



Royal College  
of Nursing

# Pregnancy and disability

*RCN guidance for midwives  
and nurses*





**This guidance is for nurses and midwives who encounter disabled women and contribute to their childbearing experience.**

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# Foreword

Midwives and nurses will welcome this publication which aims to empower and enable them to provide high quality, client-led care for disabled women during pregnancy, birth and beyond. Jackie Rotheram, herself a disabled mother, writes with the authority of long experience gained in pioneering and running the first specialist midwifery service for disabled women at a large women's hospital. With her collaborators, she gives a thorough description of how others can deliver the kind of service that meets the needs of disabled women: seeing the woman first and her impairment second.

The complex issues of what it means to be disabled, with relevant statistics, are discussed. The legal background to disability discrimination is well covered, highlighting the new Disability Equality Duty: now all public sector organisations including the NHS are positively required to promote equality of opportunity for disabled people.

Case studies of the four broad categories of disability – physical, sensory, learning and long-term mental illness – illustrate vividly the issues for health care workers. These will assist midwives and nurses to consider and plan in advance with disabled clients how their particular needs can be accommodated, working with other agencies and professionals where appropriate.

As Chair of Disability, Pregnancy and Parenthood International (DPPI), I warmly commend this new guide. DPPI is controlled by disabled parents and runs a staffed, accessible information service on disability and parenthood. A large proportion of the enquiries we receive come from disabled women considering parenthood, or who are already pregnant. They want to be as actively prepared as anyone else; they also need extra information, possibly to help them source support and equipment in good time.

DPPI is also approached by many who work in health care seeking to find out how they may assist this group of clients and overcome potential problems. We will certainly signpost professional enquirers to this new RCN guidance on pregnancy and disability as an invaluable resource.

**Rosaleen Mansfield**

Chair of Trustees

Disability, Pregnancy and Parenthood International



## 1

# Introduction

Disability is unique in that it crosses barriers of gender, age, sexual orientation, religion and race. Impairments and health conditions can take many forms and affect people in many ways, and the degree of disability they experience may change over the years. Only 17 per cent of disabled people are born with an impairment (perhaps as a result of a genetic disorder or birth injury), and for many disability is acquired through injury, disease or increasing age. No one is exempt from becoming disabled.

During pregnancy, and as parents, disabled people come into contact with many health care workers including midwives and nurses from the acute sector, as well as practice, community, mental health, learning disability and specialist community public health nurses, and GPs. They may also use other community services, including occupational, social and children and young people's services. All these providers are responsible for making sure equality of service delivery, and inclusion for disabled people, is incorporated into the core philosophy of their organisational structure.

These guidelines are designed to enable midwives and nurses to provide evidence-based and client-led care to meet a disabled individual's needs during pregnancy, birth and beyond.

Relevant to both the maternity and wider health services, these guidelines provide information on how to ensure equity in care provision and address the needs of disabled people. Throughout this guidance, the term 'nurses' is used inclusively to denote health care practitioners, other than midwives, who encounter childbearing disabled women.

The guidelines also address the responsibilities of practitioners and public bodies relating to ensuring equity of access to services, as directed by the Disability Discrimination Act 1995 and the statutory Disability Equality Duty (effective from December 2006).

Complex issues surround disability. Impairment is very specific and individual to that person alone and touches every aspect of that individual's life experience, manifesting itself in physical, emotional, psychological, environmental, educational, social, spiritual and financial dimensions. There are many types, causes and images of disability and disabled people face many barriers, including separation and segregation, stereotyping, labelling, prejudice and stigma. Misunderstood or inappropriate terminology, barriers to communication and information, and inaccessible environments also make disabled people's lives unnecessarily difficult.

The most significant barrier cited by many disabled people is the inappropriate attitudes, behaviours and lack of disability awareness demonstrated by some National Health Service (NHS) staff, and important themes and issues highlighted in the Disability Discrimination Act 1995 include:

- ◆ poor access
- ◆ unmet communication and information needs
- ◆ inadequate or inappropriate help from carers.

