

DISABILITY & REPRODUCTION

Sarah Earle and Sarah Church

Sociological definitions of 'disability'

The purpose of this article is to think sociologically about disability, the impact of disability on reproduction, and to explore how disability may affect the experiences of giving and receiving care. It is important to begin by considering what we mean by disability and how it is defined within the contemporary world.

Our understanding of disability has changed considerably over time. Traditionally, disability was perceived as a tragedy located within the individual. However now, disability is seen as a form of social exclusion located within society, rather than the individual (Oliver and Barnes, 1998). The social model of disability has emerged to reflect this change (Oliver, 1983). Most notably, this model rejects the relationship between 'impairment' and 'disability', arguing that the latter does not automatically follow the former. That is, just because someone is physically impaired, for example, does not inevitably make them disabled - it is the society in which they live which causes that person to be disabled. The social model also seeks to move away from a medical model of disability which focuses on the cure, care and rehabilitation (Finkelstein, 1993) of people with impairments.

Disability and inequality

Given the difficulties in defining disability and the fact that definitions have changed over time, it is difficult to determine an accurate picture of disability in Britain. However, most recent figures indicate that 1/5 of all people of working age are disabled, and that 3.4 million are woman and 3.7 million are men (Smith and Tworney, 2002).

Research suggests that disabled people experience considerable inequality in all areas of social life, including: education, health care, employment, housing, and transport (Barnes et al., 1999). Up to 50 per cent of all disabled people are thought to live in poverty and a substantial number of children are, either directly or indirectly, affected by this (Burchardt, 2000). For disability theorists, the inequalities experienced by disabled people are produced by the 'disabling barriers' which exist within contemporary societies (see figure 1).

Figure 1: Disabling barriers

- Architectural
- Attitudinal
- Educational
- Occupational
- Legal
- Personal

Source: Bowe (1978)

In relation to reproduction, there is also considerable evidence to suggest that the experiences of disabled people are quite different to those of non-disabled people and that substantial inequality exists. Anderson & Kitchin (2000), for example, argue that physical access to family planning services are inadequate for people with physical impairments. Research also suggests that disabled people lack appropriate access to reproductive advice and information (Graham, 1998; Seymour, 1998) and that they are often unable to access fertility services (Killoran, 1994).

Disability and Reproduction

Motherhood, disability and reproduction

Rightly or wrongly, motherhood is assumed a highly privileged status within society and women who do not, cannot, or choose not to have children are, at best, subject to curiosity and, at worst, cruelly stigmatised. Impairment can adversely impact on sexuality and fertility, sometimes dramatically. However, whether this is the case or not, disabled people are often seen as incapable of either bearing or raising children.

Kocher (1994) argues that disabled mothers challenge the conventional notions of 'good mothering'. For example, whilst it is often assumed that a 'good' mother must be physically active with her children, this is challenged by the experiences of women with physical impairment. Seymour (1998: 69) also argues:

In the cult of maternity a woman with a damaged body, it seems, cannot also be a mother. New life cannot issue from such a body. If it assumed that the body is unable to perform the obligatory mothering rituals required by our society, then it follows that the woman should not bear a child.

Brown (1994, p.125) suggests that disabled people tend to be viewed by society in one of two ways: as 'asexual or oversexed, innocents or perverts' and either way, their sexual and reproductive desires are perceived as abnormal. Whilst disabled people as a whole are infantilised, and reproduction discouraged, this is particularly so for people with learning disabilities, who have traditionally been subject to considerable scrutiny in relation to reproduction and often denied the

right to form sexual relationships, to marry, and to bear or raise children. We know that sterilisation has been used extensively and that the emphasis has been on preventing reproduction and controlling sexual behaviour rather than supporting learning disabled women and men (Begum, 1996).

More recently, however, the rights of people with learning disabilities to bear and raise children has become more acceptable (Powell and Murray, 1999) and although the number of parents with learning disabilities is not known, it is reliably believed to be on the increase (Booth, 2000). However, this is often muted by a concern with the issue of sexual abuse and whilst disabled people have the right to be protected from sexual abuse and exploitation, it is argued that this concern may be used to over-ride clients' needs (Sant Angelo, 2000). May and Simpson argue:

. . . a clear movement can be discerned in which marriage, sexual relations and, more recently, parenthood have gone from being absolutely forbidden to being accepted as of right. There remain, however, significant discrepancies between the recognition of rights and the reality of exercising them. Most adults with intellectual disabilities do not have sexual relations, do not marry and do not have children . . . (2003: 38)

Gooding argues for a cultural and practical shift in the approach to working with disabled parents (see figure 2).

