

**Disabled Fathers:  
Identifying a  
Research Agenda**

**Edited by Majella Kilkey**

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# **1: INTRODUCTION**

## **MAJELLA KILKEY**

This report is the product of a one-day workshop, partly sponsored by the UK Social Policy Association, for and about disabled fathers, which took place at the University of Hull in February 2007. The participants were broad-ranging, and included researchers working in the areas of disability, parenting, fathering and masculinities, practitioners working with disabled fathers and parents, organisations of disabled parents, and disabled fathers themselves (see Appendix 1 for a full list of participants).

The central aim of the workshop was to identify an agenda for research designed to illuminate the needs and experiences of disabled fathers. This introduction begins by making the case for such a research agenda. It then moves on to discuss more specifically who disabled fathers are, before finally outlining the structure of the report.

### **Why disabled fathers?**

We do not know the prevalence of disabled fathers. Statistical information relating to disabled parents is lacking, and available estimates are rife with difficulties, in large part because of definitional issues. (Morris and Wates 2006). Nevertheless, the current 'best estimate', which puts the incidence in Britain at about 12 per cent (1.7 million) of all parents, suggests that disabled parents are far from insignificant in numerical terms (Morris and Wates 2006: 15). If we were to have longitudinal data, the prevalence rate would be even greater, given that both disability and parenting are dynamic phenomena. While there are reasons to suspect that disabled mothers outnumber disabled fathers, this is neither an established fact (for example, non-resident disabled fathers need to be taken into account), nor a reason to discount the likelihood that a significant number of men will be fathering with an impairment.

We know virtually nothing, however, about disabled fathers. This group has been marginalised within all the relevant bodies of research. Recent reviews of research on fathering (Lewis 2000; Marsiglio *et al.* 2000; O'Brien 2005; Burgess 2007), whilst appealing for greater recognition of the diverse contexts of fathering, do not identify disability as a relevant dimension of diversity.

Within masculinities research (for example, Haywood and Mac an Ghail 2003; McMahon 1999), both fatherhood and disability are marginalised. To the extent that these themes are addressed (for example, Dunne 1999 on fatherhood and masculinities; Shakespeare 1999; Valentine 1999; and Wilde 2004 on disability and masculinities), they are treated in isolation of each other, and a focus on disabled fathers as a distinct category fails to emerge.

The literature on disability is similarly scant when it comes to fathers. There is a body of work on disabled parents (Booth and Booth 1994; Gooding 2000; Wates 2002,2003; Morris 2003; Olsen and Clarke 2003; Newman and Wates 2004; Olsen and Tyers, 2004; Wates), but this rarely separates out mothers and fathers. To the extent that it does, it is largely to focus, sometimes explicitly (Morris 1992; Wates 1997; Wates and Jade (*eds.*) 1999; Grue and Lærum 2002; McKeever *et al.* 2003), but usually implicitly, on mothers. Jenny Morris and Michele Wates (2006) draw a similar conclusion in their recent knowledge review for the Social Care Institute for Excellence (SCIE) of disabled parents' needs and experiences.

Finally, disabled fathers have not emerged within the research on parenting, which as Olsen and Clarke (2003: 2-4) argue, has failed to take up the subject of disabled parents in general, even in the context of an intensification of empirical and policy interest in parenting in the last few years.

It is probably because disabled fathers occupy incongruous positions vis-à-vis dominant discourses around fathering and disability, that they have been ignored within research. Fathering has been constituted historically mainly in economic, and more precisely breadwinning, terms (Lewis 2000). In the context of a discourse in which impairment is equated with dependency, disabled fathers have been rendered invisible. Despite an increasing interest in fathers' wider involvement in family-life, because it is men's relationship to *paid work* and care which is at the centre of this (Kilkey 2006), disabled fathers still do not enter the frame. Moreover, while feminist disability-rights agendas have sought the recognition of disabled mothers as care-givers, rather than as care-receivers (Olsen and Clarke 2003), this was a challenge not only to the asexualisation and infantilisation of disabled people, but also to what was perceived to be a masculinist disability-rights agenda, which by its very nature, also failed to take account of men as care-givers.

As policy agendas increasingly highlight the importance of fathers, and as research agendas emphasise the need to uncover the diversity in contemporary fathering, we should be careful not to miss the opportunity to bring disabled fathers into the frame. This has become all the more crucial from a social policy perspective because under the new Gender Equality Duty (Equality Act 2006) which took effect in April 2007, all public authorities, including those commissioning parenting services, will be required to have 'due regard' to the need to promote equality of opportunity between women and men.

Disabled fathers and their families matter in their own right, and their significance extends beyond the numerical. They are at a disproportionate risk of social exclusion. Their exclusion is likely to be multidimensional given the high rates of income poverty among disabled adults in general (Palmer *et al.* 2005), as well as their labour market disadvantage (Rigg 2005), and more general experiences of discrimination. (Morris and Wates 2006) The

development of appropriate responses to challenge such problems, however, will be hampered without a fuller understanding of disabled fathers' experiences and needs.

Developing our understanding of disabled fathers is also an important part of the process of improving our knowledge of contemporary fathering and masculinities in general. In occupying apparently incongruous positions vis-à-vis dominant discourses on fathering and masculinity, an appreciation of how disabled men understand and practise fathering, has the potential to unsettle and in turn, enrich, our knowledge on fathering and masculinities. By the same token, it would also contribute to our knowledge on disability more generally.

### **Who are disabled fathers?**

The question of who is a disabled father raises issues around our understandings of both disability and fathering. In organising the workshop, a broad definition of the term disabled was adopted to include those with physical and/or sensory impairments, learning difficulties, mental health problems, HIV/AIDS and drug and/or alcohol problems. This is in line with the definition used by Disabled Parents Network ([www.disabledparentsnetwork.org.uk](http://www.disabledparentsnetwork.org.uk)), and was also adopted in the Social Care Institute for Excellence's recent knowledge review of disabled parents (Morris and Wates 2006: 9-10). Similarly, a broad definition of fathers was used to incorporate not only those who are biological fathers, but also those involved in social fathering, and not only resident fathers, but also those who do not live with their child or children, or who are involved in 'shared-parenting' arrangements, in which their child or children are resident with them for part of the time in any specific time period.

### **Structure of the report**

The report contains two of the papers presented at the workshop, both of which have been subsequently revised to reflect comments received from the workshop participants, and in the case of one paper (Kilkey), also to take account of fieldwork developments in the on-going research project reported on.<sup>1</sup> The first paper - 'Disabled Fathers' Experiences: Findings from (and questions raised by) a study of parenting and disability' – by Harriet Clarke reflects on Department of Health-funded research, conducted under their *Supporting Parents* initiative, which explored disabled parents' experiences of raising children. Clarke notes that whilst (disabled and non-disabled) fathers were involved in the study, her research arguably raised at least as many questions as it answered in relation to the gendered experience of parenting roles, as disabled fathers were under-represented in the study overall. On the

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<sup>1</sup> Other contributions to the workshop are not included here, but outlines of the presentations can be accessed from the following web address:  
[http://www.hull.ac.uk/cass/research/research\\_news/disabled\\_fathers/index.html](http://www.hull.ac.uk/cass/research/research_news/disabled_fathers/index.html)

basis of the findings of her research, Clarke suggests that future research agendas on fathers' experiences could usefully include: men's experiences of disability and parenting in a life-course perspective; gendered responses to disabled fathers' parenting support needs; disabled fathers' experiences of parenting after separation and divorce; and disabled men's experiences of both access to employment and access to parenting. She concludes that her findings point to the importance of gender-aware *parenting* research (which strives to highlight both men's and women's experiences and support needs in relation to parenting), as well as the value of developing research focused specifically on *fathers'* experiences.

The second paper - 'Identities and Practices of Disabled Fathers: Some emerging research findings' – by Majella Kilkey, reports on an on-going research project which aims to develop knowledge of the ways in which disabled fathers understand fathering, how the identities and meanings they attach to fathering have come about, and how disabled fathers experience and practise fathering on a daily basis. Kilkey outlines some emerging findings from that research, around themes relating to 'time to care', 'adapting' to fathering in the context of impairment, disabled men's experiences of gaining recognition as fathers, fathers' experiences of gaining recognition as disabled men, the role that impairment plays in disabled fathers' experiences, and differences among disabled fathers. She concludes by identifying a range of issues which could be tackled in further research.

The final section of the report, authored by Anna Sandfield and Simon Unsworth, takes the question of where next for further research, by drawing together the themes to have emerged in the penultimate session of the workshop which consisted of break-away discussion groups. They also expand on the question by extending it beyond the research agenda to include also policy and practice agendas. It should be acknowledged that Sandfield's and Unsworth's section relies heavily on the input received from the workshop participants.

In addition to the list of participants in Appendix 1, there are three further appendices. Appendix 2 contains the interview schedule for Kilkey's study. Appendix 3 contains the list of questions used to guide the break-away discussion groups reported on by Sandfield and Unsworth. Finally, Appendix 4 contains a guide to useful resources related to disabled fathers / parents.

## **2: DISABLED FATHERS' EXPERIENCES: FINDINGS FROM (AND QUESTIONS RAISED BY) A STUDY OF PARENTING AND DISABILITY**

**HARRIET CLARKE**

### **Introduction**

Over the last decade there has been a rapid development of a knowledge base concerning disabled parents' experiences of raising children, and this has particularly happened in relation to disabled parents' encounters with services (Morris and Wates 2006). At least one significant knowledge gap remains: one which considers the gendered nature of parenting roles with a focus on the personal experience of mothering and fathering by disabled people. Development of research in this area would support understanding of day-to-day lived experience, including the impacts of competing discourses about parenting, and about disability, on parenting-related decisions. A research stream here could include the differential responses of professionals and service structures to disabled men and women who have (or would like, or are seeking to maintain or re-establish) a parenting role.