Two main models of disability exist; medical and social. The medical model defines disability from the viewpoint of non-disabled people; individuals are described as unable to perform an activity considered to be 'normal'. This guidance, however, is based on the social model which has two perspectives:

- ◆ impairment is seen as the functional limitation of the body, or of learning
- ◆ disability is seen as the structural restrictions or barriers caused by society (which takes little account of people who have impairments) which excludes them from mainstream activity.

Society attempts to 'normalise' disabled people in order to make them more acceptable and 'fit in'; it often finds it hard to embrace diversity and individuality, and sets boundaries to acceptance. Health care providers have responsibility to everyone, regardless of ability, and are required to respect people with disabilities as equal members of society. Disabled people's needs in terms of access to health care must be met, even if this means treating them more favourably than others.

## 2

## Background

Little research has been undertaken into disabled women's maternity needs, but they have been identified as a group which maternity services are failing. Much of the evidence for this is anecdotal in nature; for example, women relating their own maternity experiences as reported at the Maternity Alliance conference in 1994, after which the Royal College of Midwives (RCM) published, and later revised, a position paper (RCM, 2000) providing guidelines for midwifery practice.

As lead professionals, midwives have a key role in meeting disabled women's needs and ensuring that physical access and professional attitudes do not prevent access to services. This supports the principles of providing choice, control and client centred care, as outlined in *Changing childbirth* (Department of Health, 1993).

Inadequate services are unacceptable and legislative progress has been made to help rectify some of the issues. The current legislation includes:

- ◆ the Human Rights Act 1998 – promotes the recognition of individual human rights
- ◆ the Disability Discrimination Act 1995 (DDA 1995) – emphasises the duty of care concerning access, quality of service, communication and disability awareness and makes it unlawful to provide a lower standard of treatment and access to services for disabled people
- ◆ the Disability Equality Duty (DED) – new legislation introduced in 2006 requiring public authorities to demonstrate positive action to promote equal opportunities for people living with disabilities and involving them in policy.

However, parenting is not viewed as a central issue, and practice is insufficiently influenced by disabled people (Morris and Wates, 2006).

### 2.1 Defining disability

The legal definition of disability is 'a physical or mental impairment which has a substantial and long-term adverse effect on a person's ability to perform normal day to day activities' (DDA 1995):

- ◆ impairment may be physical or mental and includes sensory impairments, such as those affecting sight or hearing

- ◆ substantial adverse effect is more than minor or trivial, and means that activities are more difficult and time consuming for a person with an impairment than for someone with no impairment
- ◆ long term means that the impairment has lasted 12 months, is likely to last at least 12 months in the future, or is likely to last for the rest of the life of the person affected.

People with learning disabilities are defined under mental impairment, although they may also be affected by physical and sensory impairments. Under the Mental Health Act 1983 learning disability is categorised as a mental health problem but not a mental illness, and learning disability is termed as either mental or severe mental impairment. The Mental Health Bill 2006 revises this terminology and amends it to 'learning disabilities'; people with learning disabilities cannot be treated or detained because of their learning disability unless they are suffering from a mental illness or are a danger to themselves or others.

People who have progressive conditions (such as cancer, HIV infection, multiple sclerosis, or muscular dystrophy) that may have substantial effects in the future on their ability to carry out normal day-to-day activities are included in the DDA definition of disabled. People specifically with HIV, cancer or multiple sclerosis are considered to be disabled at the point of diagnosis, not just when activities become impaired.

Individuals who have had an impairment, and have subsequently recovered, are still protected under the DDA 1995, provided that the impairment's adverse effect lasted at least 12 months.

For the purposes of the DDA 1995 'normal day-to-day activities' are those involving mobility, manual dexterity, physical co-ordination, continence, speech, memory, concentration, understanding and the perception of risk and physical danger.

