standard Occupational Classification (SOC). In contrast to the fathers who had lost friends and not gained new ones, there were 48 fathers who felt they had not lost touch with existing friends and also felt that they had gained new friends or social networks.

The implication of this may be that some fathers struggle to have friendships following the birth of a child with learning disabilities and may need additional help to develop a support network. Family support services could play a role in this by providing opportunities for fathers to meet together or to participate in activities aimed at fathers and their children.

There were six fathers who answered all the questions negatively about the impact on their relationships (across partner, extended family and friends): cross tabulations with other variables showed they were spread across categories of their child's disability, occupational classification and income. This lack of relationships with others may have a significant impact on a father's ability to personally cope with the additional responsibilities of having a child with learning disabilities. Family support services could play a role in helping fathers where they are struggling to maintain supportive relationships.

### KEY POINTS

- Having a child with learning disabilities can place additional pressures on relationships: these can be exacerbated by the fact that partners have little time to spend together as a couple.
- Almost half of the fathers who also had non-disabled children felt they had not been able to give them enough support: this was described as leading to feelings of pressure, guilt and inadequacy.
- Over half of fathers felt that members of their extended family had found it hard to cope with their child with disabilities.
- For a few fathers, having a child with learning disabilities had had a negative impact on their relationships with their partner, their extended family and friends. This is likely to affect a father's ability to cope and family support services may need to find appropriate support.

## 4.3 SUPPORT FROM FAMILY AND FRIENDS

In the interviews in the first stage of 'Recognising Fathers' we asked fathers about the support they received but we found that fathers usually needed several prompts to discuss support for themselves rather than support for their child. The most striking feature about support networks was that there was little support for fathers from anyone other than their partners. The opportunities for fathers to develop their support networks were limited, as they were often at work at the times when formal or informal support networks develop or, if fathers did try to get involved, they were not always included. Some of the interviewees also described a reluctance to be seen to need support.

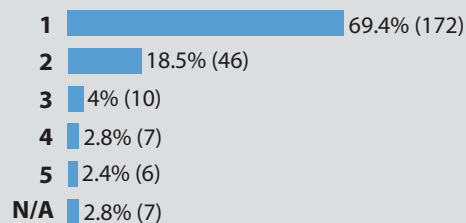
In the survey, therefore, we asked specific questions about the support that fathers received from their partners, family and friends and whether they would like this to be different. We were keen to gain a better understanding of the support networks that fathers have or would like as this could help to inform good practice, not only in sustaining fathers in their roles, but also in developing support around families' natural networks.

### Support from partners

From the interviews in the previous study we were aware that many men identified their partner as the main support: fathers often described this as mutual support gained from sharing experiences and working things out together. Where fathers were not part of a supportive relationship they had tended to look for support elsewhere, such as friends or support services. Not all received support: in the 21 interviews there was one father, a single carer, who did not appear to be receiving support from family, friends or services. A few fathers, especially those who were disadvantaged, found it hard to get the support they needed and were experiencing high levels of stress.

In the survey we asked fathers whether their partner was an important source of support.

My wife/partner is an important source of support  
(n=248)



#### KEY

- 1 Strongly agree
- 2 Agree
- 3 Neither agree nor disagree
- 4 Disagree
- 5 Strongly disagree

These findings verify those in the interviews, with over 88% seeing their partner as an important source of support. Of the 13 fathers who disagreed or strongly disagreed with this statement, seven had talked with their partner about separation. The fact that fathers see their partners as a significant source of support would seem to further reinforce the argument for families to be given additional support that enables parents to spend time together as a couple.

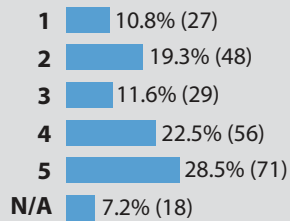
## Support from extended family

Fathers were asked about the practical support and the emotional support that they received from their extended families.

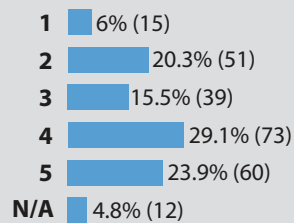
### KEY

- 1 Strongly agree
- 2 Agree
- 3 Neither agree nor disagree
- 4 Disagree
- 5 Strongly disagree

I get useful, practical support (babysitting, collecting children from school, finding information) from my extended family (e.g. parents/sibling) (n=249)



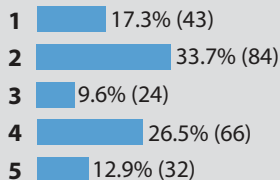
I get emotional support (such as listening to me, helping me make decisions) from my extended family (n=250)



The answers fathers gave were very similar for practical and for emotional support, which probably reflects their interrelationship. Fathers were more likely to feel that they did not receive support from their extended family (54% emotional support, 53% practical support) whilst 30% felt they received practical and 27% emotional support. In the interviews in the previous study a number of factors emerged that limited support from extended families: the ageing nature of their parents and the geographical distance between households were frequently mentioned. Also, as described in the previous section, over 60% of fathers mentioned that a member of their extended family found it difficult to cope with their child. Previous research has shown that practical interventions, such as workshops, can support grandparents to understand their grandchild's disability and be part of the support network for them and their family (Mirfin-Veitch and Bray, 1997).

## Support from friends

I have at least one good friend who I can talk to about my situation (n=249)

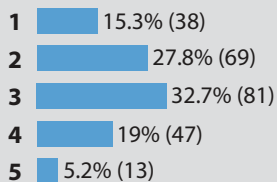


### KEY

- 1 Strongly agree
- 2 Agree
- 3 Neither agree nor disagree
- 4 Disagree
- 5 Strongly disagree

Fathers were asked whether they had at least one good friend to whom they could talk about having a child with a disability and slightly more fathers agreed with this statement than disagreed (51% compared with 39%). The considerable number of fathers who did not have a friend to talk to may reflect men's need to appear emotionally strong and therefore choose not to confide in friends or it may reflect the limited time they have to maintain old friendships or develop new ones. Given the stresses that many fathers are describing in the survey, this figure indicates a significant lack of opportunities to get emotional support from friends: it is likely that if mothers were asked a similar question they would identify a much higher level of support from friends. One of the implications of fathers not having a friend to talk to about their child is likely to be an increased dependence of fathers on their partners.

I enjoy spending time with my friends mainly because I feel it gives me a break from caring (n=248)



#### KEY

- 1 Strongly agree
- 2 Agree
- 3 Neither agree nor disagree
- 4 Disagree
- 5 Strongly disagree

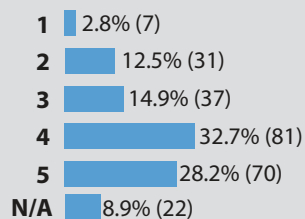
Fathers were also asked whether they spent time with friends as a break from caring and the highest number of responses (33%) neither agreed nor disagreed with this statement. More agreed (43%) than disagreed (24%), although overall these findings do not give a strong sense of fathers spending time with friends to 'have a break': this may indicate the lack of time to spend on such activities, which was also described in respondents' comments about the lack of time to look after their health through exercising and playing sport (see section 4.5).

### Additional support

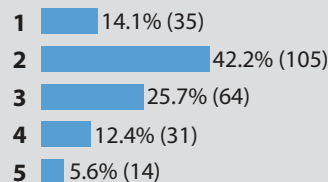
Fathers were asked whether they would like more support either from their partner or from their extended family or friends.

Key as above

I would like more support from my partner (n=248)



I would like more support, either emotional or practical, from family or friends (n=249)

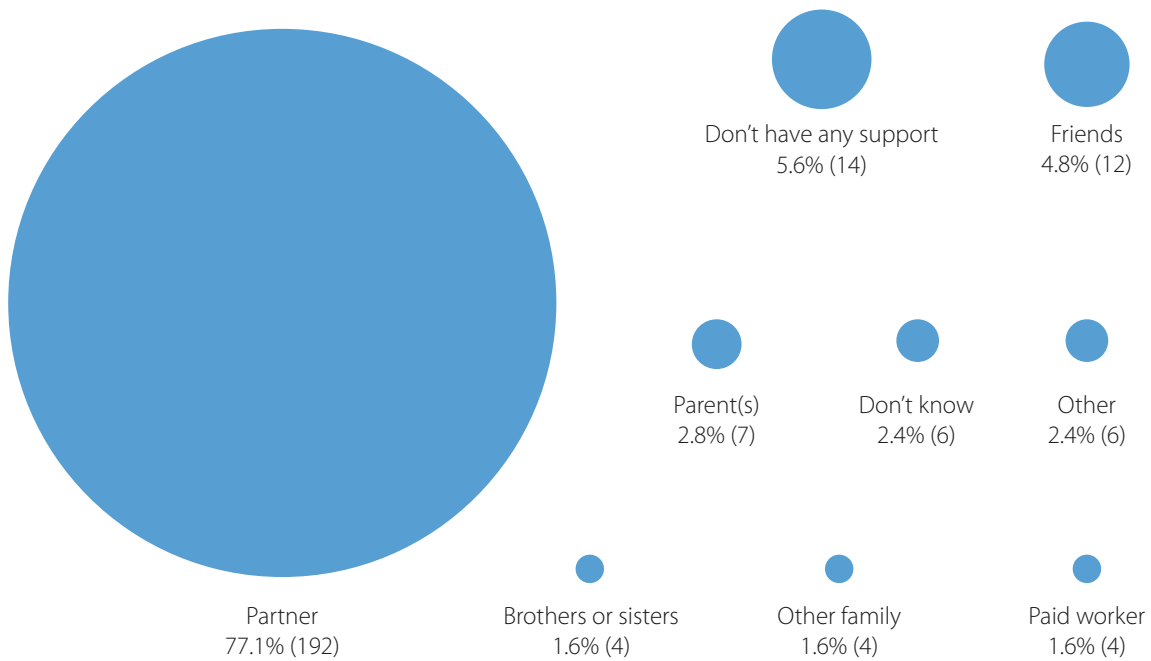


Over half (61%) of the fathers disagreed or strongly disagreed with the statement that they would like more support from their partner, with only 15% saying they would like more support. This may reflect the fact that most fathers are satisfied with the support they receive or it may reflect the fact that men would find it hard to say they needed their partner to provide more support. In comparison 56% said they would like additional support from their extended family and/or friends, with only 18% disagreeing with this statement.

