The baby and the bath water: disabled women and motherhood in social context

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Abstract

The aim of this paper is to explore key dimensions of the reproductive experiences of disabled women who are, or who are thinking about becoming, mothers. The paper reports a qualitative study which involved semi-structured interviews with 17 disabled women who were contemplating childbearing, or were pregnant, and/or had young children. The interpretation of these women's experiences is situated with reference to current debates on the meaning and nature of disability, and draws attention to the ways in which these experiences can be understood as manifestations of disablism. More specifically, the paper considers three themes which emerged in the data analysis: the women's engagement with the medical 'risk' discourse; the pressure felt by disabled women to demonstrate that they are, or could be, 'good enough mothers'; and their experiences of receiving unhelpful 'help' from health and social care workers.

Keywords: women, disability, reproduction, motherhood, maternity

Introduction

In highly industrialised societies today, childbearing is an option not an inevitability for most women. An increasing proportion of women in Britain do not give birth to children, and many are 'child-free' through choice. However, the majority of women do have at least one child, and for most the experience of bearing and/or rearing children is something they would not want to forego. Of course, some women who do want to conceive, experience the problems and distress associated with their own or their male partner's infertility. Others choose to parent singly, or to parent in same-sex relationships.

A proportion of women in all of the above categories have physical or
sensory impairment and first hand experience of disability, but their experiences have been largely overlooked in sociological studies of pregnancy, childbirth and early motherhood. This paper reports on the analysis of data from 17 interviews with disabled women. These were conducted as part of a follow-up study associated with a much larger health authority commissioned research project on the maternity preferences of women of childbearing age resident in one city.\(^1\) The disabled women who were interviewed were either contemplating childbearing, were pregnant, and/or had young children.

Whilst the voices of disabled women are almost totally absent in sociological work on reproduction and parenting, there is a small but growing literature on disabled women’s motherhood experiences springing from the disability movement itself (Finger 1990, Morris 1992, Marris 1996). My interpretation of the interview data owes much to this literature, not least because I can relate to the issues at a personal level.\(^2\) It is becoming clearer that disabled women’s desires, decisions and experiences of childbearing and parenting are interlaced with additional concerns stemming from the disablism they encounter, their personal experience of living with impairment per se, and their knowledge about the possible affects of reproduction on their bodies.

Whilst the aims of this paper is to give an account of these women’s experiences through a discussion of three of the themes which emerged in the analysis of the interview data, it can also be read as a contribution to the further development of a sociology of disability (in the Irving Zola tradition, perhaps? (Williams 1996a)) as distinct from the well established sociology of chronic illness (Bury 1991). In other words, the analysis presented here is informed much more by a disability than by a chronic illness paradigm. In relation to my usage of key terms this means that in common with those writing from a disability movement perspective, the meaning of the term disability is not the condition or functional consequence of being physically or mentally impaired. Rather, dis-ability refers to the disadvantaging affects – referred to by many as the ‘social barriers’ – faced by people with impairments flowing from disablism: the ideological antipathy to what is considered to be undesirable physical, sensory or mentally related difference or ‘abnormality’ in western culture. Disability is a form of social exclusion and not a product of impairment per se. However, conceptualising disability as a social phenomenon is not unproblematic and Gareth Williams has recently referred to the ‘hotly contested terrain’ of the meaning of disability (Williams 1996b: 194).

There are a number of dimensions to this contestation, but in conceptual terms debate revolves around the place and nature of ‘the social’ in understanding disability. On the one hand, ‘disability theorists’\(^3\) and medical sociologists are engaged in debate about the ‘divide’ between the ‘social model’ approach (a touchstone of those writing from a disability movement perspective) and mainstream sociological approaches (interactionist,
phenomenological) which focus on the experience of living with chronic illness (for a review of this debate, see Barnes and Mercer 1996). On the other hand, disability theorists and writers are engaged in a debate among themselves (a notably gendered debate) about the place in the social model of both the ‘personal experience of disability’, and the ‘experience of impairment’, (see Oliver 1996, Morris 1996, Crow 1996, French 1993). At the heart of these debates are questions such as: is disability entirely socially constructed/created as suggested by the social model of disability (Oliver 1996), or is this an over-socialised view (Bury 1996, Williams 1996a)? Can/should the social model of disability be developed to take on board the experience of disability, and/or the experience of impairment (Morris 1996, Crow 1996, French 1993), or would such a development be politically dangerous because it redirects attention back to the individual and away from the social barriers which really cause disablement (Oliver 1996, Finkelstein 1996, Campbell and Oliver 1996)?

It is not my intention to explore these debates here, but against this backdrop it is necessary to outline my approach more closely. It is one which attempts to explore the experiences of these women in order better to understand the ways in which disablism manifests itself in the reproductive arena. Much of the research in the sociology of chronic illness tradition tends to concentrate on issues of identity and meaning associated with ‘living with’ particular conditions (Bury 1991). My approach differs from this in that I am interested in looking at the common experiences of disability of women who may have a range of impairments and chronic illness. Furthermore, there are disability theorists who argue that personal experience (either of disability or impairment) has no place in social model analyses (or disability politics), because it deflects attention away from the ‘social barriers external to the individual’. My starting point is that the study of personal experience can powerfully illuminate aspects of these ‘social barriers’, and so point to areas for social change. This reaffirms the sociological position that the study of individual lives can very effectively illustrate the social (Evans 1993, Plummer 1995, Williams 1996a).

