



RECOGNISING FATHERS

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



Foundation for People
with Learning Disabilities

Foreword

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

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

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

Professor Barry Carpenter, OBE

Chair of the Recognising Fathers Advisory Committee

Copies of the full report are available to download free of charge at www.learningdisabilities.org.uk

About the Recognising Fathers project

The Recognising Fathers project aimed to gain an understanding of the issues facing fathers of young children with learning disabilities. It focused on the emotional impact of being a father, the roles and responsibilities they take on, the impact on their employment, the sources of support available to fathers and how services and practitioners interact with them.

The purpose of the project was to raise awareness of fathers as significant carers and to identify how policy and practice could be changed to improve support for fathers and thereby families as a whole.

We carried out in-depth interviews with 21 fathers living in different areas of England and Wales. They were selected to reflect a diversity of experiences relating to their social and economic situation, cultural background, family set-up and their child's disability. Agreeing to be interviewed implies that they felt they had something to say about being a father and they were likely to be involved with their children.

The following pages summarise the main findings from the project. Recommendations can be found on page 9, useful resources can be found on page 13.



Describing the emotional impact

The experience of becoming the father of a child with a learning disability was described by many of the men in the study as 'life-changing', leading them to reassess their values and priorities.

"You sort of adjust to the situation and you accept it and start doing something to make things better or you just curl up and die." (The father of an eight-year-old daughter with Down's syndrome)

- Immediately after receiving a diagnosis, fathers generally reacted with shock, bewilderment and a sense of 'entering an unknown world of disability'.
- After the initial impact of the diagnosis, fathers often described how they picked themselves up and 'got on with it'.
- Most fathers described a close emotional bond with their child and described the joy they got from their relationship with their child. However, the pleasure they expressed was often tinged with a sense of constant struggle.
- Fathers of children with autism were often frustrated by the difficulty in having a two-way relationship with their child.
- Most fathers were affected by a lack of sleep, depression or stress.
- Couples were often under a lot of pressure and had little time together. The experience has strengthened some relationships, but for others it had led to them having separate lives.
- Fathers were concerned both about their child's short-term future (often relating to their health or access to educational services) and about their prospects in the longer-term (often about the quality of their lives and their ability to live independently).

The roles and responsibilities of fathers

Fathers in the study had a high level of involvement in their children's lives.

"...You see I'm a family man really, I don't go out a lot and I like to stay around my children so I really do quite a lot." (The father of a three-year-old son with autism)

- Many fathers felt having a child with a learning disability had led them to be more involved.
- Most shared responsibility for care tasks with their partners. This was worked out through a process of negotiation around other commitments, such as work or the need for a break, and their respective skills.
- Those in paid employment tried to be involved in the daily care of their children before and after work, including providing care during the night.
- They were conscious of not always being able to provide other children in the family with the attention they deserved.
- Fathers appreciated opportunities to participate in courses and activities that supported their child's development.
- Fathers wanted to 'do their best' for their children, including fighting for appropriate services.
- Fathers had an important role in taking their children on trips outside the home and supporting their inclusion in local activities.

Impact on paid employment

Fathers in paid employment found it difficult to balance their paid work with providing support at home.

“I work till half past two and I’m home by the time he’s dropped off. I mean I work forty miles away... so it’s a mad dash up the motorway to be here before he’s dropped off.” (The lone father of a seven-year-old son with autism)

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



Support for fathers

Fathers found it hard to think of having support needs themselves.

“I wait until the kids have gone to bed and then I’ll pop round to a friend’s house... and then I’ll just chill out there.” (A father who is the main carer for his family and has three daughters with learning disabilities)

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

Interaction with practitioners

Fathers wanted to be respected and valued for the role they play in caring for their children with a learning disability.

“There is a very big difference in the way that services treat men and women... it is almost like you’re excluded from this caring relationship.” (The father of a ten-year-old daughter with a rare chromosome disorder)

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

Recommendations

From the 21 interviews conducted it is apparent that many fathers of children with learning disabilities are playing a very active role in family life – through providing care to their children, supporting their partner and advocating for resources. They are often balancing this with paid employment. The fact that they are not always recognised as carers by their employers or by service providers can lead to additional struggles.

However, the interviews identified many examples of changes to policy and practices that fathers found supportive. They were managing to set up flexible working patterns, being granted leave to attend appointments, participating in courses about their children's development and sometimes getting recognised as an equal parent by practitioners.

We have made a number of recommendations based on the premise that fathers of children with learning disabilities are a resource for the whole family, yet their role and the specific support they need to carry it out are not given enough consideration. Investment in support for fathers as carers must be seen as an effective way of supporting families.

Fathers who are 'primary carers', those who have more than one child with a disability and lone fathers have specific needs that should also be addressed. Fathers from black and minority ethnic communities may have particular support needs in terms of their ability to access services.

