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Breakthrough UK Ltd

Great expectations: the significance of concepts of normality, care, and social support in cultural discourses of disabled motherhood

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Forward

Breakthrough UK Ltd is a successful independent social enterprise, managed mainly by disabled people. It brings together disabled people, local businesses, and other agencies to plan and deliver projects and services to promote independence. Based in the North West of England, Breakthrough UK provides independent living support, training, employment and business opportunities to disabled people within the social model of disability. On average 60-70% of Breakthrough's staff are disabled people, with first hand knowledge and experience of the barriers to independence and employment.

The Breakthrough Policy Think Tank is a response to what we see as a 'policy vacuum' in relation to disability. Its membership brings together a small group of disabled people known to subscribe to the social model, who are known for their analytical approach, and their tendency to "stretch the boundaries" in a variety of areas. The Policy Think Tank has two major aims:

- To influence government, or other strategic bodies, on matters to do with disability, from a 'social model' perspective.
- To provide briefings on current matters to do with disability for general dissemination.

The Social Model of Disability: traditionally disabled people have been seen as a problem, to be tackled by focusing interventions on the individual. Developed by disabled people themselves, the social model locates the problem with the structures and organisation of society, which take little or no account of what disabled people need to be autonomous and to live independently. We believe that all policy and practice proposals relating to disability and disabled people should be rooted in the social model of disability.

This paper is one of a series commissioned by Breakthrough UK to research and report on the issues around the whole life agenda for disabled people from birth through to death, from a social model perspective. This paper specifically addresses the pressures that families / parents may face, during a pregnancy, to terminate a life due to either impairment of the un-born child

(foetus) or the mother's impairment. It details the author's findings, highlights good practice and finally outlines recommendations for health professionals, policy makers, media practitioners and academics at Appendix 1.

~~Bio paragraph: about the author of each report to establish their expertise in the field and mention or links to previous work?~~

Breakthrough UK Ltd

~~Insert date~~

~~Acknowledgements?~~

Great expectations: the significance of concepts of normality, care, and social support in cultural discourses of disabled motherhood

A Note on terminology

I will refer the terms 'culture' and 'discourse', the social model of disability, impairments, and the idea of individualism; they are defined further in the glossary at the end of the paper.

Also, whenever I use the term disability or disabled this denotes social model definitions of disability. Thus, disabled motherhood refers to mothers with impairments who are disabled by social structures and attitudes.

Introduction

It does not always require a law to force people to make certain decisions. How we live in any society and interact with others, make choices and decisions, involves a lifetime of learning about what is appropriate and inappropriate, expected and frowned upon, considered good and bad practice. Some expectations of human behaviour are made evident through laws, but much is not; instead, we just 'know' what is expected of us through commonly held beliefs or values (Wilde, 2011; Zou et al, 2005), usually framed in terms of 'common sense'.

In the UK in the twenty-first century, discrimination against disabled people is rarely in a legal form; rather it is often through 'common sense' advice that oppressive conditioning occurs.

Choices are made, but how free these decisions are, in the face of social and cultural pressures and inequalities, is less clear (Beresford and Sloper 2008). Although there are have been a number of studies of disabling culture or 'discourse' (Wilde, 2004; Yardley, 1997) there are few studies of the barriers facing disabled parents (notable exceptions include Wates, 1997, 2002; Olsen and Clarke, 2003; Olsen and Wates, 2003). Considering low cultural expectations of disabled people and the considerable discrimination towards them, it is unsurprising that literature on the pressures facing disabled parents is scant. Notwithstanding the information to be found on the websites of activist-led organisations such as the Disabled Parent's Network (DPN) and

Disability, Pregnancy and Parenthood International (DPPI), there is a considerable gap in our understanding of the pressures placed on prospective disabled parents. This is especially significant given the present shift to austerity measures, the resurgence of the idea of disabled people as an economic burden, and the prominent place of disabled people on financial resource agendas, as well as in media coverage of these issues in current affairs. (Lawrence, 2011; Williams-Findlay, 2010).

This paper will address the topic of the pressures facing disabled mothers, bearing these cultural values in mind. It will investigate the ways that different concerns affecting disabled women interact and shape choices about parenthood, especially those affecting the decision to remain childless or terminate a pregnancy, due to the mother's impairment.

Clearly, discourses of disability will impact on both prospective mothers and fathers. Although there is also a compelling case to examine fathers' experiences (Kilkey, 2007) this paper focuses on the distinct experiences of prospective disabled mothers who will bear the brunt of social and cultural expectations of maternity and obligations of care. I will examine the ways in which social beliefs about, and practices towards, disabled motherhood impact upon prospective disabled mothers' self-belief, and shape their decisions on whether to enter into parenthood. With few studies undertaken in the area of disability and women's pregnancy in the United Kingdom (UK) or elsewhere (e.g. non-Western societies), the discussion will focus on the UK (and comparative societies such as the United States) whilst acknowledging that the pressures placed on prospective mothers will vary across and within cultures.