So, what can these women’s experiences tell us about the ways in which disablism presents itself on the journey through conception, pregnancy, childbirth and early motherhood? The quotations and examples which are selected for use in this paper are those which best exemplify what I interpret to be manifestations of disability. Put it another way, they illustrate the problems and issues that the women faced, which were embedded in the social fabric of services and structures, and particularly in the social relationships in which they engaged. The manifestations of disability are considered in connection with the following themes which emerge through the data analysis: first, engagement with the ‘risk’ discourse; second, the pressure felt by disabled women to demonstrate that they are, or could be, ‘good enough mothers’; and third, the experiences of receiving unhelpful ‘help’ from health and social care workers. Whilst not the only themes
yielded by the data, these are the ones reported here because of their particular sociological significance. They connect with much wider concerns within medical sociology: medical discourses and risk, the social construction of motherhood, and the social interaction between lay people and health professionals. Other themes, reported elsewhere, related to issues of practical and environmental significance, for example, the design of maternity departments, the utility of equipment, and information needs. Evidence is presented which draws in particular on 11 of the 17 interviews, but exemplars relating to at least one of the themes could have been drawn from any of the interview transcripts. I make no pretence to be representing these women's experiences in their totality (and, of course, in many respects their maternity experiences are the same as those of non-disabled women documented extensively elsewhere). Following a discussion on methods the three themes are considered in turn.

Methods

The data from 17 interviews were the product of a study on maternity, motherhood and disability which was a follow-up of a much larger research project on (all) women's 'maternity preferences'. In the wake of Changing Childbirth: Report of the Expert Maternity Group (DoH 1993), the main Maternity Preferences study was commissioned in 1994 by a health authority in the north of England to gather information on the forms and features of maternity provision which women of childbearing age favoured. It involved a postal questionnaire survey in 1995 with an achieved sample size of over 1,400 women of variable parity, aged between 16 and 44 years, resident in one city. The questionnaire contained items about experiences and intentions in connection with: preferences about the place of birth, features of ante-natal care, care during labour, and care and support in the immediate post-natural period. Through the medium of the questionnaire, women were invited to indicate if they would like to participate in a follow-up interview if they were disabled (that is, considered themselves to be disabled) and felt that this had affected or would affect their maternity care needs. Attempts were made to contact all of the women who responded to this invitation by telephone and/or letter (there were 17 responses in total; some women sent in only a name and phone number, others an address and phone number). As a result, 10 in-depth semi-structured follow-up interviews were conducted. A further three interviews with disabled women were organised through 'networking' with a midwife and an occupational therapist. These two health professionals had worked with a number of disabled mothers and they agreed to contact a few women on our behalf to ask if they would be willing to be interviewed by a member of the research team. Another two interviews were arranged with women who were known to the researchers. Also included in the analysis were the data from
interviews with two more disabled women which had been conducted in the pilot phase of the Maternity Preferences study, again using networking/reputational methods to obtain names. Thus, there are interview data from a total of 17 interviews. This ‘mixed method’ of obtaining the sample of disabled women reflects, in part, the difficulties that there are in obtaining a sample when no pre-existing sampling frame is available. It was fortunate that a broad range of experience was represented in the sample associated with differences in: parity, age, the nature of the impairment(s), and the women’s socio-economic status. However, it should be noted that all of the women were white.

The range of physical and/or sensory impairments represented in the sample is as follows, and included one woman with mental health problems: deaf (Janet, Susan), hearing and visual impairment (Sheila), arthritis in spine (Helen); limb amputation above right knee (Fran), amputation below left elbow (Sarah); Crohn’s disease (Sally); systemic lupus erythematosus (SLE) (Mary); diabetes (Ann); epilepsy (Penny); back injury resulting in chronic back pain (Rachel); asthma (Lorna); mobility problems associated with cerebral palsy (Pat); Addison’s disease (Angela); back pain and mobility problems associated with dislocated hip at birth (Sarah); bilateral dysplasia and osteoarthritis (Clair); high levels of anxiety, panic attacks and agoraphobia (Terry). The names used here are not real names, and care has been taken to avoid the inclusion of identifying details.

The in-depth semi-structured interviews were sensitively conducted in a conversational style. The author conducted the two ‘pilot’ stage interviews and the rest were conducted by one interviewer recruited for the purpose, and overseen by the author. With the women’s permission, all interviews were tape recorded and transcribed. All covered issues to do with pre-conception plans and intentions, pregnancy, labour and delivery, the post-natal period, childcare and ‘being a mother’ – building on the areas covered in the postal questionnaire. However, because of their variable childbearing histories, not all of these areas related to the actual, or past, experiences of all of the women:

- four were childless but were actively thinking about having a baby in the next few years;
- two were pregnant – one with her first and the other with her second child;
- four had one child ranging in age from nine weeks to seven years;
- six had two children (children’s ages ranging from 1 to 12 years); two of these mothers had been sterilised at the time of interview;
- one woman had six children, the youngest of whom was 1 year of age.

