

Recognising fathers: the needs of fathers of children with disabilities

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In this article, the authors aim to develop a better understanding among practitioners of the issues faced by fathers of children with a learning disability, and suggest how schools can involve the parents who are regarded by many as 'hard to reach'. They recontextualize the roles and perceptions of fathers in the light of outcomes from the recent 'Recognising Fathers' report published by the Foundation for People with Learning Disabilities.

Following an introduction to Government policy and literature relating to fathers, the outcomes of semi-structured interviews conducted with 21 fathers in the course of the 'Recognising Fathers' study are summarized in terms of the emotional impact, the roles and responsibilities, the impact on fathers' paid employment, support and father-practitioner interaction. The article concludes with practical suggestions for how practitioners might meet the needs of fathers in their own schools and provide them with an effective support network.

Keywords: fathers, research, roles, professionals.

Introduction

There is a growing interest in fatherhood in twenty-first-century Britain. In national family policy, there is recognition of the important contribution fathers make to family life and that strategies need to be developed to promote their involvement. The Green Paper, *Every Child Matters* (DFES, 2003), advocates a stronger emphasis on parenting and families, including an understanding of 'the vital role played by fathers as well as mothers'. 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 in public services including SureStart and Early Support. They have also supported the development of a national information centre on fatherhood called Fathers Direct (<http://www.fathersdirect.com>).

The needs of fathers of children with disabilities

When referring to fathers, in addition to considering biological fathers who are resident with their families, it is important to recognise the differing needs of those fathers who may not be resident with their children, as well as those of step and adoptive fathers. Research around the needs of fathers of children with disabilities has been infrequent (Gavidia-Payne and Stoneman, 2004) and usually focused upon biological fathers who live with their families.

Fathers have been identified by researchers in this field as 'hard to reach' (McConkey, 1994), 'the invisible parent' (Ballard, 1994) and the 'peripheral parent' (Herbert and Carpenter, 1994). Sheila West (2000), based on her research, described them as 'just a shadow', where, generally, fathers felt that the support systems that were in place were beneficial to their partners, but not to them. They identified that improved support, information and the opportunity to access services would enable them to be much more involved with their children. Carpenter and Herbert (1997) observed that fathers found it difficult to assert their involvement: neither health and education professionals nor employers recognised the need of the father for inclusion in the family situation. Fathers were forced by professional structures and social expectations to fall back on the nineteenth-century, stereotyped role of protector, of being competent in a crisis, yet emotionally uninvolved.

In families of children with disabilities, mothers and fathers can react differently to the news that their child has a disability or special need (Fidalgo and Pimental, 2004).

Emotional reactions by fathers to the birth of their child with a disability vary (Rendall, 1997). Meyer (1995) tells how the birth brings about life-transforming experiences. For some fathers, it is a challenge that allows them to display aspects of their personality not previously acknowledged. For others, it causes stress, disorients their life goals and affects their work patterns. Many fathers in the New Zealand study, *Perilous Passage*, spoke of their almost immediate worry about their child's long-term future (Bray, Skelton, Ballard and Clarkson, 1995). This study also reported that fathers consumed more alcohol more frequently as a way of dealing with their emotional trauma.

While family members may look to the father for support at this time, his own needs often go unrecognised by professionals (Social Care Institute for Excellence, 2005). Throughout all these studies, the provider/breadwinner role of the father is central, a finding confirmed by Contact a Family (CAF) in their investigation (CAF, 2005). However, a recent report from the National Deaf Children's Society (NDCS) stated that fathers of deaf children actually believe they are overlooked by service providers (NDCS, 2006).

'Recognising Fathers' research

In 2005, the Foundation for People with Learning Disabilities (FPLD) began a research project to look at the issues faced by fathers of children with a learning disability (Towers and Swift, 2006). The purpose of the project was to raise awareness of fathers as significant carers and to identify how policy and practice could be changed to improve support for fathers and thereby families as a whole.

