



Let's not forget about fathers

Steve with his sons Stan and Harry

'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 that you have with Eleanor and I find that really quite annoying because as I say we have done it 50:50 from the beginning and we've played an equal part in looking after Eleanor and her development. We share 50% of the anxiety of that.'
Andy, father of a ten-year-old daughter with a rare chromosome disorder

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Introduction

Most children with learning disabilities live at home with parents who provide their care and support. Fathers are one half of this parenting equation yet when we talk about 'parents' we

are usually referring to mothers – who are seen as the main providers of care for children. This remains the case even though fatherhood has gradually been changing in recent decades and men are now spending more time with their families. Recent research on fathers has generally shown that they provide one third of the childcare in the UK and that fathers would like to be able to spend more time with their children (O'Brien, 2005). The contribution of fathers is even more important in families who may be experiencing additional emotional and physical commitments through raising a child with a learning disability.

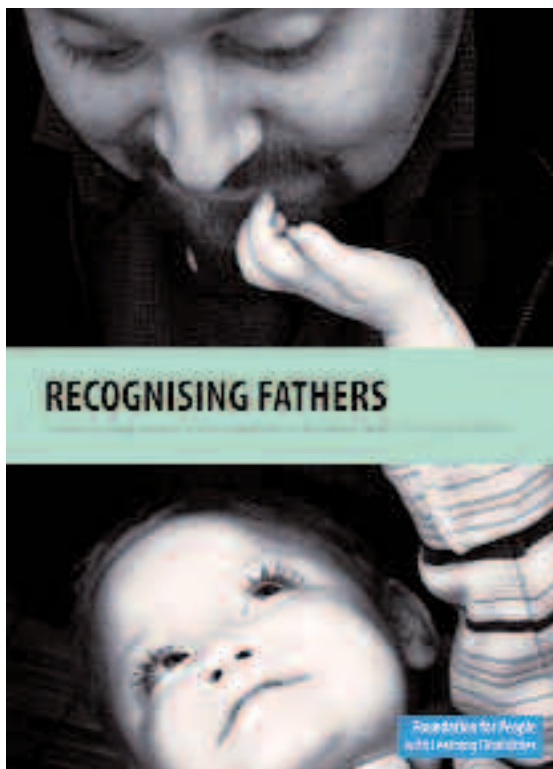
Key points

The research project, *Recognising Fathers*, showed that:

- ▶ fathers are often very involved in their children's support and attach great importance to ensuring they have opportunities in their lives and are included in mainstream activities
- ▶ however, fathers are often marginalised by practitioners
- ▶ practical advice to support fathers has been developed from this research.

Why do we fail to recognise fathers?

In 2004 the Foundation for People with Learning Disabilities' (FPLD) *First Impressions* ▶



Recognising Fathers
report

project (FPLD, 2005), which looked at the families of young children diagnosed with a learning disability and their needs during the first five years of a child's life, found that men were often marginalised when it came to arranging care and support for their children. This corroborated findings from previous research (Hornby, 1992; Herbert & Carpenter, 1994; West, 2000). Given that fathers are usually an important part of a child's support network, why do we persist in organising support to children and families that neglects the role they play? Maybe it simply reflects societal attitudes and widely held stereotypes about fathers being 'the absent parent' or the fact that men can be reluctant to talk about their feelings or seek help for their needs. In addition, family support is usually arranged and provided by services that are predominantly staffed by women and that are 'open' during normal working hours when men are likely to be less visible in their caring roles.

What did we do?

The Recognising Fathers project aimed to get a better understanding of the experience of fathers of children with a learning disability. It did not specifically set out to look at the difficulties faced by fathers, but to look more generally at what they contribute to family life,

what supports or hinders them in this and what has been the impact on their lives.

We interviewed 21 fathers of children with a learning disability aged 11 and under. This age was chosen in order to capture experiences in the early years, through primary school and include preparation for transfer to secondary school. We were keen to interview fathers from a variety of backgrounds and with differing life experiences and so took into account the type of family unit, their employment status, residential location, ethnicity and age. We also sought fathers of children with a range of ages, a variety of diagnoses and in receipt of different levels of support from services.

Fathers were asked about four key areas of their lives: the roles that they take on to support their family; the impact on their employment of having a child with a learning disability; their own networks of support; and their experiences of support services, both for their children and, where applicable, for themselves.