In relation to validity, I can claim, first, that the data generation methods were well matched to my research question: what can disabled women’s experiences tell us about the ways in which disablism presents itself on the
journey through conception, pregnancy, childbirth and early motherhood? Semi-structured interviews were an appropriate way to access experiences, allowing respondents to ‘tell their stories’ and recount their experiences in ways which were meaningful to them with minimal researcher constraint. Second, I would defend the validity of my interpretation of the women’s accounts in terms of disablism. Essentially, these accounts did three things: (a) outline the nature of their impairment(s), (b) tell their reproductive story, and (c) reflect upon how (a) affected (b) and vice versa. The analysis of the interview transcripts involved cross-sectional indexing of all of the data in the building up of 19 categories relating to aspects of experience and other social characteristics. It became apparent that these categories could be readily grouped into a number of substantive themes relating to the social, that is, to the problems and issues the women faced which were embedded in the social fabric of relationships, services and structures. Informed by a disability paradigm (as outlined above), it was possible to argue that these experiences/themes could be interpreted as manifestations of disability. Whilst the number of interviews was small and the findings are not empirically generalisable, the arguments are theoretically generalisable (Mason 1996) in the sense that the sample was not atypical of disabled women and the analysis has a much wider resonance.

Taking ‘risks’?

The strongest theme to emerge from the data was that of ‘risk’, an issue of growing interest to medical sociologists more generally (Gabe 1995). Most of the women interviewed had faced issues to do with reproductive ‘risk’ either to themselves or to their babies: would the health and/or survival of the foetus be put ‘at risk’ because the condition was hereditary or because of drug treatments? Would their own health be placed ‘at risk’? The women could not avoid a close encounter with a medical discourse which has at its core the belief that if there is a risk of abnormality, or the risk of worsening an already abnormal bodily condition, then steps must be taken to avoid it; genetic counselling outlining the ‘risks’, or the option/recommendation of a termination, should be given to those parents who are ‘at risk’ of producing a baby with a serious impairment; women with impairments who are ‘at risk’ of worsening their condition through pregnancy should be advised not to bear children. Of course, all women who come into contact with maternity services during pregnancy experience this medical risk discourse in some way (Lane 1995), but for women whose bodies are already ‘abnormal’, the encounter is a particularly sharp one, and there may be heavy personal costs to be borne. In what sense can this experiential encounter with the risk discourse relate to manifestations of disability? Before exploring this question, let us look at the nature of the women’s encounters.

In general, the women interviewed did not question medically-defined
reproductive risks, and tended to share in wider lay beliefs that 'passing on' or 'causing' impairment in a child was irresponsible and 'unfair' to the child (see also Parsons and Atkinson 1992). Sheila, for example, had retinitis pigmentosa (a hereditary visual impairment involving 'tunnel vision' caused by progressive degeneration of the retina) and deafness in one ear (not hereditary) and spoke about the decision to be sterilised some years after the birth of her two sons in terms of risk. Sheila herself had had no signs of the visual impairment when her two sons were born. Now, she had marked impairment and her eldest son had signs of the condition, but it was too early to say whether her second son had this inheritance. She explained how the pattern of inheritance of retinitis pigmentosa cannot be predicted, it 'skips' some offspring, and others become merely carriers. Her GP had suggested that she should be sterilised because of the hereditary nature of the condition. Sheila reported that her mother, to whom she was very close, had strongly supported the GP's view on the grounds that, 'It's not fair, is it, on the children you bring through, cos you don't want them to suffer do you?' This had clearly been an emotionally painful course of action for Sheila. She and her new partner wanted a daughter: 'otherwise I'd have kept going until I got a girl . . . I still pine a lot for a little girl but it weren't to be so . . . end of subject. You get over it'. What is particularly interesting about this woman's account is that the decision to be sterilised was made reluctantly in the context of pressure from trusted figures of authority (her GP, her mother), and in the context of considerable uncertainty about the likelihood that any additional child would in fact 'suffer' from the condition.

Another mother, Mary, with systemic lupus erythematosus (SLE, a chronic inflammatory disease of connective tissue affecting the skin and various internal organs requiring steroid and other drug treatment) had made the decision not to try for a second child because 'it wasn't worth the risk' either to her own health or that of the baby. When she became pregnant with her first child, the medical team responsible for the treatment of her SLE had refused to believe her claim that she was pregnant, because they were convinced that her prescribed medication would prohibit conception. A scan had to be conducted to confirm her pregnancy for these specialists. The doctors advised her to continue with her medication at current levels throughout pregnancy, although following a move abroad during her pregnancy, she was later told by doctors in that country that 'because of the tablets I'm on he could be slightly deformed – fingers and toes or something' (Mary). She describes herself as having been 'fit and healthy' throughout the pregnancy and her son was born, prematurely, with no apparent 'deformities'. On her return to the UK she was referred to a consultant rheumatologist who was the first doctor to give her detailed information about SLE, and in whom she had much confidence. Mary explained that she now knew that her steroid medication could and should have been reduced during pregnancy to reduce 'the risks' to the baby. She talked about how her health had deteriorated in the years following the birth of
her son. At one stage she had decided to try for another baby, and had been in contact with both her rheumatologist and the maternity hospital for advice about conception and pregnancy. She was given contradictory advice about 'the risks' associated with her medication. The rheumatologist told her that one of her drugs was contra-indicated and that an abortion would be absolutely necessary if she became pregnant whilst on this drug, but the doctors at the maternity hospital asserted that the drug was 'safe'. She had stopped taking this drug but then had a 'flare up' of her condition, 'so I decided myself that it's not worth the risk . . . there's no point in having another child if there's no mum there to look after them'. She knew of cases where mothers had died of SLE following childbirth. This decision not to have another child had not been an easy one to make, and the health services had certainly indicated a willingness to assist her with conception and pregnancy if she had wanted to persist in her attempts to have another child:

I said to my husband, I've got to go through the grieving process and he said why?, why?, why? and I said because I've made a decision, I said that I can't risk having another one. I said the maternal instincts are still there so I sense, like, you've lost something, you've lost a part of you . . . I've to go through the grieving process, I said you've got to give me time for that. . . . I mean they told me [my son] was a miracle really, and at least I've got one (Mary).