It is argued here that gender-focused research with disabled parents should be developed to: make public and transparent the private (personal) experiences of current and would-be parents' experiences of family life, and how these are gendered; explore the impact that professional (and other external) assumptions concerning gender and family life have on men's and women's experiences and choices; and crucially, to locate the gendered experiences of disabled people as parents within the gendered experiences of all mothers and fathers. Research in this area should maintain at its centre a concern with parents' voices and perspectives, understanding that the way in which mothering and fathering is actually enacted is bound up with personal experience and identity. (Smart and Neale 1999) Ideally, the actual experience of parenting itself should be considered as part of the process of self-knowing and identity development. (Rapoport *et al.* 1977)

There is an important step which should be taken prior to this: as a significant amount of previous social policy and social work research on 'parenting' has arguably been largely about 'mothering', there is a case for developing a specific focus on fathers' experiences, before developing a gender-focused disability and parenting research agenda. Daniel *et al.* (2005) have highlighted how the use of parenting as a term in policy documents, in order to be inclusive of fathers, has largely resulted in the implications of gender not being fully considered. Others have focused their calls for future research on service-delivery and engagement with fathers (for example, Ashley *et al.* 2006); given the negative pictures which can emerge from service-focused research with professionals (e.g. 'men as threat' as a dominant construction

in child protection work, as identified by Scourfield 2006), there is also a need for social policy and social work research with fathers to look beyond specific service-orientated concerns, and when service-use is of interest to look beyond children's services.

In this paper I will attempt to contribute to a solid starting point for gender focused research on disability and parenting, by drawing on research<sup>2</sup> funded by the Department of Health's *Supporting Parenting* initiative, which was conducted in England (predominantly within the East Midlands) between 1997 and 2000. This research focused on disabled parents' and their families' day-to-day experiences of family life, and of support. It is reflected on here in order to consider what can be learned about the conduct of parenting research and its ability to inform gendered understandings of family roles and relationships. The findings are considered to explore what further areas of research might be necessary to support a deepening and broadening of our understanding of disabled fathers' experiences, as part of the development of a strong base from which to build a gender-focused research agenda in this area of disability and parenting.

#### *Research with Disabled Parents: ensuring and increasing visibility*

Who, then, are disabled parents? Research over the past decade has largely focused on making disabled parents visible – sometimes in relation to specific experiences of impairment, at other times with a focus on shared barriers which parents with different impairments might face. The definition provided by 'Disabled Parents Network' and the approach taken within Morris' and Wates' (2006) review, highlights that this second approach ensures that 'disabled parents' can include parents with physical or sensory impairments; parents who experience mental distress and/or use psychiatric services; parents with learning difficulties; Deaf parents; parents who have a drug or alcohol dependency; and parents with long-term health difficulties. (see [www.disabledparentsnetwork.org.uk](http://www.disabledparentsnetwork.org.uk); Morris and Wates 2006) Further consideration might also be given to the inclusion of parents who identify with neurodiversity as a specific set of experiences which also includes disabling responses and environments. Ideally, research on parenting experiences includes both biological and social parenting roles, and non-resident parenting: just as 'parenting' has been an attempt to include fathers, an inclusive approach to the diversity of forms and experiences of family life and parenting should not lead to an implicit denial of significantly different issues for some groups of parents.

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<sup>2</sup> Initial research funded by the Department of Health and conducted with Dr Richard Olsen: we were at that time both researchers at the Nuffield Community Care Studies Unit, University of Leicester.

## The 'Supporting Parenting' Study of Parenting and Disability

The research drawn upon in this paper was committed to making disabled parents' and their families' experiences visible without having to resort necessarily to problematising their roles and relationships. Our own immediate concern as researchers was on the significant absence of disabled parents from the social policy and related literatures; whilst we were aware that research with parents could not be gender 'neutral' we did not have gender of parent as an organising feature of our sampling strategy, and the recruitment of fathers was by far less successful than mothers. Not all of the impairment experiences or parenting experiences listed above were included, as this study focused on (biological and social) parents who had a physical or sensory impairment, or mental health concerns, and who were currently living with dependent children. We did seek to include families whether or not children in the family were considered to have any involvement as 'carers', and whether or not parents considered either impairment or disability to be a central factor in shaping their families' lives.

We were concerned to avoid a focus on specific impairments, as historically more clinical approaches have often done exactly that without reference to parents' personal and social circumstances: there could therefore be a tendency to inappropriately hang any problems faced by parents or children on a peg labelled 'impairment'. We instead took a social model of disability-informed approach, and conceptually understood that disability is socially created, and can be seen as operating through, for example, the existence of specific financial barriers, inappropriate housing, oppressive practices and other (physical and interpersonal) features of disabling environments. This approach enables a focus on identifying the disabling barriers faced by parents (and highlights that, therefore, to some extent these are often also experienced by their partners and/or children either directly or indirectly).

The experience of conducting a 'parenting' project has provided learning points and some useful data to inform future work on disabled people's experiences of *both* fathering and mothering. The extent to which disabled parents have often been rendered invisible was apparent within the *Department of Health Disabled Parents* project: when as researchers we spoke about 'disabled parents', people often seemed to hear 'parents of disabled children': whilst this might in part reflect a relatively higher profile of disabled children in research and practice, it could also be because people did not have their eyes open to disabled people as parents – *as nurturers, supporters, providers, care-givers*. Parenting and disability were equally important domains of interest and whilst we did engage with the significance of gender for the way in which people parent, fathering and mothering were not central aspects of the analysis or specifically part of any research question.

The primary aim of the research was to achieve an exploratory account of experiences of being a parent in the context of disability, and to include

within this the perspectives of both disabled parents and their families (through interviews with any resident partner, and a child aged 7-18). More specifically, the research was concerned to identify the barriers which disabled parents faced in day-to-day life, and the encounters that parents and family members had of supportive and, by default, less supportive forms of intervention, whether from professionals and organisations, or within personal family and other community-based networks.

We instigated a range of recruitment strategies (e.g. visiting organisations and services; advertising (e.g. newsletters; leaflets); snowballing from initial recruits; increased representation of parents with mental health difficulties via GPs, following ethical clearance): this was so we could speak to families with a variety of experiences, as the overall aim was to explore and map out the range of issues faced rather than to draw a 'representative' picture. Parents recruited to participate in the study may or may not have used social care services: whilst much research has been concerned to look at disabled parents' experiences through a 'service-user' lens, this study was interested in the range of factors, including and beyond service provision, which can shape people's experiences of family life.

Whilst gender was *not* part of the sampling strategy, the study was specifically interested to:

- contrast the experience of parents who have a physical or sensory impairment with parents who experience mental distress (these were the 2 impairment experiences included within the remit of the study);
- contrast the experience of single parent families and dual parent families.

Given our concern to include single parent households, the sample was arguably initially already skewed towards engaging with mothers' experiences. Semi-structured interviews were conducted within 67 families (disabled parent; spouse, if applicable; minimum of one child) and these interviews collected detail on family experiences of day-to-day parenting and support, and of children's experiences with the home (including any domestic or 'caring' responsibilities). In ten of these households a disabled father was interviewed as the principal respondent, whilst 57 mothers identified and were interviewed as such. Twenty-three single parent households were included at this stage, only one of which was headed by a disabled father. The majority of parents had either a physical or sensory impairment (35), and a further 12 respondents stated that they had both mental health concerns and a physical impairment. Twenty respondents had mental health concerns, and no physical or sensory impairments. Of the fathers interviewed, three had mental health impairments only, six had a physical impairment, and one reported both mental distress and physical impairment. Many (though not all) families lived on low incomes – with around a quarter of households living on basic income support levels, but, given this, there was also a relatively high level of home ownership as about three-fifths of families lived in owner-occupied homes. The focus of this part of the research was largely the 'here

and now', with some retrospective questions for context (e.g. onset of impairment).

A second stage of research allowed us to focus in on experiences of change, as 12 families who were in the process of adjusting to a new situation (e.g. in relation to impairment; family shape; and so on) were interviewed specifically to identify personal and professional responses to altering circumstances.

### **Gender, Disability and the Life Course**

A valuable starting point for introducing some of the data from this research is to recognise that we only spoke to disabled men and women who had become parents, and to fathers and mothers who were currently bringing up their children in their own household. Amongst disabled parents currently parenting dependent children there will be different experiences of becoming a disabled person once a parent, and becoming a parent as a disabled person. Returning to a prior point in the life span in relation to gender, there may be important questions that need to be asked about what may support or hinder a man or woman in becoming a parent, including the specific barriers which some disabled people may face here.

Within this research we did not set out to seek detailed retrospective reporting, for example of 'life stories': however, for many parents there was space taken during the interviews to refer back to childhood experiences, others' expectations and how they themselves developed aspirations and relationships, and responded to parenthood. For example, within our study a small number of women said that they had experienced negative (i.e. potentially disabling) attitudes which led them to feel either anxious or defiant in childhood and early adulthood about their aspirations towards, and future prospects for, relationships and children. Unfortunately our sample did not include enough fathers for us to discover whether some disabled men, too, had felt that similar potentially limiting expectations had impacted on them.

