

Summary

In the past few decades there has been an increasing interest in the role of fathers within families and a growing understanding of the substantial benefits to children, as well as mothers, of their involvement. This briefing focuses on the experiences of fathers who have children with learning disabilities and the approaches that could make it easier for them to be involved parents. This knowledge results from the 'Recognising Fathers' research project, carried out by the Foundation for People with Learning Disabilities since 2005.

The briefing suggests how current policy initiatives and service delivery programmes could include specific consideration of fathers. The findings indicate that fathers need to be recognised, especially by employers, family support services and GP practices, as significant carers. The current lack of recognition leads to fathers struggling to combine paid employment with caring responsibilities and to look after their health. Greater awareness of the experiences of fathers would contribute to improved outcomes for children with learning disabilities as well as other family members.

Introduction

This briefing describes the experiences of fathers who have children with learning disabilities and the factors that shape these experiences. It is based on applied research carried out by the Foundation for People with Learning Disabilities (Towers, 2009; Towers and Swift, 2006), which involved in-depth interviews with 20 fathers, a national survey involving 250 fathers, a literature review and discussions with practitioners and organisations working with fathers and families. Most of the fathers participating in the research lived with their partners, although small numbers of separated, divorced, single and widowed fathers were also involved. A small number of adoptive, foster and stepfathers also participated.

This briefing is aimed at commissioners, service providers and practitioners in children and family services as well as policy makers with responsibility for family carers and for disabled children and their families.

Background

The experiences of fathers whose children have learning disabilities are shaped by the changing nature of families with disabled children 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). Studies have identified many factors faced by families bringing up disabled children, including inadequate housing, poverty and diminished employment opportunities (Joseph Rowntree Foundation, 1999; Emerson and Hatton, 2004).

The need to acknowledge the contribution of fathers of disabled children should be viewed in context: there is 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 by 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." Yet it is still the case that support services for families focus primarily on the needs of mothers and are predominantly provided by women. In order to change this situation, the Government has introduced, over the past decade, a number of initiatives aimed at engaging fathers, including Sure Start and Early Support.

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.

The findings from the research are discussed within this broader context and suggestions are made for action within policy and practice. Percentages and other statistics quoted refer to the results from the national survey.

Fathers' involvement in their children's lives

The 'Recognising Fathers' project heard from many fathers who had a strong sense of involvement in providing care and support for their child and who also had a shared sense of responsibility with their partner, or ex-partner if separated. Fathers were more likely to be in paid employment than mothers, but even when this was the case, or both were working, fathers were adapting their work arrangements so that they could take on more care responsibilities.

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. This trend is also apparent amongst fathers with non-disabled children (EOC, 2006) but, interestingly, 60% of fathers in the survey felt they made more effort to spend time with their child because of their disabilities. When asked about their motivation for spending time with their child, fathers said their main motivation was that they enjoyed their children's 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 resulting from having a child with disabilities.

This involvement often seemed to go unrecognised by practitioners, employers and support services and it was apparent that many practitioners, spoken to independently, viewed fathers negatively.

Relationships with family and friends

Research has shown that having a child with disabilities can place additional pressures on partner relationships (Contact a Family, 2003) and that there is a higher risk of separation when compared with families without a disabled child: this is particularly apparent in the early

years (Clarke and McKay, 2008). In the survey fathers identified their partners as an important source of support, with over 75% describing partners as their main support. This may be experienced as mutual support or it may be the case that mothers experience this as an additional pressure. All these factors highlight the need for additional support so that couples are able to have time together away from their caring responsibilities as well as the need to be able to access relationship support. A good practice review should be carried out to identify what helps to sustain partner relationships and guidance should be provided to practitioners in universal and specialist services.

Many of the fathers who participated in the research described fairly limited support networks across their extended family and friends and less than half had got to know other fathers who had children with disabilities. Almost 40% of fathers did not have a good friend they could talk to about their situation and fathers said that they would like more opportunities to participate in events and activities that were for fathers with their children. Support networks can be vital to sustain parents in their caring roles and therefore these findings indicate that family support services should provide more opportunities for fathers to link with one another.

Fathers' contact with services and involvement in decision making and appointments

Fathers identified the importance of being able to attend meetings and appointments about their children and of being included and shown respect by practitioners in both formal and informal settings. The research showed that they wanted to attend meetings so that they could: participate and contribute to discussions and decisions about their children; share the responsibility, with mothers, of understanding and retaining often complex and detailed information, and have the opportunity to fight for resources for their children. When compared with research from previous decades (West, 2000), the 'Recognising Fathers' research showed that services were developing more opportunities for fathers to attend and participate in meetings. However, this was not consistent and some fathers, especially those from lower socio-economic groups, felt they were unwelcome and treated disrespectfully at meetings.