The Disability Rights Commission (DRC) proposes that the terms 'substantial' and 'long term' be removed from this definition in order to protect everyone who is perceived to have an impairment. This will shift the balance and will help to identify who has protection from discrimination. Producing a more positive and systematic approach will bring the law in line with best practice.

### 2.2 The scale of disability

Around 10.8 million of the UK population identify themselves as disabled. Approximately 52 per cent of those who qualify as disabled under the terms of the DDA 1995 do not describe themselves as disabled.

## 3

In terms of statistics relating to the scope and scale of disability across the UK:

- ◆ approximately four million people have physical impairments
- ◆ five per cent of the disabled population are wheelchair users
- ◆ 2 million people are blind or visually impaired
- ◆ 3.5 million are deaf or hard of hearing
- ◆ around 62,000 are believed to use British Sign Language as their preferred language and may consider themselves as members of the deaf community
- ◆ 25,000 people have dual sensory deafness and blindness
- ◆ 1.5 million people have learning disabilities
- ◆ 12 million are diagnosed with some form of mental health issues
- ◆ 8.6 million have long term mental health conditions.

There are around 1.7 million disabled parents in the UK (Morris and Wates, 2006), most being people with physical and sensory impairments. Exact numbers for disabled mothers are unknown because of lack of data, difficulties with calculations and because birth notification does not routinely record maternal disability.



## The statutory framework

### 3.1 Disability Discrimination Act 1995

The Disability Discrimination Act 1995 (DDA 1995) represented a major extension of civil rights for the 10.8 million disabled people living throughout the UK. Addressing disability from civil rights and social model perspectives, it is consistent with the public health approach in which midwives and nurses have an active part to play. The DDA 1995 applies across the UK; Northern Ireland, Scotland and Wales have specific equality bodies, and strategies that apply (see Appendix 3).

The DDA 1995 draws attention to service providers' duty of care to:

- ◆ provide equal access
- ◆ remove physical barriers
- ◆ improve quality of care
- ◆ communicate effectively, and make information accessible.

According to the DDA 1995 it is unlawful to discriminate against a disabled person. Although the definition of discrimination differs slightly (depending on whether it arises from employment, the provision of services, education and so on), it generally occurs when disabled people are treated less favourably than others on the grounds of their disability and this cannot be justified, or where there is failure to make reasonable adjustments for disabled people to access services. Service providers are required to make reasonable adjustments to anything that makes it impossible or unfairly difficult for disabled people to use services, including:

- ◆ changing policies, practices and procedures
- ◆ providing aids or services
- ◆ making reasonable alterations to premises where necessary.

It is important to understand what is meant by reasonable adjustment; according to the DDA 1995, how much is expected depends in part on the organisation's size and resources, and the overall impact of the measures to be taken. For example a small general practice would not necessarily be expected to install a lift to an upper floor but would be expected to provide appropriate services on the ground floor where possible (DRC, 2006a). Further guidance is available in the DDA 1995 Part 3, section 21.



### 3.2 Disability Discrimination Act 2005

There have been two key changes to the DDA 1995. Firstly, the Disability Discrimination Act 2005 (DDA 2005) applies across the UK. It gives greater protection to disabled people, extending the definition of disability to people with cancer, HIV and multiple sclerosis from the point of diagnosis. The original Act provided legal rights to individuals who had experienced disadvantage. Now the obligation of service providers is to be proactive in promoting greater general access and equality of opportunity to disabled people.

### 3.3 Disability Equality Duty

The second key change to the DDA 1995 is introduction of the Disability Equality Duty (DED) which, since December 2006, now applies to all public authorities and service providers and features general and specific statutory duties.

#### DED general duty

The DED general duty covers all public bodies and deals with discrimination, promoting equality of opportunity, eliminating harassment and involving disabled people in order to promote positive attitudes towards disability. To achieve this the DED considers ways to make disability integral to service provision, rather than focusing on a person's individual needs alone, as in the past.