Whilst none of the fathers we interviewed in stage one of this research thought it likely that they would have further children, a question arises (which again this particular study cannot answer) about whether or not it is less likely for professionals to offer advice to families where there is a disabled father. Family planning issues may often be limited to concerns about getting and staying pregnant, particularly in relation to any possible impacts of or on impairment and medication, for example. It was clear from mothers in this research that advice and information about potential risks and supports available would be welcomed in planning for a future child, however there were several experiences of dissuasion when hoped-for pregnancies were discussed with professionals.

Our research did, however, suggest that a father's impairment may influence a couple's decision about whether or not to have another child. This father

explained how his impairment and lack of employment were both significant factors when considering whether to have further children:

*MS is very important – we do talk about it – my wife would like to [have another child] – I know it would be a struggle and now I'm not working.*

Father (Physical Impairment)

Of course, many disabled parents did not express being overly distressed or concerned around decisions of whether or not to have further children: many of the thoughts here were 'mainstream' rather than specific to disability/impairment related concerns; some simply felt comfortable that their families were complete, others considered whether existing child(ren) would benefit from a further sibling, whilst others balanced family needs and resources alongside their own feelings towards having another child (which could be linked to employment, security of income, and therefore disability-related concerns; but also to enjoyment of the parenting role). Further research to explore fathers' role in family planning decisions and shared ownership (or otherwise) of a 'family' project should integrate considerations of gender (and disability).

One particular issue raised by a small number of fathers in the present study was around the experience of being an *older* dad (as well as a disabled dad). Some fathers spoke about this current experience of parenting as being 'second time around', as benefiting from a range of improved circumstances. These circumstances included being in a better relationship with the mother, having a different personal attitude towards fatherhood (e.g. being more relaxed; more positive about parenting), and having more invaluable knowledge and experience on which to draw. As fewer women have young dependent children and adult children, and for most women all their children are brought up within the same household, this 'second time around' experience was not expressed.

The small sample of fathers within this study has identified some pertinent issues about understanding fatherhood in life-span perspective, then, but particularly highlights that a study which focused on 'second time around' fatherhood could provide very rich data on disability and fatherhood, given the particular contrasts which such experiences can offer (between being disabled and non-disabled; older and younger; in a positive or negative relationship; and so on). Previous research has identified how some fathers can experience a significant 'switch' in primary identity, from worker to father at divorce and of course particularly if labour market withdrawal occurred at about the same time. (Smart and Neale 1999) Second-time around fathers may be able to provide significant detail on the difficulties faced when trying to maintain a parenting role with a non-resident child, after separation or divorce, in the context of employment (or otherwise) and the extent to which different roles were experienced as competing or complementary. This experience is also of interest because the particular contexts in which they

have fathered throughout their lives may have changed in respect of wider societal norms and expectations about fathering.

### *Gender, employment and experience of parenting*

It would seem clear that personal life-story frameworks in which family decisions occur and personal understandings are developed may themselves be considered through a gender lens which views employment and parenting roles alongside one another. Whilst stressing again that this research was not 'life-story' focused, the findings suggested that the gendered experience of paid employment and home-making roles can intersect with disability in interesting ways. Although only five out of the ten fathers in stage one of the 'parenting and disability' project were in employment of more than 10 hours a week, this was exceptionally high when compared to a figure of only seven out of fifty-seven mothers. Further, whilst four out of ten fathers describing themselves as 'looking after the home' may at first seem high, forty five of fifty-seven mothers considered this to be their status.

This research did not include many families where both the mother and father were disabled: in one family where both parents had a physical impairment, interestingly the couple decided that the mother should undertake the main (disabled parent) interview, suggesting that they either considered the parent role to be most significant to her (she had never had paid employment) and/or that she experienced disability to a greater degree. The father explained that he had given up work to support his wife in parenting when their son was a toddler. He was also key to supporting her mobility (for example, as he was a driver and she was not). Gender differences in both work and care would be interesting to investigate further in households where both parents report experiences of impairment.

Priestley (2000) has highlighted the ways in which welfare policy has been involved itself in the construction of (early to mid-) adulthood, with employment and parenting as core roles within 'normal' adulthood. Such ideas about normal progression through the lifespan are also reflected in some psychological models of development, perhaps most famously that of Erikson (1963) who stressed the importance of achieving intimacy (not necessarily but often through sexual partnerships) and of achieving generativity (demonstrating care and involvement in shaping and giving to the world beyond yourself and to future generations, for example through parenting and/or employment). These ideas, considered through a gender lens, enable us to consider individuals' experiences of different roles in early and mid-adulthood alongside one another (and not falsely 'cut off' parenting from the range of adulthood roles and experiences which may be available, and/or wanted or rejected). For some parents (mothers and fathers), the opportunity to stay in, or return to, work was a key issue. Work could be seen as important for both financial security and social contact.

The relationship between different roles and the way in which they intersect are likely often to be different for men and women. Williams (2004) identifies from recent research that both men and women continue to balance mother- or father-identity and their work identity in different ways; whilst gender roles might be less fixed than they were previously, both economic differences and expectations, and the meanings of motherhood and fatherhood continue to exert powerful influence. Changing patterns of work, how these are gendered, and the experiences of both dual income and no-income households will all be relevant to understanding fatherhood (Burghes *et al.* 1997): this should include disabled fathers' experiences, and might provide an avenue for exploring age-related or generational differences (for example with reference to access to employment, economic marginality and so on).

Here, then, we can attempt to bring experience of impairment and disability into an analysis of these ongoing negotiations. By way of example one mother expressed to us that she would like to have more children but that *'no one will let her'*. Until her mental distress she had been a qualified nurse, and she very much spoke about her adult life in terms of 'before' and 'after' she considered herself to be mentally ill (such as well worker contrasted with unwell mother); the desire for further children to some extent seemed to be bound up with enjoying caring for others, particularly a baby given both the love and intimate care role which that involves. Like most women in the sample she was not working currently; however, as stated above, the disabled men were much likely to have maintained work. Our research study engaged with her primarily as a parent/mother, but because of the way in which she presented her story we were able additionally to see the importance of seeing her in the context of other (in this case, past) roles.

It would be interesting to be able to explore further how the relationship between worker and parent identities are gendered in the context of disability, and additionally how manual/professional (or working class/middle class) identities are inter-related in this context. The 'supporting parenting' study suggests this would be a valuable avenue to explore. Within Stage Two, we spoke to a father who was concerned about whether or not work would be maintained, following a traumatic road accident. Married, with two children, his injury to his leg and the implications of this physically were clear and stable, however the *uncertainty around his future role* was a potent source of distress:

*Never been on the dole in me life, I've always found something to do, I've never been out of work and I don't want to ... sit and go to an office and sign on (...) if I have to I will do but I, I'll strive to get a job somewhere ... I'll feel like I'm just dragging everything out of the system and I don't want to do that, I still want to put into it if I can, but if I can't in the end well I'll have to accept that but then that's going to be a bit more of my self-respect gone.*

Father (Physical impairment: interview Stage 2)

We also spoke to a mother in Stage Two who had experienced a traumatic road injury, and she too saw her return to work as a matter of central importance; in her professional environment she received the support of her employer, and she had also accessed a psychologist (to support improving function following a head injury). Whilst the father cited above had received positive messages about his job being 'held open', he felt that he received quite contrasting messages when the company sent him letters offering him voluntary redundancy. Whilst some aspects of both of these experiences will be gendered, they are also shaped by the different roles and environments (manual and professional), and different employers' responses to impairment.

All of the above examples highlight times when parents' lives were experienced as 'before' and 'after' impairment/onset; whilst they are useful illustrators of some core issues it is important to note that more complex stories arise when impairments are variable (including sometimes absent, sometimes present), and when 'onset' is not a clear event.

### *Gender and experiences of co-parenting and lone parenting*

The experiences of both mothers and fathers highlighted a number of interesting ways in which activity (or not) in paid work, 'caring' activity, and parenting roles were either traditional or non-traditional for men and women. Whilst our numbers of disabled fathers were too small for statistical analysis in comparison with the mothers, we found in the sample overall a heterogeneous picture: for example, whilst some women partners of disabled men felt that they had very female roles (such as 'carer', primary child carer), significant numbers of male partners of disabled women also perceived themselves to be 'carers' particularly when they had no ongoing secure work. Some disabled men commented on the impact of impairment on involvement in childcare/domestic work. This varied - for some, this seemed to reinforce traditional roles and was something that they were not fully comfortable with; or some fathers found that they had greater involvement in domestic and childcare than other non-disabled dads (or greater involvement than with their 'first time around' children) and other domestic work *especially* if they were not in employment.

We spoke to only one single parent father in this research who, whilst living apart from his ex-wife, did continue to provide care in very close negotiation with her. This was demonstrated in his telling of how he parents, and in his actions (he felt it improper to consent to his son's taking part in the research without her permission): this level of 'co-parenting' (or concern about the other parent's perspective) was not found when interviewing single mothers. This father was concerned about the potential to be criticised by his son's mother. Another father in our research who had one daughter from a previous relationship, but who had now re-partnered, also demonstrated concern and some felt lack of power in relation to the mother's role and relationship with their daughter. He was worried that she would respond badly if he either explained his impairments to the mother or daughter, and

that an (inappropriate) response might occur beyond his control (e.g. his ex-partner rushing their daughter to the doctors to be 'checked out'). These two experiences suggest that fathers, perhaps particularly after separation, can feel more limited in their ability to be in control of disability-related sharing of information with their children.