In the previous year, the FPLD had carried out a project, *First Impressions* (FPLD, 2005), which looked at the needs of families during the first five years of life following a baby or young child being diagnosed with a learning disability. The findings suggested that fathers were often marginalised by services in the process of arranging care and support for their children. Compared to mothers, fathers' support needs were overlooked and men often had less of a support network than their partners. 'Recognising Fathers' was commissioned to investigate these issues and develop a broader understanding of fathers' experiences.

Methodology

Following a search of relevant literature, and research and discussion with organisations providing family support, it was decided that the main method of data collection would be in-depth interviews with fathers of children up to the age of 11 years. This age was chosen as it would capture experiences in the early years, through primary school and include preparation for transfer to secondary school. The option to interview mothers also in order to provide a comparative perspective was considered, but there was a strong sense that fathers' voices were so rarely heard that the

resources needed to be directed at them and that their views should stand alone and be accepted.

The sample

The researchers aimed to interview a group of fathers embodying as much variety of life experience as possible, and therefore selection criteria were set that would help them to identify this diversity among potential study participants. These criteria focused on the fathers' family unit type, socio-economic profile, employment activity, regional location, ethnicity and age of the father, age and diagnosis of their children and their level of contact with support services.

A combination of sampling approaches was used to recruit participants. Publicity about the study was produced and disseminated using the FPLD's website. A leaflet was distributed via learning disability services and national organisations, and information was placed on various forums and in newsletters. Direct contact was also made with a number of existing fathers' groups. As this generated a purposive sample, it is not possible to claim that these fathers' views are representative of all fathers of children with a learning disability: the fact that the fathers in the sample contacted the FPLD, were present at a fathers' event or were suggested by a practitioner indicates that they were fathers who were involved in their children's lives.

Interviews

Twenty-one fathers were interviewed in areas of England and Wales using a semi-structured interview guide designed to encourage discussion through the use of prompt questions. This provided a framework for addressing four areas of fathers' lives: the roles that they take on to support their family; their employment; their networks of support; and their experiences of receiving support. Participants were given the option of the researcher going to their home or meeting at another place that would provide privacy and would be convenient for them. Interviews were arranged at times that fitted around their home and work commitments, including evenings and weekends.

The interviews usually lasted 60–100 minutes and, in addition, background information was collected. The interviews were recorded, and their transcripts were coded to identify the key themes and concepts: some of these were introduced through the interview schedule while others were introduced by the participants.

Research findings

The findings from the research have been set out in five main themes that emerged from the categorical content analysis: the emotional impact on fathers of having a child

with a learning disability; the roles and responsibilities of fathers; the impact of having a child with a learning disability on fathers' paid employment; how fathers get support; and the interaction between practitioners and fathers. The findings on support to fathers and interaction with practitioners are perhaps most relevant to those working in schools, but all the sections give an overview of fathers' experiences and set a context for schools when they are considering how to involve fathers.

Emotional impact

The semi-structured interview questions did not particularly focus on the emotional impact of the situation for fathers, so the fact that fathers spontaneously mentioned those issues seemed to indicate a willingness to talk about the emotional aspects of their experience. This would appear to contradict the widely held belief that fathers are uncomfortable discussing their feelings. Eighteen fathers described a close emotional bond with their child, and most of these also described the joy they got from this relationship. Over one-third of fathers indicated that their commitment to their child was stronger because of their disability. However, the pleasure they expressed in their child was often tinged with a sense of constant struggle, and fathers whose children were on the autistic spectrum were often frustrated by the difficulty of establishing a two-way relationship with their child. Almost all of the fathers described how difficult it had been to receive the news of their child's diagnosis, yet almost all appeared to have made a decision to 'get on with it' fairly rapidly and to be a support to their families.