## Main source of support

The final question in this section asked fathers to identify their main source of support.

**Who would you say is your main source of support?** (n=249)



Overwhelmingly, partners were identified (77%) with small numbers (5% and below) identifying parent(s), friends, siblings, other family and paid workers. There were four men whose main support was a paid worker, two of whom were married, one was separated and one divorced and they were spread across income groups and Standard Occupational Classification (SOC). There were 14 fathers who stated that they did not have any support: 10 were married or living with their partner and 2 were separated or divorced (data missing for the other). Again, these fathers were not from any particular occupational classification and had a range of incomes.

Overall, the questions about sources of support indicate that many fathers have a limited support network with a high level of dependence on partners. It is not possible to know whether mothers would attribute equal importance to support from their partner: this may be the case or it may be that mothers experience this as an additional responsibility and would benefit from their partners having a broader support network. Education, health and social care services and the third sector could all play a role in helping men to extend their support network for themselves and their family. This could be achieved through having an awareness about involving fathers and connecting them with other families. It could also be achieved by the way in which services are delivered: the personalisation agenda (DH, 2007) offers opportunities to build a network of support around the family that builds on their own connections. An example of this could be involving relatives and friends in the provision of additional support or short breaks for their child with learning disabilities using individualised funding or direct payments. This would provide opportunities for couples to have time away from caring or to spend time with other children as well as potentially widening the support and social network of the family.

**KEY POINTS**

- Fathers see their partners as an important source of support with over 75% seeing them as their main source of support.
- Over 50% of fathers felt they did not receive emotional or practical support from their extended families.
- Almost 40% of fathers did not have a good friend they could talk to about their situation.
- Over 50% of fathers felt they would like more support from their relatives or friends.
- Services have a role to play in providing fathers with more opportunities to meet other fathers and families.
- The personalisation agenda provides opportunities to develop families' natural support networks and involve relatives and friends in providing care and support.



## 4.4 CONTACT WITH SERVICES

In the previous study, fathers talked about their experiences of coming into contact with services either for their children or for themselves and about their experiences of attending reviews and appointments. A picture emerged of fathers having a greater level of contact than found by studies of fathers with disabled children in previous decades (West, 2000; Bray et al. 1995), but that this did not always result in fathers being included as an equal partner or being shown respect for the roles they had.

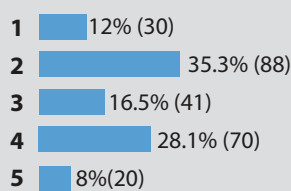
### Level of involvement and inclusion

In the survey we explored this further by giving participants six statements about their contact with services and using a five point Likert-type scale to rank these. This was to test whether the points that we had identified in the interviews were valid.

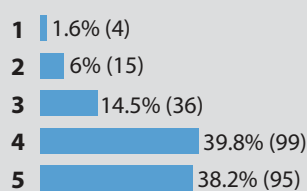
#### KEY

- 1 Strongly agree
- 2 Agree
- 3 Neither agree nor disagree
- 4 Disagree
- 5 Strongly disagree

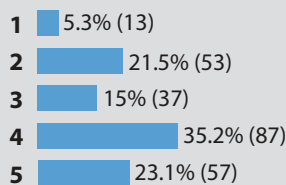
Appointments and meetings (e.g. at assessment centres, clinics, schools) are usually arranged so that I can get to them (n=249)



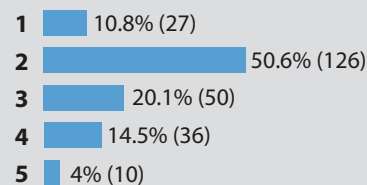
I tend to avoid going to meetings and appointments because I feel I am not included in discussions (n=249)



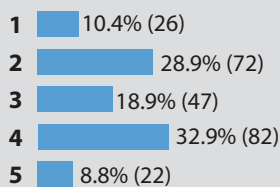
At the time of diagnosis I felt that I was given support (either separately or with my partner) to understand or come to terms with the news I was being given (n=247)



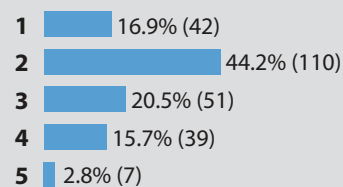
At meetings and appointments I am given the information I need to be fully involved in discussions (n=249)



I feel that I do not get many opportunities to talk to practitioners (e.g. teachers, health workers) who are supporting my child(ren) (n=249)



I think practitioners (e.g. teachers, health workers) make more effort to communicate with mothers than fathers (n=249)



The picture that emerged was partially positive in that there were more fathers, than not, agreeing with the positive statements about reviews and appointments being arranged so that they could attend (47%) and being given the information they need at meetings to participate (61%). Only a small number of fathers (7.6%) agreed with the statement that they avoided going to meetings as they did not feel included.

However, fathers were not so positive about their opportunity to talk with practitioners, outside arranged meetings. A slightly higher number of fathers disagreed than agreed with the statement *'I feel I do not get many opportunities to talk to practitioners who are supporting my children'* and significantly more fathers agreed with the statement that *'practitioners make more effort to speak with mothers than with fathers.'*

These findings would seem to indicate that, whilst fathers are more involved than in previous decades in formal interactions with practitioners, such as reviews, they still lack opportunities to interact informally. This lack of informal contact is likely to have an effect on the extent to which fathers feel included and the degree to which their confidence is developed in relation to supporting their child. Informal contact provides opportunities for teachers and clinicians to engage with fathers and may be particularly important to fathers who have had lower levels of educational opportunities who could find more formal settings, such as reviews, intimidating. This highlights the need for practitioners across education, health and social care services to organise their practice and service delivery in order to provide more opportunities for fathers to have informal contact with practitioners.

We also asked whether fathers felt they were given support at the time of diagnosis, to which 57% answered negatively and only 25% agreed. It is not possible to tell from the survey whether fathers felt they were treated any differently from their partners but it does indicate that fathers are not well supported during this difficult period. The inclusion of the fathers at the time of diagnosis and in the early years may help them to form longer term bonds and commitment to their child.

### Positive experiences with services

We also asked three open questions to identify what led to positive experiences with services and how services could be more helpful to fathers.

#### ***Which service or services has offered you the most positive experiences?***

Answers to this open question covered the range of statutory and voluntary services that parents are likely to come into contact with but there was no clear pattern to show which services provided the most positive experiences. Most were services for their child rather than for themselves. Nine fathers said that no service had provided a positive experience.

#### ***Why was the experience positive?***

The previous question was followed up by asking why the experience was positive. Responses to this could be collated under a number of themes: focused on their child's needs and achieved outcomes for their child; the staff had knowledge, skills, information and experience that was valued; a specific service was provided, for example a short break; the attitudes of the staff who listened, were caring, showed respect and empathy; spending time and being available when needed; they fully included and involved them as a father. Overall, it seemed that fathers appreciated services that provided a positive experience for their children with staff that respected them as a parent and supported their family.

#### ***Is there one thing that services could do that you would have found helpful to you as a father?***

The most common theme to emerge from this question was around recognition for them as fathers, getting equal respect to mothers and being included in discussions and decision making (23):

*'Explicitly acknowledge that as a father my responses might be different from the responses of my wife.'* (167)

*'Recognise that fathers have feelings too and are just as affected by the news of having a child with a disability. That we too, do have our own important contribution to make to our child's life. Stop shutting us out and making us feel inadequate and like a bystander in our child's needs.'* (187)

*'Particularly when she was a baby I was ignored, so to be helpful it would be to be given equal status.'* (108)

*'Support immediately after the birth and discovery of Down Syndrome. There is a lot of support for mothers but I had to go back to work and just get on with life.'* (202)

Appointments were mentioned by 11 fathers and these were mostly suggestions about arranging meetings so that they could attend rather than being excluded because of their work commitments:

*'Appointments at more convenient times (i.e. outside work or at the beginning or end of the working day rather than in the middle).'* (197)

The opportunity to meet other fathers was mentioned by seven men:

*'Meeting other fathers (without mums being present!). Most support services are geared to the child or child and mum with fathers being an 'extra' benefit to raising their kids.'* (181)

Practical support was also highlighted with the need for respite and short breaks mentioned by 11 fathers and support with planning for the future by four. Four fathers who were separated from their partners and not living with their child asked that they be given information about decisions:

*'Send copies of medical reports etc. automatically to non resident parents (usually fathers).'* (183)

*'Recognise that fathers not living with their children still want to be involved in their lives.'* (171)

The findings from these questions about fathers' contact with services indicate that many fathers want to have positive contact with practitioners in education, health and social care services. The growing emphasis within Government policies and programmes on working in partnership with parents, such as Every Child Matters (DfES, 2004) and Early Support Programmes, needs to result in inclusive practice towards fathers as well as mothers.