## **Discussion**

Overall the data collected in the 'supporting parenting' study of disabled parents' experiences have identified that, whilst parenting research has usefully included fathers and avoided stereotyping of different parents' roles, there is a need to re-assert a gender focus in future work. Looking beyond the current study to other streams of research in family life, it would seem clear that mothers and fathers do have different experiences of family life, often undertake different aspects of parenting roles, and, where there is a 'less traditional' division of labour, can still experience a gender-based assessment of themselves and their relationship with others.

It is important to retain awareness of the potential power of parenting policy and research literature to underplay the ways in which experiences of family life, and of services, are impacted upon by gender and gendered assumptions; indeed, parenting research without reference to gender can mask some different needs and perspectives amongst men and women. The research reconsidered here did not seek to offer a full gender-based analysis, however a review of the data has provided some key findings and some pointers for future work in this area.

What emerges is that there are both conceptual reasons for challenging a largely gender-neutral approach to the study of family and of parenting, and there are also specific positive practical reasons to engage in gender-based research in this area. It would seem that researchers and policy-makers have often been able to develop debate and knowledge in relation to parenting, and in relation to employment, and, aside from some interest in the issue of 'work-life balance', have struggled more significantly to consider the management of a range of roles in the context of social disability; a gender-aware focus may help us to consider people's choices (and lack of choices) in relation to *both* employment and parenting. In this there are echoes of the assertion made 30 years ago by Rapoport *et al.* (1977) that parents are people whose experiences should be considered in full, as their parenting is only one element of their overall interests and activities. In developing future research, we should ensure that this is a principle which does not remain more understated with reference to women than men.

It may be that some disabled men develop the fathering role to a greater degree than their non-disabled peers, particularly if access to other roles (such as paid work) has proved more difficult to gain. Such experiences of disabled men could be contextualised amongst a wider research theme

concerning how families organise responsibility for parenting and household management in female-breadwinner/male-homemaker situations.

Whilst the thrust of the argument here has been that disabled parents' experiences should be considered in a way which avoids a 'service user' focus, use of services and the perspectives and actions of professionals should still be developed as an area of study. It would be useful specifically for future research to consider fathers' experiences of services (both mainstream and specialist), and to look at how interactions with professionals may be shaped by particular ideas about men's roles (and disabled men's roles) within the family. Further work could also be conducted in relation to professional education and training, to examine the ways in which and extent to which fatherhood is included when developing practitioners (as Ashley *et al.* [2006] recommended to the General Social Care Council). Whilst the focus here is responding appropriately to disabled fathers' circumstances, it is useful to recognise that writers within the field of child protection have also identified that analysis of gender and the care, protection and support of children could usefully enable a better understanding of the benefits which fathers can offer their families, and should not only concern themselves with fathers where they are perceived to be marginal or threatening. (Daniel and Taylor 2006)

Men who are not resident with their children were not included in the 'supporting parents' study, and yet they should not become absent from research and policy agendas where they remain (or wish to remain) a present and positive force in their children's lives. Interestingly Bradshaw *et al.* (1999) found from their research with non-resident fathers that whilst many non-resident men are motivated to maintain contact, there are a range of practical and emotional challenges faced. Disabled parents, and especially disabled men, may find that they face specific challenges when partnerships dissolve: future research should consider both men's and women's experiences of this process, the long-term or ongoing difficulties faced, and the solutions/supports which can enable continued choice and control in parenting involvement. The Bradshaw *et al.* (1999) study of non-resident men suggested that many fathers felt only having a financial (maintenance) role with their children to be unsatisfactory: the relationship between the disability issues faced in relation to both parenting and employment are likely again to be gendered amongst non-resident parents.

## **Conclusions**

Further research which explores men's experiences of disability and parenting should be pursued, both in order to increase the visibility of disabled men within debates around supporting parents, and to improve responses in policy and practice to disabled fathers and their families. Some of this research could explicitly engage with policy agendas and practice issues, but would benefit from engaging with fatherhood as one aspect of men's lives, and

Speak to parents as adults in their own right: this enables the development of understanding of where fatherhood is experienced positively, and when or why other roles (such as employment) are or can become less central, and whether this is felt to be through choice or an experience of marginalisation.

Current work is beginning to build a more in-depth picture of fathers' experiences, (see Kilkey in Section 3 following) and both that work and the analysis presented here make it clear that any attempts to be gender-neutral in parenting research may mask the more nuanced ways in which gendered assumptions and gendered aspects of identity intersect with experiences of disability.

### **3: IDENTITIES, PRACTICES AND EXPERIENCES OF DISABLED FATHERS: SOME EMERGING RESEARCH FINDINGS**

**MAJELLA KILKEY**

#### **Introduction**

As Harriet Clarke argued in the preceding section, it is not only important to develop gender-aware *parenting* research (which strives to highlight both men's and women's experiences and support needs in relation to parenting), but also to develop research focused specifically on *fathers'* experiences. This paper is concerned with reporting on research which took the latter approach. It presents some emerging findings from an on-going research project which aims to develop knowledge of the ways in which disabled fathers understand fathering, how the identities and meanings they attach to fathering have come about, and how disabled fathers experience and practise fathering on a daily basis. In particular, three themes which have occupied prominent positions in the accounts of those fathers involved in the research to date are explored: firstly, the re-articulation of fathers' identity as breadwinners in the context of impairment, secondly, the adaptation of men's fathering practices in the context of impairment, and thirdly, the experiences of disabled fathers regarding the recognition of them as fathers, particularly on the part of services. A key purpose of the research is to contribute to the current policy agendas around fathering and parenting by focusing on disabled fathers. The paper begins, therefore by outlining these policy agendas as they have developed under New Labour.

#### **New Labour, fathers and fathering**

For much of the post-war period in the UK, social policy and the political discourses framing it were largely silent on the subject of fathers and fathering. In the context of the male breadwinner society, marriage triggered men's role as economic provider, initially for his wife, and then, with the onset of fatherhood, for his children too. As long as the economic, social and moral conditions underpinning the male breadwinner model were maintained, it could be assumed that husbands and fathers were fulfilling their responsibilities. (Lewis 2002)<sup>3</sup> The increasing prevalence of lone-mother families in the 1980s, however, signalled the separation of marriage and fatherhood, and in the context of the neo-liberal agenda of reducing public

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<sup>3</sup> The assumption that within marriage a man could be trusted to share his income with his wife and children, however, had long been questioned. Initially female social policy campaigners such as Eleanor Rathbone were at the centre of this, arguing for a system of family allowances to be paid to the main carer over a family-wage. Subsequently, feminist social policy researchers revealed empirically how the distribution of money within marriage was shaped by gendered power relations. (for example, Pahl, 1989)

expenditure, the social policy concern became one of enforcing so-called 'absent' fathers' responsibilities to maintain their children. (Clarke and Roberts 2002) As Lewis (2002) points out, although there was a range of other discourses around father-absence, which framed the importance of fathers in broader terms, it was the 'fathers as economic-providers' discourse which dominated politically, and became translated into policy in the form of the Child Support Act 1991. The failings of that initial legislation and all subsequent attempts to reform it have been well documented. (see Barnes *et al*/ 1998 for a review) Since gaining power in 1997, New Labour has been engaged in further efforts to develop a workable system of child maintenance, indicating that it shares the Conservatives' construction of fathering as breadwinning. As early as 1998, however, there were also signs that New Labour was sympathetic to those discourses which framed fathering in broader terms.

The "overt naming" (Scourfield and Drakeford 2002: 633) of fathers by New Labour began in the 1998 Home Office Green Paper *Supporting Families*. In that document, the naming of fathers occurred within a broader family policy agenda, which constructed contemporary family life as being "under considerable stress". (Home Office 1998: Foreword) Within this discourse, fathers tended to be problematised. So in the *Supporting Families* Green Paper, fathers were rarely ordinary; they were "absent", "non-resident", "under-age" and "teenage", for example. At the same time, though, fathers were constructed as having the potential to become a positive force in family life, if only they could become more "involved" in their children's upbringing. Precisely what should constitute father-involvement, however, was left vague. There was clearly an expectation that it should extend beyond financial provision, with an emphasis on fathers as mentors and role-models, particularly as Featherstone and Trinder (2001) point out, in respect of their boys. Following the 1998 Green Paper, New Labour has developed its meanings of father-involvement through two main policy agendas: the reconciling work and family life agenda, and the parenting agenda.

#### *Reconciling work and family life: fathers as care-givers*

In the 1998 Green Paper the role of fathers as care-givers was not signalled; when it came to care-giving, and especially the question of how to combine care and paid work, the language used was gender-neutral: "being better able to retain and recruit *parents*" (HO 1998 para. 3.2: emphasis added), for example, was held up to employers as their reward for helping families balance paid work and home. Implicitly, however, the reconciliation challenge was clearly seen as one facing women, since it is their attachment to the labour market, which is adversely affected by parenthood, while if anything, becoming a father strengthens men's. (O'Brien 2005). Subsequent to the 1998 Green Paper, there has been a raft of policy measures in the UK around the reconciliation of work and family-life. Some of these have been concerned with strengthening mothers' rights to maternity leave and pay. Others have introduced ostensibly gender-neutral and individualised rights to mothers and

fathers as either working parents (parental and emergency leave and the right to request to work flexibly), or as employees (part-time working directive and working time directive). Still others, however, have extended rights to fathers as an explicit category (Paternity Leave and Pay and Additional Paternity Leave and Pay). (Kilkey 2006) The latter policies in particular signify a growing expectation that as mothers' attachment to the labour market is strengthened, some of the 'care deficit' will be met by fathers. As O'Brien (2005: 2) notes, '[T]he amount of male caring implicit in this new legislation extends beyond an intermittent and discretionary form of paternal involvement to a more continuous and integrated routine workday father role'.

