Women living with disability are increasingly choosing to become mothers.

There is growing evidence that disabled parents and parents with long term health conditions do not get enough support to fulfil their parenting roles (Morris & Wates, 2006: Royal College of Midwives, 2007). This is despite the fact that in the last 20 years there has been a plethora of Government policy documents advocating greater choice and control for all childbearing women (Department of Health 1993; 1999; 2004) alongside Legislation which states that there should be equal access to all maternity service users and Legislation that prohibits discriminatory care (Disability Discrimination Act, 1995: 2005); much of this legislation has been incorporated into professional regulations for example, Nursing and Midwifery Council Code of Conduct (NMC 2008) and Midwives Rules and Standards (NMC, 2004).

The new Equality Act (2010) brings together nine separate pieces of legislation into one single Act to help tackle discrimination and inequality; the forthcoming Equality Duty, expected to become law later this year, is a duty on public bodies and others carrying out public functions to embed equality considerations into the day to day work of public authorities such as hospitals and health centres.

The Equality Act (2010) strengthens previous legislation and hopes to make it easier for someone to show that they have difficulty carrying out their day-to-day activities, and so come under the definition of a ‘disabled person’ and are protected under this Act (Equalities Office, 2010).

However, have maternity and neonatal services embraced these concepts sufficiently to ensure that all women receive the appropriate information needed to support their parenting decisions so meeting our legal and professional obligations?

Legislation has been incorporated into professional regulations for example such as the Nursing and Midwifery Council Code of Conduct (NMC, 2008) and Midwives Rules and Standards (NMC, 2004) suggesting some of our responsibilities are to:

- Know our legal and professional responsibilities concerning disability
- Know our legal and professional responsibilities in connection with informed consent and competency
• Be prepared to confront and challenge personal views and prejudices
• Attend mandatory updates on equality and diversity issues
• Know local policies and guidelines for equality and diversity issues
• Be familiar with the social versus medical model of disability debate

(Other Professional Codes of Conduct are likely to propose something similar)

NHS services have a duty to assess how well we are meeting the needs of all new parents. The resulting findings suggest that maternity services struggle to meet the demands of its users (Commission for Healthcare Audit and Inspection, 2008; The King’s Fund, 2008).

**How do we know what the particular needs of disabled parents are?**
Before we can start to answer this question we need to define “who are the disabled?” (there are many definitions and interpretations).

It is also difficult to know how many people are living with a disability in the UK; should we use data involving benefit uptake or does the fact that many people do not claim available entitlements due to concerns over the perceived social stigma of being labelled as a benefit claimant make this data flawed? It is estimated that there are just over 1.7 million disabled parents in the United Kingdom (UK) (Morris & Wates (2006) although support groups estimate the figure to be higher at over 2 million, and increasing (see [www.parentsnetwork.org.uk](http://www.parentsnetwork.org.uk)). Factors which drive the increase in numbers include advances in medicine and pharmacology but social policy changes are also encouraging more social inclusion including the right to parent.

It is estimated that there are approximately 10.8 million of the UK population who identify themselves as disabled (RCN, 2007:5).

• Approx. 4 million people have physical impairments
• 5% of disabled population are wheelchair users
• 2 million people are blind or visually impaired
• 3.5 million are deaf or hard of hearing
• Approx 62 000 use British Sign Language (BSL)
• 25 000 have dual sensory impairments
• 1.5 million people have learning disabilities
• 12 million people are diagnosed with mental health problems
• 8.6 million have long term health conditions

(RCN, 2007:6)

It appears that the need for these disabled parents to access information and equipment to help fulfil their role as parents is not being met. Women with disabilities experience similar concerns of all women embarking on motherhood but their additional concerns are not always acknowledged by midwives and the maternity services.

The following are a sad reflection of some women’s views of the maternity services

‘I felt very isolated. As a disabled parent I felt I was an anomaly and was offered no help. I was just left to get on with it. I needed someone to turn to.’

‘Lots of questions but no one to turn to’

‘There is no accessible provision for disabled parents in hospitals, health centres and GPs’ (Sic)


In research papers on this topic such as Morris, (2003); Olsen & Clarke, (2003) and McKay- Moffatt and Lee, (2010) and in our own interviews it appears that there are recurring themes emerging surrounding 3 key areas.

This learning package addresses disability using these key themes :

• Access
• Attitudes
- Evidence based practice
- Communication

Specific conditions are not considered here as many of the issues apply to all parents who are living with a disability. However, the Resource Section has a number of resources which address both general and specific disability issues.

**Key questions to ask yourself**

- Do you have a working knowledge of the Equality Act (2010) in relation to maternity and neonatal services?

- How well could you support a disabled parents to prepare and adapt for parenthood?

- Does the your practice environment further ‘disable' women living with disability?

- If you are a midwife do you know how to support a woman in labour with a disability?

- Do we label women with disabilities as unfit mothers?

**Overview e-tivity (2 hours)**

**Purpose**
To reflect on how service users can be central to the research process and make their views heard.

**Task**
In order to prepare for this learning package on Parenting and Disability read the recent report by Rokasha Padya about involving service users in the research process paying particular attention to the service users views of the process.

*Research Involvement PCPs share experiences PDF.pdf*
References


Nursing and Midwifery Council (NMC) 2004 Midwives Rules and Standards London. NMC.

Royal College of Midwives (2005) Position paper No.11a; Maternity care for women with disabilities. London R.C.M. available from position paper archive jfyle@rcm.org.uk