## KEY POINTS

- Services appear to be making progress in developing more opportunities for fathers to attend and participate in meetings about their child and fathers welcome this. However, arrangements for some meetings are preventing fathers from being as involved as they would like to be.
- There are limited opportunities for fathers to have informal contact with practitioners supporting their child: informal contact leads fathers to feel included and can give them confidence and skills in providing care and support.
- Fathers experience a lack of support and poor involvement at the time of diagnosis: this involvement right from the start may help to form longer term bonds and commitment to their child.
- Fathers emphasised the importance of being recognised and respected by practitioners for what they contribute and being included in discussions and decision-making.

## 4.5 IMPACT ON HEALTH

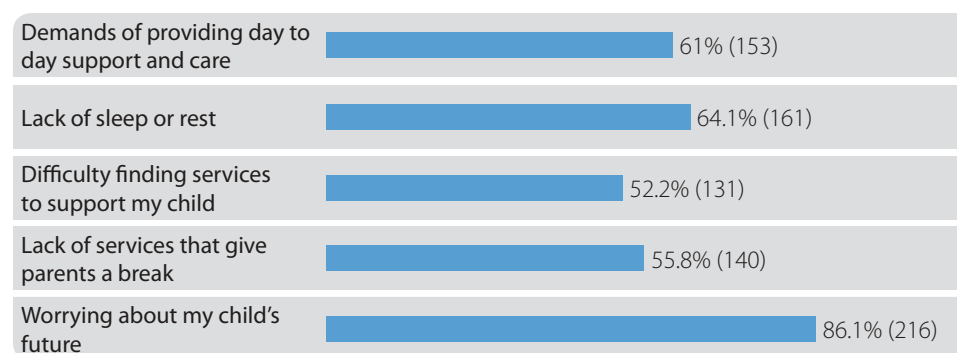
In the previous study we did not initially have health as an area for discussion but during the first few interviews it became apparent that fathers were experiencing a wide range of health problems that were affecting their daily lives. However, they were receiving little, or no, support to care for their health even though some were experiencing constant stress and a few were also the main carer for their child. There seemed to be a lack of awareness of men as carers and the potential impact on their health; two of the fathers had received no support even when they had talked to their GP about the stress they were experiencing.

Therefore, we wanted to use the questionnaire to explore the impact of having a child with learning disabilities on both mental and physical health and the support that fathers received. We used the term 'stress' rather than 'mental health' as it was felt this was a term that was more understandable and that was more likely to elicit a response. The distinction between mental and physical health is not always clear and in fact many fathers used the opportunity to describe symptoms of stress and mental ill health under the question about physical health.

### Causes of stress

First, we asked what caused fathers to experience stress, giving them a number of options, and asked them to tick whichever applied.

#### **Which of the following have caused you stress?** (n=250)



The two statements which are about the stress of providing day to day support were both ticked by over 60% of fathers ('*lack of sleep or rest*' (64%), '*demands of providing day to day support and care*' (61%). The two statements about the lack of support from services both received over 50% ('*difficulty finding services to support my child*' and '*lack of services that give parents a break*'). However, the highest response rate (87%) was for '*worrying about my child's future*' which would seem to indicate that, even though fathers are worried about day-to-day difficulties, they are even more concerned about the long-term support and opportunities for the future independence of their children. One father, in response to an open question, wrote:

*'The future is grim. I worry what will happen to my child when I die.'* (30)

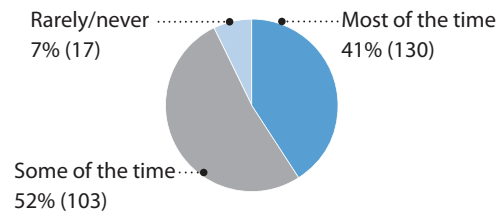
Fathers' concerns about the future are also highlighted in other research (Lamb and Laumann-Billings, 1997) which noted that fathers tended to be more concerned than mothers about the long-term implications of their child's disabilities. It may well be that fathers would find it helpful to be supported to take a proactive role in planning for the future of their child through, for example, facilitating person centred planning, involvement in programmes such as Partners in Policy Making™ or transition planning during secondary school years.

We also provided the option to say whether there were other factors that caused stress. Seventy-seven fathers responded to this with a wide variety of issues. Common themes were financial worries, coping with medical emergencies, juggling work and providing care, their child's behaviour, their partner's health or stress, the impact on their other children and fighting for appropriate services. Struggling with the system, especially in relation to education, was mentioned by 26 fathers. A number of fathers described the emotional pain they experienced because of their child's disabilities. Most of the fathers who were not resident with their child described the stress of not seeing their child enough and the attitudes of practitioners towards them as fathers which led them to feel excluded from decisions about their child.

## Amount of stress

### **How often do you experience stress as a result of having a child with additional needs?** (n=250)

When asked how often they thought they experienced stress as a result of having a child with additional needs, 52% (130) said some of the time and 41% (103) most of the time, with less than 7% (17) saying they rarely or never experienced stress. Whilst it may be predictable that a high percentage would say they experienced stress some of the time, the high number saying they experienced stress most of the time has significant implications for maintaining men's health and well-being when they have caring responsibilities.

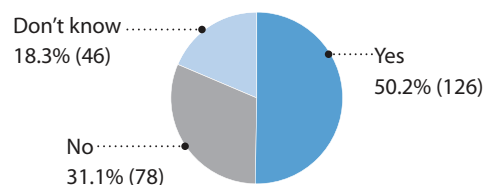


When levels of stress were explored in relation to employment status, the fathers who experienced stress most of the time were more likely to be those who were not working. There was also some indication that fathers in middle income jobs that were office-based (perhaps with less flexibility to take time off) were likely to regularly experience stress. Cross tabulations with the question about the degree to which employers gave flexibility indicated that this might lessen levels of stress fathers experienced: those who had regular or occasional flexibility arrangements were more likely to experience stress some of the time rather than most of the time. Similar findings resulted from a study carried out in Australia with fathers generally (i.e. not specifically of children with disabilities) which found that new fathers with the lowest workplace flexibility and autonomy reported the most unhappiness, anxiety and general levels of stress (Bolzan et al. 2004, cited in Fatherhood Institute, 2008).

## Physical health

### **Do you think your physical health has been affected by the pressures of looking after your child?** (n=250)

When asked whether their physical health had been affected by the pressures of looking after their child, half of the fathers agreed that it had, with a further 18% saying they did not know whether it had been affected. When these responses were analysed in relation to their child's disability there was a predictably higher response to their physical health being affected by fathers whose children also had a physical or sensory disability (67%) or multiple disabilities/complex support needs (60%). Nineteen of the children with complex support needs were living, either during the term or 52 weeks, in residential schools and this may well explain the slightly lower number of these fathers experiencing stress than those whose children had additional physical or sensory disabilities.



Those who answered that their physical health had been affected were asked to explain and this provided rich data about the symptoms and illnesses they were experiencing. Many fathers described more than one illness, and they were often relating stress to physical ill-health either as a cause or an exacerbating factor. The overall picture was of a high number of respondents experiencing stress that had an impact in a variety of ways on their physical health, whether these were pre-existing conditions exacerbated by additional demands or caused solely by the extra demands of having a child with a disability.

Suffering stress was one of the most frequently mentioned problems (21) and in addition a number of fathers described physical symptoms that are often seen as being caused or exacerbated by stress such as Irritable Bowel Syndrome, high blood pressure, Myalgic Encephalopathy (ME) and digestive problems (18). Eight fathers mentioned that they had low immunity or poor recovery from illnesses because of exhaustion or stress.

Nineteen fathers described how the lack of sleep affected their health. A number of fathers (15) described behaving in a way that was detrimental to maintaining good health and they often related this behaviour to being exhausted or stressed. The behaviours they identified included drinking and smoking too much, too little exercise, over-eating and having a poor diet. The implication was that the level of time that was taken up through work and caring responsibilities left little time to eat well, exercise or generally take care of their health.

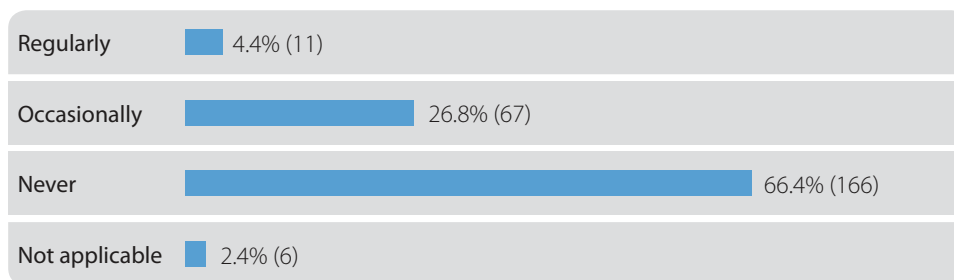
*'Lack of sleep, exercise and poorer diet, all due to demands on time from caring.'* (150)

### Support to maintain health and well-being

During the early stages of the in-depth interviews with fathers, in the original study, it became apparent that fathers were sometimes struggling with significant health problems relating to providing high levels of care, yet some thought their GP did not even know they had a child with disabilities. We explored this further in the survey and found that most respondents' GPs did know they had a child with learning disabilities (84.5%, n=212), although 6.4% (n=16) said their GP did not know and 8.8% (n=22) did not know whether their GP was aware. The fact that they do not know whether their GP is aware implies that they have never talked to their GP about their health in relation to their caring role.