The rationale for greater father involvement in care goes beyond the immediate economic one of facilitating mothers' employment. It is also being framed within a discourse of 'social investment' - a "child-centred social investment strategy" (Esping-Andersen 2002: 20), in which children are seen as "citizen-workers of the future". (Lister 2003: 427) From this perspective, father involvement is advocated for the positive developmental impact it has on children, the next generation of workers. (Kilkey 2006) Thus, a 2005 consultation paper from the Department of Trade and Industry which set out proposals for extending fathers' right to leave, argued "...when mothers work during the first year of their child's life and fathers play a greater role in bringing up children, this can lead to strong, positive educational effects later on in the child's life. ...The new law enabling mothers to transfer a proportion of their maternity leave and pay to fathers will help give children the best start in life by supporting fathers' involvement in their care". (DTI 2005: paras. 4.2-4.6)

### *The parenting agenda: engaging fathers*

Whilst the policies around the reconciliation of work and family life tend to be of most relevance to the fathers of young (pre-school) children, a second policy agenda around improving the quality of parenting is extending the expectation of more involved and active fathering to fathers of all ages of children. (Henricson 2003; Featherstone 2003, 2004, 2006; Featherstone and Peckover 2007) Under New Labour, and reflecting its communitarian and Third Way influences, parenting deficits have been implicated in a range of social problems, including social exclusion, crime and disorder and teenage pregnancy (Gillies 2005; Clarke 2006), and a variety of initiatives have been developed to improve parenting practices and standards. These include for example, the establishment of the National Family and Parenting Institute, the availability of parenting support within the Sure Start programme, and the development of parenting education within the Criminal Justice System. Within this broad agenda, fathers have become a particular focus. Thus, paralleling the establishment of the National Family and Parenting Institute, an organisation concerned with "promoting support for the child-father relationship", Fathers Direct, was launched with government funding, and monies were also made available for a number of time-limited 'father projects'

in the voluntary sector. (Featherstone 2003, 2006) Responsibility to involve fathers is being extended to statutory health and social care services. As Featherstone and Peckover (2007) observe, this goes beyond service provision targeted at the 'socially excluded' (for example, Children's Centres), to the population at large (for example, the National Service Framework for Children, Young People and Maternity Services), reflecting perhaps a mainstreaming of the father-involvement agenda.

*Involving fathers: how much and whom?*

Whilst the above policy developments might suggest a shift in the normative ideal of what constitutes 'good fathering', critics have pointed to a gap between the discourse within which policy is framed and the ensuing policy and practice. Thus while the consultation document preceding the 2005 'Work and Families' Bill (House of Commons 2005) highlighted the importance of father involvement, analysis of the subsequent legislation – Additional Paternity Leave and Pay – identified a number of limitations. (Kilkey 2006) These include the fact that the scheme is not designed along the lines of an individualised non-transferable use it or lose it model, which tends to be associated with higher take-up rates among fathers (OECD 2005), and that the payment will be a low flat-rate benefit, rather than a high earnings-related payment which also tends to promote higher take-up rates. Making a similar set of criticisms, Lister (2006: 319) concludes that the measures introduced to date to encourage fathers to become more involved in care are "little more than tokenistic". Evaluations of just how far the interventions developed to support parenting have engaged fathers reach similarly pessimistic conclusions, arguing that both because of the gendered division of caring responsibilities and a construction within some areas of family welfare of men "as a threat, as no use, as irrelevant and as absent" (Scourfield 2006: 443), initiatives have turned out to be predominantly mother-focused. (Henricson 2003; Scourfield 2003, 2006; Gillies, 2005; Featherstone 2006;)

Still other critics have taken issue with the normative ideal of the 'good father' that is emerging in current discourse. Those writing largely from the perspective of child and family welfare (for example, Featherstone and Trinder 2001; Scourfield and Drakeford 2002; Featherstone 2003, 2006; Scourfield 2006; Featherstone and Peckover 2007) have challenged the elision of men as perpetrators of violence and abuse towards women and children in the construction of fatherhood as a positive resource within families. As Scourfield (2006: 442) notes, such men "are seen as offenders and not fathers", and constructed in this way, have become the focus of the Criminal Justice System, rather than the agencies of social welfare (Scourfield and Drakeford 2002). Moreover, evidence that violent men, rather than being uninvolved with their children, can have had considerable levels of involvement in childcare, sometimes using this a mechanism to exert power and control over partners, leads Featherstone and Peckover (2007) to question New Labour's assumption that father-involvement is universally good and unproblematic.

Henwood and Procter (2003) meanwhile warn that the naturalising and normalising tendency of such a dominant discourse might serve to mask variations among fathers. These differences will relate not just to notions of 'good fathering', but also to fathers' capacity to meet the normative ideal of the 'good father'. Writing about New Labour's parenting agenda, Gillies (2005) argues that the norm of the 'good parent' has been constructed with reference to assumed middle class values and practices, which in turn are rooted in class privilege. It is quite likely that the ideal father for New Labour is similarly based on white middle class men's expressions of fathering, whether realised or not. This echoes Hondagneu-Sotelo and Messner (1997) critique of the American "New Man": they make the point that the ability of some men to realise the ideal of the "New Man" is based on class, gender and ethnic power and privilege.

### **The disabled fathers study**

It was in relation to the above criticisms that the on-going research project reported here was conceived. The project sets out to contribute to the current policy agendas around fathering and parenting by focusing on disabled fathers. In rendering a hitherto invisible group more visible, it is hoped that the research can contribute to awareness about diversity in fathering and parenting practices, and add weight to calls for the development of more inclusive models of fathering and parenting, with which to underpin policy and practice.

More specifically, the research has three aims.<sup>4</sup> Firstly, to develop knowledge of how disabled fathers understand fathering, in particular: what is their notion of 'good enough fathering?'; how does this fit with normative ideas on fathering?; what are some of the ways in which notions of 'good enough fathering' differ between disabled fathers, and in relation to what factors? Secondly, to develop knowledge of how the identities and meanings disabled fathers attach to fathering have come about, and the ways in which they are reconstructed over time, in particular, the roles played by: impairment, disability and experiences of discrimination; socio-economic circumstances (for example, housing, income and paid work status); significant life events (such as changes in impairment state, family-life and paid work); their own experience of fathering; and significant others (mother of child/ren, current partner, child/ren, wider family and social networks). Thirdly, to develop knowledge of how disabled fathers experience and practise fathering on a daily basis, in particular: what do they do that they do specifically as fathers?; what supports them to undertake fathering?; and what prevents them from fathering as they would want to?

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<sup>4</sup> Anna Sandfield and Ruth Butler contributed to the formulation of the research aims, and I am grateful for their contribution.

The study aims to recruit 30 disabled fathers, who will be delineated in relation to both fathering and disability. By fathers, the study is taken to mean men with child/ren aged 18 years or under, either biological or social, and either resident or not resident. By disabled person it is taken to mean anyone with physical and/or sensory impairments, learning difficulties, mental health problems, HIV/AIDS and drug and/or alcohol problems. This is in line with the definition used by Disabled Parents Network ([www.disabledparentsnetwork.org.uk](http://www.disabledparentsnetwork.org.uk)), and was also adopted in the Social Care Institute for Excellence's (SCIE) recent knowledge review of disabled parents. (Morris and Wates 2006: 9-10) It is recognised that both fathering and disability are highly complex and diverse social categories; however, it is beyond the scope of the current study to take account of all relevant dimensions. The above definitions are designed to capture as broad a sample as possible in terms of for example, nature of impairment, time of onset, residency, age and sex of dependent child, and marital status.

Participants are being drawn from throughout England and Wales, and from community settings, rather than service or support contexts. The latter is important for research on disabled fathers in particular, because as the SCIE knowledge review indicates, much of our existing knowledge-base on disabled parents comes from service users, and relates largely to their experiences of services, rather than their more general experiences of parenting. (Morris and Wates 2006) The intention is to attract from as broad a range of contexts as possible. Participants are being recruited using a variety of strategies, including talks about the research to relevant groups (for example, disability groups, fathers groups, and young-carers groups) and appeals in newspapers, newsletters, and websites (for example, Fathers Direct and Disabled Parents Network).

The research is being conducted using semi-structured interviews, which are taking place either face-to-face or by telephone. The interviews are gathering information on fathers' biographies, exploring how they understand fathering, how the identities and meanings they attach to fathering have come about, how their understandings are reconstructed over time, in relation to significant life events and to significant others, and how they experience fathering on a day-to-day basis (see Appendix 2 for the interview schedule).