The issue of the risks to the woman of ceasing medication, or of reducing or increasing its levels, versus the risks to the foetus of continuing with pre-pregnancy levels of medication was also a key one for some other women – particularly those with either chronic back pain, epilepsy, diabetes, asthma, or mental health problems. Some of these women had experienced, or would expect, extra monitoring during pregnancy to ensure that the baby was developing 'normally', and that their own health was not being compromised. The balance was sometimes a very fine one. For example, Penny (with epilepsy), said that because her medication meant there was a slim chance of foetal deformity, it was kept to a minimum. However, she did have one fit during pregnancy because her medication dosage was too low. This had distressed her because she had read that the oxygen supply to the baby can be dangerously reduced during a fit: 'it can cause you to lose the baby'. Penny believed that the doctors were at fault for not increasing her medication in proportion to her weight increase.

Rachel, who had chronic back pain following an accident, talked about having a baby in the future as a kind of 'trade off': living with increased pain during pregnancy in return for having a 'beautiful baby' at the end. She knew that her injections at the pain clinic would 'have to stop' during pregnancy:

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I know I’m going to be in pain, it’s my decision to have a baby and I’ve got to weigh it up... I can always think ‘well at the end of this I’m going to have a baby’, you know, and then I can go back to the pain clinic and have some more treatment and so... I think that’s the way I would have to look at it (Rachel).

Terry, a respondent with mental health problems (anxiety and panic attacks, agoraphobia, depression) which had developed in the time since the births of her two children, agonised about the problem of medication and pregnancy. She experienced this as a real dilemma: she desperately wanted more children, especially with her new partner (she had two children by previous partners both of whom had abused her emotionally and/or physically), but was terrified that she would not be able to ‘cope’ without her drugs (especially Prozac):

I’ve been told I can’t ’ave a baby on medication so... I don’t know if I’ve got the guts to actually start coming off them [the tablets], I want to but the fear of being how I were without them is stopping me. I really, really want to come off ’em, I’m so scared I don’t... I think if I, if I were going to be like that I wouldn’t even attempt to come off ’em, no matter how much I wanted a baby (Terry).

Terry had not felt able to seek help from health professionals about this and clearly struggled alone with these tensions. In a life of considerable emotional hardship, she had gained tremendous satisfaction and self-belief through becoming a mother: ‘Satisfaction of thinking they’re a little human being and... it depends on you for its care and you giving it and its thriving and you think, oh! you’re doing something right’.

Two mothers, Sarah and Pat, did give birth to children with impairments associated with hereditary conditions. Feelings of guilt after the birth of her first child were expressed by Sarah, a mother of six who was herself born with a dislocated hip – a hereditary condition which may or may not manifest itself in offspring:

... when my first daughter as born, they thought that she had a dislocated hips as well and that was very sad, well it was a very sad time for me because I felt that I’d done it to her you know... they told me when she was a day old when I think you are quite fragile anyway, and so that was a very bad time then for me because, you know, my beautiful new baby – and I’d made her not quite right, and then she had to have a harness when she was six months old and that particular consultant thought she should wear it the whole time so we never took it off for a bath or anything for six months... there was a lot about our baby that didn’t look normal and... it was a big iron thing round her legs (Sarah).
Sarah’s fourth child was also born with the condition but a different consultant suggested that a harness only need be worn at night. Sarah experienced this as much less problematic – it carried considerably reduced ‘guilt’.

Pat’s first child was diagnosed with a chronic condition as a baby. However, this child had cystic fibrosis which was completely unconnected to Pat’s cerebral palsy. She and her husband were, unknowingly, carriers of the gene for cystic fibrosis. What is particularly interesting is her account of how some people made assumptions that her child’s condition was a direct result of her own impairment (or at least, of its visible manifestations: some difficulty in walking, in maintaining balance, and a weakness in one hand) – with the unspoken implication that she was irresponsible to have this child: ‘... I’ve just had a couple of people say erm ‘is it related in any way to what you’ve got?’, but that’s, you know, their ignorance rather than anything else’. Pat admitted to feeling ‘relieved’ that her son’s condition was not related to her cerebral palsy, and that his CF could not have been predicted. In fact, she had sensed some hostility from other people when she had been pregnant:

I do think that sometimes they thought that I shouldn’t be pregnant. You know, nobody actually said anything but, and it wasn’t anybody I knew or anything like that but ... if I went on public transport and things like that. Not all the time, just once or twice ... well they’d probably think that whatever I’d got the child has got a chance of being the same and they wouldn’t know that what I’d got wasn’t passed (Pat).

Pat talked about her decision, made with her husband, to have a second child. She described this as ‘murderously difficult’. They wanted another child, and thought their son should have a sibling, but they had to weigh this up against what they saw as other factors to take into consideration: the chances of a second child having CF or a different impairment, the effects that an early death of the first child would have on the second, her assessment of the impact of her own impairment on her ability to manage another child, especially one with CF, ‘cos you get less capable of doing things as you get older’. She did have a second child and it did not have CF. Six months after this birth, she decided to be sterilised: ‘... you can’t have any more taking those risks can you? ... I thought with all the odds against us’ (Pat).