Roles and responsibilities

One of the key areas for the study was to gain an understanding of how these men saw their roles and responsibilities as the father of a disabled child. Mothers are usually seen as being central to children's well-being as the primary caregiver, whereas fathers' roles are regarded as more peripheral to the caring role. Yet almost all of the fathers in this study described considerable day-to-day engagement with their children, although the type and intensity of the involvement varied. Indeed, three of the fathers were the main carers for their children. The reasons for this varied: one was a single father following the death of his partner; the wife of another was housebound due to ill health; and the other had developed an extremely close bond with his son and had taken on the main responsibility for his care and development.

Fathers also described their roles and responsibilities in relation to their partner and other children. Two-thirds of the men talked about how they worked closely with their partners. Two fathers, whose partners were not working, recognised how difficult it was for their partners who were at home all day with their young children who had complex needs. They tried to support their partners by fitting in

around them and helping out with 'whatever needed doing when they got home from work'. Fathers who share care responsibilities in this way may not be visible to practitioners as they are providing 'care' outside normal working hours when practitioners are in contact with the family.

Fathers in the study talked about their commitment to finding resources and advocating for their children. About two-thirds mentioned their involvement in their child's learning and development. Some were supporting their child's learning at home through reading, providing learning activities and help with homework. One father, who had had a negative experience of school in his own childhood, had been welcomed at his son's special educational needs early years service and had spent time observing how they taught his autistic son. Through this experience, he had learnt how to support his son at home and felt that it had helped him to understand and be more patient towards him.

Paid employment

One of the main ways in which fathers supported their families was through paid employment. There has previously been considerably more focus on the impact on women's employment patterns when they have a child with a disability. The extra caring responsibilities and the lack of suitable childcare are both factors that make it difficult for women to return to work. However, findings from this study indicate that having a disabled child also had an enormous impact on these men's working lives in terms of the choices of work they made, the loss of opportunities and earnings, and the struggle to get the flexibility they needed to combine employment and providing care. It was apparent that the fathers in the study were receiving little formal support to combine employment and care responsibilities such as being given time off for planned appointments or emergencies. This appeared to be easier for men who managed their own time – often those in higher socio-economic groups. Men in lower paid and less skilled jobs struggled more to gain the involvement they wanted without experiencing a loss of income.

Support for fathers

In order to identify the sources and types of support that were helpful to fathers, they were asked about the relationships they had with their immediate family, extended family, friends and the wider community. To gain a picture of whether they found services supportive, they were asked about their contact with services and organisations in both the voluntary and statutory sectors that were delivering a service to their child or offering parental support. Eleven fathers mentioned that they had not been asked about their support needs or been offered support. One of these men had strongly felt that he needed support as a father when his wife became ill and they were experiencing difficulties in their relationship.

When asked about what support they had received, fathers were most likely to mention the support needs of their children rather than their own. Ensuring their children's needs were met was in itself a source of comfort and support to them.

The support networks that fathers described were fairly limited. Most had a family member or friend they could talk to, but only three described a more comprehensive network of support across family, friends and neighbours. The main source of assistance identified by fathers was their partner, which corroborates findings from previous research (Salovita, Italinna and Leinonen, 2003), and took the form of talking things through together, sharing concerns and ideas, and trusting one another. This raises questions about the support needs of fathers who are lone parents or where the relationship is under pressure or has broken down.

Much has been written about the reluctance of men to engage with practitioners and services, but the findings from this study seem to indicate that fathers are keen to have contact where they feel this leads to improved outcomes for their children.

Interaction with practitioners

The level of involvement fathers had with services varied considerably – often depending on their age and the complexity of their support needs. Overall, there appeared to be two key issues that either facilitated or hindered men's involvement: having the time available to be in contact; and the ways in which practitioners responded to them when they were able to be present.

Having the time available was usually related to their employment patterns (such as shift work) or the flexibility provided by their employer, as contact with services tended to be during working hours of 9.00 a.m. to 5.00 p.m., Monday to Friday. Because of this, the main opportunities fathers had to interact with practitioners tended to be at meetings and appointments concerning their child rather than in informal settings. However, for fathers who were not working, or who had flexibility within their work, there was the opportunity to have informal day-to-day contact with services supporting their children, such as dropping-off times at playgroups and schools.