Figure 2: Working with disabled parents

- recognising the rights of disabled people, within the bounds of current legislation, to be supported in fulfilling their roles and responsibilities as parents;
- knowledge of child welfare principles described in the Children Act 1989;
- an understanding of the social consequences of disability (for all staff);
- a multi-professional shared vision and system for planning and developing services;
- needs led assessment which focuses on the whole family;
- protocols, practical arrangements and strategies to improve interdivisional/
- and, inter-agency work at an individual and strategic level.

Source: Goodinge, 2000

Prenatal screening: choice or eugenics?

The inclusion of prenatal screening and diagnosis as a routine part of pregnancy care has been met with scepticism and concerned opposition both by disability rights activists and feminists, amongst others. Hubbard (1997), for example, argues that the growth of prenatal diagnosis is based on the eugenic ideology of selecting and eradicating 'imperfections'. Concurring with this, Ettore argues that by normalising prenatal screening and the selective eradication of disability, 'disabled bodies become progressively de-valued and disabilism shapes the dominant discourse' (2000: 414).

Under the provisions of the 1992 Human Fertilisation and Embryology Act, abortions are only permitted beyond 24 weeks if there is evidence of 'severely

handicapping' mental or physical abnormalities. It is notable that of the 170 countries that currently permit abortion, the majority have some provision for terminating pregnancy on the grounds of severe impairment (Sharp and Earle, 2002). However, in spite of the fact that advances in ultrasound and in serum screening techniques have increased the number of abnormalities being detected, screening per se cannot guarantee a 'healthy' baby.

Promoting the issue of choice in relation to prenatal screening for disabled women also raises many issues. Davis (1999: 10), who describes herself as having 'spina bifida and is a full time wheel chair user' writes:

Members of the medical profession often justify screening and abortion for spina bifida to me on the grounds that 'you are exceptional.' My answer is twofold. Every human being is exceptional, unique, beyond price. And if they had had their way 43 years ago, I would not have been exceptional - I would have been one of the nameless 'defective fetuses' that they consign to the medical waste bin every year, all in the name of 'choice'.

Women may well feel an obligation to accept prenatal screening on the grounds that they may not be able to cope. However, they may also feel that to accept prenatal screening may in some way deny their own existence.

Many sociologists have argued that women are not really offered a choice and do not understand the consequences of prenatal screening for themselves, their families or for society as a whole (Katz-Rothman, 1989; Shakespeare, 1998; Press and Browner, 1998). Others have also argued that the information given to clients

about disability is biased and distorted (Press and Browner, 1997). Given a choice, most people would wish for a healthy baby and it is increasingly so that many women both expect and accept prenatal screening (Press and Browner, 1998). However, it is important for midwives in practice to consider how and why prenatal screening has become normalised and to reflect on the ethics of prenatal screening.

Implications for midwives in practice

Pregnancy, childbirth and motherhood are a challenge for all of us. However, impairment poses further challenges. Some of those challenges relate to the impairment itself and the restrictions that these pose for reproduction. Other challenges are created by those who work with disabled people, who often impose unjustified barriers. For example, a recently published report on disabled parents commissioned by the Joseph Rowntree Foundation states:

Some of the things (disabled people) were told by social workers and other professionals were not accurate, but the parents usually did not have the necessary knowledge about their rights to challenge these statements. (Morris, 2004: 1)

When working with disabled clients, you may need to 'think outside the box', be flexible and creative. You may also need to seek advice from appropriate specialists or community organisations. Take a look at Figure 3 and ask yourself the following questions:

Figure 3: Establishing good practice

1. Could I be more creative and innovative in meeting clients' needs?
2. Am I being flexible enough?
3. Could I work better with other professionals or agencies?
4. Do I need to seek advice from specialist organisations or community groups?
5. Am I empowering disabled parents?
6. Am I providing effective information?
7. Am I imposing barriers which prevent people with physical, sensory or intellectual impairments from accessing appropriate services?

Useful further resources

Disability, Pregnancy and Parenthood International (www.dppi.org.uk)

Disabled Parents Network (www.disabledparentsnetwork.org.uk)

Fawcett B. (2000) *Feminist Perspectives on Disability*. London: Prentice Hall.