From the above we can see that considerations of ‘risk’ were an important feature of the women’s reproductive journeys, and we can also see that disabled women often share, albeit sometimes ambivalently, in the wider social and medical discourses about what constitute reproductive ‘risks’. Having a child with an impairment is seen as something to be avoided, and if it occurs, is experienced with feelings of ‘guilt’ which spring from the knowledge that their actions in having a child are widely seen as both irresponsible and ‘unfair’ to the child. Such women often face very difficult
decisions about whether to take the ‘risk’ of childbearing if they have a hereditary condition which might be ‘passed on’, or if they are on medication which may ‘damage’ the foetus, or if their own condition may be worsened through reproduction. The women’s accounts bear witness to the considerable ‘emotion work’ involved in personal encounters with the risk discourse: worry, anxiety, guilt, lost hopes, unfulfilled dreams, spoilt identities.

But is this emotional burden simply an inevitable feature of the ‘personal tragedy’ of living with impairment”? Of course not. These individual experiences are shaped by encounters with wider discourses about personal responsibility, which accompany all women on the journey into motherhood, coupled with encounters with disablism. The key point is that the risk discourse is not a neutral one. What is and is not judged to be an acceptable risk hinges not just on life or death questions, or on purely biological criteria, but on social assumptions about the quality of life and intrinsic value of children and adults with impairments. As Freidson pointed out so well, medical knowledge about illness (or impairment) is social, and as such is ‘inevitably evaluational’ (Freidson 1988: 208). Despite its apparently ‘scientific objectivity’, medical knowledge inevitably draws on deep-rooted cultural antipathy for, and prejudices about, people with ‘abnormalities’. Jenny Morris (1991) has argued that in our society, judgements are made about the quality of life of people with impairments which equate physical impairment (particularly severe impairment) with ‘lives not worth living’, and that impairment is considered in abstraction from the social, economic, cultural and spatial circumstances which really do determine the quality of life. It is noteworthy that medical sociologists who have considered the reproductive risk discourse (for example, Parsons and Atkinson 1992, Lane 1995) have described lay encounters with it in connection with impairment and disability but have not commented upon or questioned its disablist character.

Drawing on Morris’ work, and a wider literature springing from the disability movement, it is clear that a minority of disabled women have rejected the socio-medical discourse about risk and see it as part of an all-pervasive disablist ideology. They know that there are medically defined ‘risks’, that is, probabilities of impairment affects for self or the baby, but they do not necessarily evaluate these risks negatively. Impairment per se is not equated with ‘the problem’. Their perspective is clear: the problem is disability – the social barriers which socially exclude. Micheline Mason (1992), for example, has written about her great joy and sense of achievement in becoming a mother (a single parent) and about her decision to continue with an unplanned pregnancy though she knew that her child would inherit her own condition – ‘brittle bones’ (osteogenesis imperfecta, giving her a tiny stature, deformed limbs and the need for assisted mobility):
Once I had made the decision to choose life, and whatever that may
bring, the confirmation that the baby did indeed have brittle bones only
seemed to make the initial decision more meaningful and special (Mason
1992: 115)

Micheline Mason, who describes herself as a disabled activist, has been able
to throw off disablist attitudes about the 'tragedy' of having a child with an
impairment, and, rather, to celebrate it and to demand that the disabling
social barriers which are the real source of the disability experienced by dis-
able children and mothers, are removed.

To see the 'risk discourse' as disablist (something of significance for all
women) requires a change in consciousness which Morris (1991, 1996),
Mason (1992), Anne Finger (1990) and others have made. The women in
my study, like most disabled women, had not travelled that journey, or per-
haps, had not had the opportunity to do so. This does not lessen, however,
the power of their personal accounts to 'tell of disablism'. I would argue
that in some very fundamental ways, their engagement with the medical
risk discourse was an engagement with disablism, and that the considerable
personal costs to be borne were one important aspect of the 'manifestations
of disability' they faced. To put this another way, that is, in 'disability
rights' terms, the powerful medical (and wider) discourse on reproductive
risk acts as a social barrier in the sense that it plays an important part in
'restricting activity'; in its light, decisions are made not to have a
child/another child, or to be sterilised, or to terminate a pregnancy.

'Good enough' mothering?

A second theme which emerged strongly in the data analysis revolves
around the fear of being judged inadequate as a mother, and of the conse-
quences that this might bring. Again, all women who become mothers (and
particularly those in pilloried groups such as 'single mothers') experience
this to a greater or lesser degree, especially in these times when public and
professional discourses highlight concern for 'children at risk', but this
study suggests that disabled women are particularly vulnerable. A number
of the women lived with this fear, believing that they might be seen by
others – representing either the powers of the state (health visitors, com-
community midwives, doctors, social workers and so on) or the power of the
wider family – to fail to live up to being a 'good mother'. Two women had
actually experienced the threatened or actual loss of their children, but per-
haps surprisingly, not as a consequence of action by 'officials' but as a con-
sequence of family members taking unofficial action against their wishes.
For example, Jane, who had lost her left arm below the elbow as the result
of an accident, described the way in which her own mother wanted to 'keep'
her two-year-old daughter (born before the accident) because she believed
that Jane would not be able to cope. Jane’s mother had become involved in sharing the care of the child whilst Jane was in hospital having a series of operations over a number of months following the accident.