The discussion will focus on a number of related themes. It will examine the importance of cultural pressures that disabled women face to deter them from becoming pregnant, or to terminate if they do. Exploring the links between cultural, medical and professional practices, it will examine how disability and parenting are often constructed as mutually exclusive categories.

The following section begins with some personal reflections which, as a starting point, are carried through the paper contributing to its structure. The next two sections will consider the roles of health care professionals and social services,

examining common sense ideas of responsible parenthood and health risks.

The significance of popular media in constructing ideas of parenthood and disability will be examined in the following section. Finally, the impact of the focus on the children of disabled parents as 'young carers' will be explored.

The overall aims are to challenge current assumptions of deficit parenting that are still prevalent in the health and social support services, and in society at large, and to begin a much-needed discussion about the marginalisation of disabled mothers' identities.

Beginnings

Why do you want to do this? Don't you think this is selfish? How are you going to be able to look after this child? What if you become ill? Who will look after your children then? You do realise that the child has a higher than average chance of inheriting your 'disability'? What if your child has to look after you?

These are just some of the questions which were put to me when, fifteen years ago, I saw a health professional from family planning services with a view to becoming pregnant with my third child. Unfortunately, they are questions that many disabled mothers have faced, and they will continue to be asked in a cultural and professional climate which conceptualises disabled people in individualistic, medicalised ways, as problems to be fixed rather than citizens to be supported.

Disabled women face many obstacles on their paths towards parenthood and in their lives as parents (see, for example, Department of Health's Expert Maternity Group, 1993). For many parents these difficulties go far beyond the type of interrogation I received (above) creating fear, anxiety and, for some leading to the loss of their children. For others, cultural beliefs of disabled parents and oppressive social practices exert compelling pressures to remain childless or to terminate a pregnancy.

Cultural myths of parental incompetency have substantial long-term impacts on parents and children. There is considerable evidence that all disabled parents face barriers to parenthood,

especially in coping with the effects of discrimination and prejudice (Shakespeare, 1998). It is also clear that these experiences vary according to a number of social and cultural factors. For example, disabled mothers will encounter greater scrutiny of their parenting roles than prospective disabled fathers due to the gendered expectations of parental care, anticipating mothers as primary carers. Family income and resources will also play a crucial role in professionals' assessment of parental capacity as well as their perceptions of the costs of social support, especially where services are scarce. Individualistic discourses on the potential economic burdens placed on 'the taxpayer' by those deemed as less deserving are central to the current economic and political climate.

Ostensibly then, there is nothing to stop disabled people becoming parents, no legislation or official policy on removing or preventing parenthood for disabled people to challenge or oppose, on a collective basis. Instead, the barriers to parenting are individualised and felt at a deep psycho-emotional level, shaping personal ideas of 'who to be' and 'how to act' (Giddens, 1991, 70), or 'who we can be' and 'what we can do' (Thomas, 1999, 45), limiting our strategic resources on how to get there.

As the poet Mary Duffy wrote:

"I know I am not expected to have children
I don't know how I know, I just do.
Nobody ever said anything
It's probably what they didn't say
That made the difference."

(Keith, 1994, p.29)

Such felt stigma, with no apparent cause, can have profound effects on 'internalised oppression', on people's sense of themselves in relation to their social context, creating socio-emotional stresses which render people less confident and competent, reducing their capacities for informed decision-making and care taking responsibilities (Affolter, 2009). Here the social model of disability is crucial to a critical analysis of disabling *emotional*, as well as physical, barriers to access, particularly as 'cultural outlooks' (Gleeson, 1999) continue to be permeated by disabling practices.

By the time most disabled people reach child-bearing age they have received a long and informal education about who they can be, having faced a wide range of disabling attitudes in every area of life. Those who acquire impairments at a later stage are equally well versed in the 'common-sense' individualistic ideas of disablement (Iwakuma, 2002; Wilde, 2004b). Seen from the privileged view of the 'non-disabled gaze', cultural prejudices about disabled people's competency will often exert considerable influence on newly disabled people's self-expectations as they face new challenges and forge new identities.

So, before they begin any journey towards parenthood, most disabled people will have gained an awareness of the challenges they will face as parents, underpinned by a formidable range of cultural discourses. Added to this are the worries that most parents face, especially those reported as the most common; fear of the birth and of the health of the baby. (Petersen et al, 2009)

Uncertain futures – disabled parenting, social care professionals and social support

There is clearly a great deal of diversity amongst disabled parents, and some will have very little need for support services. But for those who do, an anticipation of critical professional attitudes towards themselves and their children can exert significant pressure to terminate or avoid pregnancy.

This is especially so for those deemed as unsuitable parents who are at risk of having their children removed. This awareness of the potentially negative outcomes of any pregnancy represents significant pressure imposed upon prospective disabled parents.

Although disabled parenting has received some attention from within the disability sector in the last thirteen years (Wates, 1997, 2002; Olsen and Clarke, 2003; Olsen and Wates, 2003), recent explorations of the barriers confronting prospective disabled parents from a *social model* perspective on disability are scarce. Further, there is little known of the pressures that would-be parents may face during a pregnancy to terminate an unborn child, and this is not addressed in the few publications on pregnancy and disability (McKay-Moffat, 2007).