Interviews with disabled fathers began in January 2007, and at the time of writing, ten have taken place. Boxes 1 and 2 show the characteristics of those fathers already interviewed, firstly in terms of disability and secondly, in terms of fathering. It is clear that there remain gaps in the range of impairments that the research is aiming to capture. To date, only fathers with physical and/or sensory impairments and learning difficulties have been interviewed; none of the fathers interviewed have mental health problems, HIV/AIDS, or drug and/or alcohol problems. To a large degree this reflects the fact that the recruitment strategy so far has relied on fathers coming forward in response to requests transmitted through fathering and disability organisations. Those groups absent from the study currently may be less likely to identify with

those organisations (for some at least, this will be because they do not self-identify as 'disabled'). This suggests that alternative recruitment strategies need to be developed. Among those interviewed so far, both those whose impairment precedes fatherhood and those who experienced impairment after becoming fathers are represented, as are those with life-long and acquired impairments. Similarly, there is a good mix of fathers in terms of the experience of disability among partners and children, as well as use of adult services. There is also considerable diversity among those interviewed so far in terms of their fathering contexts. Whilst all are biological fathers (none are social fathers), they are mixed in terms of whether currently resident or not with their biological children. Among those fathers who are not resident with their children, in some cases children are living full-time with the mother, in other cases they are shared between parents, in other cases children are in the care of the State, and in still other cases they are 'independent' and have left the parental home. Most of the fathers have one set of fathering experiences, but some have had multiple experiences of fathering, and are currently engaged in what might be termed 'second-time around' fathering. Similarly, whilst some are living with their life-long partner who is the mother of their children, most have had more fluidity in their adult intimate relationships, and are currently living with someone else, or are living alone (the majority).

**Box 1: The disabled fathers – dimensions of difference in relation to disability**

<b>Impairment type</b>	
Physical and/or sensory	Yes
Learning difficulties	Yes
Mental health problems	No
HIV/AIDS	No
Drug and/or alcohol problems	No
<b>Onset of impairment</b>	
Pre-fatherhood	Yes
Post-fatherhood	Yes
Life-long	Yes
Acquired	Yes
<b>Other family members and disability</b>	
Partner disabled	Yes
Partner not disabled	Yes
Child disabled	Yes
Child not disabled	Yes
<b>Service-use</b>	
Adult-service user	Yes
Non adult-service user	Yes

**Box 2: The disabled fathers – dimensions of difference in relation to fathering**

	<b>Biological / social</b>	
Biological		Yes
Social		No
	<b>Residency of father</b>	
Resident		Yes
Non-resident		Yes
	<b>Residency of child</b>	
With father and mother		Yes
With mother		Yes
Shared parenting		Yes
With state		Yes
Independent		Yes
	<b>Fathering biography</b>	
Single		Yes
Multiple		Yes
	<b>Partnership status</b>	
With child/ren's mother		Yes
Partnered with other		Yes
Single		Yes

**Some initial reflections on the identities, practices and experiences of disabled fathers**

In what follows, some preliminary description and analysis of the data gathered from the ten interviews conducted to date is presented. More specifically, three themes which are emerging from the data are explored: firstly, the re-articulation of fathers' identity as breadwinners in the context of impairment, secondly, the adaptation of men's fathering practices in the context of impairment, and thirdly, the experiences of disabled fathers regarding the recognition of them as fathers, particularly on the part of services. Due to the research being still in its early stages, the discussion remains highly descriptive. It should also be treated with considerable caution, not least because, as we noted above, it remains based on the experiences of a group constituting a far from comprehensive range of impairments.

*Time to care*

For the majority of fathers interviewed, being disabled has placed constraints on their performance of the male breadwinner role. At the time of interview, all but one of the fathers were either not employed or had spent significant periods of time out of paid work. Previous research conducted with "men whose identities are put on the line" (Haywood and Mac an Ghail 2003: 37), has revealed the difficulties experienced by those unable to fulfil the expectations of the male breadwinner because of for example, unemployment

or ill-health. Much of that research (for example, see Warin *et al.* 1999) has found a reluctance on the part of men (and indeed women, who can act as gate-keepers) to re-evaluate their identities and roles, by for example being unwilling to become more involved in the care of children and home – what Segal (1990) has termed “domestic refusal”. This was not, however, the dominant narrative of the disabled fathers interviewed in the current study. Many described themselves as “stay at home” and “hands-on” dads, who were “involved” in the day to day care of their children. Moreover, they placed a high premium on the time opportunities afforded by being disabled, frequently counter-posing this with the time constraints experienced by fathers in paid work, or indeed, by themselves prior to the onset of impairment and interruption of their working lives:

*I suppose I had more time as I say when I was at home and the boys were young and Paul had been born. I had more time than if I'd been working, if I'd been running around and able-bodied and had a hectic life. Would I have spent as much time with them if I had been able-bodied? I think I would have personally. As I've said before, the boys are really important to me, whether I'd had a disability or not I would have been over the moon if I'd had sons and I was able-bodied and all this business but I suppose because I had my disability and I was at home more I had more time ...*

Featherstone and Trinder (2007: 193) seem to caution against an overly positive reading of fathers' expressions of strong attachment to their children, suggesting that in the context of instability and the absence of other sources of legitimation, “children can become the repository for feelings of stability which cannot be attained elsewhere. Children in such circumstances become lost as people in their own right and become ciphers for adults' feelings”. While acknowledging their concern, the current study suggests that this may be valid in relation to only some fathers' stories, and, even then, only one of a range of equally plausible ways to interpret their narrative. Thus, the fathers spoken to so far are generally very conscious that they are doing things differently to how they themselves had been fathered, and/or to how they had done things before becoming disabled, and draw on external discourses around gender equality, children's wellbeing and/or the importance of father involvement to rationalise their behaviour. Some for example, located their fathering practices within a “co-partnering” project, while the stories of others were framed by something akin to New Labour's social investment discourse – “I now understand the value of fathering our children”.

It is important to recognise though that despite wanting to do things differently, for some, the re-articulation of their fathering role following the onset of impairment can be ridden with conflict and tension:

*I loved spending time with my son and staying at home but I felt it wasn't the right thing. I just felt I should be the main breadwinner ... My life drastically changed; I wouldn't have even considered being a stay at*

*home dad prior to my accident but I think the fact that there was a possibility it just made me feel less of a I suppose it sounds really bad against women, but it made me feel less of a man being the person who was provided for instead of providing for.*

This father believed that such tensions were largely responsible for the breakdown of the relationship with the mother of his son. There is evidence that while other fathers are more comfortable with their new role following the onset of impairment, they experience external challenges which serve to undermine their confidence:

*One of the hardest things has been not as a disabled dad but as a stay at home dad; it's hard being accepted in some circles.*

In some fathers' accounts, there is criticism of the attitude of children's services, which are seen as keeping them "in the background", despite them adopting the main care-giver role. This is in line with Scourfield's (2006: 443) account of the attitude of some practitioners towards fathers as 'irrelevant' to their children's lives.

#### *The opportunity to father differently*

A striking theme emerging from the accounts of fathering practices is that of adapting what they do as fathers within the constraints imposed by physical and/or sensory impairments. The men who had become disabled when well into adulthood (whether before or after becoming fathers) reported, without exception, of having subscribed to the construction of the 'masculine' rough-and-tumble, physical father which has dominated in much of the psychological writing on fathering (see for example Lupton and Barclay 1997 for a review). All, though, had been forced subsequently to do fathering differently. This shift is particularly sharp in the accounts of second-time around fathers, whose impairment was not present in their first experience of fathering. Describing his first-time around experiences, a father reported:

*When I caught my eldest child, who's 26 now, but when I caught him smoking at the age of 15 I really tore into him and then I said "right you". I suppose that would have been 10 years ago, so I would have been 36, 37, but I said "right, give me the fags", I threw them in the bin and then I said "right get changed, get your trainers on I'm going to take you running", and I'd really go for it and I ran him to the ground, but I know now I can't do things like that and he's been in trouble but now I can listen more and I just advise him a lot more, I don't have to do this "come running with me anymore", that's mainly because I can't .*

The same father proceeded to describe what he does now with his three-year-old child:

*When I take him to the park now there's climbing frames and I have problems with showing him how to do it and I'd have gone off and done it but now I'm more supportive, I'm behind him in case he falls and walking alongside holding on and just more supportive than being a leader.*

This father and others reported such changes in a positive way, and suggested that they presented opportunities for more loving and intimate fathering practices to emerge:

*We possibly spend longer cuddled up on the sofa reading books than some parents might do because they can do the charging around. So that in itself kind of brings the closeness because you do spend more time sitting down and that sort of thing and that's really nice; he loves reading or being read to at least, and so its great that we can do that.*

The responses adopted by these fathers to their inability to conform to the expectations of physicality bound up with hegemonic masculinity, might be understood as lying on the rejection/reformulation end of the continuum of strategies Gershick and Miller (1995) suggest are pursued by disabled men in the context of the erosion of hegemonic masculinity status. Rejection involves the replacement of hegemonic masculinity with alternative norms and practices, while reformulation is a "middle-ground, where hegemonic ideals are renegotiated in a more achievable manner". (Wilde 2004: 364)

#### *Denying fatherhood and experiences of services*

In common with the experiences of disabled mothers documented in other research (for example, Grue and Laerum 2002; Prilleltensky 2004), the fathers interviewed reported encountering difficulties in being recognised and taken seriously as fathers:

*It's hard as a blind person to be taken seriously anywhere and in some ways I feel it's hardest when its in front of your children ... Being a father has been a big part of my identity; for a number of years it was more important for me to look after them than to work full-time. I worked part-time. I wanted to look after them half the time all those years and it was very important for me. It was hard when that wasn't received by other people. I felt it had another layer of contempt because of my sight, because they didn't quite believe that I was looking after them anyway. A common reaction was 'oh I expect they look after you don't they?' assuming that they're your carer rather than I'm a dad doing the caring.*

Most of the fathers have had little contact with services – either children's or adult services. Having a non-disabled partner seemed to act as a buffer between fathers and services. This no doubt reflects gendered assumptions about the availability of a non-disabled woman to provide the care for both

her partner and children. As noted above, however, such assumptions meant that often the main care-giver for children – the father - was sidelined in encounters with children's services.