A key principle is that people with disabilities should have their needs for access to care met, even if this means treating them more favourably than others.

The DRC has produced an overview to guide the public sector, *Doing the duty* (DRC, 2006a). From October 2007 the DRC, along with the Commission for Race Equality (CRE) and the Equal Opportunities Commission, will merge to become the Commission for Equality and Human Rights (CEHR). The CRE requirements apply also to disability policies (CRE, 2006).

#### DED specific duties

DED specific duties centre on the introduction of Disability Equality Schemes (DES) to help achieve and support the general duty, and which apply to health service providers. Key requirements include:

- ◆ a DES must be in place, or in development, from 6 December 2006
- ◆ there will be a government review every three years
- ◆ full involvement of disabled people (DRC, 2006a).

In Scotland, the DRC and the Scottish Executive are collaborating together in the Fair for all strategic partnership initiative which has developed a good practice guide for NHS staff (DRC, 2006b).

Individual health care workers, NHS trusts and other health care providers have specific responsibilities and these requirements, in relation to the needs of disabled childbearing women, are discussed in detail in the following sections. The duty of care for nurses and midwives is articulated in the Nursing and Midwifery Council's (NMC) Code of professional conduct (NMC 2004a).

### 3.4 Laws on consent to treatment

Some people with disabilities lack the capacity for making some or all decisions for themselves. Their rights are protected by legislation and this is explored further in the Royal College of Nursing's (RCN) guidance on learning disabilities (RCN, 2006) (see Appendix 3). The current regulations relating to consent to treatment for the UK countries applies as follows:

- ◆ England and Wales – Mental Capacity Act 2005 (in force from Spring 2007)
- ◆ Northern Ireland – Guidance on Consent to Treatment 2003
- ◆ Scotland – Adults with Incapacity Act 2000.

### 3.5 Midwifery and nursing responsibilities

In order to ensure women have access to the full range of services and have their individual needs met, midwives and nurses need to:

- ◆ understand how the NMC Code of professional conduct and Midwives rules and standards relate to supporting people with disabilities to access services (NMC 2004a, 2004b)
- ◆ know their responsibilities under the DDA
- ◆ be prepared to confront and challenge personal views and prejudices
- ◆ attend mandatory equality and diversity training to update their knowledge
- ◆ be familiar with the social model of disability; understanding how society, rather than the individual, is the cause of disability will help avoid asking inappropriate questions rather than applying the medical model (which results in disabled people being asked about their impairment rather than the barriers they face in accessing services such as stairs, equipment, intercoms and voice-only telephones, poorly lit rooms, staff behind screens, or barriers in accessing information because of inappropriate formats)

- ◆ understand the laws on consent to treatment; who can give consent and for what
- ◆ have knowledge and awareness of local policies and procedures, and the use of guidelines, checklists and care pathways
- ◆ have the confidence and ability to make reasonable adjustments to provide care in more accessible ways, removing barriers that cause disability while taking health and safety issues into account
- ◆ use resources effectively to meet need; networking and collaborating with other organisations, individuals, support groups and multidisciplinary teams
- ◆ provide flexible, creative and innovative midwifery and nursing care to meet individual needs.
- ◆ developing services through clinical audit, patient satisfaction surveys and research in line with the organisation's clinical governance strategy
- ◆ providing mandatory disability equality training for all staff
- ◆ development of new roles, for example, specialist midwife or disability advisor who will also facilitate disability equality training
- ◆ the design of a joint working framework with common pathways of care and joint decision-making with others, such as occupational therapy, mental health and learning disability teams
- ◆ having written procedures and check lists available to all hospital and community staff for supporting women with disabilities
- ◆ creating effective multidisciplinary referral mechanisms for specialist care and support
- ◆ observing protocols on the management of risk, record keeping, confidentiality and data protection, so that information is transmitted only when essential
- ◆ the identification of positive role models and examples of good practice
- ◆ the audit of service provision to ensure services are accessible and without barriers of access and communication, and to identify gaps. This should include;
  - facility design
  - equipment
  - communication and literature
  - the provision of sign language interpreters for deaf parents
  - advocacy services for all parents who need support in negotiating with service providers
  - accessible information for all.