There was also evidence that fathers experienced a lack of support and poor involvement at the time of diagnosis: this early involvement may be particularly significant in that it can lead to fathers being valued right from the start and this can help to form longer

term bonds and commitment to their children. Midwives and paediatricians need to give fathers equal support to mothers in coming to terms with a diagnosis.

The Foundation has produced good practice guidelines on arranging meetings, appointments, reviews and home visits in such a way as to maximise the opportunities for both parents to be involved (Towers, 2009). In addition, services should consider how they can provide more informal opportunities for fathers to have contact with staff and other parents (Carpenter and Towers, 2008). Knowledge about what works for fathers could be developed further if the DCSF commissioned work to identify existing good practice in relation to involving and supporting fathers of disabled children; this should then be disseminated to all Children's Trusts to develop the knowledge and skills of practitioners.

The impact on fathers' health and what helps

The national survey provided evidence that fathers were experiencing high levels of stress, with 41% saying they experienced stress most of the time and an additional 52% saying they sometimes experienced stress. In addition, half of the fathers felt their physical health had been affected and many described a strong interplay between stress, mental ill-health and physical ill-health.

It was also apparent that fathers were receiving very little help with looking after their health, with 66% saying that neither their GP nor others ever asked them about their health in relation to being a carer. Almost half said they needed to receive more help, especially those on lower incomes. There are a number of recommendations from the research that aim to address these issues. First, 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 their child, with the purpose of ensuring that GPs and other health practitioners are aware of parents' caring responsibilities. Second, the Carers Strategy (DH, 2008) prioritises the need to look after the health and well-being of carers and we suggest that this should include fathers, even when their partner is the main carer. The health needs of fathers and approaches that work for them need to be understood.

The Carers Strategy also identifies the need for carers to receive annual health checks and we suggest that both mothers and fathers should receive these checks, which should cover mental and physical health. Again, these should not be dependent on the father being identified as the main carer. In addition, fathers who take on caring roles for their disabled children should be provided with

skills and knowledge in maintaining their health and well-being and this could be disseminated through peer training.

The impact on paid employment and what helps

Families with a disabled child are often able to have only one earner, usually the father, and this can cause considerable pressure to maintain employment and income. The research showed that fathers were making significant changes to their work, such as reducing hours, becoming self-employed, changing their type of work and stopping work altogether. The main reason for these changes was the need to have flexibility in their employment in order to be involved in their child's care. Almost 50% of fathers participating in the survey said they had experienced a loss of income as a result of having a child with learning disabilities and a third of these said the loss had 'left them struggling' financially. This loss of income can have a cumulative effect over fathers' working lives and into retirement and adds to the impact on the family of the additional costs of having a disabled child.

In recent years legislation has been introduced to support carers in their employment, but in the research we found that fathers were not taking advantage of these entitlements. Over half of the fathers were not aware that they were entitled to request flexible working: only 15% of fathers completing the survey had used it to gain flexible working arrangements. In addition, 75% of fathers were not aware that they were entitled to unpaid parental leave: less than 6% had used this entitlement.

The research indicated that this low take-up is related both to the lack of recognition of fathers as carers by employers and to the poor information they receive to support them in their employment. The Carers Strategy makes a number of proposals for better support to carers to move into and maintain their employment as well as to develop their careers: the implementation of these proposals provides an opportunity to ensure that Jobcentre Plus, human resources departments and employers in SMEs (Small and Medium Enterprises) support fathers of children with disabilities to combine employment with caring responsibilities. 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 disabled children in order to identify how appropriate uptake could be increased, including any improvements to the regulations to make them more effective for families with disabled children.

Conclusions

Fathers of children with disabilities can contribute enormously to family life and improve outcomes for their children and the rest of the family. It is therefore vital that DCSF policy initiatives continue to reinforce the need - within education, health and social care - to include fathers as well as mothers and to ensure they gain the skills and knowledge they need to feel confident in their caring role. It is also necessary for policies across Government departments, including DH and DWP, to have a joined-up approach to considering the specific needs of fathers of disabled children in relation to employment support, benefits and pensions. Similarly, a joined-up approach is required to respond to the health and well-being of fathers in order to sustain them in their wage-earning and caring roles. Research and development initiatives with fathers need to continue with the long term aim of improving outcomes for children with learning disabilities and their families.

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Further information

The full report, 'Recognising Fathers: a national survey of fathers who have children with learning disabilities' and the earlier report 'Recognising Fathers: understanding the issues faced by fathers of children with a learning disability' can be downloaded from the Foundation's website.

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