In situations where both parents were disabled, fathers reported a very different set of experiences with services. Social services, for example, were highly interventionist in the case of the fathers with learning disabilities. One father spoke at length about his experience of having his fitness to have parental responsibility assessed when his child was an infant. While he passed the assessment, and has maintained parental responsibility throughout his son's fifteen years, his experience is one of continual surveillance of his fathering standards, which he feels are required to be of a higher order than among non-learning disabled parents:

*You should be able to wash the pots, watch the kids, Hoover-up, cut the grass in the garden and see what the next door's dog is doing all in about five seconds. You've got to have your radar on overdrive ... You have to work harder with being a person with a learning disability.*

Despite no case of sexual, emotional or physical abuse, another father with learning disabilities reported having had his (learning disabled) child removed from his (and his learning disabled wife's) care at the age of five and a half. Two years on, the child is now being offered for adoption. The judge has ruled that the child needs 'better than average care'. With appropriate support, the father believed that he and his wife could deliver the standard of care required, but no support was ever forthcoming.

## **Conclusions**

It is clear from the interviews conducted to date that disability and fathering intersect with other 'problem' fathering and parenting categories, including single fathers, non-resident fathers, older fathers, non-employed fathers/parents and poor/'socially excluded' parents. Further reflection on the data gathered to date, and crucially further fieldwork, is required to explore more fully how these categories intersect with disability to frame the contexts in which disabled fathers imagine and practice their fathering. It is also apparent that disabled fathers are not a homogenous group even when it comes to impairment. Fathers with learning disabilities for example, seem to face a tougher job than the other fathers interviewed in establishing and maintaining parental responsibility. Research involving parents with mental health problems has suggested that this group also experiences particular difficulties when it came to judgements about their capacity to parent. (Read and Baker 1996) It seems important, therefore, that fieldwork is developed in such a way that captures a broader range of impairments than is reflected in the current set of interviews.

Despite a recognition of the heterogeneity of disabled fathers, it is also clear from the data that impairment and the experience of being disabled can situate men in particular ways that produces some commonalities when it comes to fathering. We have noted for example, the opportunities impairment can present for the re-articulation of fathers' identity as breadwinners, as well as the re-working of a 'masculine' form of father-involvement with its emphasis on fathers' physicality. There is a sense emerging from the data, that whether impairment was perceived as constraint or opportunity when it came to fathers' roles and behaviour, varied among the fathers. Further reflection on the accounts of those already interviewed, as well as further fieldwork is required though to explore more fully what factors matter here. It is likely that disabled fathers' experiences have to be situated within a wider family ecology to be fully understood. Future research, therefore, should also aim to triangulate fathers' accounts with those of their partners and children.

## **4: DISCUSSING DISABLED FATHERHOOD: SUGGESTIONS FOR RESEARCH, POLICY AND PRACTISE**

**ANNA SANDFIELD & SIMON UNSWORTH**

After listening to speakers, delegates who attended the workshop formed two breakaway groups to discuss experiences of and views pertaining to disabled fatherhood, and to highlight issues that had been raised by speakers for further consideration. As group facilitators, the present authors initiated and encouraged discussion, using the questions included in Appendix 2 as a starting point. The main themes to have emerged from those discussions are brought together here in order to promote their further consideration and disseminate the ideas generated, including recommendations for researchers and service-providers working with disabled fathers and their families.

### **Who are disabled fathers?**

A preliminary challenge facing service-providers and researchers planning work with disabled fathers is knowing who they are looking for and where to find them. The following issues are important considerations for those wanting to gain a fuller picture of disabled fathers and their experiences.

*Fathers may choose not to be 'disabled'*

It is often not useful for people to classify themselves as 'disabled'. Where agencies and individuals are unclear about what will be done with information they are requesting, individuals may choose not to disclose details that could disadvantage them or make them seem 'different'. Some individuals do not wish to engage with 'disability services' and consequently avoid this label. This presents a problem for service providers and researchers looking to put together a picture of the numbers of disabled parents and their experiences, and highlights the importance of trust and transparency when collecting information.

*Fathers may not use services*

Research commonly concentrates on, and defines disabled parents through their involvement as service users – predominantly adult social care services, but also children's services. Consequently, a large number of disabled person's opinions and experiences are not heard by or reflected in the outputs of researchers. It was suggested that there needs to be a clear understanding that 'disabled' does not necessarily mean 'service user'. Disabled fathers might see being a service user as a weakness and consequently avoid definition as 'disabled' and also avoid asking for help (i.e. becoming a service user) in case they are seen as less masculine or capable.

### *Fathers with learning disabilities may not be 'disabled'*

Many individuals with learning disabilities do not consider themselves 'disabled'. As such, they may not recognise themselves as the potential research participants and service users being sought by researchers and service providers seeking to contact disabled parents. As a result, learning disabled individuals may be excluded from accounts of the experiences of disabled parents or their numbers underestimated and appropriate services not provided. Learning disabled parents need to be included in research on disabled parenting and fatherhood; their exclusion provides a skewed picture of experiences.

### *Fathers may not be 'disabled' first*

Disabled fathers belong to many identifying groups and hence issues pertaining to their disability may not be the most relevant to their experiences. To gain a better understanding of their experiences we need to acknowledge that disabled fathers may share their parenting with disabled/non-disabled others and that their central concerns may not be, or not only be, connected to being disabled fathers. Researchers and service providers should view disabled fathers in the social context of their broader relationships and acknowledge the many commonalities shared with non-disabled parents rather than seeing them exclusively as a distinct and different group.

## **How should we find out more about disabled fathers?**

Groups saw common problems with the ways that information about disabled fatherhood has been gathered. Proposed improvements to the research process included increasing involvement of disabled fathers and encouragement for researchers to acknowledge, examine and challenge negative assumptions about disability.

### *Researchers should involve disabled fathers throughout*

It was suggested that in order to find out more about disabled fathers research needs to be done in a different way, involving disabled fathers and their families throughout the research process. Ways of engaging with disabled fathers throughout the entire research process need to be identified and put into practice including involvement with: setting the research agenda, carrying out research, analysing the results and drawing conclusions.

### *Researchers should involve men*

The involvement of men, and especially disabled fathers themselves, was seen as important to research reporting on their experiences, as researchers and interviewers, as well as involvement as participants. Disabled fathers

participating in research should be offered the option of speaking to men when they are interviewed to ensure that they are as comfortable as possible.

#### *Researchers should examine assumptions*

Work needs to be carried out with service providers and others working with and for disabled fathers to examine the assumptions and understandings of disabled fathers that they draw upon. It was noted that these understandings will impact how they approach interactions with disabled fathers, and thereby the experiences of disabled fathers and their families. Research in this area would contribute to a broader goal of providing information examining the experiences of disabled fathers within social context.

#### *Researchers should not endorse assumptions*

It was noted that negative assumptions about disabled fathers and their families commonly colour the way others interact with and write about them. Assumptions considered important to challenge included: that to be a 'carer' or 'young carer' is problematic and a negative thing, that 'parenting' means 'mothering' and that the employment of a disabled person is seen as indicating that they do not need support. It is important that people working with disabled fathers and researching related issues avoid these assumptions, and that they are challenged through training.

### **Where is change needed?**

Discussions around disabled fatherhood were primarily about highlighting areas where change is needed, where disabled fathers and their families could benefit from more information, better support, recognition and understanding. These points are the most important outcome of the discussions as they embody both recommendations for good practice and improvement in service provision and directions for future research.

#### *Fathers need information before becoming fathers*

More information for disabled men who are to become, or wish to become, fathers is required at all stages of contact with health and social care organisations. For example, materials at first contact could provide important information around the effect of a particular condition on a man's ability to become a father or the effects on his ability to parent. It was also noted that fathers need more accessible information about their rights as fathers. Information must be up to date, available in a range of formats and revisited at various points with the father to ensure that he has what he needs.

#### *Fathers need support when becoming fathers*

Services around pregnancy, childbirth and early years parenting are often provided by women and directed towards mothers. It would be beneficial for workers to also attend to fathers, e.g., local services have employed male workers or 'mid-husbands' to ensure fathers' experiences are integral to the care process, and therefore direct them to any information or support that could assist fathers, disabled and non-disabled, in becoming the fathers they want to be.

*Employers should support disabled fatherhood*

Companies should ensure that their employment policies are 'joined-up' – currently, disabled fathers may be wary of accessing an employer's disability support information and services, as well as its paternity policy, for fear of being seen as difficult or unable to satisfactorily do their job.

*Fathers can benefit from each other*

Professionals involved with fathers need to provide networking opportunities for all fathers. Many of the issues faced by disabled fathers are similar to those faced by involved non-disabled fathers and relate to difficulties undertaking activities, e.g., attending a mother & toddler group, traditionally associated with mothers.

*Fathers' negative experiences should be acknowledged*

Fathers need to be made aware that there are negative aspects to and experiences associated with disabled and non-disabled fatherhood. Fathers may be reluctant to admit these feelings and are also likely to be unprepared for them. Researchers and service providers should acknowledge these feelings without making men look like 'bad' fathers. People who work with fathers should be aware that fathers will have these feelings, prepare them for this and provide forums where fathers can talk honestly and overcome the challenges they face.