### 3.6 NHS trust corporate responsibilities

NHS trusts (acute and primary care) and other health care providers have corporate responsibilities under the DDA. Specific initiatives can be summarised as:

#### Organisational policy and procedures

Corporate responsibilities in this arena include:

- ◆ the development of individualised disability strategic documents, with action points and time targets
- ◆ ensuring the needs of disabled people are reflected in all policy and procedures
- ◆ identifying disability champions to lead in patient care, with a strategic role within the organisation
- ◆ introducing a mechanism to identify disabled people and involve them in the decision-making process, as well as prioritisation, strategy planning and service delivery.

In addition, all policy documents must have a race equality impact assessment completed (CRE, 2007).

#### Service development and quality

Corporate responsibilities in this arena include:

- ◆ writing a recommended best practice document and quality statement for disability

#### Resource provision

Responsibilities include the production of resources and information accessible to all service users (see Appendix 2):

- ◆ write and publish newsletters communicating relevant and contemporary information
- ◆ signpost disabled parents to existing local and national resources such as;
  - telephone support/access

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- local contact register for peer support between disabled parents and the exchange of ideas and information
- local support groups, relative to specific impairments and needs
- contacts for voluntary groups and practical help with access to relevant organisations and other networks
- ◆ provision of antenatal and parenting classes appropriate to disabled users' needs.

## Service provision for disabled pregnant women – practical issues

### 4.1 Who are our disabled clients?

Clients with disabilities may have physical, mental, sensory or learning disabilities, or other impairments that are less easy to classify. All people with an impairment that fit the criteria of the DDA 1995 are defined as disabled. Impairments can be wide-ranging and people face barriers in society that make them disabled. The categories of impairment are:

- ◆ *physical impairment* – includes all people who have impairment that affects gross movements of mobility (for example, spina bifida, cerebral palsy, spinal cord injury, amputation and orthopaedic impairments, muscular dystrophy and long-term conditions such as multiple sclerosis and rheumatoid arthritis, which also affect fine hand and finger movements)
- ◆ *sensory impairment* – involves sight and hearing
- ◆ *learning disability* – a significant impairment of intelligence and of adaptive functioning; people with learning disabilities may have difficulty with a number of daily activities simultaneously (for example, telling the time and reading) and may find it difficult to give specific details (for example, their age or date of birth); some may also have Downs Syndrome, Fragile X or other genetic conditions. Many people have no specific diagnosis. **Midwives and nurses will find it helpful to contact the local learning disability team for support, as explained in the Royal College of Nursing's guidance on learning disabilities (RCN, 2006)**
- ◆ *progressive disease* – includes HIV and AIDS, cancer, and hidden impairments such as asthma, epilepsy, diabetes, sickle cell anaemia, and people with a chronic illness such as heart disease, tuberculosis, neurological conditions and arthropathies
- ◆ *mental health illness* – mental health illnesses that are classified as disability include schizophrenia, bipolar affective disorder, psychosis, severe postnatal depression, chronic depression, obsessive compulsive and eating disorders.

Some individuals may have speech and language impairment, or be identified as 'disfigured'. It should also be noted that dyslexia and dyspraxia are often classified as learning disabilities, but are usually considered as learning 'difficulties' in specialist practice because functioning and intelligence are not impaired and are therefore not included here.

