NEW WRITING

Opinion

Christine Towers



Christine Towers is Research and Service Development Manager at the Foundation for People with Learning Disabilities. Since 2005, she has worked at the Foundation on a research project about the experiences of fathers of children with a learning disability. Christine previously worked with the Foundation as an Associate on research projects examining the 'Modernisation of Adult Social Care and Direct Payments' and the 'Impact of Person Centred Planning'. In her work at the Foundation, Christine focuses on fathers of children with a learning disability, developing support for older family carers and people with learning disabilities living with older family carers, managing change within service delivery with a particular interest in day-time opportunities, and service evaluations.

Summary

The Foundation for People with Learning Disabilities has found through its research that fathers of children with learning disabilities can feel excluded from health and social care services set up to support their children. Fathers often play a major role in the care of their child/children, but feel practitioners do not always appreciate their contribution or needs. Feeling disengaged can affect family relationships and lead some fathers to develop emotional problems as a result of stress. The Foundation has developed guidelines and recommendations on ensuring that fathers feel involved and engaged.

Recognising Fathers: The experiences of fathers who have children with learning disabilities

There is a very big difference in the way that services treat men and women.

A father

Research by the Foundation for People with Learning Disabilities (called the Foundation from now on) has found this to be a recurring theme when fathers and mothers talk about education, health, social care and family support services for children with learning

disabilities. The father who offered this opinion is one of many who feel practitioners see them as secondary players in their children's care.

The Foundation has undertaken extensive research into the role fathers play within families where there is a child (or children) with a learning disability. The research, called *Recognising Fathers* (see references 1 & 2 below) set out to document the roles that fathers play in family life, and found that fathers are often heavily involved in all aspects of their child's care. However, it appears that practitioners often overlook this, regarding mothers as the main care provider and treating them accordingly.

For example, the majority of care meetings take place during office hours when fathers tend to be working. The research heard that some practitioners seem surprised when fathers attend. One father said that he felt practitioners were uncomfortable when he attended review meetings. This was sometimes the reaction even when the father was the main or sole carer. If a father is unable to attend meetings, their partner/wife may be given information about their child's condition that the father is not offered. This can lead to the father feeling undermined because his partner is acknowledged as the 'expert' on their child. There may also be times when fathers are not encouraged to participate in activities that help them to bond with their child; the research heard from one father who was not encouraged to attend Makaton classes. This made it harder for him to learn and understand about his daughter's communication needs and thus build a closer relationship with his daughter.

Parents of children with learning disabilities are under significant amounts of pressure and need all available resources to flourish, including the commitment of both parents where possible. There is a high level of marriage breakdown within families where there is a child with a learning disability, especially within the first three years after birth. Fathers' feelings about their value within the family are likely to be a causal factor. If they feel excluded and that their contribution is perceived as less important than that of the mother, there is a risk that they will disengage. Valuing fathers' contribution and encouraging their involvement could lead to a more supportive relationship between fathers and their children.

Practitioners need to recognise that fathers in employment can also be under a lot of additional pressure. Employers tend not to be sympathetic towards men as carers and the implications this has for needing flexible working or time off. One father, who asked to leave work to collect his son from school following a seizure, was asked, 'Why can't your wife go?'. Fathers are often torn between the need to earn and the desire or need to provide care and support. The strain of juggling responsibilities as both a father and a breadwinner can result in debilitating stress, which in turn can lead to men leaving paid work or taking jobs with less responsibility.

The potential for mental ill health among families of children with learning disabilities, brought about by the additional stress of the caring role, is recognised. Here again though, emotional support tends to be focused on the mother. Additionally, many of the fathers who participated in the research admitted they felt obliged to be the strong, 'macho' one, and not confess to experiencing mental ill health as a result of stress or to needing emotional support.

There is a lot that practitioners can do to prevent fathers from feeling excluded, to build their confidence in their parenting role and to make them feel valued for their contribution to their child's life. A key part of this is to arrange review meetings and appointments about their child so that fathers can attend. This may require greater flexibility when scheduling meetings but it may simply be a case of talking to parents about what would work best for them. The

Foundation has produced guidelines for practitioners about including and involving fathers in meetings (see reference 3 below). Fathers have said that it would be helpful if practitioners were aware of practical and emotional support that is available to fathers locally and nationally, and signposted fathers to this. This could include information about their rights at work or how they could get support to look after their health. Fathers are also appreciative when an organisation or support service offers something specific for fathers. This encourages them to come along, makes them feel welcome and provides an opportunity to meet other fathers.

Overall, services need to find 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. Children with learning disabilities deserve the support of their fathers. Fathers need more recognition and more support in their role.

For further information, including reports and practitioners' guidelines, about the Recognising Fathers work, visit www.learningdisabilities.org.uk/fathers

References (All from the Foundation):

- Recognising Fathers: Understanding the issues faced by fathers of children with a learning disability (2006).
 http://www.learningdisabilities.org.uk/publications/?entryid5=32902&q=0%C2%ACrecognising+fathers%C2%AC
- 2. Recognising Fathers: A national survey of fathers who have children with learning disabilities (2009).
 - http://www.learningdisabilities.org.uk/our-work/family-support/fathers/
- 3. Ideas for practitioners in education, health, social care and family support settings to involve fathers in meetings and appointments about their children with learning disabilities (2009)
 - http://www.learningdisabilities.org.uk/fathers/