Prohibitive attitudes towards disabled people as parents are apparent in many medical and welfare services, where disabled families are expected to fit themselves to the assumed norms of non-disabled families, (regardless of barriers to mobility and in accessing to leisure facilities and schools, for example) in order to fit administrative categories. Professionals continue to define disability individualistically, as a personal attribute rather than seeing the causes of disability as organisational, economic and attitudinal (Olsen & Wates, 2003).

Despite governmental recognition that disabled parents should get support (for example, on the directgov website), disabled parents may be referred to the adult social services team, rather than children and families team, effectively separating them from family-oriented services. There is little evidence to demonstrate that social services departments have developed any protocols for disabled parents, despite recommendations to do so (Keep, 2006). As such, local authority services provided for disabled people rarely consider parenting and parenting services seldom consider disabled parents (Millett & Wilde, 2006).

So, despite some official recognition of disabled parents specific needs, policy and service provision adds to the 'administrative invisibility' (Olsen and Wates, 2003) of disabled families, generating little information or understanding with which services can make appropriate or improved provision. In general terms, disabled parents are an 'administratively invisible' group in official statistics and policy-making, outside the range of policymaking and services provided for both disabled people and for parents and prospective parents. Due to this official invisibility disabled parents are 'misrecognised' (Fraser, 1997) seen, at best, in terms of 'special needs'. Framed in these terms, attitudes towards disabled parents are informed by an 'unacknowledged distinctiveness', as different from 'normal' parents. Shaping social attitudes and the practices of professionals this distinctiveness invariably renders disabled parents as pathological, as 'difficult', rather than catering for personalised needs.

The expectations of 'normal' motherhood act to exclude other women from services if they do not conform to administrative expectations, which implicitly highlight desirable aspects of identity such as those pertaining to age, ability, sexuality, ethnicity, income and other aspects of social background. For

example, the combination of age-related expectations and physical incapacities to conceive often results in the exclusion of older women from IVF treatment. Park's examination of attitudes towards post-menopausal women and access to IVF were based on arguments about the scarcity of resources, ideas of fairness, the 'inappropriateness' of motherhood and risks of orphaned children (1999, 77). These criteria for exclusion are often unspoken, and are likely to be invoked in the decisions relating to other women deemed less typical or 'inappropriate' particularly where social support and medical services resources are few.

There is considerable evidence to suggest that the assumptions of difference made by service providers can exacerbate conditions for many families, disabled or otherwise. It is clear, for example, that disabled parents are aware of these opinions, and often reluctant to approach potential welfare agencies as they fear the pathologising approaches of professionals and unfavourable outcomes for themselves and their children (Wates, 1997). This is particularly understandable given the tendency of children's services to frame 'disabled families' in terms of 'child protection' rather than family support. This process effectively separates the family, overlooking the welfare of the parents and thereby of the whole family.

This is often framed in individualistic terms of children's needs, many of which are defined in relation to stereotypes of 'normal childhood'. In some cases, this can result in policies to support 'young carers'; in other cases this division results in the removal of children who are considered to be at risk and is particularly common for parents with the label of 'learning difficulties' and mental health difficulties, where parenthood might be possible with appropriate support. Where social support is poor or unavailable to aid their parenting role, the risk of children being removed (unnecessarily) from their parents is much higher. Baum and Burns (2007) indicated that there is often an emphasis placed on expectations of maternal failure and there is a significant need for joint working between children's and adult teams and a greater awareness of social inclusion within generic services. Parenting issues tend to be overlooked by both children and adult services. Presently, where services are received, parents' roles as parents are seldom considered within calculations of need in assessing support. A focus on the whole family will frequently be seen as outside the remit of Direct

Payments and Personalised Budgets for individual adults, where needs are interpreted in an individualistic manner.

Although these are considerations which will affect parents *after* a baby is born they are also issues which disabled parents are urged to contemplate as soon as they reflect on their potential roles as parents.

The fears associated with requesting support can be overwhelming for prospective disabled parents who are already multiply stigmatised by pathological discourses of status, dependency, morality and worth, exacerbated for many by class, race, ethnicity, race, sexuality and age-based oppressions and inequalities. It is also clear that disabled people face considerable difficulties in establishing parental networks of reciprocity (Wates, 1997). Furthermore, disabled parents are less likely to have a partner, or to re-partner (Olsen and Clark, 2003) and where parents parent alone they are more likely to be isolated from other adult networks and potential sources of advocacy and information.

Although many disabled mothers will be painfully aware of judgements that may be made of their capacity to parent, there are many obstacles that they may not foresee which place even greater pressure on them to terminate once the baby is expected. Crow, for example, cites a case where, on becoming pregnant, a woman was warned, by social services, that her child would be taken from her due to the 'turnover of personal assistants' (2003,7) which was perceived as an impediment to the unborn child's best interests. In examples such as this, preconceived pressures to remain childless or terminate pregnancies are compounded by barriers in the interface between social services and health and maternity services.