## 4.2 Disability awareness

One of the components of the DDA 1995 is disability awareness; the process of informing and empowering individuals in disability etiquette. The biggest barrier cited by disabled people is that of negative attitudes and behaviour and many find that professional carers are not disability aware. Disabled childbearing women often experience poor understanding of their needs from GPs, obstetricians, midwives, nurses, and others; women may not be asked directly about their needs, there may be no mention of the impairment and its implications, and there can be an obvious lack of specialist knowledge. Midwives and nurses may need support from the multiprofessional team in providing appropriate services to women. As well as specialists, people's normal carers, who may include for example partners, parents and siblings, are also important resources. The individual is best placed to be the expert in their own needs. Developing strategies to meet those needs should be a matter of collaboration.

### Disability awareness and the disability equality duty of care

Decision-making, and consent for examination and treatment, are both key areas that nurses and midwives need to understand. UK law on consent applies to everyone who has the capacity to make decisions, including people with learning disabilities, who benefit from equal rights. This is explored in more detail in the RCN guidance Meeting the needs of people with learning disabilities (RCN, 2006).

Key points in laws and guidance applicable in the four countries of the UK are that:

- ◆ no adult can generally make decisions for another adult (subject to the provisions of the Mental Capacity Act 2005)
- ◆ without evidence to the contrary, the capacity to make decisions must be assumed
- ◆ all adults with such capacity may refuse treatment, whatever the result
- ◆ assessment of a person's capacity and the ability to communicate choices is the duty of the lead health professional
- ◆ support and information for decision-making must be provided in an understandable format (RCN, 2006)
- ◆ the patient's capacity to consent must be evaluated in relation to every treatment decision, and must not be based upon a general assessment or any stereotyping (RCN, 2006).

It is the responsibility of all carers to be informed, enabled and empowered to provide care from a philosophy of inclusiveness. This means treating disabled people with the same respect as non disabled people, avoiding over-reaction or ignoring a person's disability, and seeing the whole person, not just the impairment. It involves ensuring women who have disabilities have the same choices as other pregnant women. Disabled people like to be as actively involved in their own care as anyone else and need relevant and accessible information that helps to remove barriers of communication and access.

### Disability etiquette and use of correct terminology

In the past, phrases such as 'deaf and dumb', 'wheelchair bound', 'handicapped', 'invalid', 'crippled' or 'spastic', 'mad' or 'mental' were used to label disabled people. All these are unacceptable and many are offensive, especially if used to make assumptions about people.

The way in which terminology is used can be a stumbling block for many people, including health care workers, and it is important to recognise that using inappropriate terminology is discriminatory (DDA, 1995).

More acceptable words to describe disabled people include:

- ◆ hearing impaired
- ◆ hard of hearing
- ◆ deaf with speech or deaf without speech
- ◆ blind
- ◆ partially sighted
- ◆ visually impaired
- ◆ people with mental health issues
- ◆ wheelchair user
- ◆ learning disability.

It is good practice to ask individuals what is acceptable to them, and to use this term in all verbal and written communication. Individuals may feel strongly about words they are most comfortable with, and this may not be 'correct' terminology. In this document for example, the terms 'deaf' and 'hard of hearing' are used as these are the Royal National Institute for the Deaf's preferred options.

There will never be complete agreement about terminology when referring to people collectively, and words can never describe individuals' situations adequately (Royal National Institute for

the Blind, 2006). People with disabilities may not wish to be defined as 'disabled' and sensitivity to this is vital.

### 4.3 The impact of pregnancy on disabled parents

Disabled women and their partners are often anxious about pregnancy, delivery and parenting. Fear of the unknown is even more likely than for other first-time parents.

#### Women

There are many concerns that are highly specific to women's individual circumstances and impairments. For example, some may wonder how their bodies will adjust to pregnancy in terms of the effect of weight gain on mobility and independence, or difficulties they may encounter in performing day to day activities. Some women, such as those who are of short stature or have cardiac or breathing problems, may particularly fear the impact of advancing pregnancy. There may be requirements for specific equipment, for example an appropriate bed, cot, mobility aids, or larger wheelchair.