I actually then had to ask solicitors to get involved because mum decided she wanted to keep [my daughter] — so mum went to the solicitors to try and . . . there was an argument over access because I was quite happy for mum to see her whenever. It was over coming home at night custody really . . . I think looking at it from her point of view, now, she just decided that because I’d only got one arm I couldn’t cope . . . [that I] should be sat there in my rocking chair almost, you know, in a wheelchair and give up on everything . . . I just said to mum, ‘you can see her whenever but I can cope’, and I think that’s what actually made us decide we’d like another child. Just to sort of prove that we could cope (Jane).

The other respondent who had experienced a struggle over custody was Terry, who had mental health problems. Whilst she was going through a divorce with her first husband he took their child, without Terry’s consent, to live with his own parents. Terry reports that these grandparents ‘tried to make me out to be mentally unstable’, and only allowed her to visit her son for one hour per day over an eight month period until the custody case finally came to court. On one such visit she had been physically assaulted (requiring hospital treatment) by the grandmother when she tried to take her son out of the grandparents’ house. She got legal assistance through the intervention of health care workers and was finally granted custody of her son by the court. Her fears about her children being removed from her care were ever present and certainly not helped by her own mother’s refrain—‘if you don’t get better they’ll take your children off you’.

The fear of losing her children had begun to creep into Sarah’s mind after the birth of her sixth child. She had begun to experience a lot of difficulties in walking and bending and had discomfort and pain (associated with residual impairment having been born with a dislocated hip):

It’s very hard to think that I can’t look after my own children, it’s a very hard thing to come to terms with really. And I’m not quite at the point of saying ‘look, I can’t really do this’, but if I was I don’t really know what would happen. I suppose the children get taken into care, don’t they, when the parents say they can’t cope? — but, you know, that’s a very frightening prospect really so its easy just to think of treading along (Sarah)

These fears had been heightened by a health visitor with whom Sarah had been discussing a future hospital admission for a hip replacement operation. Sarah was worried about child care arrangements because she would need some kind of help during the hospital stay and for some months after-
wards whilst she was relatively immobile. The health visitor’s reply was quite astonishing to Sarah:

... she said ‘well, the children won’t all be able to go into care together you know’, which wasn’t what I was asking for because I wouldn’t want my children to go into care you know, I mean, who would? What a response! (Sarah)

Living with the fear of losing the right to care for their children forces some mothers to go to great lengths to ‘present’ themselves and their children as managing ‘normally’ – often at significant personal cost in terms of comfort, and emotional and physical well-being. One consequence is that assistance may not be requested when it is needed because the mother feels that her request may be interpreted to mean that she is not capable. Clair, a women in the study with quite severe impairment (a wheelchair user from a very young age), spoke about her joys at giving birth to her son, but her anxieties that other people’s prejudicial judgements might lead to her child being removed from her care, particularly as she was a single parent:

I felt that it was going to happen very soon, that maybe the prejudice of someone who lived around me [a neighbour] would make them think that they’d got to ring up social services and that an investigation would start ... it terrified me, it really did. I don’t think I relaxed into motherhood until he was bout 18 months or two years old, I really don’t think I did ... . I would love to have those months again cos I was so scared, tidying the house cos I knew somebody was coming who was from authority, you know, that when he was asleep ... I was too busy doing jobs rather than enjoying him and relaxing (Clair)

Jane also worried about professionals’ judgements that she might not be able to manage. Despite having some practical difficulties in getting her new baby dressed and undressed several times a day for nappy changing whilst she was adapting to life without her left arm below the elbow, Jane struggled on with the dressing routine in the early weeks in order to ‘present’ herself to others and to herself as a ‘fit’ mother:

I felt that she had to be dressed every day and I had to ... otherwise people would think that I couldn’t do it cos ... certainly for the first six or eight weeks I felt that I ... was letting her down because I couldn’t get her back dressed properly, but after that I just got to the point where I thought, well, she’s warm, she’s healthy, as long as she’s clean it doesn’t matter (Jane).

Jane noted that after the birth of her first child, before her accident, she had not worried at all about always having the baby dressed because she had ‘felt in control of things much more’. The baby and the bath water 635
These accounts testify to the particular vulnerability that many women with impairments feel when they become mothers, or if they become impaired whilst fulfilling the socially defined obligations of motherhood. This feeling of vulnerability and insecurity is caused, in part, by their own concerns about managing some of the practical child care tasks because of the impairment, but in the main it is caused by disablism: the prejudicial attitudes of others and the failure to provide appropriate assistance to disabled women on their own terms. While the majority of non-disabled parents can take it for granted that the quality and character of their ‘parenting’ is their own business – although this may be increasingly illusory (Abbott and Sapsford 1990), disabled women really do feel under surveillance, and that feeling is usually well founded because disabled women are often assumed by professionals and lay people (often including close relatives) to be incapable unless they can prove otherwise: guilty until proven innocent.

Given the strength and widespread nature of disablist ideas which doubt the ability of women with impairments to be ‘good’ mothers, to be able ‘to cope’, it is not surprising that many disabled women – especially those with a recently acquired impairment – have to overcome doubt about their own capacity to become mothers, or may privately share in some of the social anxieties about the welfare of the children of disabled parents. Once again, the personal costs involved, including the actual loss of the right to parent, are in fact the consequences of the way that disability manifests itself rather than as something inherent in being impaired.