Health care professionals and maternity care

To some extent, it is inevitable that disabled women will feel their sense of difference or 'abnormality' in an area of medicine which has become increasingly characterised by 'supermarket syndrome' - the selection of foetal characteristics with the intention of avoiding impairment (Shakespeare, 1998, 666). As Crow argues, screening for impairments are seen as 'a

judgement on me and my friends' (2003, 5). The stigma associated with the 'screening out' of some impairments will often be experienced particularly intensely by those defined as being at greater 'risk' of producing children with genetic 'abnormalities', mothers with muscular dystrophy for example. The stigma felt by pregnant mothers can be exacerbated further by the informal pressures exerted in interactions with health professionals, particularly in a first pregnancy. So, not only will disabled women face pressure from health professionals not to have babies with impairments, disabled mothers also have the added pressure that there will be little support with bringing them up if they proceed.

According to Health Central (2011), the chances of a child inheriting Multiple Sclerosis (MS) from their mother is estimated at less than 5%. Yet the radiographer who did the first scan of my daughter would have placed unintentional pressure on me to terminate if this had been my first pregnancy.

She had recently been diagnosed with MS, and had been told that she should not have children due to the risks of her children inheriting the condition and the low expectations of her capacities as a mother. To some extent this reflects the deficit model of impairment which is often experienced in formal or informal interactions with health professionals, where disabled pregnant women's needs as prospective parents are ignored, yet simultaneously pathologised on the grounds of their impairment. Crow's experiences of pregnancy highlight the many pressures placed on expectant disabled mothers. Overall, she shows how obstetric practices can reinforce these barriers and induce feelings of 'vulnerability, dependency and trauma' (2003, 8). She wrote:

"As a disabled woman, I was largely invisible in policies and working practices, as soon as I was noticed, I became centre stage. At the time, I wrote in a journal: "I want to be a pregnant woman - not a problem, not a phenomenon". (Crow, 2003, 3)

Crow suggests that maternity services can be a battleground for disabled women, creating discomfort, uncertainty and anxiety in relationships with service providers who are crucial to the care of mothers and their babies. She demonstrates how expectant disabled women's experiences can evoke some of the worst

fears of previous medical encounters, especially as health professionals tend to take an overly clinical approach to the maternity care of disabled women. She also outlines the difficulties which are likely to be faced by women who need personal assistants to be present at the hospital.

Those who impose restrictions on disabled women's use of personal assistance at the birth and in post-natal care render disabled women more helpless or depersonalised as new mothers, leaving significant personal needs unmet. This is will often cause great anxieties for women during their pregnancy.

Other pressures can affect a strong sense of difference and anxieties about personal selfishness during the ante-natal process. Crow shows how ante-natal classes, often strengthening identifications and bonds between non-disabled women, can serve to heighten a sense of isolation for disabled women when they are 'singled out for public questioning' and asked about coping strategies and special arrangements (2003, 5).

Worries, genetics and risk

Petersen et al's psychometric-based study of pregnant women found that the most common concerns were 'worries about birth and the possibility that something might be wrong (sic) with the baby' (2009), though notably, there was no mention that any women with impairments were included in the sample of 344 prospective mothers. However, the fear that any child born will be disabled, having inherited the impairment of one or both of the parents, will generate a sense of caution and risk for many.

This shows a misunderstanding of the nature of most impairments, since the majority are not congenital and develop later in life (Kallianes & Rubenfeld, 1997, 209). Thomas (1997) examined the experiences of a number of pregnant disabled women, identifying various professional practices which have disabled women from different backgrounds and impairment groups. Discourses of risk were one of the most common themes encountered in these women's experiences of maternity care. The thought of producing a baby with an impairment had the greatest tendency to provoke fear, anxiety and guilt for these women, this being seen as unfair and irresponsible behaviour

towards the child. As Thomas suggests this type of risk rests upon professional and 'social assumptions about the quality of life and intrinsic value of children and adults with impairments' (p. 632).

The focus of obstetrics generally, even in the case of non-disabled women, has increasingly been on issues of risk. The dominant philosophy of modern obstetrics, particularly within the UK context, appears to be that of risk prediction (Henley-Einion, 2009, 182)

While 'risky' births are the preserve of obstetricians, less 'risky' births are dealt with by midwives (Henley-Einion, 2009). Not surprisingly, where the mother is disabled, the focus on risk (and its avoidance) is even greater.

Whilst inducing feelings of doubt and guilt, the health professionals' tendency to focus on the risks they perceive that disabled mothers are taking with the lives of their unborn children obscures their unmet maternity or future parenting needs. These pressures are amplified by discourses of parental inadequacy, another common theme identified by Thomas's participants. Thomas found that many women were frightened of losing their children due to the judgements made of them by health professionals, social workers or other family members. She suggests that these forms of surveillance are likely to deter disabled mothers from seeking any external support in case their children are removed by social services. Social and professional interference into their private lives may go much further; the pressure to terminate may be at its greatest for those who fear their baby may be removed and taken into care. As a matter of personal pride, the choice not to mother may well be preferable to the identity of a 'bad mother' for those who fear they will be deprived of the prospective relationship with their child and have to face the fears and uncertainties of their unborn child's future welfare in social care.