This was followed with a question as to whether anyone ever talked to them about their physical health or stress.

***Does anyone (e.g. your GP, a counsellor, health worker, child's key worker) ever talk to you about your physical health or stress, related to the pressures of having a child with a learning disability?*** (n=250)



Only 11 fathers had someone, such as a GP, who regularly spoke to them about their health: this lack of consideration being given to fathers' health by GPs and other health workers is problematic, given the level of physical and mental ill-health that men were describing. Of the fathers who described experiencing stress 'most of the time', 61% were never spoken to about their health, along with 69% of those who 'sometimes' experienced stress. Of those who felt their physical health was affected by having a child with learning disabilities, 59% were 'never' spoken to and 32% were 'occasionally' spoken to about their health.

Men generally are often seen as being reluctant to talk to their doctors about their health or to seek medical advice and so we wanted to investigate whether the fathers in the study felt they were receiving the support they wanted or needed. If fathers felt they needed more support, then there would be an argument for a more pro-active approach to supporting men with their health in order to maintain their well-being as carers. Therefore, we asked whether they felt they needed more support with looking after their health and almost half said that they did (45.4%, n=114). We also investigated whether there was a link between fathers who said they needed additional support and income level: fathers on higher incomes were less likely to feel that they needed more support (26% of those earning over £40,000) whilst 58% of those earning under £10,000 and 48% of those earning £10,000-£40,000 felt they needed additional support.

Fathers are not usually seen as the 'primary carer' and because of this their health needs may often go unrecognised by health practitioners and employers. The Carers Strategy (DH, 2008) recognised the need for carers to be offered better support with their health. The strategy included proposals to develop GP training programmes to improve their understanding of carers' needs and to provide health checks for carers. The findings from the survey highlight the need to ensure these developments include fathers with caring responsibilities for children with disabilities regardless of whether or not they are the main carer.

### Fathers' ideas about maintaining their health

In reply to an open question about what support would be helpful, 110 fathers gave ideas, some giving one idea and others providing a number of suggestions. These comments cover a number of themes: the need for a break from caring; the need for emotional support; the benefit of regular health checks and improved preventative healthcare such as exercise; a more supportive attitude from practitioners and practical health information.

The highest number of comments (29) concerned having a break from caring through their child going on a short break/receiving respite, having additional help in the home, help in school holidays or having the opportunity for a break with their partner.

Another common theme was more support to look after their health, with 13 fathers suggesting there should be regular health check-ups (*an annual MOT*), 10 saying they would benefit from using a gym or exercising, four, help with sleep problems and three suggesting help with improving their diet:

*'A regular check-up initiated by the GP without my having to justify myself.' (172)*

*'Just need time to get more exercise, play more sport. So need more respite care/babysitting services.' (85)*

One father described the negative attitude he had experienced when trying to look after his own health:

*'One result of long working hours is not taking enough exercise and poor diet. I used to book an annual health check at my local surgery but was told by the nurse that the people who needed check-ups were not those like myself, who booked them. I tend now to suffer any complaints I have in silence through a lack of time to do anything about them. I do worry that I am storing up problems for the future when my dependents will still need me to be able bodied.' (47)*

The need for emotional or psychological support was mentioned by 20 fathers: nine said that stress management would be helpful, six mentioned counselling and five wished to have someone to talk to:

*'Someone not personally involved to talk to just to voice my fears and worries and blow off steam.'* (247)

A few fathers said they would like the opportunity to meet with other fathers as they felt they would share common experiences. Related to this are comments from a number of fathers about receiving more understanding from practitioners such as: being listened to, a belief in their expertise, and an acknowledgement of their needs:

*'Some recognition that having a learning disabled child impacts on my emotional well-being. I think I am doing a bloody good job coping with this, but I am not sure anyone acknowledges, or even agrees with this.'* (75)

*'Nobody ever asks how I feel - my partner seems to have more support, I am expected just to get on.'* (33)

These findings indicate the need for family support services to consider how they can support fathers to maintain their health and well-being, either by directing them towards medical check-ups and interventions or by providing services that help to achieve this.

## KEY POINTS

- Fathers are experiencing high levels of stress with 41% saying they experienced stress most of the time and an additional 52% saying they sometimes experienced stress.
- Their child's future was a major cause of concern: enabling fathers to have a proactive involvement in planning for their child's future may help to alleviate this stress and be beneficial to the long-term outcomes for children.
- Half of the fathers felt their physical health had been affected: there was a strong interplay between stress, mental ill-health and physical ill-health.
- Fathers were receiving very little help with looking after their health whilst almost half said they needed more help to look after their health, especially those on lower incomes.
- A number of suggestions were made by fathers to improve their health including having a break from caring and being given regular health checks.
- The Carers Strategy (DH, 2008) provides an opportunity to ensure fathers' health needs are responded to.



## 4.6 IMPACT ON PAID EMPLOYMENT

The findings from the previous study indicated that having a child with learning disabilities had a significant impact on men's paid working lives. It influenced decisions about what kind of employment fathers would look for and it led to loss of opportunities and earnings. Many fathers also described a struggle to get the flexibility they wanted and needed to combine paid work with their caring responsibilities.

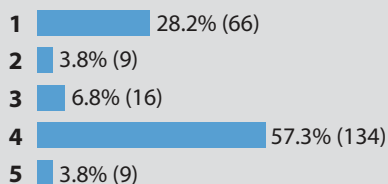
We wanted to explore this in more depth and asked fathers to answer the questions in relation to any paid work since the birth of their child with a learning disability. Fathers who had not been employed prior to the birth and had not been employed since did not need to complete this section.

### Changes to employment

We asked seven questions about possible changes in employment that fathers may have made and explored whether these were made through their own choice or because of pressure from their employer. We followed this up with an open question about their reasons for making any changes.

#### **Has having a child with learning disabilities resulted in any of the following?**

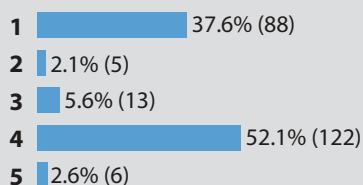
Changed your roles or responsibilities within your workplace (n=234)



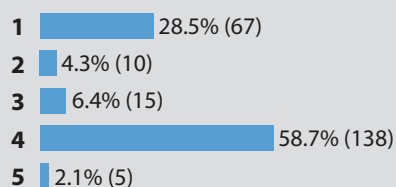
#### KEY

- 1 Yes through my own choice
- 2 Yes due to some pressure from my employer
- 3 Yes a mixture of choice and employer pressure
- 4 No
- 5 Not sure

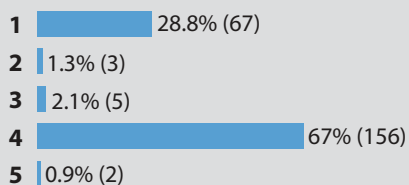
Changed your pattern of work e.g. become self employed or change to/from shift work (n=234)



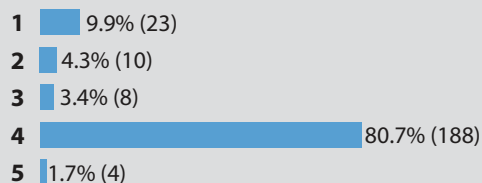
Changed the type of work you do (n=235)



Caused you to reduce your hours (n=233)

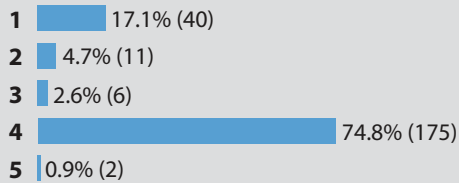


Caused you to take sick leave for longer than a month (n=233)

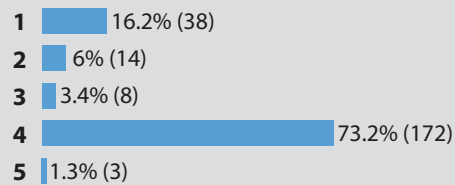


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#### Caused you to take a break from paid work or stopped working (n=234)



#### Caused you to leave a job (n=235)



Overall, there were a significant number of changes that fathers were making to their work and 70% (165) of fathers had made one or more of these changes, 38% (89) had made three or more and 8% (19) had made six or seven. The highest number of changes (45%) had been made in relation to changing their pattern of work, such as becoming self employed or changing their shift patterns.

Further analysis was carried out to explore the extent to which fathers had made the decision themselves to change aspects of their employment and the extent to which their employer had influenced their decision.