When ‘help’ is not helpful

The third but closely related theme concerns the women’s experiences of receiving inappropriate or inadequate ‘help’ from health professionals and social care workers. At issue here is the nature of the social interaction between professionals and disabled patients/clients in contexts where the professional maxim that ‘we know what is in the patient’s best interests’ finds full expression. Once again, a large literature on the medicalisation of childbirth suggests that many women experience a sense of loss of control over their bodies during pregnancy and childbirth as doctors and other health professionals ‘take over’ (Roberts 1981, Oakley 1981, Garcia et al. 1990). However, this experience of loss of control can be intensified when ‘disability’ is an additional factor in the lay – professional encounter. Now, from a professional perspective, it is not just the ‘management’ of the pregnant woman and new mother that is of concern, but the management of women with the additional problems that come with ‘being disabled’. A number of women in the study gave accounts of individual health workers who, although well intentioned, had ‘taken over’, had been unhelpful, or had lacked the information or skills they required. However, it is important
to point out that all of the women said that some midwives, doctors (particu-
larly some GPs), health visitors, 'home helps' and others were 'brilliant',
'great' or 'wonderful'. Similarly, some friends and relatives were 'great',
'always there for me' (often this was their own 'mum'), a 'real safety net',
but others were 'hopeless', 'fussing', 'over-protective' or 'taking over'.

Jane's experiences illustrate this theme particularly well (she had lost her
left arm below the elbow). She reported her well-meaning GP as saying: '...right, we'll get someone in, they can bath the baby and dress the baby, give
the baby to you and you can sit there and nurse it and if you want we'll get
someone in to help you bath'. The first time the baby had needed a bath in
hospital the midwives had said 'we'll do this'. Jane went on to explain that
what she had really wanted was for someone to assist her with tasks like
bathing the baby but not to do it for her. Her experience of professional
assistance was a largely disempowering one. It had been a source of dis-
tress, and had undermined her self identity as a mother: '... when people
wanted to take over I found I was getting really cross and I didn't want to
get cross with the nurses. I'd take it out on [my husband] later - "they said
they're going to bath that baby!"'. 'Taking over' also occurred in relation
to breast feeding:

I just really felt that I was being left out of the important decisions, you
know, and as if, I did start feeding her myself and then felt it just wasn't .
. . there was always someone fussing around me and, you know, 'you can
cope?' and 'you'll have to put the head further into the crook of your
arm' and it was always . . . wanting to prod and poke and 'are they all
right?' I mean I only stuck with it about four or five days and then
started feeding her with a bottle because I could to that myself. You
know - they used to bring the bottle with the teat on and I could do that'
(Jane).

One midwife had said:

'We'll come everyday and put the baby on the breast' . . . they've got this
vision of it all being so awful . . . I must admit it didn't feel, being a mum
didn't feel as natural with [my second], everything seemed much more
difficult and I did get depressed . . . (Jane)

Jane thought there should be 'more emphasis on helping, not doing it -
helping mum not doing it for the baby'. By the time the Health Visitor had
started to call at home: 'I'd already started saying "right I can manage
that" and she went the other way and said "oh you can cope, you're man-
aging really well and you can do this"'. In short, Jane's experience was
largely one of inappropriate help or no help.

For other women, having taken the risk that they might be signalling
their inadequacy as a mother by asking for 'help', there were further
personal costs to be borne. For example, Sarah, who had problems with walking and bending after the birth of her sixth child, had to endure being 're-assessed' by the Home Help Organiser in connection with a service she received which involved a Home Help transporting her older children to and from school:

She [the Organiser] turned up just before my daughter's first birthday party which was a bit difficult really and she only saw me sitting down and her line was 'why are we only doing this for you two days a week?', you know, and I said I could manage the other days and she said 'well, perhaps we should stop then?'. I found that very difficult really. I thought afterwards perhaps I should have got up and showed her how difficult it was for me to walk, but there's something really horrible about that. Well, that's something I've had to do for doctors all my life really and I found that quite demeaning, I didn't actually want to do that (Sarah).

Sometimes, technological aids were required - and what women wanted was information about, and access to, appropriate aids. For example, the three hearing-impaired women in the study mentioned the use of aids such as 'alarms' to indicate that the baby was crying, ante-natal information videos for hearing-impaired people, adapted telephones and doorbells and other equipment. In some instances, these women found out about aids by chance, or more often through meeting with other deaf mothers. This form of practical assistance was rarely offered by professionals in the health or social services; it was a case of repeatedly asking for and pursuing information. Another disabling barrier experienced by these hearing impaired women was associated with face-to-face communication with health professionals. Most professionals encountered did not know how to communicate effectively. For example, midwives rarely knew any basic sign language (and signing was not always wanted, anyway), and Susan reported having repeatedly to ask the midwives to 'slow down' so that she could follow what they were saying by lip-reading. Janet was very angry when unwanted 'help' was thrust upon her when she was in labour. The hospital midwives had arranged for an 'interpreter' to be present at the birth to assist with communication. Janet felt that she did not want a stranger present at such a private time. In fact, she did not feel that an interpreter was needed at all, and that if anyone needed to interpret, then it could be a close family member chosen by herself.

Pat, who had mobility and balance difficulties, would have appreciated help with some housework tasks both during her pregnancies and whilst her two children were small. She had also found bathing her babies difficult, although her husband helped with this. Additional assistance with housework and other tasks was not asked for, in part because she did not believe that services would be available, but in the main because she felt that asking for help makes 'you feel a burden'. This feeling was a common one among
the women interviewed; you just had to ‘get on with it’ and ‘do the best you can’. As Sarah said, ‘I think its very, very difficult to ask for help’. As noted previously, this is partly associated with the need to be seen ‘to cope’ without additional help, to be a ‘good mother’, but it is also because women feel they ‘should’ be able to cope – that women always do have to cope. As in Pat’s case, disabled women may also assume that there is no entitlement to assistance, or they may lack information about the services available.