The ideas and themes that emerged were many and varied. However, the research provided significant insight into two particular areas – the role that fathers play within families, and the degree to which they are forgotten when it comes to arranging support for their children.

The roles of fathers

The fathers taking part in the study talked openly about their lives and the relationship they had with their children. It was apparent that most enjoyed a close emotional bond with their children and experienced joy through spending time with them. A number also described how their commitment was stronger because of their child's disability. However, the pleasure they expressed was often tinged with a sense of constant struggle resulting from the difficulties they faced getting the support they felt their children needed.

The fathers reported having a high level of involvement in the lives of their families: it was often the case that having a child with a learning disability had led them to become more involved. The type of involvement varied enormously depending on factors such as their children's needs, whether their partner was working, their partner's need for a break, their respective skills and the availability of local support. Those in paid employment tried to be involved in the daily care of their children before and after work, including tending to

'I'm ever so close to Jessica, particularly in terms of music, and that to me is brilliant. We can have conversations about music in her language for hours ... I play guitar as well so if I'm playing the guitar she'll sing and then she'll play the keyboard, then I'll say "your solo" she'll say "solo" ... and it's wonderful you know.'

them at night. They were also conscious of not always being able to provide other children in the family with the attention they deserved.

Most of the fathers placed considerable importance on providing their children with opportunities such as taking part in ordinary day-to-day activities and being included in group and community activities. They were keen to ensure that their children were involved with the local community through trips outside the home, including visiting family and friends, going to the mosque, trips to the park and shopping together. Some mentioned being more comfortable than their partner was about taking their children out to public places, as they did not worry as much about other people's reactions to their children's behaviour.

Paul described how his main priority has been to provide his daughter with opportunities that help her to connect with other people and the world around her – opportunities that she could miss because of the nature of her disabilities (which include autism, blindness and epilepsy). He gets great enjoyment from her company and they have a real connection through playing music together:

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Dave described how he spent time with his son at the weekend:

'Saturday I spend basically all day with him really. We go out shopping in the morning. He likes going to the supermarket and chucking things around, getting things off shelves.'

Fathers described how they wanted to 'do their best' for their children by making sure they were included in mainstream services. Some of

them had supported their children when they first started at nursery or primary school or at activities out of school to facilitate their inclusion. However, opportunities to shape and influence the support provided to their children were limited by the fact that services are rarely organised to encourage their participation.

Including fathers in meetings and appointments

Almost all the fathers wanted to go to meetings about their children and tried to attend as many as they were able, sometimes losing a day's pay to be there. A few men felt that practitioners did not seem to expect them to turn up at meetings. This was sometimes experienced as surprise, while others actually felt unwelcome. As Andy put it:

'It was almost like "What are you doing at the appointment? Get out and earn some money." It's bizarre the way that happened. I found that quite difficult sometimes.'

Others talked about how practitioners focused on their wives at meetings, even though they fully shared the care with their partner:

'I think it's seeing her really more as the expert ... she's quite confident and she has the knowledge. They tend to look at her ... as the focus of the consultation if you like, which is fine you know, but I sense that I'm a little bit secondary.' (Philip)

Philip felt that he was carried along in discussions and not given enough information to be fully involved in the decision-making even though he took an equal share in looking after his son, whose behaviour was often very difficult to manage at home.

Shaun, who had given up work to care full time for his children and attended meetings on ▶

his own because his wife was not able to leave the house through illness, said he felt pushed out of meetings:

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

He had come to the conclusion that fathers have to work harder than mothers to be included and that practitioners were unable to understand or appreciate the level of involvement he took in caring for their children. Similarly, Owen, a single father, who lived in a rural area, felt that local practitioners were not comfortable with his role as the main carer because it was less common than it might be in a city. Despite having a limited support network and caring for his son on his own, education and social services had offered him minimal assistance.

What are the implications for providing support to families?

The research suggests that the fathers are an under-utilised resource in the planning and organising of support for children with learning disabilities. While our interviews with fathers found evidence that their role is recognised by some practitioners, all too often they remain marginalised from key decisions affecting their children's lives.

Fathers want to be respected and valued for the role they play in caring for their children with a learning disability and this needs to be

understood by those with responsibility for organising support for families. A more holistic approach to supporting families would follow from understanding the existing relationships and responsibilities within families and building support around this.