Women may feel vulnerable, especially if they have never been in hospital, or conversely may have spent long periods there, or are nervous about seeing doctors; memories of past negative experiences and barriers encountered can increase anxiety. First time expectant mothers may have concerns about the actual birth process in terms of choice of delivery (vaginal or caesarean section), pain relief (including availability of epidural analgesia if required), and recovery post delivery.

Women with sensory impairments may have specific concerns relating to communicating their needs effectively, making the right choices and obtaining the information they need in appropriate formats. They should be given the opportunity to have a carer, advocate or interpreter involved for support with communication. They will need to familiarise themselves with the layout of facilities and may need help to orientate themselves. Training in basic awareness and guiding techniques should be available to staff.

The hormone changes of pregnancy need to be explained as these may have a major impact, for example on women with serious mental health difficulties or impaired mobility. Sleep patterns may change or disturbances be experienced during pregnancy and the postnatal period, and this can affect women's wellbeing.

Those who have progressive physical impairments, such as multiple sclerosis or rheumatoid arthritis, may fear exacerbation of the condition following the birth. For women with significant mental health difficulties there is a 1:2 risk factor that their mental health will deteriorate and postnatal depression is a concern for many women.

There may be additional complications such as epilepsy or diabetes, and consultation with the wider health care team or specialists involved in the management of other conditions is important; some women may be taking medicines that have the potential to harm the foetus or breastfed infant and will need clear advice about this.

Other issues may preoccupy women, such as fatigue, pain, length of hospital stay, the impairment itself and its limitations. They may worry about their ability to look after a new baby; handling, bathing, lifting, changing and feeding, locating and using specialist equipment to help with this, the added responsibility of just being a new mother and care of the child as it grows. Furthermore, being dependent on others may give women concern, for example meeting personal needs such as coping with mealtimes, showering, toileting and mobilising.

Women with learning disabilities may need information about pregnancy, birth and baby care presented in different ways, for example using visual aids, and often need more time, repetition and opportunities than other women (Tarleton et al., 2006).

#### Partners

The needs of fathers must be also considered. If they themselves have a disability, then their specific needs will need to be addressed early in the pregnancy by performing a needs assessment; within a hospital setting the most significant needs are access, information and communication. They may experience sleep deprivation too and this may impact their own health.

Fathers with learning disabilities will need the same support as women with learning disabilities when information is provided.

Fathers should be included and involved in all aspects of care as much as they and their partners want. They may require specific and accessible information on equipment and other resources for the postnatal period at home, such as how to access information about suppliers and cost.

Disabled fathers, as well as mothers, should be informed about support and information organisations and how to contact them (see Appendix 2).

### 4.4 Knowledge, skills and attitudes for effective care provision

#### Knowledge

Carers need knowledge and awareness of conditions, including those that are hereditary or congenital, in order to ask specific and appropriate questions and provide information. For example:

- ◆ how the impairment will affect the pregnancy

- ◆ how the pregnancy will impact upon the condition
- ◆ the implication of taking specific medications such as antidepressants
- ◆ specific tests and investigations for genetic conditions and possible referral for genetic counselling
- ◆ issues, such as those related to diabetes or epilepsy, and the implications for pregnancy.

The midwife needs to know about organisations that provide information for disabled parents and how to contact them and use such resources. Information should be made available in accessible formats and media (see Appendix 3). As the main care provider, a midwife should be familiar with the benefit system and disability allowances (no extra financial support is available to pregnant disabled women). Many women and their partners have wider issues that may require the midwife's assistance, for example writing letters to support housing applications.

Understanding disability is the key to providing positive pregnancy care experiences alongside supportive attitudes, rather than the patronising imposition of perhaps unwelcome assistance.