What unites the accounts of inappropriate or inadequate assistance is that nobody appears first to have asked the women themselves what assistance, if any, they really wanted and how assistance could best be given. Professionals (and non-disabled lay people) assumed that they ‘knew best’. It can be argued that this is a classic feature of disablism: the impaired person is constructed as ‘dependent’, as reliant on the wisdom and help of expert others. Jenny Morris has written powerfully about this, that is, the disablism which constructs disabled women as the ‘cared for’, ignoring and excluding them as ‘care givers’ (1991, 1995). There is no recognition that dependency, which is a feature of everybody’s life to some degree, is socially created. So pervasive is this view, that non-disabled feminist writers have reproduced (and reinforced) it in their critique of community care policy in the UK (Morris 1991, 1995, 1996, Keith 1992). In this critique, the characterisation of disabled women as cared for rather than as care givers is taken as given.

In fact, what is striking about the situation of the disabled women interviewed in this study is that their care-giving role was fundamental to the physical and emotional maintenance of others in the household, and that, even where a male partner was present, disabled women were, or continued to be, the main carers of children and other family members. The traditional sexual division of labour was very much intact whether or not the women needed any assistance over and above the help that women ‘normally’ get within families. Furthermore, these women’s self identities and aspirations were very firmly tied in with being a successful mother and running a home. Like many other disabled women, their personal fight in the face of disablism was fundamentally about the right to be mothers and home makers.

Nevertheless, it seems that the normative assumption that disabled people are dependent profoundly colours the way in which ‘help’ is offered to women with impairments both by well-meaning professionals, and often by friends and relatives as well. Non-disabled people generally assume that disabled women will need particular forms of help and that they know best how to give it. In reproductive contexts, where maternity services already construct women as patients to be cared for by expert others, many disabled women receive a double dose of dependency creation. However, it is certainly not always the case that assistance is needed or wanted. Where it is, for example in the form of practical help with child-care tasks, the ‘help’ which is offered is quite likely to be inappropriate, and/or conditional, or it may not be offered in any guise. Where ‘help’ is unwanted but forced upon
disabled mothers, or is inappropriate in its form, it can be experienced as a threat to the right to parent (as we saw in the previous section), and/or as intrusive and disempowering. These are some of the 'manifestations of disability' faced. No help or the wrong help is the common lot of disabled women.

Conclusion

This paper has reported on the experiences of 17 disabled women who were at different stages in their reproductive journeys at the time of interview. It has explored the ways in which disabled women's decisions about and experiences of childbearing and motherhood are interlaced with additional concerns which originate in the social fabric of services and structures, and particularly, in the social relationships between themselves and others. It has focused on three themes which emerged in the analysis of the interview transcripts: engagement with the medical 'risk' discourse; the pressure felt by disabled women to demonstrate that they are, or could be, 'good enough mothers'; and the experiences of receiving unhelpful 'help' from health and social care workers. The interpretation of these personal experience narratives has taken place against the backdrop of current debates about the nature and meaning of disability, and the emphasis has been on what these women's accounts tell us about the manifestations of disability, or disabling, which women with impairments face when they think about having a child, become pregnant, come into contact with maternity and related services, and when they become mothers.

Disablism was evident in a number of ways: in the women's close encounters with the medical 'risk' discourse with its unspoken evaluative assumptions that, for example, to give birth to an impaired baby is to give birth to a life of lesser worth. This could entail living with the fear that one might be judged to be an inadequate mother, and that actions might follow involving the denial of the right to be a mother. Furthermore there might be disempowering encounters with (usually well-meaning) health and social care workers who frequently offered inappropriate help informed by a professional ethic that 'we know best'.

The paper has highlighted those features of the women's accounts which tell us something about the 'differences' disability brings. It suggests that disabled women's reproductive journeys are strewn with social barriers of an attitudinal, ideological and material kind. I hope to have demonstrated that the exploration of these women's experiences can provide a deeper insight into the nature of these 'social barriers'. In doing so I also hope to have made a contribution to a sociology of disability which, whilst starting out from the experience of individuals, allows the examination of the social manifestations of disabling rather than pursuing ever deeper exploration of the 'subjectivity of experience' (Williams 1996b: 202). The point of it all it is
not, however, to generate knowledge for its own sake, but to inform those engaged in disability praxis.

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Notes

¹ The findings of the Maternity Preferences study are not yet fully in the public domain, and thus the identity of the Health Authority which funded the study is protected here.
² I was born without a left hand and now have a four-year-old child.
³ ‘Disability theorists’ is a term which has come to be used to identify those academics, most of whom are themselves impaired, who are researching/writing about disability from a ‘disability rights’, or radical socio-political perspective (for example, see Swain et al. 1993, Oliver 1996, Barnes and Mercer 1996).
⁴ Please contact the author for information about the research report and papers in preparation.
⁵ Whilst not an impairment as conventionally defined, mental health problems are, nevertheless, associated with disability because they carry the medical label of 'mental illness' and, as such, gives rise to the experience of social exclusion.
⁶ It is important to acknowledge the contribution of Sue Greig who carried out these interviews with considerable skill and sensitivity.

References


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