Action points

Some practical advice flows from the project that may help to ensure that fathers are more involved.

- ▶ When arranging meetings, appointments and home visits professionals should maximise the opportunities for both parents to be involved by being aware of parents' work commitments, preferences for days and times of meetings and how much advance notice they need to arrange time off work.
- ▶ Provide information about the purpose and significance of meetings in advance to help fathers decide how much priority they should give to attending.
- ▶ Take account of other obligations such as prayer times or religious holidays.
- ▶ When fathers are not able to attend significant meetings they should be contacted directly by telephone or email to inform them of discussions and decisions.
- ▶ During meetings, appointments, clinics and other discussions the input and expertise of fathers should be acknowledged.
- ▶ Have an understanding that fathers may respond differently to situations and may need time to discuss things separately from their partner.
- ▶ Have an awareness of the cultural needs of some fathers who may not be comfortable discussing sensitive topics with female members of staff.
- ▶ Men should be given opportunities to participate in courses and development programmes that build up their skills to support their child's development. This might include running courses in the evenings, at weekends and considering whether some should be run for men only.
- ▶ Be aware of practical and emotional support that is available to fathers locally and signpost fathers to this.

Developing our knowledge

The Foundation for People with Learning Disabilities is beginning the next stage of research to further develop our knowledge about the experiences of fathers of children with a learning disability. We will be carrying out a national survey through fathers completing a questionnaire. This survey will provide a valuable opportunity to find out about the experiences of a greater number of fathers and to explore in more depth some of the issues we have already learnt about. ■

Some names in this article have been changed.

Further information

If you would like to discuss any issues arising from this article please contact:

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The full Recognising Fathers report can be downloaded from:

www.learningdisabilities.org.uk

and a pamphlet summarising the key findings and recommendations is also available on the website or from

Email: customerservices@mhf.org.uk

References

Foundation for People with Learning Disabilities (2005) *First Impressions. Emotional and practical support for families of a young child with a learning disability: a guide for practitioners and service commissioners*. London: Foundation for People with Learning Disabilities.

Herbert E and Carpenter B (1994) Fathers – the secondary partners: professional perceptions and a father's recollections. *Children and Society* **8** (1) 31–41.

Hornby G (1992) A review of fathers' accounts of their experiences of parenting children with learning disabilities. *Disability, Handicap and Society* **7** (4) 363–374.

O'Brien M (2005) *Shared Caring: Bringing fathers into the frame*. Equal Opportunities Commission working paper number 18. Norwich: University of East Anglia.

West S (2000) *Just a Shadow: A review of support for fathers of children with disabilities*. Birmingham: Handsel Trust.

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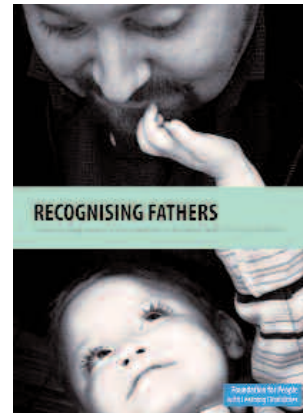
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Let's not forget about fathers: article summary

The Foundation for People with Learning Disabilities did some work to learn about fathers who have a child with a learning disability.



We talked to fathers in England and Wales.



They told us that they liked to help their children to have choices and take part in things. They also told us that they enjoyed going out and about with their children.



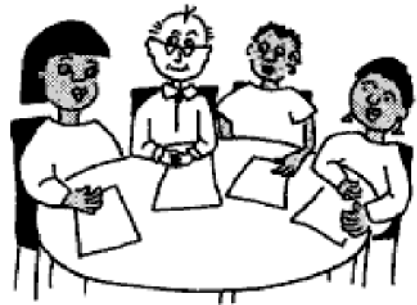
Fathers said they sometimes felt cross because people whose job it is to help families did not talk to them and did not make them feel included.



They wanted to be included because it helped their children and all of the family.



The Foundation for People with Learning Disabilities wrote ideas about how to include fathers in meetings and events.



If you would like more information on 'Recognising Fathers' please go to the website:
www.learningdisabilities.org.uk



Pictures are from the CHANGE Picture Bank CD-rom and book; for details visit www.changepeople.co.uk