This showed that fathers were experiencing some pressure to make decisions that are likely to have an impact on their career path and earning potential. The area where there was least pressure was in relation to reduction of hours, with only 10% feeling pressure to do this. This may indicate the fact that many employers do not view part-time working as an acceptable option for men and therefore do not encourage men to reduce their hours in order to support them in combining employment and child-care responsibilities.

Participants were then asked an open question to describe the nature of the changes they made and the reasons why they made them. There were over 150 responses to this question that described a huge variety of changes and the reasons for them. Some fathers had made a number of changes during their child's life:

*'Before I became the main carer for my daughter I had a full-time job, but I had to ask for one day a week off as my partner found it hard on her own. I eventually had to leave work because my partner had had enough.'* (78)

Some fathers had adapted their working hours such as by using flexitime, reducing their hours or working compressed hours in order to spend more time with their child or to give their partner more support:

*'I tend to get to work at 7.30-8.00am so can do hours and any extra (flexi time) and get home at 4.30-5.30pm to help with feeding, play and bedtime routine.'* (241)

*'Work five days in four day week. Having five days compressed into four days to allow time to catch up on paperwork, tidying house etc.'* (3)

Some of the fathers who had adapted their working hours described a difficult juggling act in order to maintain their income:

*'I have agreed to work longer shifts in one day in order to gain more time off to try and support the rest of the family and undertake more than 100 appointments a year - each year of my child's life so far. Would like to reduce hours but wife cannot earn a wage and we need finance for transport, extend the house, wheelchair etc.'* (36)

Some fathers had changed their job or type of work so that they could gain more flexibility either to be around on a more regular basis or to be available for appointments or to respond to emergencies:

*'Moved to a job with greater flexibility and more understanding.'* (164)

*'I have had to completely change my job to one which is one minute from my children's school and to an employer that will allow me to leave at no notice if there is an emergency - fortunately this is a rare occurrence ... However, I am now on a fifth of the salary I used to have and I miss my old job.'* (24)

*'I left my employment rather than undertake further travelling which would have meant increased time away from home.'* (37)

The language that some of the fathers used to describe the changes they had made implied a significant sense of loss in their working lives: words such as loss, reduction, limitations, leaving are regularly used.

On the other hand a few fathers described the changes they made as having a positive impact on their lives:

*'I changed my start time so I could leave work earlier to be home as soon as possible to help when my daughter returned from school - I wish I'd done it years ago!'* (106)

A few fathers described how their experience of having a child with learning disabilities had led to positive outcomes in their employment: four fathers said it had resulted in positive career developments as they had either used their experience to change direction or their experience had been recognised by their employer:

*'My first hand knowledge of fostering and adopting a disabled child has been useful to me in my career. I am currently my employer's specialist fostering social worker for disabled children.'* (16)

One father had changed his work and had used his new position to adopt employee-friendly practices:

*'My previous employer did not support my family needs towards my children. My partner needed my support more than I could give in time so I left. I became Chief Executive of a local charity and we have adopted family recruitment policies and conditions of employment that support all staff and volunteers.'* (119)

A number of fathers pointed out that because of their child's disabilities they had not felt able to change their job. This was because they wanted to retain the flexibility or understanding that they received in their post or because they could not cope with the additional stress of changing jobs:

*'Remained in present job/grade where I can be more flexible.'* (227)

*'No changes. ... Couldn't cope with promotion and caring role so stayed at same job when previously I might have changed jobs by now.'* (141)

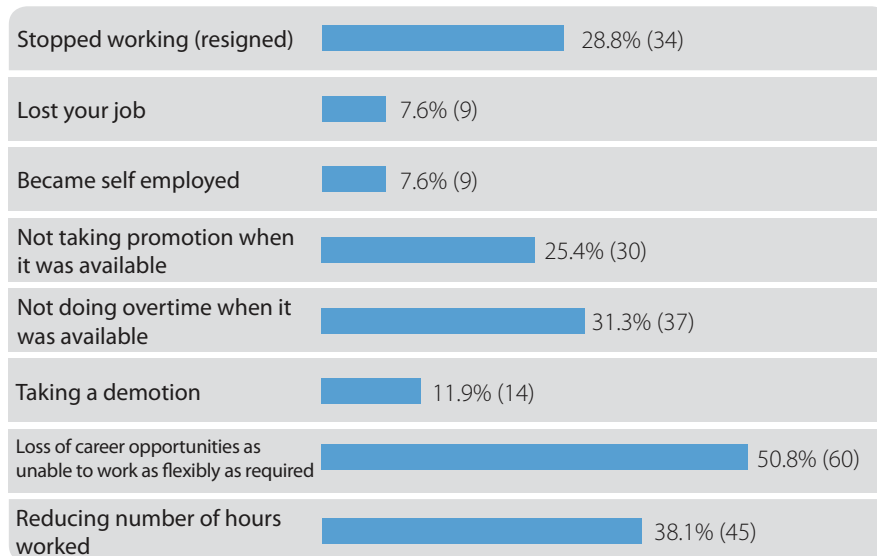
## Loss of income

The need for flexibility at work often resulted in a loss of career opportunities and income and, in the section above, fathers often described changes they had made to their employment that resulted in a significant impact on their career and earnings.

When asked specifically whether they felt they had ever lost any income as a result of having a child with a learning disability, slightly more fathers answered yes (49.4%, n= 120) than no (45.3%, n=110) with a few unsure (5.3%, n=13).

Fathers were then given a number of reasons as to why they might have experienced a loss of income and to tick whichever were relevant.

**If you have experienced a loss of income, please say which of the following reasons apply:** (n=118)

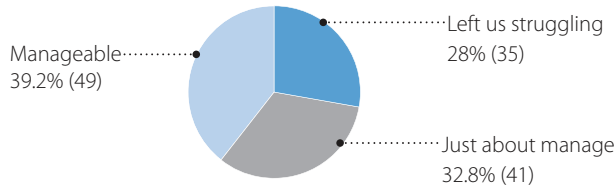


The highest number of respondents (60) replied that their income had been reduced through the loss of career opportunities due to not being able to work as flexibly as required, followed by a reduction in the number of hours worked (45) and a loss of overtime (37). Some fathers had experienced a loss of income for more than one reason which has a potentially significant cumulative effect over their working years and into their retirement. This negative impact on a family's income and status probably goes unrecognised by people in contact with the family, such as children and family practitioners, yet will often affect the outcomes for children with learning disabilities.

This loss of income highlights the need for fathers to receive professional advice about employment decisions. In many families it would be beneficial to receive advice as a couple to make decisions that work best for them in order to provide support for their child with learning disabilities and maximise their income. In addition, financial support to families with children with disabilities needs to reflect the fact that family income is often significantly reduced because of caring responsibilities and that these losses can continue over many years and into retirement.

These questions were followed up with a question about the impact of this loss of income to identify whether this was an easy choice to live with or whether it presented families with financial difficulties.

**What has been the impact of this loss of income?** (n=125)



Of the fathers for whom the loss of income had 'left us struggling', 54% were not aware that they were entitled to request flexible working, 73% were not aware they were entitled to parental leave and 76% had not received information about their legal entitlements at work. Of those who were 'struggling' or 'just about manage', 87% had not received information about their entitlements.

Fathers were asked to give reasons why they had made the decisions that led to the loss of income, to which 108 answers were received. Many of the answers gave a combination of reasons, covering the amount that needed doing at home, the change in their values from work to family life and the difficulties they encountered in trying to combine work and providing care:

*'Being a father of a disabled child means you don't fit into the 'work mould'. The pressures of home life force you to surrender your career prospects. I stayed in a low paid job for thirteen years purely because the hours were fairly flexible. I needed to be at home a lot to help.'* (106)

Approximately half of them mentioned that they needed to spend more time with their child for a variety of reasons such as needing to share the responsibility of caring for their child with their partner, too much to do at home for one person, their partner was struggling to cope, or that they were a sole carer:

*'Guilt about being absent when spouse is struggling to cope, trying to prioritise between finance and quality of life for self and family.'* (36)

Some of the fathers who had more than one child with learning disabilities mentioned that the additional responsibilities at home had led them to make changes at work leading to loss of income:

*'My wife could not cope with two severely disabled children in the evening and overnight without my help. It was also necessary for me to be within calling distance in case of medical emergencies occurring.'* (102)

Others mentioned that they wanted to spend more time with their child, often citing changed priorities in their life from work to supporting their child (17) or improving the quality of their family's life by working less (8):

*'My daughter and family needed me and that was more important than the job.'* (185)

A few fathers suggested there was no choice but to leave work or reduce their working hours because of the stress levels within their family:

*'Something had to give – work or family breakdown. No contest - family first.'* (2)

Ill-health, either of themselves (9) or their partner (8), was also a deciding factor:

*'My desire to be at home was affecting my work, which I was not doing well. I became stressed and depressed. My partner and I agreed that the job was not that important.'* (119)

Some fathers also mentioned factors about their work that led them to make changes that resulted in a loss of income:

*'Unable to commit to a career move that involved travelling due to having to leave my wife to cope.'* (54)

*'Employers tend to be discriminatory and restrictive in offering the support needed.'* (40)

### KEY POINTS

- Fathers are making significant changes to their work because of the needs of their children with learning disabilities: some are making a variety of changes during their working life.
- The need to have flexibility at work in order to be involved in their child's care often results in a loss of career opportunities and income.
- This loss of income can leave families struggling financially: it also can have a cumulative effect over their working lives and into retirement.
- Fathers need to receive information and advice from employers and advisory services in order to make employment decisions that enable them to stay in employment or move on in their career in order to maximise their income and achieve the balance they want and need between paid work and providing care and support to their child.
- Financial support for families with children with disabilities needs to compensate them for their loss of income as a result of providing care.

