



Fathers with learning disabilities and their experiences of adult social care services

Being a father was important to all fathers in the study; they had a strong desire to prove people wrong about their perceived abilities as men and as fathers

Practitioners should be mindful of the high probability that fathers with learning disabilities have experienced discrimination throughout their lives

Fathers spoke about the stresses of being a parent which sometimes had a direct impact on their mental health. They need to be included in family-focused social care practice

Fathers rarely received support for their parenting and felt that they were left out of support provided to mothers. Practitioners should insist on referral information about the father to help to talk to him separately about his role in the family and needs for support

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BACKGROUND

With the right support, parents with learning disabilities can bring up their children in a caring and loving environment, but how this support is best provided is debated. Good practice guidelines recommend that adults' and children's services are joined up to support parents with learning disabilities, and Think Family guidance recommends that adults' as well as children's services should work with family members to improve outcomes for children. The Care Act 2014 recently introduced an eligibility outcome for adults in relation to their caring responsibilities for a child. However, most of what is known in this field focuses on and reflects the experiences of mothers.

The research reported here focused on fathers with learning disabilities to hear their own experiences of being fathers and their experiences of adult social care services. To understand some of the issues related to practice, we also spoke to practitioners in adult learning disability services about working with fathers.

THE AIMS OF THE STUDY WERE TO:

- Understand learning disabled men's experiences of being fathers
- Gain insight into learning disabled fathers' experiences of accessing adult social care services
- Investigate the experiences of adult care practitioners in providing services to learning disabled fathers including how they work with their counterparts in children's services
- Identify how practice can be improved to best meet the needs of learning disabled fathers.

STUDY METHODS

Eight fathers were interviewed for the study, recruited through social media, advocacy organisations and the network.

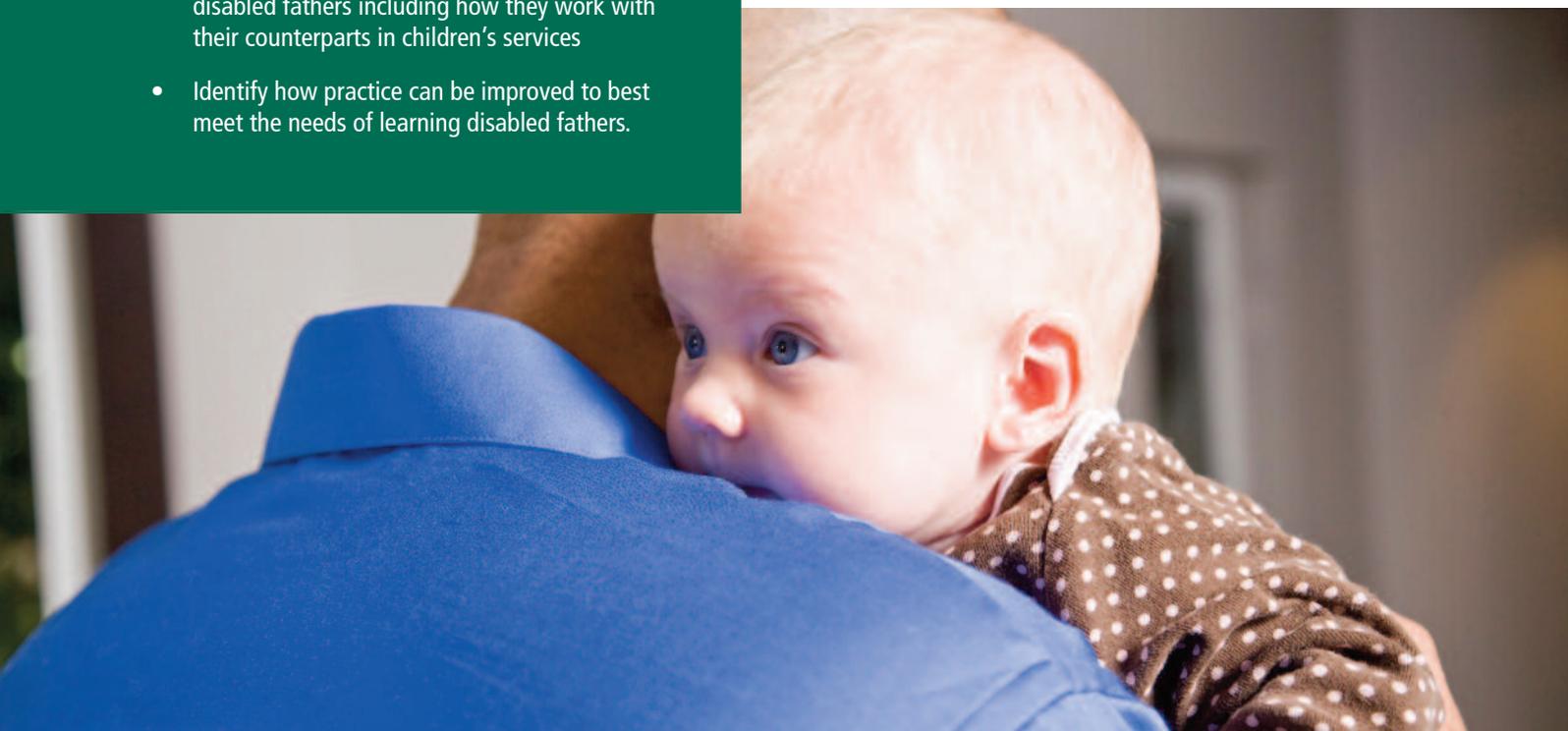
The ages of the fathers ranged from 26 to 60 years. They had 18 children between them and three of them had become grandfathers.