Finger A. (1991) *Past Due: A Story of Disability, Pregnancy and Birth*. London: The Women's Press.

References

Anderson P. and Kitchin R. (2000) Disability, space and sexuality: access to family planning services. *Social Science & Medicine*, 51(8), Oct 15, 1163-1174.

Begum N. (1998) General practitioner's role in shaping disabled women's lives. In: C. Barnes and G. Mercer (eds), *Exploring the Divide: Illness and Disability*. Leeds: The Disability Press.

Booth T. (2000) Parents with Learning Difficulties, Child Protection and the Courts. *Representing Children*, 13(3): 175 - 188.

Bowe F. (1978) *Handicapping America : barriers to disabled people*. New York, Harper & Row.

Brown H. (1994) 'An ordinary sexual life?': a review of the normalisation principle as it applies to the sexual options of people with learning disabilities. *Disability & Society*, 9(2), 123 - 144.

Burchardt T. (2000) *Enduring economic exclusion: disabled people, income and work*. London: YPS.

Davis A. (1999) A disabled person's perspective on prenatal screening, *MIDIRS Midwifery Digest*, 9(1), 8-10.

Ettorre E. (2000) Reproductive Genetics, Gender and the Body: 'Please Doctor: May I have a Normal Baby?'. *Sociology*, 34(3): 403-420.

Finkelstein V. (1993) Disability: An Administrative Challenge?. In: M. Oliver (ed.) *Social Work: Disabled People and Disabling Environments*, Research Highlights in Social Work 2, London: Jessica Kingsley.

Graham N. (1998) Sex and disability. *Nursing Times* 94(29), July 22, 28-30.

Gooding, S. (2000) *A jigsaw of services: Inspection of services to support disabled adults in their parenting role*. March. London: DoH - Social Services Inspectorate.

Hubbard R. (1997) Abortion and Disability. In: L. J. Davis (ed.) *The Disability Studies Reader*. London: Routledge.

Katz-Rothman B. (1989) The meanings of choice in reproductive technologies for people with disabilities. In: A. Arditti, R.D. Klein and S. Minden (Eds) *Test-tube Women: what future for motherhood?* London: Pandora Press.

Killoran C. (1994) Women with Disabilities Having Children: It's Our Right Too. *Sexuality and Disability*, 12(2): 121 - 126.

Kocher M. (1994) Mothers with Disabilities. *Sexuality and Disability*, 12(2): 127 - 133.

May D. and Simpson M. K. (2003) The parent trap: marriage, parenthood and adulthood for people with intellectual disabilities. *Critical Social Policy*, 23(1): 25 - 43.

Morris J. (2004) *'They said what?' Some common myths about disabled parents and community care legislation*. York: Joseph Rowntree Foundation.

Oliver M. (1983) *Social Work with Disabled People*. Basingstoke: Macmillan.

Oliver M. and Barnes C. (1998) *Disabled People and Social Policy: From Exclusion to Inclusion*. London: Longman.

Powell H. and Murray G. (1999) Mother's pride. *Nursing Times*, 95(4), 27 Jan: 24 - 26.

Press N and Browner C H (1997) 'Why Women Say Yes to Prenatal Diagnosis' *Social Science and Medicine* 45 (7) pp. 979-989.

Press, N. Browner, C. H. Tran, H. Morton, C. and Le Master, B. (1998). Provisional Normalcy and 'Perfect Babies': Pregnant Women's Attitudes Toward Disability in the Context of Prenatal Testing. In: Franklin, S. and Ragoné, H. (eds). *Reproducing Reproduction: Kinship, Power, and Technological Innovation* University of Pennsylvania Press: Pennsylvania, Philadelphia.

Sant Angelo D. (2000) Learning Disability Community Nursing: Addressing Emotional and Sexual Health Needs. In: R. Astor & K. Jeffereys (eds) *Positive Initiatives for People with Learning Difficulties: Promoting Healthy Lifestyles*, London: Macmillan.

Seymour W. (1998) *Remaking the body: Rehabilitation and Change*. London: Routledge.

Shakespeare, T. (1998). Choices and Rights: eugenics, genetics and disability equality, *Disability & Society* 13(5) pp. 665-681.

Sharp K & Earle S (2002). Feminism, Disability and Abortion: Irreconcilable Differences? *Disability & Society*, 17(2), March.

Smith A. and Tworney B. (2002) Labour market experiences of people with disabilities. *Labour Market Trends*, 110(8) London: ONS.