## 4.7 SUPPORT WITH PAID EMPLOYMENT

From the interviews in the previous study we were aware that fathers were faced with decisions about balancing paid work and providing hands-on support to their child, their partner or other children. An understanding and supportive employer was a significant factor in reducing the stress that fathers experienced in trying to achieve this.

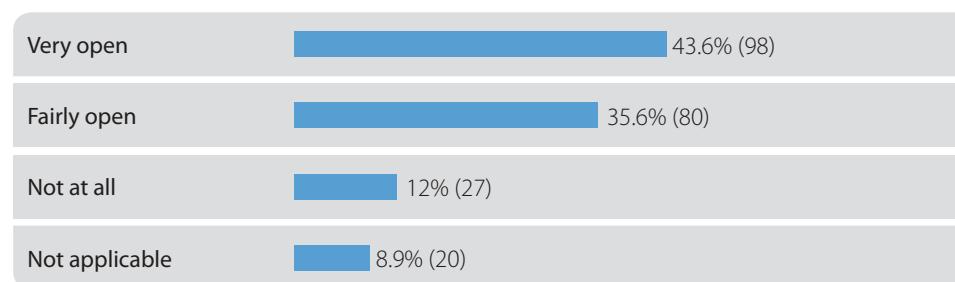
### Openness with employer

In the interviews mentioned above, all but one of the fathers had made their current employer aware that they had a child with disabilities although they had not always explained the impact this had on their life. A number of reasons were given for not disclosing this including the fact that they did not want to be seen to be asking for special favours or to be taking domestic or caring roles into the workplace.

Therefore, in the survey fathers were asked whether their current or most recent employer knew they had a child with a disability, to which 15.2% (34) said that their employers did not know. A further 6.3% (14) said they were unsure whether their employer knew, which would imply that they had not discussed it with them.

We followed this up by asking fathers how open they felt they could be with their employer about their children and their care responsibilities in order to get an indication of the level of open discussion there was between fathers and their employers.

#### **How open do you feel you can be with your employer/manager about your child(ren) or your care commitments?** (n=225)



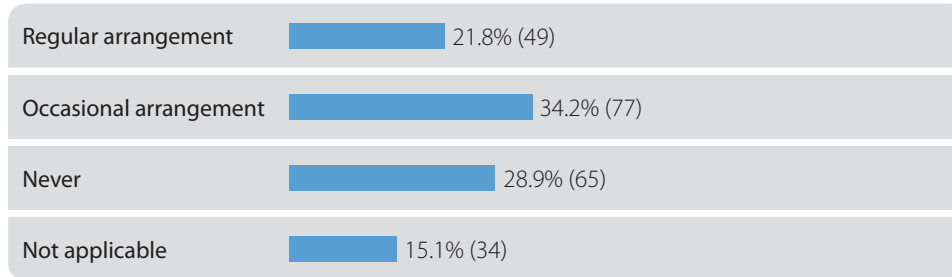
Most fathers felt that they could be open, to some degree, with their employers. However, 12% (27) said they could not be open at all: this in itself is likely to create additional stress and pressure.

### Supportive employment arrangements

We were keen to find out whether fathers had received any specific support in relation to carrying on with their work and we explored this in relation to being given flexibility at work, time off to attend meetings and appointments and support at the time of diagnosis.

In the previous study, flexible working arrangements came up as very important in helping men to sustain their work commitments whilst being involved in care arrangements. Therefore, in the survey we asked whether fathers' employment had been adapted to give more flexibility.

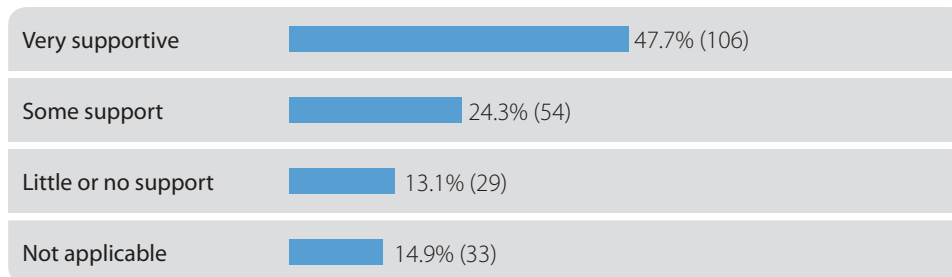
**Has your current (or most recent) employment been adapted in any way to give you more flexibility?**  
(n=225)



Just over half of the respondents said they had either a regular or occasional arrangement to give them additional flexibility, but almost a third said they had never had any such arrangement.

Fathers attribute a good deal of importance to being able to attend meetings and appointments as this is often their main point of contact with people providing support to their child. The previous study identified that fathers were more involved in meetings than they had been in previous decades: the two factors that enabled fathers to get to meetings were being given time away from work or practitioners adopting flexible meeting arrangements to suit both parents. The number of appointments can be high, especially in the period leading up to or following diagnosis or when a child has additional health needs or complex disabilities, and can create additional pressure on parents in employment.

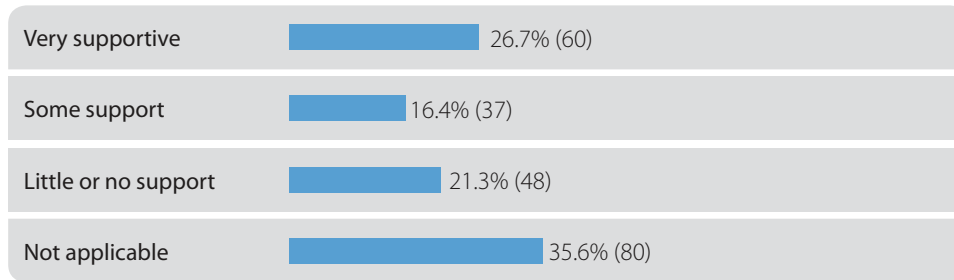
**Has your current (or most recent) employer been supportive to enable you to attend appointments and meetings?** (n=222)



These findings indicate a higher level of support to attend meetings than might be expected, but it needs to be taken into account that fathers may have changed from employment that was not as supportive. However, there were still a number of men (33) who were being given little or no support. Although these men were spread across the Standard Occupational Classification, when looked at in relation to income, 21 of the 29 men who provided data on their income earned less than £30,000 and only 2 earned over £40,000.



**Was your employer supportive at the time of your child's birth/diagnosis?** (n=225)



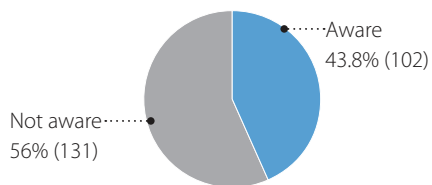
When asked about support at the time of diagnosis only 60 of the 145 fathers for whom this question was applicable felt their employer had been 'very supportive': given the trauma and readjustments that many parents experience following diagnosis, this figure would seem to indicate that employers need to be better informed about offering support, such as parental leave, at this time. Herbert and Carpenter (1994) found that fathers' grief is often unrecognised by health practitioners and employers at this crucial time: providing time away from work would enable fathers to have a sense of involvement and inclusion at this time which could have long term implications for their involvement in their child's life.

**Knowledge of legislation to support parents at work**

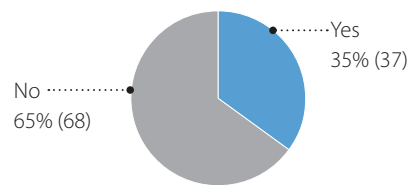
In the previous study we were aware that knowledge about legislation to support parents of disabled children at work was variable and that even when men were aware of its existence they were sometimes reluctant to use it. However, a few fathers had received advice about the legislation and used it to negotiate flexible working or to have time off for meetings and appointments or during times of crisis.

Therefore we asked fathers in the questionnaire whether they were aware of their entitlements in relation to flexible working and parental leave and whether they had ever used these entitlements.

**Were you aware that parents of disabled children, up to the age of 18, are legally entitled to request flexible working?** (n=233)

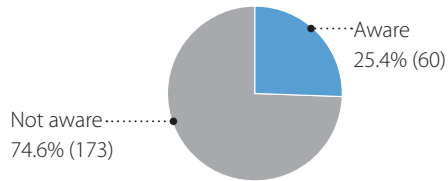


**If you were aware of this entitlement, have you ever taken advantage of this provision?** (n=105)

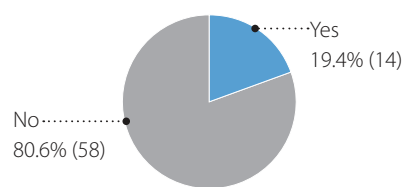


This showed that less than half of the fathers completing the survey knew of their entitlement to request flexible working and only 37 fathers said they had used this legislation.

**Are you aware that parents of disabled children are legally entitled to 18 weeks parental leave before their child reaches the age of 18?** (n=233)



**If you were aware of this entitlement, have you ever taken advantage of this provision?** (n=72)



This showed that almost three quarters of respondents were not aware of their entitlement to parental leave and that only 14 fathers from the entire sample had taken advantage of it.