Four men brought up their children in a married, two parent household. Two men had separated from the children's mothers, but had ongoing contact with their children. One man had separated from the mother and had only supervised contact with their children. One man had separated from the mother during the pregnancy and their child had been adopted shortly after birth (he maintained letterbox contact).

Nine practitioners were also interviewed from three different adult learning disability services. They worked in different parts of the country from the fathers to avoid them recognising each other in the findings.

The study took place between October 2015 and November 2016 and was based at the School for Policy Studies, University of Bristol. Dr Daryl Dugdale and Dr Jon Symonds worked on the project supported by Professor David Abbott and Beth Tarleton who coordinates the Working Together with Parents Network.

They also worked with four fathers with learning disabilities from the Elfrida Society who acted as consultants to the study, giving advice on the easy read versions of materials and the topic guide.



FINDINGS



The fathers we spoke to had experienced little support in their role as a father, a situation confirmed by practitioners in the study who had little experience of working with fathers. This lack of contact is in spite of evidence from fathers' accounts that spoke of challenges they faced through having a learning disability, having periods of mental illness and/or facing discrimination in their lives.

With rare exceptions, the fathers in the study had poor experiences in childhood. Three men had been brought up by both parents, but five spoke of being brought up mainly by their mothers because their own fathers were emotionally unavailable, absent, or hurtful:

'My real dad thought me, the only son ... were a let-down because I've got a learning disability. He thought I weren't man enough.'

All but one father said their experience of school (mainly special schools) were of being bullied or told they could not do anything. Involvement in extra-curricular activities, such as a local scouts group, provided a strong sense of support, inclusion and identity for some men in the study.

These negative experiences continued into work where routes into employment were difficult to achieve and could be tainted by being bullied in the workplace.

Several men spoke of the importance of proving people wrong and defying others' low expectations of them in relation to work and family. Two men had built successful career pathways through self-advocacy work and one was a self-employed property owner.

None of the men felt prepared to become a father and most described the event as a surprise. However, this was followed by feelings of excitement, fear and plans to prepare for fatherhood. The experience of being at the birth was a profound event in their lives.

The men described a full range of fathering activities that they were involved with from changing nappies, setting boundaries, being at the school gates and providing emotional support:

'My youngest boy, because he was very close to [his grandparents], so he took it hard [when they died]. So I literally explained to him, I – because he used to cry every night. So I used to say, "Look. Look out the window. See that bright star there? That's nanny and the other one next to it is granddad."'

Fathering with a learning disability also presented challenges for some fathers in relation to their own skills in talking calmly to their children, or difficulty in reading bills or letters about benefits or the children's school.



FINDINGS

Four men spoke of the impact of these challenges on their mental health. Three spoke of being admitted to psychiatric hospital due for reasons such as having thoughts of suicide following a child going into care or having a nervous breakdown because of the pressures of parenting alone. When fathers were in couples, their poor mental health also, inevitably, placed strains on the parental relationship:

'[I struggled with the] sleepless nights...I had a nervous breakdown. And my wife actually left for six months.'

Fathers gained support in their role mostly from female members of their family, mainly their own mothers, but some also spoke of grandmothers and sisters. Advocacy organisations were particularly supportive and some fathers spoke positively of going to parenting support groups.

The men had little experience of statutory support for their parenting because of high thresholds in adult social care which focused on their housing, finance and independent living skills, but did not provide or arrange parenting support. Children's services were viewed by the men as unnecessarily focused on investigations of suspected harm and when support had been offered, it was given to the mother to provide emotional and parenting support. To a greater or lesser extent, all fathers felt excluded by this:

'And I felt like what do I do? Am I a spare part or what?'