Additionally, some fathers of children with a learning disability may also have a disability themselves. It should also be recognised that these factors, amongst others, may increase the likelihood of families experiencing poverty, which can create additional needs and affect a father's ability to access support.



We recommend:

- The Government's Policy Review of Children and Young People led by **HM Treasury** and the **Department for Education and Skills** recognises the roles played by fathers of disabled children and acknowledges the benefits of early support as an effective and efficient way of supporting the whole family.
- The **Department for Education and Skills** ensures that the development of the lead professional and keyworker role and of the Common Assessment Framework leads to better partnership working with both fathers and mothers.
- The **Department for Communities and Local Government** promotes the use of the Gender Equality Duty to tackle discrimination faced by fathers of children with disabilities.
- The **Department for Trade and Industry** considers strengthening and extending the employment rights of parents to acknowledge the additional burdens faced by the fathers of children with disabilities.
- **Children's Service Directorates, Children's Trusts and Primary Care Trusts** appoint local 'champions' for fathers of disabled children.
- **Children's Trusts** establish standards for involving fathers at key stages in the lives of their children with disabilities.
- **Lead professionals** are equipped with the knowledge and skills required to engage with fathers of disabled children.
- **Carers Assessments** are used to identify help required by working fathers whose children have high support needs.
- **Commissioners** prioritise services that enable the parents of children with disabilities to spend time together away from their caring responsibilities, such as short breaks and through Direct Payments.

- **Commissioners** monitor services to ensure they consider and address the particular support needs of fathers of disabled children from black and minority ethnic communities, lone fathers, fathers who are primary carers and fathers who have learning disabilities themselves.
- **Primary Care Trusts** are able to identify fathers providing care to a child with a disability.
- **GPs** and **primary health workers** are aware of the health problems faced by fathers of children with disabilities.
- **Midwives** and **health visitors** include fathers when providing information and in decision making during or after pregnancy.
- **National organisations** for people with learning disabilities and family carers ensure that the role of fathers is addressed in their work.
- Information produced by **national and local organisations** is 'father friendly' and refers to both 'mothers' and 'fathers'.
- **Local family support services** consider how they can involve fathers of children with disabilities and help them to support one another.
- **Early Support, Children's Centres, SureStart local programmes** and other UK wide initiatives encourage fathers' involvement in the early years by producing materials for families and staff that address the needs of fathers of disabled children.
- **Early Support** ensures its training packages reflect the specific needs of fathers and it targets fathers to participate.
- **Professional bodies** ensure that training and continuing professional development promote a holistic approach to supporting whole families including the needs of fathers.

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- **Practitioners** working with families of children with disabilities should maximise the opportunities for mothers and fathers to attend appointments and meetings by:
 - being aware of parents' work commitments
 - providing information about the purpose and significance of meetings
 - considering whether meetings could be arranged outside normal working hours
 - taking account of other obligations such as prayer times or religious holidays.
 - **Practitioners** contact fathers, when they are not able to attend significant meetings, to inform them of discussions and decisions.
 - **Practitioners** acknowledge the input and expertise of a father during meetings and clinics.
 - **Practitioners** provide opportunities for fathers to participate in courses and development programmes.
 - **Practitioners** 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 together and/or separately.
 - **Practitioners** have an awareness that some fathers may not be comfortable discussing sensitive topics with female staff.
 - **Practitioners** such as health visitors and social workers are able to 'signpost' fathers to support with employment.
 - **Employers and human resource managers** enable fathers of children with a learning disability to make reasonable adjustments to their work patterns and provide information about their entitlements.
 - **Trades Unions** are aware of the issues for fathers of children with a disability who are in paid employment and offer appropriate advice and representation.

Useful resources

Carers UK: Action for Carers and Employment project

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

Tel: 020 7490 8818
Email: info@carersuk.org
Website: www.carersuk.org

Contact a Family

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

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

Early Support

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

Tel: 020 7296 8238 or 020 7296 8307
Website: www.earlysupport.org.uk

Fathers Direct

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

Tel: 0845 634 1328
Email: mail@fathersdirect.com
Website: www.fathersdirect.com

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

Tel: 020 7803 1100
Email: fpld@fpld.org.uk
Website: www.learningdisabilities.org.uk

National Autistic Society

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

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

National Deaf Children's Society

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

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

National Family and Parenting Institute

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

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

Partners in Policymaking

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

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

Pre-school Learning Alliance

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

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

Working Families

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

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

This booklet will be of interest to:

- fathers of children with a learning disability and their families
- commissioners, service providers and practitioners involved in delivering support to children and their families
- those involved in policy relating to children with learning disabilities and their families
- employers, human resource managers and trades unions.

It describes the main findings and recommendations from the Recognising Fathers research project, which aimed to provide an understanding about fatherhood in the 21st century for fathers of children with a learning disability.

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The Foundation for People with Learning Disabilities is part of the Mental Health Foundation, registered charity no. 801130.

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