All of the fathers gave a high priority to attending meetings and appointments, although the difficulty of attending was frequently mentioned. Fathers said that the high number of meetings, particularly in the early years, made it difficult for them to attend them all. Some pointed out that, after a while, they realised that some meetings were important to attend as issues would be discussed and decisions made, whereas others were routine or screening. They therefore worked out with their partner whether they were needed or, if they were both working, who could attend.

Fathers talked about a variety of experiences in the way practitioners included them, with approximately one-third feeling they were included. However, another third felt that practitioners focused on their wives at meetings and that they were carried along in discussions and not given enough information to be involved fully in decision-making. Three of this latter group talked about the attitudes of others (for example, practitioners, other parents, the general public) that made them feel it was unacceptable for a man to be providing a high level of care for their disabled child.

Key messages from the findings

Fathers wanted to have a high level of involvement in their children's lives: to be involved in their day-to-day experiences and in the decision-making about their lives. They had considerable commitment to the learning and development of their children and to providing them with opportunities. It was enormously helpful to fathers to have flexibility in their employment. In order to be involved in discussions and decision-making about their children, fathers needed practitioners to consider their work patterns when arranging appointment and meeting times. Most fathers wanted to be seen as equal partners and shown respect for what they contributed to family life.

What are the benefits of involving fathers in their children's education?

There is a growing recognition in education policy of the impact that the involvement of fathers can have on outcomes for children and that early years services and schools need to encourage the involvement of both mothers and fathers. The DfES developed guidance for mainstream schools on 'Engaging Fathers' in their children's education (DfES, 2004), and some of the SureStart Local Programmes focused on involving fathers in early years settings (Hughes and Fisher, 2006). The developing Children's Centres have been given a remit by the DfES to increase the involvement of fathers (DfES, 2005).

Involving fathers in their children's education should be seen as being beneficial to children, fathers themselves, families as a whole and schools. Research in the field of education has been carried out into the benefits for children when fathers are involved. The benefits noted include improved examination results, better school attendance and behaviour, and higher quality of later relationships (Goldman, 2005). This has not been researched specifically in relation to fathers of children with special needs, but is likely to have a similar impact on educational achievement and the father-child relationship.

In the 'Recognising Fathers' research, fathers indicated a desire to be involved in the learning and development of their child and attached importance to contributing to this.

Fathers were motivated to read home-school communications, give support with homework and provide learning opportunities outside school hours. Acknowledging and supporting their contribution is likely to make fathers feel valued in this role and motivate them to remain involved. This involvement would have additional benefits for children's mothers and for family relationships as a whole.

School is often the main service, and sometimes the only service, that children with special needs receive, and therefore is a significant point of contact for fathers, as well as mothers, to receive support in their role and to be able to contribute to decisions about their child's future. Schools can also create an expectation for fathers that they will have opportunities to be involved. This can give fathers the confidence to assert their right to have a continuing role in their child's life when they come into contact with other services; for example, at transition.

Some of the issues to consider when involving fathers

Fathers are a heterogeneous group and as a result have differing needs. There will be fathers who are not resident with their children, but still want to be involved in their education: for example, they may need opportunities to attend meetings independently of the child's mother. Lone fathers may need additional considerations as they may find it difficult to develop supportive social networks and may feel stigmatised as a result of being a lone, male carer. The 'Recognising Fathers' study did not interview any fathers who were stepfathers or adoptive fathers, but these are also a group who may have specific needs.

Some fathers may not have had a positive experience at school and may not feel confident in a school environment. Fathers with higher qualification levels are more likely to feel comfortable in their contact with school professionals, but it should not be assumed that others would not welcome opportunities to be involved. They may need additional encouragement to step over the threshold. Indeed, some fathers may have mild learning disabilities themselves, and, if this is the case, extra consideration will need to be given, for example, to home-school communication.