We followed this with an open question about who had told them about these entitlements: employers (9 fathers) and the voluntary sector (7 fathers) were the main answers, but trade unions (2) the media (3) and word of mouth (1) were also mentioned.

A father who said he had found the information through his employer described the difficulties:

*'It was hidden away so deeply in the information on the internal internet pages that I don't think I would have found it had it not been pointed out to me. In addition it was written in such a way that it did not make sense! I pointed this out to personnel and they said they would get back to me - they never have.'* (59)

The lack of knowledge and use of this legislation is a significant finding given that fathers are also describing the need for flexibility in order to support their children with learning disabilities, their partners and other children. The extent to which fathers should be made aware of their rights is particularly important given the recent 2008 European Court of Justice case in *Coleman v. Attridge Law and Steve Law*, which gave Mrs Coleman, a mother and primary carer of a child with disabilities, rights<sup>1</sup> not to be discriminated against equivalent to a person with disabilities<sup>2</sup>.

The Carers Strategy (DH, 2008) recognised the need for an awareness campaign to ensure carers and employers are aware of the rights and benefits in relation to flexible working. It also highlighted the need to improve the way that advisers at Jobcentre Plus work with carers and to increase the availability of flexible opportunities for training and skills development. With any of these initiatives it will be necessary to emphasise that fathers of children with disabilities, whether or not they are primary carers, should receive this additional support. Fathers may feel they need to conform at work, rather than ask for special dispensations or for extra consideration as they feel they should be able to cope or do not want to draw attention to themselves as carers. In his comments at the end of the questionnaire, a father highlighted the need for society to be more understanding towards men as carers and that the right support to be economically active and to care should be available:

<sup>1</sup> Council Directive 2000/78 of 27 September 2000 establishing a general framework for equal treatment in employment and occupation (OJ 20000 L 303, p.16).

<sup>2</sup> Judgement of the Court of Justice in Case C- 303/06, July 2008.

*'Society's natural assumption is still that the mother will be the primary carer. When I take time off to care for Alfie it is often asked why my partner cannot do it, or is there anybody else. Why do people assume that I don't want to do it? Not only did I want to look after Alfie I want to do it well, that means that I have to be able to work flexibly, caring for someone doesn't mean you have to be economically inactive....Employers made it quite clear that flexible working etc. is ...primarily for women. It is seen as career suicide for a man to try for parental leave or part-time working or, heaven forbid, a career break.' (201)*

## KEY POINTS

- Most fathers felt that they could be at least fairly open with their employer about their caring responsibilities. However, a number felt they could not discuss this with their employer.
- Half of the respondents had either a regular or occasional arrangement to give them additional flexibility but a third had never had such an arrangement.
- Over half of the fathers were not aware that they were entitled to request flexible working: only 37 of the fathers completing the survey had used it to gain flexible working arrangements.
- 75% of fathers were not aware that they were entitled to unpaid parental leave: only 14 fathers had taken advantage of this entitlement.
- Employers, employment advisory agencies and family support services need to have a greater role in providing information and guidance on employment or signposting fathers to it. The implementation of the employment strands within the Carers Strategy needs to promote the needs of fathers who are combining paid work with involvement in the care of their child with disabilities.

## 5. CONCLUSIONS

Understanding the experiences and addressing the needs of fathers of children with learning disabilities are important for a number of inter-related reasons:

- Many fathers of children with learning disabilities are very involved in their children's lives and their contribution is a valuable resource for their partners and for their children.
- Some fathers want a higher level of involvement but find this hard to achieve, mainly due to work commitments, but also for other reasons, such as divorce or separation or their own ill-health.
- Recognising, encouraging and sustaining this involvement through policies and practices within education, health and social care services, as well as within employment and benefits legislation, will have life-long implications for children with learning disabilities.
- Fathers are not always recognised as parent carers by support services for children and families, employers and GPs and often there is an assumption that mothers are the primary carer: this can lead to feelings of exclusion, additional stress and may contribute to family breakdown.
- Fathers often have more limited support networks than mothers and see their partner as an important source of support: this has implications for single or separated fathers and also for mothers who may experience this as an additional burden.
- Families with a child with disabilities are often able to have only one earner which puts considerable pressure on the working partner, usually the father, to maximise their income. The need to earn can be exacerbated by the additional costs related to their child's disability such as the need for equipment, house adaptations and fuel. Fathers can be torn between the need to earn and the desire or need to provide care and support.
- Employers do not always recognise fathers as parent carers and therefore do not provide them with the information and support they need to combine their paid employment and caring roles. Fathers who are unaware or who find it difficult to find information in their workplace on their rights as a parent of a child with disabilities to seek parental leave, flexitime or other benefits, will inevitably find themselves in a weaker position without sufficient guidance to enforce their rights.
- This lack of support and information can lead to fathers making decisions at work that result in a loss of employment, training and career opportunities which in turn result in a loss of income for the family over many years, including in retirement. This reduction in family income has implications for the life opportunities available to children with disabilities and for the rest of their family.
- Fathers' struggle to maintain their work and their involvement in their children's care and support can lead to increased physical and mental ill-health. This can become a cycle as ill-health can, in turn, reduce men's capacity to earn and to provide care for and support to their children and partner.
- Some fathers are also providing support to their partners who are experiencing physical or mental ill-health that is often related to the additional responsibilities of having a child with disabilities.
- The impact on fathers' health often goes unrecognised by GPs and other health workers: fathers are rarely offered preventative health care or support to promote emotional well-being.

## CONCLUSIONS

- There is often a lack of understanding amongst family support services about the experiences of fathers as described above and therefore of ways of working that include, engage and support fathers. Services that adopt an approach to family support that is inclusive towards all family members can find solutions that work for individual families and build on the skills of each family member.
- Fathers who are disadvantaged in terms of their income, housing and social networks of support may need additional support to achieve the involvement they would like and to feel confident in their parental role.
- Children with learning disabilities deserve the support of their fathers: fathers need more recognition and more support in order to provide this.

## 6. RECOMMENDATIONS

The following recommendations aim to achieve:

- the involvement and inclusion of fathers in discussions and decisions about all aspects of their child's life in order to improve outcomes for children with disabilities, for their siblings, and for both parents
- improved information, advice and support to fathers so that they can combine employment with active involvement in providing care and support to their child with learning disabilities
- improved support to fathers to maintain their own health and well-being
- improved support to families, through including fathers, that enables them to have the help that is most effective for them as a family.

In all the recommendations it needs to be ensured that the additional support proposed for fathers reaches, in particular, those who are more disadvantaged in terms of their financial, social and information resources. It also needs to be recognised that, in some cases, the father may live separately from the mother and their child: in this situation, every effort must be made to enable both parents to have a valued and continuing role in supporting their child.

Although these recommendations are specific to policies and programmes in England, they should be considered and adapted as necessary to suit the circumstances in Scotland, Wales and Northern Ireland.

### 1. Health

1.1 We recommend that an alert is made from child health services to the GP practices of both parents, with their consent, following the birth or diagnosis of a child with learning disabilities, with the purpose of ensuring that GPs and other health practitioners are aware of parents' caring responsibilities.

**Action to be taken by Children's Trusts**

1.2 The Carers Strategy identifies the need for GPs to have a better understanding of carers' needs and that GP training programmes should be piloted in order to achieve this. This training needs to encourage GPs to recognise fathers as carers, even when the father's partner is the main carer, and to understand the health needs of fathers and approaches that work for them. Fathers identified approaches that would improve their health and well-being and these should be routinely available to fathers with an assessed need:

- learning stress management skills
- referrals to talking therapies
- gym referrals on prescription
- screening for high blood pressure
- help with leading a healthy lifestyle (diet, alcohol consumption, exercise)
- help with sleep problems.

**Action to be taken by the Carers Strategy implementation team**

1.3 The Carers Strategy also identifies the need for carers to receive annual health checks. The evidence from this research suggests that both mothers and fathers should receive these health checks, which should cover mental, as well as physical, health and that these should not be dependent on the father being identified as the main carer. Fathers are likely to need encouragement to prioritise the time to do this and GP practices may need incentives to ensure the necessary time is allocated to ensure uptake is high amongst fathers.

**Action to be taken by the Carers Strategy implementation team through the health checks demonstrator sites**

1.4 Fathers who take on caring roles for their children with disabilities should be provided with skills and knowledge in maintaining their health and well-being. PCTs should pilot the use of peer group training to enable fathers to support other fathers to look after their health.

**Action to be taken by DH through the implementation plans for the Carers' Strategy**

## 2. Employment

2.1 The Carers Strategy makes a number of proposals to provide better support to carers to move into and maintain their employment as well as to develop their careers: the implementation of these proposals needs to ensure that Jobcentre Plus, human resource departments and employers in SMEs (Small and Medium Enterprises) recognise fathers of children with disabilities as carers with specific needs around combining employment and caring responsibilities.

**Action to be taken by the Carers Strategy implementation team, human resource departments and employers in SMEs**

2.2 Fathers, as well as mothers, should be informed of their own rights to a carer's assessment. This assessment should have regard to their wishes in relation to: access to education or training; entering, retaining or re-entering paid employment, and access to any benefits or tax credits that might assist with the additional costs of having a child with disabilities.