Most practitioners recognised that fathers were not routinely engaged by services. Practitioners suggested reasons for this such as that fathers with learning difficulties are sometimes perceived as more 'lazy' than mothers and less likely to contribute, or that they might be perceived in terms of the potential risk they represent. There was wide agreement that services focus on the mother as the 'primary carer'.

Most practitioners viewed their role as supporting the adult, but not in their parenting role which was viewed as the responsibility of children's services. Only one was aware of the outcome in the Care Act that related to an adult's caring responsibilities for a child.

Practitioners regularly spoke of the challenges in working with colleagues from children's services whom they characterised as only being able to deliver short-term interventions which were not sufficient for parents with learning disabilities. Practitioners in adult social care services valued being able to sustain a working relationship with service users over a significant period of time.

Examples of successful practice with fathers with learning disabilities included a manager who had experience in both children's social work as well as adults and therefore knew the systems and people in order to negotiate support.

Two mental health practitioners described extended pieces of work supporting fathers to maintain contact with their children through court proceedings or contact sessions. Both pieces of work were inextricably linked to the men's identities as fathers, even though the focus of the referral and the practitioner's background was mental health.



CONCLUSIONS & RECOMMENDATIONS

The fathers in this study expressed the full range of emotions, tasks and challenges that face other parents in caring for their children and they placed great importance on their identities as fathers.

For most fathers in the study, their experience of learning disability was associated with discrimination at school, in preparation for relationships and in some cases from their own fathers. When these men became fathers themselves, they felt largely excluded by services that focused on providing practical and emotional support to the mother. Combined with the stresses of parenthood, this sometimes resulted in these men experiencing serious mental illness.

For these needs to be addressed, local authorities should consider their Think Family framework to inform how parents with learning disabilities, including fathers, can be supported in caring for their children.

At a practice level, adult social care services should identify who the father is at the point of referral and engage him in conversations about his emotions on becoming a father, on being a father and how he can best be supported to manage the practical tasks of parenthood.

Nine years after the *Good Practice Guidance on Working with Parents with a Learning Disability* (DoH/DfES 2007¹, University of Bristol 2016²), this study found continuing gaps in how social care services are coordinated, one of the consequences of which was that fathers with learning disabilities were almost invisible in the work. For their needs to be met and for their children to flourish, fathers with learning disabilities need to be included in family-focused social care practice.

Further research should investigate successful examples of how this has been achieved for dissemination more widely and to inform future policy on this topic.

¹ Department of Education and Skills & Department of Health (2017) *Good Practice Guidance on Working with Parents with a Learning Disability*, The Stationery Office, London.

² University of Bristol (2016) *Working Together with Parents Network (WTPN) Update of the DoH/DfES Good Practice Guidance on Working with Parents with a Learning Disability (2007)*, University of Bristol, Bristol.

COMMENT

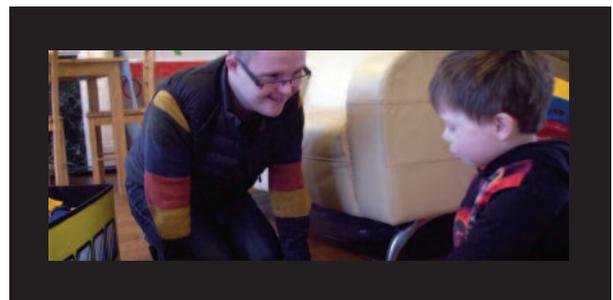
Fathers with learning disabilities face particular challenges. This is the first study in England to explore them. At the Elfrida Society we've been working with parents with learning disabilities for more than 20 years. Existing support processes aren't accessible and aren't made accessible for parents with learning disabilities. As a group they are quite marginalised in themselves, and then the fathers even more so. We need to ensure that social workers are taking that much more time to understand what learning difficulty the parents might have; more time and money is needed for that extra support.

This study raises important implications for support for fathers with learning disabilities, and highlights the need to coordinate support for these fathers across adults' and children's services.

Ali Jabeen
The Elfrida Society

'Being a father with learning disabilities is hard, and it's difficult to get people to listen to you and take you seriously. For us, a learning disability is not a loving disability. Some of us do hide our learning difficulty because we're frightened that people will say or think we're daft or silly. We know what we're saying but have to explain that to others. Practical and emotional support focuses on mothers, but ignore fathers. The same support is needed for fathers. This study shares what we need as fathers in our voice'.

Kevin and Sandy, Research Consultants
(fathers with learning disabilities)



Watch the video at
www.sscr.nihr.ac.uk/projects/p76.php



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