Fathers from black and minority ethnic communities may have different roles in relation to their children's education from those with white European backgrounds, and their needs in relation to school involvement need to be considered.

What can schools do to support and involve fathers?

In most school settings, there will be a father of a child with special needs who has been through some of the experiences

and emotions described earlier in this article. It would be unrealistic to expect every school to have resources available to support fathers directly, but they can develop an environment and practice that is 'father friendly'. The starting point for many schools would be to understand the barriers that fathers may experience and to audit their practice to identify whether it is inclusive of fathers. Schools need to develop an expectation that fathers will become involved rather than being surprised when they do.

The key elements of a father-friendly school are:

- encouraging fathers to be involved in the general life of the school including informal contact with staff and other parents;
- enabling fathers to attend and participate fully in meetings concerned with their own children;
- enabling fathers to have contact with other fathers either face-to-face or virtually through the internet.

Getting involved and having informal contact

There are often more opportunities for mothers and fathers to be involved at pre-school and primary school stages than in secondary schools. Some fathers will have come through early years programmes, such as SureStart and early years centres, where they have been actively involved in the care and education of their child. Opportunities to continue this involvement should be developed, such as fathers coming in with their children to share their knowledge and skills about supporting their child or though taking opportunities to talk with fathers when they drop off their children. Good experiences in these early years will establish a pattern for future involvement.

Fathers in the 'Recognising Fathers' study were aware that it was mostly mothers who had informal contact with schools, and that teachers and support staff, who are predominantly women, were generally more comfortable talking to other women. A father who had been included in this kind of informal conversation felt that it validated him in his role as the person who provided hands-on support to his daughter. Informal contact with schools chiefly comes about through taking and collecting children: this was an option for men who were not working or who had negotiated flexibility in their working hours to enable them to achieve this – an option probably not available to many men.

Most schools operate only within defined hours, Monday to Friday, and this gives little or no opportunity for fathers to visit the school or participate in school-related activities. Can we not generate more flexibility in how school staff discharge their working hours? One school organised a termly Saturday morning computer club where fathers supported their child with special needs; the school benefited directly in that several of the fathers were able to offer particular expertise regarding IT. Another school organised a summer holiday working party, where fathers volunteered

to carry out painting of classrooms. The headteacher reported that, during these three days, the fathers not only achieved a lot for the school, but bonded as a group, exploring their attitudes, feelings and thoughts around rearing a child with disabilities (Carpenter, 2005).

Many fathers have specific skills from their professional lives, which means that within a model of reciprocal partnership that relies on skill-sharing as an approach to problem solving and development (Carpenter, Attfield and Logan, 2006), they can assist many aspects of school policy development.

Involvement in children's meetings

In the research, fathers gave a high priority to attending meetings concerned with their children: they wanted to be there to gain information, argue for resources and support their partner. However, there has been a worrying trend towards parents' evenings being held between 4.00 p.m. and 6.00 p.m. when many fathers (and mothers too) may not have returned from their own day jobs. If only the mother is able to attend such parent-teacher interviews, then she again becomes the holder of complex, detailed information, which it is assumed she will transmit to the father. Why are we putting such unnecessary pressure on relationships when some optional later evening times would have enabled both parents to attend the consultation?

Similarly, many fathers of children with Statements of Special Educational Needs would welcome the opportunity to attend their child's Annual Review, but research reported by Carpenter (2002) discovered that many were given little, or no, notice of the review meeting date, and the school's expectation was often that the mother only would attend. Fathers in this study recommended that schools should always give them the option to attend. To achieve this, they felt several months' notice in advance would help them either to plan time out, take leave or, as one father who worked in a manual post suggested, skip a lunch break or ask for unpaid leave. Most of all these fathers wanted their right to attend acknowledged and for the decision to rest with them.