It should be noted that in the UK the Royal College of Nursing (RCN) Pregnancy and Disability guidance for midwives and nurses (2007) is comprehensive and based (according to the document itself) on a social model approach. This approach is necessary and valuable, but as yet evidence is lacking that this

has led to a service-wide revision in medical practice around pregnant disabled women.

Midwifery has not been exempt from the shift in emphasis toward techno-medical interventions as normal practice; and as the discipline has become more oriented to a scientific and medical approach, the distinctive nature of the midwife's role – as supporting the mother in a natural procedure – has become less clear. Midwives then find themselves in a difficult position of balancing between rejecting the medical model, and alienating themselves from other practitioners; or going over fully to the monitored, medicalised and risk-management approach to maternity care. (Henley-Einion, 2009; Teijlingen 2005). Despite the best intentions of the RCN to implement social model centred services, personal, woman-focussed and disability-aware support may be difficult to find in practice.

The cultural avoidance of disabled mothers

Ingstad (2001, 776), demonstrates how closely biomedically-based concepts of disabled people's difference are tied to wider cultural (and medical) constructions of what it means to be a person – to have full personhood. Varying over time and location, perceptions of full personhood are seen to be linked to the fulfilment of standard social characteristics. This might include characteristics such as particular social identities, kin relationships, economic contributions made to households, and social and familial responsibilities. These criteria will vary according to cultural context.

But in most Western cultures, the expectation that disabled people are most likely to be recipients of care, support and welfare benefits perpetuates pre-existing ideas of lesser forms of personhood and lower worth. Echoing traditional gender stereotypes of public and private roles, these forms of devaluation are amplified for disabled women if they are perceived as insufficient in their familial responsibilities. (Morris, 1991)

Attitudes towards women and disability are also shaped by religious beliefs and values. Whilst it would be an onerous task (and outside the scope of this paper) to trace the religious roots

of contemporary attitudes towards disabled women, it is probable that religious beliefs exert heavy and often conflicting pressures on prospective disabled mothers. There is a considerable range of opinion across religions about both disability and the role and status of women. One issue that can arise is whether disability can be seen as a sign of divine punishment, which can impact on decisions about whether to accept medical interventions. It is also possible that disabled women will have to grapple with some religious opposition to both contraception and abortion alongside any fears about their capacity to parent and the social support available for parenthood. Those with strong religious beliefs may often find that religious obligations affect self perceptions of worth or increase their medical risks, adding to any other feelings of guilt, uncertainty, and fear impacting on their decisions to have a baby or remain childless. These social, and often religious, imperatives can result in a cultural denial of two aspects of a disabled woman's identity – as a (potential) mother and as a sexual being.

This is also part of a wider discourse around the perceived a-sexuality, non-sexuality, or deviant sexuality of disabled women.

“In a society obsessed with bodily ‘perfection’ and health and intolerant of difference, non-disabled people view sexual activity by disabled people (even when healthy) with discomfort or alarm” (Kallianes & Rubenfeld, 1997, 206).

One argument is that there is considerable social pressure on women to ‘celebrate’ conformity to pre-existing images of bodily perfection – through clothes, makeup or even cosmetic surgery. In these circumstances, failures in this arena, where they cannot be corrected or cured, should be at least hidden. Women who not only refuse to conform to these norms, but do so visibly and openly, will often be seen as being exceptionally, and unnecessarily, challenging (Killoran, 1994).

Disabled motherhood in the media

The force of dominant media discourses on ‘disability’ as an individualised, deficit conception of faulty personhood is likely to be of considerable significance in shaping non-disabled people's attitudes towards disabled people but also in forging disabled

people's perceptions of their own worth, competencies and expectations of social support.

At worst these pathological images feed into damaging attitudes, policies and practices *towards* disabled people and lowered feelings of self-worth *for* disabled people; at best they perpetuate tediously stereotyped images of disability and offer few positive points of identification for disabled people.

The disparity between cultural representations of non-disabled women and disabled women is also clear. Although there many examples (although not always positive) of girls' illness and disability in nineteenth and twentieth century children's literature (Keith, 2001), until recently there were few depictions of disabled women in mainstream media (Wilde, 2009; 2010).

Disabled women, as mothers or prospective parents remain barely visible within media culture, denoting a marginalised identity which is apparent in wider social attitudes towards disabled mothers. As Duffy's poetry suggests, disabled women just 'know' they are not supposed to have children, just like the boy (or girl) from the council estate knows that he will not become a Professor of Classics. At the same time, disabled women are surrounded by images of 'normal' womanhood, where motherhood is often seen as a desirable and increasingly consumerist option, and is usually framed politically as a fundamental female choice. Nonetheless, the few portrayals of disabled women that can be found in popular media give us some indication of what their cultural significance. It is to these that I now turn.