*Disabled fathers should be recognised as engaged parents*

Researchers and service providers should challenge negative associations with disability and recognise that disabled fathers can provide as much stability, support and stimulation for their children as their non-disabled counterparts, though they may do things in different ways. Some disabled fathers bring an advantage to their children through having time to undertake a lot of the emotional labour parenting requires. This can result in the positive outcomes for children, commonly resulting from all highly engaged fathering. The children of disabled fathers may additionally learn earlier about the concepts of responsibility and interdependence.

### *Recognising the complex context of fathering*

Everyone working with fathers should be aware of the changing and complex nature of fatherhood and therefore not look for singular or simple conceptualisations of fatherhood - disabled fathers are not only biological fathers but also foster fathers, adoptive fathers, stepfathers and grandfathers. Understandings of fatherhood result from an individual's class, age, previous experience with this family and other families, experiences of being parented and the culture of the time and place fathers live in. Increasing involvement of grandparents and support networks and professionals also should be considered when looking to understand fatherhood. Fathers should be seen within this context. Additionally it was noted that more needs to be found out about how disability impacts negotiations around childcare in dual-parenting relationships and whether fathers consider their positions weakened or strengthened by their disability.

### *Disability education should be a priority*

Disability should be taught within all undergraduate and professional training courses to increase levels of understanding and awareness. This should emphasise issues around equality and diversity rather than negative and biological aspects, i.e., disability should not be understood as an abnormality.

### **Where next for work around disabled fatherhood?**

It was agreed by both groups that in future work, researchers and service providers need to gather more information about disabled fatherhood, collected in a different way, listening and giving voice to the concerns of disabled fathers and their families in order to gain a clearer understanding about the issues important to them.

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## **APPENDIX 1. WORKSHOP PARTICIPANTS**

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## **APPENDIX 2. DISABLED FATHERS INTERVIEWS: TOPIC GUIDE**

### **1. Introduction to interview**

- Thank you for agreeing to do the interview
- What the research is about
- What this interview covers
- How the material from the interviews will be used
- Issues of confidentiality and anonymity
- Tape recording
- Timing of interview and breaks

### **2. About you**

- Family biography – children (number and ages), relationship with children's mother/s, living arrangements
- Disability biography – type/s, history of development, especially vis-à-vis fathering history
- Employment biography

### **3. Experience of parenting as a disabled father**

#### **A. Expectations before becoming a father**

- Can you remember when you first found out that you were going to be a father?
- What kind of father did you imagine you were going to be?
- Have things been as you expected?

#### **B. Experience of fathering**

- Can you tell me a bit about what kind of father you are now?
- What relevance does the fact that you are disabled have to the ways in which you father?
  - Does it prevent you fathering how you would like to? (what is their ideal?)– if so, in what ways?
  - What is it specifically about being disabled that poses the problem?
    - the impairment - how?
    - the disability and experience of discrimination - how?
    - socio-economic circumstances (housing, income, paid work status) - how?
    - other people acting as 'gate-keepers' to your fathering - how?
    - other – what and how?
  - Do you think there are some things you do better in terms of fathering because you are disabled?
  - Are there some things you just do differently?

- For those who became disabled after becoming a father, how did the way in which you father change?
- What supports and has supported you to undertake fathering?
- What prevents and has prevented you from fathering as you would want to?
- Do you feel that you are getting and have always gotten the support you need to father as you want to?
- What types of support would you like that you are not currently getting, or would have liked in the past but didn't get, in order to help you father as you want/wanted to?

#### **4. Experience of services – state, non-state, etc.**

***A. I am interested in learning about your experiences of using adult services, whether state or non-state, for disabled people or people with additional support needs, and in particular whether you felt that these services recognised you as a father, as well as a disabled person.***

- Do you or have you ever used any services, whether state-provided or voluntary, for disabled people or people with additional support needs? Which?
- Can you describe your experiences of using adult services, and specifically did you feel that you were treated as a father, as well as a disabled person?
- What was bad about your experiences?
- Have you any good experiences to recount?
- Is there anything you'd change about the services?

***B. I am also interested in learning about your experiences of using any services directed at fathers, rather than disabled fathers in particular.***

- Do you or have you ever used any such services? Which?
- Can you describe your experiences of using these services, and specifically how did you feel as a *disabled* father?
- What was bad about your experiences?
- Have you any good experiences to recount?
- Is there anything you'd change about the services?

***C. I am also interested in learning about your experiences of using services provided for your children (e.g. education, leisure....), whether state or non-state.***

- Can you describe your experiences of children's services, and in particular your thoughts on how the fact that you are disabled and a father influenced those experiences?
- What was bad about your experiences?

- Have you any good experiences to recount?
- Is there anything you'd change about the services?

## **5. Final comments**

- Is there anything about your experiences as a disabled father that you would like to tell me about, that we haven't already talked about?
- If a man you knew with a similar impairment to yours wanted to become a father/was about to become a father, what kind of advice would you give him?
  - If he asked you about the biggest challenges?
  - If he asked you about the biggest rewards?
- If you were to summarise the three most important things for you about being a father/disabled father, what would they be?
- If you were doing a research project about disabled fathers, is there anything that you would ask them that you think is important?

### **APPENDIX 3. QUESTIONS FOR BREAKAWAY GROUPS**

What are the most important things about fathers?  
What are the most important things about disabled fathers?

What are the positive things that disabled fathers bring to children's lives, to families, to fatherhood?  
What kinds of complications do disabled fathers face?  
What are the best ways of overcoming challenges that disabled fathers face?

What are the most important things for friends, family, colleagues and service providers to know about disabled fathers?  
Are there unhelpful things that friends, family, colleagues and service providers do for/with disabled fathers?  
Are there things other people do that make things more complicated for disabled fathers? Could these be avoided?  
Are there examples of helpful things that friends, family, colleagues and service providers can do with/for disabled fathers?  
What should other people know about disabled fathers?

What would help disabled fathers be recognised?  
What can be done to better meet the needs of disabled fathers?  
Are there things about disabled fathers that other people should know more about?  
Where could and should changes be made by those working with disabled fathers?

## **APPENDIX 4. DISABLED FATHERS: SOME USEFUL RESOURCES**

### **Disabled Parents Network** [www.disabledparentsnetwork.org.uk](http://www.disabledparentsnetwork.org.uk)

"A national organisation of and for disabled people who are parents or who hope to become parents, and their families, friends and supporters. We are here for all parents, including parents with physical or sensory impairments, people with learning difficulties or long-term illnesses, people with mental health issues and Deaf parents. We believe that disabled people have the right to have children and that they should be properly supported to carry out that right at each stage of parenting".

### **Fathers Direct** [www.fathersdirect.com](http://www.fathersdirect.com)

The National Information Centre on Fatherhood

"Fathers Direct is the leading organisation in the UK promoting support for the child-father relationship. It was founded 1999 by men and women with expertise in communications, social policy and child development. It seeks to promote good practice in public services and in industry that recognises the aspiration of fathers to be more involved in their children's lives and responds to an increasing body of research that demonstrates the importance of the father-child and the mother-father relationships to children. The aim of the organisation is "to create a society that supports children to have a strong and positive relationship with their fathers and other male carers and prepares boys and girls for a future shared role in caring for children".

### **European Fatherhood** [www.european-fatherhood.com](http://www.european-fatherhood.com)

A website launched in February 2007, which is "dedicated to presenting new knowledge and best practice for improving gender equality for fathers. Our goal is to promote and assist professionals involved in promoting and supporting men in their role as fathers. The need for knowledge concerning the psychological transition to fatherhood and an examination of methods to overcome gender stereotypes and obstacles to parental leave is also a priority".

### **ESRC Seminar Series – Disabled Parents: The Way Forward**

[www.iass.dham.ac.uk/esrc\\_seminars](http://www.iass.dham.ac.uk/esrc_seminars)

A seminar series for and about disabled parents, hosted by the Institute of Applied Social Studies at the University of Birmingham. Six seminars will be held between autumn 2006 and winter 2007.

### **Working Together with Parents Network** [www.bris.ac.uk/norahfry/right-support](http://www.bris.ac.uk/norahfry/right-support)

A network of parents and professionals working together to improve support available for parents with learning disabilities.

### **Change** [www.changepeople.co.uk](http://www.changepeople.co.uk)

A national organisation working for equal rights for people with learning disabilities.

**Deaf Parenting Project** [www.deafparent.org.uk](http://www.deafparent.org.uk)

A working group which is developing resources for Deaf and hard of hearing parents.

### **Working Papers in Social Sciences and Policy**

is a new series of papers drawing on theoretical and policy-oriented research associated with the social sciences at the University of Hull.

Policy interest in the UK around fathers and fathering has increased rapidly since 1997. Researchers have cautioned against homogenising fathers' experiences. Instead, they have emphasised the need to uncover the diversity in contemporary fathering. This report focuses on *disabled fathers'* experiences of raising children. It is the product of a national one-day conference for and about disabled fathers held in February 2007. The report includes original empirical research evidence about how men understand and practice fathering in the context of impairment and disability, and examines evidence on how disabled fathers' experiences might differ from those of disabled mothers. It also presents the perspectives of practitioners working with disabled fathers and parents, organisations of disabled parents, as well as disabled fathers themselves, about what research, policy and practice agendas for and about disabled fathers should consist of. The report will be relevant to those with an interest in fathering, disability, parenting and masculinities, and to those working in a range of contexts, including policy, practice and research, and statutory and non-statutory organisations.

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