Father-specific activities

Schools may decide that they want to provide specific activities or opportunities for fathers to meet. For some fathers, support groups around disability might be a good way of meeting other fathers who are in a similar situation. In a study carried out by CAF (2005), one father reported how useful it had been to make friends with another father: 'You need support from people who "get it" – only dads who are in the same situation can really understand' (p. 8). A school may not run its own support group, but it may be possible to network fathers to groups that exist in the area. Groups do not necessarily need to meet: some groups may be 'virtual' either because of practical considerations or preferences.

Sunfield School in Worcestershire runs an email group for its fathers – SunDads.

The same school has also developed a model of training, 'Celebrating Families', which specifically addresses the needs of particular family members and brings them together annually for their own training events (for example, 'Mum's the Word', 'Siblings') alongside a general family training programme (Carpenter, Addenbrooke, Attfield and Conway, 2004). Specific 'Dad Days' have focused on such topics as housing, sex education, challenging behaviour and fatherhood. Men process information differently: research on fathers of children with disabilities has indicated that they tend to focus on the 'big picture' (Gray, 1992). Their concerns are often for the future – employment, housing, work, money. Training needs to be tailored to these topics and to male brain modes of learning and acquiring information (Baron-Cohen, 2003).

Hughes and Fisher (2006) describe the 'Daddy Cool' programme at a SureStart Children's Centre in Southampton, which has developed a Saturday morning breakfast for male carers and their children. It has a special magazine for fathers, and runs a weekly five-a-side football game for them as well as other activities. The result is a large increase in the number of dads at the Centre, learning about child-care, first aid, debt management and a host of other issues vital to the lives of their children. What is the potential for transference of such ideas to the concept and practice of Extended Schools?

There is also a range of paper-based resources that schools could have available: the DAD Pack (Fathers Direct, 2006) or the Fathers Factsheet (CAF, 2005). The DAD Pack is a basic toolkit for organisations to use in supporting dads in being, and becoming, more involved with their children. It covers issues such as pregnancy, birth, work, relationships, health, benefits, legal rights and responsibilities, and how to praise children (Fathers Direct, 2006). Advice to staff is also downloadable from the Social Care Institute for Excellence, who have produced a summarised literature review. Outcomes from the 'Recognising Fathers' project are also available via the internet (www.learningdisabilities.org.uk). Books written by fathers of disabled children are increasingly available (such as *Ollie* by Stephen Venables (2006)). The NDCS (2006) has recently published a blog written by a father of a deaf child on its website, and the BBC OUCH website had a blog written by a father with a young son with Down's syndrome.

Further research

The 'Recognising Fathers' study identified a number of areas that require further research. In the study, men talked about some of the factors that motivated and supported them to be involved with their children, but looking at this in more depth and with a larger cohort would provide useful data to enable support to be targeted more effectively.

This study focused on fathers of children up to the age of secondary school, but fathers indicated that the transition to secondary school, the teenage years and the transition to adult life were of concern to them. Looking at the issues for fathers throughout these years would develop understanding of how fathers can be supported to maintain and develop their roles as their children move towards adulthood.

As schools develop their 'father-friendly' practice it would also be helpful to evaluate, share ideas and learn from each other.

Conclusion

The 'Recognising Fathers' project has echoed some of the key messages found in the earlier research studies cited. What is new is that it has articulated these messages in the context of twenty-first century fatherhood. The range of initiatives around fatherhood generally (such as the introduction of paid paternity leave in April 2003 as a means to encourage fathers to become involved in the early weeks of their children's lives) may at long last mean that the messages will be heard and acted upon. Government policy and service provision need to be challenged, so that finally fathers can be liberated from the 'myth of manhood' that has trapped them within a previously unquestioned set of expectations, both in their role as providers and as family members. Fatherhood needs to be offered status and equality with motherhood, and the fathers of disabled children warrant respect and support. For the sake of disabled children and their families, we need to ensure that we are 'Recognising Fathers'.

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Postscript

Since this article was written, further funding has been received to carry out a national survey of fathers to test out the findings from this research with a larger sample of fathers and to investigate further specific areas that arose from these interviews.

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