Disabled mothers in the news

If any topics of disabled motherhood are addressed at all in the news media, it is the non-disabled perspective on the undesirability of potential disabled womanhood and motherhood which holds sway.

When keywords of 'disabled mother' or 'disability pregnancy' were searched in the archives of the biggest selling UK newspapers they revealed a strong bias towards disabled children. Searching the leading tabloids (thepaperboy 2011) more reports on disability and motherhood were found in the

Daily Mail than *The Sun*, limiting further examination to the *Daily Mail* and the top broadsheet *The Telegraph*. *The Guardian* was also searched for comparative political purposes. However none of the recent tabloid reports were on disabled mothers (the twenty reports accessed before April 2011).

Significantly, alongside a few reports of benefits cheats and criticisms of Prime Minister David Cameron's betrayal of parents who care for disabled children (21.01. 2011), the *Daily Mail* demonstrates a preoccupation with stories which emphasise the 'burden' of disability (defined individualistically). This is very evident in most news stories, especially as over half of these accounts are devoted to stories of women who are suspected of killing their disabled children – twenty seven out of fifty news reports. Out of the fifty most recent reports on disability and mothering, only three refer to disabled mothers or prospective disabled motherhood.

Examining a broader range of newspapers further, there was little difference found in the types of topic which are reported according to the political bias of news reporting. Overall, the archives of the *Guardian* contain similar content to those of *The Telegraph*, *Daily Mail* and *The Sun* with few exceptions. This may be due in part to the growth of 'churnalism' whereby a large majority of journalists process external news rather than writing original reports (Davies, 2008). Nonetheless, from 2007 to 2011, three articles were found which dealt more directly with issues directly relevant to disabled motherhood. These were Amie Slavin's self-reported story on her own blindness and good mothering (2009); Deborah Orr on the need for public discussion on and monitoring of the Court of Protection's judgements on the involuntary sterilisation of disabled people, and its differential treatment of non-disabled and disabled people (2011); and a considerable number of articles mentioning Alison Lapper (or her statue), a disabled artist and mother. Of these, it is Slavin's report on her life as a blind mother which stands out. Importantly, she comes across as a 'likeable' person struggling to achieve mothering tasks that are recognisable to most women, feeding, guiding and generally caring for her children. Stimulating a number of impassioned comments, she demonstrates how it is attitudes towards her which disabled her and her children more than any other factors and emphasises the urgent need for information and support for blind and other disabled parents:

Equally shocking to me was the absence of any of the NHS pregnancy and birth information in either braille, audio or electronic formats. I embarked on motherhood blind, in more than one sense (Slavin, 2009).

Well known disabled mothers in the news

Although the majority of coverage of Alison Lapper has focussed on Marc Quinn's statue of her as a pregnant disabled mother, occupying the fourth plinth in Trafalgar Square, London, from 2005 to 2007, there has also been considerable attention given to her status as a disabled mother. She was first portrayed in the BBC's *Child of Our Times* programme on contemporary parenting, and has shared her views on and experiences of disabled parenting in a range of media since her pregnancy in 1999. As such Alison Lapper is perhaps the most well known disabled mother in the UK.

While there are a number of other disabled women 'celebrities' who are parents, they are rarely identified as such, (e.g. the athlete Tanni Grey Thompson). Perhaps the most famous and emblematic icon of disabled motherhood is found in the persona of Heather Mills. (regardless of her own self-identification). She is often portrayed as a desperate figure that is seen to be a 'gold digging fantasist' (Celebitchy, 2010), usually counter posed to heroic images of her ex-husband Paul McCartney as the victim of her devious manipulations.

Even if they are seen as disabled mothers, these few celebrity figures offer us a very polarised and restricted range of identifications, reflecting a tendency to portray disabled women as either inspirational or wretched. There is an urgent need for better images of disabled women as well as disabled mothers.

As Alison Lapper said:

"Anything that we're uncomfortable with we avoid. But now I'm up 15ft – you can't avoid me any more" (Thorpe, 2004).

Regardless of its aesthetic worth, Quinn's statue forced its wide audience of passers-by and cultural commentators to think about disabled women as mothers. At the very least, this initiated debates about disabled motherhood and disabled women's beauty and sexuality, whilst providing a rare source of

identification for prospective disabled mothers, should they choose to engage with it.

Any investigation of the cultural pressures placed on prospective disabled mothers would be incomplete without a consideration of images of 'young carers'.

The idea of Young Carers

Perhaps the worst injustice visited on the children of disabled parents is the label of young carers. This is a term which is in common usage and is a cause identified in government policy, taken up by a number of children's agencies, including social services, The Children's Society, and Barnardo's. Whilst the children of disabled parents are often placed in marginalised positions due to discrimination facing their parents, their lives are often assumed to be blighted by their parents' impairments, reinforcing individualistic ideas of disability, perpetuating the denial of disabled parents' lives.