**Action to be taken by DCSF, adult social care (fathers or mothers may be themselves disabled or requiring additional support in their parenting role), DWP and child health services through Children's Trusts**

2.3 The Government's 'Health at Work' agenda across the DH, DWP and the Health and Safety Executive, which aims to improve the health of people of working age, should specifically consider the needs of fathers who have children with additional needs. Good practice in occupational health support for these fathers needs to be disseminated so that employers, human resource managers, unions, other employees and health care professionals respond appropriately.

**Action to be taken by DH, DWP and HSE**

2.4 The use of paternity leave, parental leave and flexible working should be audited to gather information about the use of these regulations by mothers and fathers of children with disabilities. The data gathered should be used to identify how appropriate uptake could be increased, including any improvements to the regulations to make them more effective for families with disabled children.

**Action to be taken by DWP**

2.5 A guidance leaflet for employers should be produced on the implications of the Coleman judgement, with particular relevance for enforcing fathers' rights in light of the 'Recognising Fathers' research.

**Action to be taken by DWP**

## 3. Informing and involving fathers

3.1 Good practice in relation to involving and supporting fathers should be collated and the results disseminated to Children's Trusts to develop the knowledge and skills of practitioners in working with fathers. This knowledge should also be used by DCSF to inform future policy related to children with disabilities.

**Action to be taken by DCSF**

3.2 Practitioners in education, health and social care should be provided with good practice guidance about arranging meetings, appointments, reviews and home visits in such a way as to maximise the opportunities for both parents to be involved. Fathers as well as mothers need good information to understand fully the treatments or therapies arranged for their child. Appendix 3 contains good practice guidelines to involve fathers in reviews and appointments for their children.

**Action to be taken by DCSF**

3.3 Practitioners in education, health and social care should be provided with good practice guidance to involve fathers in meetings that are concerned with planning for their child's future, such as person centred planning and transition planning. Fathers should be offered appropriate training and support to be actively involved.

**Action to be taken by DCSF and adult social care services**

3.4 The development work to establish the Parents' Forums that are being set up through 'Aiming High for Disabled Children' should seek to ensure that fathers, as well as mothers, are actively involved.

**Action to be taken by the DCSF through the Aiming High for Disabled Children programme**

3.5 Children's Trusts should identify indicators by which the work of practitioners in education, health and social care can be audited in relation to involving and supporting fathers to ensure improvements are made and sustained.

**Action to be taken by Children's Trusts**

## 4. Family support

4.1 Carers' assessments, as referred to above, should be offered and carried out separately for fathers and mothers, to identify their needs for support: to help maintain emotional and physical well-being; caring for their other children without disabilities and for having a life outside of caring.

**Action to be taken by DCSF, adult social care, DWP and child health services through Children's Trusts**

4.2 Assessments and planning around the needs of a child with a learning disability should take account holistically of the wishes, feelings and capabilities of both the father and mother and any other involved relatives such as siblings or grandparents. The delivery of personalised support and individual budgets should be used to work for all the family and improve their life chances.

**Action to be taken by Children's Trusts**

4.3 The Children's Plan identified the need to 'introduce new ways to support parents at times when their relationships come under strain': the support needs of parents with disabled children should be given specific consideration due to the higher levels of relationship breakdown in the first eight years after a child with disabilities is born. A good practice review should be carried out and guidance provided to practitioners in universal and specialist services.

**Action to be taken by DCSF**

4.4 'Aiming High for Disabled Children' and the Children's Plan identify the need to expand the provision of short breaks for children with disabilities and their families. Development work on short breaks should include discussions with fathers as well as mothers about the kind of short breaks that would be most effective for them as a family or as sole carers. This should be used to inform commissioning strategies on short breaks.

**Action to be taken by DCSF, through Local Authorities and other delivery partners involved with the Aiming High for Disabled Children programme**

4.5 Models of family support should be developed that include attention to the support networks of fathers, including providing opportunities for fathers to link with one another. Commissioning strategies should reflect the fact that fathers particularly identified that they would like more opportunities to participate in events and activities that were for fathers with their children.

**Action to be taken by DCSF**

4.6 'Aiming High for Disabled Children' and the Carers Strategy emphasise the role of parents and family carers as partners in care and as experts. Fathers should have opportunities to participate in programmes that use their expertise to support other fathers or to train professionals in involving and supporting fathers.

**Action to be taken by DCSF and the Carers Strategy implementation team**



## 7. FURTHER RESEARCH

The first two stages of the 'Recognising Fathers' research have focused predominantly on the experiences of fathers who are involved in their children's lives. A small number of the participants in the interviews and survey were not living with their child although they remained involved to varying degrees. The research so far has provided some indication of the factors that enable some fathers to move beyond the shock and sense of inadequacy that many have described and to feel valued and confident in their role of bringing up a child with learning disabilities. Further research could develop a more in-depth understanding of the factors that support fathers to be engaged in their children's lives and those that lead to disengagement. One option for exploring this would be carrying out in-depth interviews with fathers, especially those who have left their partners or are not involved in their child's care. This research would aim to identify whether there are national or local policies and practices that could be changed that would support fathers to remain engaged in their children's lives and prevent relationships from breaking down.



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## Appendix 1: Membership of the project advisory group

### Advisory Committee Chair

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### **Justin Pearce-Neudorf**

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### **Paul Swift**

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### **Christine Towers**

Research and Service Development Manager

<h1>Recognising Fathers</h1>	<p><b>A national survey of fathers who have a child with a learning disability</b></p>
<p><i>Are you the father of a child with a learning disability? We would like to hear about your experiences.</i></p> <p><b>Why are we carrying out the survey?</b> The Foundation for People with Learning Disabilities would like to get a better understanding of the impact on men's lives of having a child with a learning disability. The survey will cover issues such as:</p> <ul style="list-style-type: none"><li>• your involvement in childcare</li><li>• whether it has led to changes in your paid work</li><li>• the impact on your relationships with family and friends</li></ul> <p>We would also like to find out what is helpful to fathers:</p> <ul style="list-style-type: none"><li>• would you like to see changes in the way support is provided to you and your family?</li><li>• how can employers support fathers involved in their children's care?</li></ul> <p>We will use this information to think about how fathers and families could receive better support through changes in policy and practice. This is the second phase of our 'Recognising Fathers' project which began in 2005. Visit our website or contact us to find out more about the project.</p> <p><b>Who can take part?</b> We would like to hear from you if you are the father of a child (or children) with a learning disability aged 19 years or under. You will also need to live in the UK and be aged 18 years or over.</p> <p>We are interested in your responses whether you are the child's biological, foster, adoptive or step father and whether or not you are living with the mother of your child with a learning disability.</p> <p>If you would find it difficult to complete a questionnaire, for example, because of language difficulties we will try to find someone who can help you to complete it.</p> <p><b>How do I take part?</b> You can complete the survey on-line or, if you would prefer, receive a paper copy or attachment to an e-mail. The survey will be carried out in autumn 2007.</p> <p>You will be asked a number of questions that will take about 40 minutes to complete but you will not need to do this in one go. If you change your mind you will be able to opt out of completing the questionnaire at any point.</p> <p><b>Will it be confidential?</b> The information you provide will be kept confidential and secure and will only be looked at by researchers at the Foundation for People with Learning Disabilities. You will not need to provide any contact details on the questionnaire so your answers will be anonymous.</p>	 <p><b>What to do next?</b> If you would like to take part please visit our website at <a href="http://www.learningdisabilities.org.uk">www.learningdisabilities.org.uk</a> or contact us by telephone, e-mail or letter.</p> <p>If you would like to speak to someone in person about the project call Christine Towers on 020 7803 1158 or email <a href="mailto:ctowers@fpld.org.uk">ctowers@fpld.org.uk</a></p>
<p>The Foundation for People with Learning Disabilities Sea Containers House, 20 Upper Ground, London SE1 9QB <a href="mailto:fpld@fpld.org.uk">fpld@fpld.org.uk</a> <a href="http://www.learningdisabilities.org.uk">www.learningdisabilities.org.uk</a></p> <p><small>The Foundation for People with Learning Disabilities is part of the Mental Health Foundation, registered charity no. 801130</small></p> <p><b>Foundation for People with Learning Disabilities</b></p>	

## Appendix 3: Good practice guidance for practitioners in education, health and social care settings to involve fathers in meetings and appointments

Fathers need to be given the opportunity to attend meetings to enable them to participate and contribute to discussions and decisions about their children. This also shares the responsibility, with mothers, of understanding and retaining often complex and detailed information.

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 and mothers decide what priority they should give to attending as well as to deciding who would be the most appropriate person to attend if only one of them was able to do so
- be aware that last minute changes to the times of appointments can lead to fathers being unable to attend or to losing pay unnecessarily
- 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 should involve ensuring that they are informed of discussions and decisions through direct contact by telephone or e-mail. This is particularly important when there is complex information to convey so that mothers and fathers have the necessary information to understand any interventions or treatments arranged for their children.

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.



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

We promote the rights, quality of life and opportunities of people with learning disabilities and their families. We do this by working with people with learning disabilities, their families and those who support them to:

- do research and develop projects that promote social inclusion and citizenship
- support local communities and services to include people with learning disabilities
- make practical improvements in services for people with learning disabilities
- spread knowledge and information.

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