

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.

Recognising Fathers:

understanding the impact of having a
child with learning disabilities

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**Foundation for People
with Learning Disabilities**

Background: First Impressions

First Impressions (FPLD 2004)
found men were often
marginalised in the process of
providing care and support



'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'

(a mother speaking about her partner's experience following the birth of their child with Down's syndrome)

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Background: Fathers & Children with Disabilities

- Little research or good practice guidance in UK on fathers of children with disabilities: focus on children, mothers and parents.
- Described as 'hard to reach' (McConkey, 1994), 'the invisible parent' (Ballard, 1994), 'just a shadow' (West, 2000)
- In last few years growing interest in fathers of children with disabilities (Social Care Institute of Excellence, National Deaf Children's Society, Fathers Institute)

Context: Fathers and Social Policy

Growing recognition in children and family policy in the UK of the need to engage fathers in their child's upbringing:

- Introduction of paternity leave (2003)
- Programmes and guidance to involve fathers generally e.g. Department for Education and Schools, Engaging Fathers: guidance to involve fathers in schools (2004), SureStart Programmes were given targets to engage fathers in early years setting
- The Children's Plan: Building Brighter Futures (2007) stresses 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'

Desired Outcomes for the 'Recognising Fathers' Project

- Recommendations for national and local policy and practice
- Improved support for fathers to enable them to be involved in their children's lives
- Contribute to the understanding of the lives of families when they have a child with learning disabilities



Method

- Advisory Group
- Literature review
- In-depth interviews
- Feedback - national conference (included fathers)
- National survey

Aims

Interviews:

Explore the experience of fathers of children with learning disabilities

Survey

Investigate further the experience of fathers of children with learning disabilities

Test out and validate findings from interviews

Clarify fathers' needs, especially unmet needs

Data Collection

Interviews

21 fathers

England and Wales

Children up to age of 11

Biological fathers

Survey

251 fathers (173 online/ 78 by post)

UK wide

Children up to age of 19

Biological fathers, foster or adoptive fathers, stepfathers

Fathers not living with their children

Main Issues

Findings from Interviews and Survey

- Fathers' involvement in their children's lives
- Support from family and friends
- Contact with services
- Impact on health and support to look after health
- Impact on paid employment and support with employment

Involvement in Children's Lives

- Wanting to be involved in daily routines – but related to availability if in paid employment
- Specific care tasks- such as support with continence issues, medical interventions- taking their share
- Involvement often not recognised by practitioners because it happens outside of service hours

Involvement in Children's Lives

- 60% felt they made more effort to be involved because of their child's disabilities
- Main reason given for their involvement: 'I enjoy the company of my child'
- Most fathers (77%) satisfied with type of activities involved in
- Under half (46%) were satisfied with amount of time- main preventative factor was 'work'



Support from Family and Friends

- Fathers find it hard to think of themselves as having support needs
- Partners seen as main source of support-implications for mothers and for separated or lone fathers
- Some members of extended family find it hard to accept child with learning disabilities
- Sometimes difficult to sustain existing friendships or develop new social networks – specific support for fathers often seen as beneficial

Support from Family and Friends

‘(My friend) will listen, but he’s so far removed, his world is so completely different to mine that I can talk to him but I don’t feel it’s a sort of outlet really... the release I need.’

“I’d talk to my mother more than my dad....my dad loves him to bits but he just can’t understand him at all. It’s a horrible thing to say but he’s a bit alien to my dad’

‘It tends to be the mums who know each other’

Contact with Services

- Attendance and involvement at education, health and social care appointments and reviews was variable: some fathers welcomed and given the information they need
- Not so positive about informal contact with practitioners:
 - Few opportunities to talk to practitioners as services operate in working hours
 - Practitioners make more effort to speak to mothers
- Indications that fathers from lower socio economic groups have more of a struggle to be shown respect and be included

Contact with Services

Fathers wanted services to change their practice to be more inclusive towards them and gave practical ideas:

Acknowledgement that 'as a father my responses might be different from the responses of my wife'

'Appointments at more convenient times i.e. outside work or at the start or end of working day rather than in the middle'

'Recognise that fathers not living with their children still want to be involved in their lives'

Impact on Health

- Fathers experiencing wide range of physical and mental ill health
- Biggest problem identified was stress and stress related illnesses
- Receiving very little support to look after their health – family doctors don't see them as parent carers
- Not taking care of their own health- not exercising, poor diet, smoking and drinking excessively

Impact on Health

- 93% experienced stress (41% most of the time)
- Greatest cause of stress- 'worrying about my child's future' (86%)
- 50% felt their physical health had been affected
- 66% of fathers said that their GP or other health workers never talked to them about their health needs resulting from being a parent carer

Support With Looking After Health

- Almost half (45%) said they needed more help to look after their health:

‘A regular check-up initiated by my doctor without my having to justify myself’

‘Someone not personally involved to talk to just to voice my fears and worries and blow off steam’

‘Just need time to get more exercise, play more sport. So need more respite care/ babysitting services’

Impact on Employment and Income

- Fathers made a variety of changes to their employment to help them to combine paid work with caring responsibilities
- Lack of support and understanding at work led to significant changes, such as, leaving work, changing nature of work or being demoted as well non uptake of career opportunities
- These changes often resulted in loss of income – long term impact including pensions.

'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'

Impact on Employment and Income

- 45% had changed their pattern of work e.g. become self employed, moved to or from shift work
- 39% changed type of work
- 25% left a job
- 49% experienced loss of income (main reason 'loss of career opportunities as not able to work as flexibly as required')
- For 28% this loss of income left the family struggling

Support in Paid Employment

- A supportive or understanding employer – minor adjustments had a big impact
- Flexibility in hours was highly valued - allowed men to be involved in daily routines, attend meetings, and take time off when their family needed extra support
- Indications that it was harder for fathers from lower socio economic groups to get flexibility at work
- Legislation in place to support family carers in employment – but low take up as not known about and reluctance to use it

Support in Paid Employment

- 46% said they could be very open with their employer (13% not at all open)
- 66% had either regular or occasional arrangement to gain more flexibility (34% never)
- 55% of fathers felt their employers very supportive to enable them to attend meetings (17% little or no support)
- 25% unaware of their entitlement to unpaid parental leave
- 56% unaware of entitlement to request flexible working
- Only 13% been provided with information about above entitlements

Conclusions

- Lack of recognition of fathers' caring responsibilities by support services, family doctors and employers leads to feelings of exclusion, stress or anger
- Lack of support and flexible practices in employment can reduce fathers' capacity to earn
- Fathers are experiencing a high level of physical and mental ill health – impacts on capacity to work and increases likelihood of poverty

Conclusions

- Fathers from lower socio economic groups may find it harder to get support in their caring roles from education, health and social care services and by employers
- Sustaining involvement of fathers could lead to improved life long outcomes for children with learning disabilities

Implications for Policy and Practice

- Education, health and social care agencies develop practices that engage fathers
- Family doctors and other practitioners talk to fathers about their health and provide preventative health care
- Agencies provide information to fathers about their rights at work and advice to combine paid work with caring responsibilities
- Fathers from lower socio economic groups may need specific interventions to help them combine employment and caring roles

Further Research

- Learn more about the factors that support fathers to be engaged in their children's lives and those that lead to disengagement by exploring this with fathers, including those who have left the family situation or are not involved in their child's care
- Share findings with similar studies from other countries to learn about impact of different policies and practices towards fathers with children with learning disabilities

References

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Further Information About 'Recognising Fathers'

Full report and summary from first stage of research are available on FPLD website

www.learningdisabilities.org.uk

Report from national survey available on website in November 2008

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