Young carers are invariably portrayed as tragic, long-suffering figures, perhaps most commonly seen in news stories and charity appeals. They are often depicted as a 'hidden army' who 'shoulder intolerable burdens' and who are 'deprived of their childhoods' (BBC News, 2010). The causes of their burdens are rarely revealed and do not expose disability discrimination or the lack of social support provided to their families.

Aiming to offer more carefree images, Michelle Sank's photographic portraits of 'young carers', published in *The Guardian* in 2009 (Chris Arnot, 2009) offer compelling images of sad, forgotten lives, of the lost melancholic childhoods of her subjects reinforced by dialogue which underlines their 'fleeting freedoms' and (for the girls) 'the rare chance to wear a party dress'. Images such as these frame 'disabled families' in terms of the discourse of 'child protection' rather than family support. These photographs are not reportage and seem to define young carers in direct relation to stereotypes of normal childhood. They made me question my value as a parent more profoundly than anything I had previously experienced; they would undoubtedly put considerable pressure on prospective disabled mothers, who already share the worries about pregnancy, birth and subsequent childcare most mothers face. Perhaps most importantly, these

presumptions of 'abnormal' care relationships render disabled mothers selfish and 'unlikeable'.

Speaking of television, Sancho (2003) demonstrates that portraying disabled people as 'likeable' and 'matched' to other people's experiences provides essential 'triggers for the acceleration of acceptance', principles which take on even greater significance alongside judgements of the welfare of children.

The experiences of disabled parents and the strategies that are often adopted by family members offer ways of 'doing family' that may be valuable or instructive in discourses on parenthood, challenging conventional norms and values. There is a notable shortage of images showing the potential benefits of having disabled parents. However, such 'positive' images do exist. They can (infrequently) be found in films and television representations of disabled parenthood and on the specialist websites for disabled parents', such as DPN and DPPI. Without knowledge of these resources, it is probable that the messages sent by images of 'young carers' exert the strongest pressure of all – that parenthood for disabled people is a selfish act which hurts the children we want to love and protect.

Conclusion

This paper has examined several aspects of social and cultural life which impact upon the lives of prospective disabled mothers in both direct and indirect ways. There is a list of recommendations aimed at starting to break down these barriers in Appendix 1.

Although it is impossible to know the full impact of cultural attitudes and media images on individual disabled women, it is clear that assumptions made about, and cultural representations of, disabled mothers and their families do not serve their best interests. The pressures facing disabled mothers will vary according to a range of cultural factors, particularly 'common sense' discourses that impact on social service and medical professionals as well as friends and family members. These can determine how, if at all, their specific individual needs are understood and acted upon. Where these needs are met, disabled women can be as effective and capable as other

mothers; often, though, the 'misrecognition' of disabled women combined with a lack of support a means they are likely to face additional pressures to terminate a pregnancy or remain childless.

Pathological or 'positive', all the imagery discussed in the paper speaks of white heterosexual women's experiences, albeit from a range of social backgrounds. Nonetheless, there are no images which would help most white disabled women to recognise affirmative reflections of themselves, given the predominance of suicides and murders in newspaper reports. With the exception of the 'celebrities', almost all the direct coverage of (prospective) disabled mothers covers accounts of women whose womanhood is in question, who face the absence or removal of their children, or who are at risk of enforced sterilisation in order to 'protect' their children or themselves. This lack of progressive images impacts on prospective disabled mothers in a number of ways.

Media images feed into cultural and professional attitudes, informing professional practice (Gatfield 2003) creating 'common-sense' understandings of disabled mothers as an aberration and as a locus of difficulty. In an era of austerity and increasing rationalisation of resources these opinions will inevitably be strengthened in favour of those who fit the right administrative categories, diminishing sources of social support even further for disabled mothers.

The pressures on prospective disabled mothers to terminate or avoid pregnancy are great. It is clear that the factors contributing to worries about motherhood are complex, interwoven and often invisible, extending far beyond those likely to be faced by non-disabled mothers. Although these factors have largely been discussed in isolation, social, medical, cultural and media influences affect one another as interlocking parts of a wider social whole. The assumptions that disability equals dependence, non-sexuality, and being cared for as opposed to being a carer, combine to locate disabled women as not 'naturally' mothers. Along with often incorrect beliefs about the likelihood of passing on inherited impairments, the idea that a disabled woman could be a mother is often met with considerable resistance. Medical and social support services are not exempt from these negative and discriminatory attitudes, which can subtly permeate maternity services which excessively focus on

the idea of a 'normal' birth process and the management of risk, to the detriment of the specific needs of individual women.

These medical practices in turn act to redefine common sense attitudes to disability, through, for example, screening technologies which allow the possibility of termination based on the identification of an impairment. Disability is seen as a medical problem to be eliminated rather than a social one to be managed and possibly overcome.

The situation does not always improve when disabled women have successfully become parents. The focus on 'young carers' can lead to a generalised idea of the children of disabled parents as unnecessarily burdened with caring responsibilities, distracting both from the successful accommodations that most disabled parents make in managing their parenting role, and the sometimes significant lack of support offered to them. And for those disabled women considering becoming mothers, these stories and images do little to dispel their own fears, doubts and anxieties. Rather, they confirm the widespread view that disability and mothering don't mix.

There is little wonder then that disabled women just 'know' they are not expected to have children.

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Glossary of terms used in this paper

Culture

Culture refers to familiar systems of meanings in wider communities or social outlooks (Alasuutari, 1995, 25) and the generally shared knowledge, beliefs and values of members of society. (Online Dictionary of Social Sciences) As such, individuals shape culture and are shaped by it.

Alasuutari, P (1995) *Researching Culture- Qualitative method and cultural studies* Sage: London

Deficit model

This model refers to blame being placed on an individual (for example, the disabled parent) for what is seen as their own shortcomings, rather than examining the structural problems (such as poverty and inequality) and barriers (such as discrimination) that they face.

Discourse

The term 'discourse' or 'discourses' is used throughout this paper. In everyday usage, discourse means some form of communication; but it also has a more specialist meaning, in the social sciences, where it refers to a system of knowledge or thought, more specifically outlining the boundaries of what knowledge is seen to be true (for a particular culture at a particular time). The status of any discourse is linked to those with authority in that society – in the context of disability and parenting, doctors, scientists and other medical personnel are key figures in this respect. These discourses organize knowledge and truth, and define how we think about and understand ourselves.

They have been defined as 'systems of thoughts composed of ideas, attitudes, courses of action, beliefs and practices' (285) which shape everyday life and people's ideas of themselves and others.

Lessa, I (2006) Discursive struggles within social welfare: Restaging teen motherhood in *British Journal of Social Work*, 26, 283-298

Social model of disability

This defines disability as the oppression of people with impairments, imposing social, environmental, cultural and emotional barriers to full inclusion and participation in society. Disability is a form of social oppression and not an individual deficit. In the social model, it is society that disables people not their individual health conditions.

Impairment

The term impairment is used to refer to health conditions that deviate from medical norms. Impairment is a characteristic, feature or attribute within an individual which is long term and may, or may not, be the result of disease, genetics or injury (Thomas et al, 1997).

Individualism/Individualistic

The term 'individualistic' is used in opposition to the social model of disability to denote an understanding of disability as a property of the individual; hence impairment and disabling attitudes and environments are attributable to individual disabled people. From an individualistic perspective, disability is seen as a personal attribute rather than seeing it in an organisational, economic and attitudinal context.

APPENDIX 1

Recommendations for Health Professionals, Policy Makers, Media Practitioners and Academics

1. Prenatal testing should be carried out in a sensitive manner; the parents should be given full information regarding risks and accuracy of testing, and should not feel pressured into undergoing tests. Counselling services should be available, and should be informed by a social model of disability perspective.
2. Advice to terminate, or suggestions that children should be removed from their parents, should be seen as a last resort, after all other options, including extended support to the parents, has been considered.
3. There should be shift in emphasis from a medical to social model of maternity. Women should have access to midwife-led care, including Birth Centres and home births if appropriate. Risk management should not be the most important element of obstetrics.
4. Health professionals should be trained in the social model of disability
5. A comparison with a supposed 'normal' mother or birth experience should be avoided; the aim should be for good enough parenting and the mother should be supported in, and validated, for achieving this.
6. The mother (and father) should be provided with appropriate information so that she can make informed choices. Peer support should be available wherever possible.
7. All health and social care providers should have a protocol on disabled mothers' potential needs, based on the social model, ensuring reasonable adjustments are anticipated and professionals are well-informed.
8. There should be access to necessary equipment and support, including access to personalised education classes.
9. Disabled parents should have access to a PA in order to support their childcaring role. The PA should be facilitated in assisting the mother in the birth process if appropriate.
10. There should be developed and integrated aftercare support services, and these should be linked to the maternity services.

11. There should be a reassessment of the term 'young carers', referring to children caring for their disabled parents. This should be in three parts: 1. increased support given to disabled parents to decrease expectations of support from children; 2. ongoing awareness campaigns to highlight problems facing children and offering support where appropriate; 3. focus on some of the positive sides to being involved in caring, emphasizing that it is ok for children to have some caring responsibilities, and highlighting that most disabled parents have positive relationships with their children.

Social care and health professionals should be made aware of the social model approach to the issue of 'young carers' and help families to build resiliency.

12. Particular care should be taken by the media when representing and reporting on 'young carers' with the emphasis shifted to the resiliency and value of disabled families, highlighting social barriers to inclusion.

13. There should be greater awareness in the media of how disabled women are negatively represented – this includes both fiction and journalism. It would entail using disabled writers, directors and producers, and maintaining a greater awareness of the reality of the lives of disabled people, and a committed and ongoing reluctance to resort to easy negative stereotypes.

14. There is a need for a greater number and range of disabled mothers in all forms of media.

15. More research should be carried out, from a disabled positive perspective, with the aim of objectively assessing the reality of disabled parents' lives, avoiding deficit model assumptions.