Midwives and nurses must take account of the quality standards requirements in their country of practice. Examples are:

- ◆ the National Service Frameworks (Department of Health, 1999, 2004, 2005)
- ◆ *The same as you?* (Scottish Executive, 2000) for learning disability
- ◆ *Fair for all* (DRC and Scottish Executive, 2006b)
- ◆ specific orders in Northern Ireland, for example the Disability Discrimination (NI) Order, 2006.

The National Service Frameworks require proactive services that involve women from disadvantaged groups and communities and ensure services are accessible, and that Sure start principles are followed to improve outcomes.

### Communication skills

Midwives and nurses need to take time to listen to disabled parents, and need to gain appropriate listening skills for gathering information and communicating effectively from women, their partners and other health professionals.

Relevant information about a person's impairment should be disclosed by the GP but in practice this may not happen. Disabled people often arrive at hospital to discover barriers of

access and communication and have to initiate adjustments themselves to overcome these barriers.

Early identification, preferably before the first antenatal visit, will help to remove barriers and empower midwives and nurses to give specific care and provide up-to-date and relevant knowledge in both maternity and other settings. Observation and asking appropriate questions when taking histories are key ways of identifying women who may encounter barriers to services. Identification of other health care professionals who are, or may need to be involved in the woman's support should also be made early on in the pregnancy.

### Attitudes

It is clear from talking to women who have a disability that how they are approached is very important. They need to have the opportunity to develop confidence and trust in carers whose attitudes are helpful. Women should not have to justify the impairment or prove their ability to others. Women with mental health issues are especially vulnerable to being judged or labelled and this may include having to bear criticism of their right to parent or even to be sexually active.

Women need to be treated with respect, listened to, spoken to directly rather than having their partners or carers addressed instead, and should not be treated casually. They and their partners need information about pregnancy, freedom to make choices, and to be consulted and informed of decisions that need to be made with no assumptions being made about incapacity for decision-making and consent.

Women expect to be provided with relevant and current information on equipment and to have resources made available. It is important for parents to try equipment before the birth. Many pregnant women with disabilities expect their partners to be involved to give a sense of security.

Care providers should be flexible and innovative in order to meet needs and overcome barriers; women have the right to expect that carers will avoid making assumptions and will consult and discuss needs as they arise. Negative, patronising and discriminatory remarks, making excuses for poor service, and looking at the impairment rather than identifying a person's strengths are all unhelpful. Positive responses – encouraging and praising what women achieve, and assisting them to take responsibility for themselves – nurtures confidence in their ability to parent.

Disabled women, who are encouraged to be vocal and assertive, rather than passive and quiet, can collaborate with their midwives and nurses and move forward with confidence. If the woman wishes, the extended family can become involved too, assuming that they will have become familiar with the impairment long before the pregnancy. Such inclusive attitudes

increase the confidence of women and their partners.

Staying independent and in control, contributing to their own care and having dialogue with their midwives is important for women. This may involve discussing sensitive and personal issues and confidentiality is vital; all women need a safe place to talk and an environment of genuine care and concern. Nevertheless there will be occasions when confidentiality cannot be guaranteed, such as when an illegal act is disclosed by a vulnerable woman, or intention to harm her or her infant is shared.

#### 4.5 Effective care – general practice points

Similar principles apply at home or in hospital, including admission to general wards during pregnancy or the postnatal period. Preconceptual advice may be required when women take medication with possible harmful effects for the foetus, or by women who have hereditary conditions and want to be informed and explore issues to make choices for themselves before becoming pregnant.

In terms of antenatal care:

- ◆ identify disabled clients early, either from the GP letter or at the first booking visit, and ensure this information is passed to other service providers involved
- ◆ refer to the specialist or named midwife with responsibility for disability
- ◆ robust and flexible referral systems encouraging disabled women to refer themselves for specialist care are essential
- ◆ the first booking visit should be comprehensive and inclusive and the woman's preferred medium of communication should be identified
- ◆ offer antenatal care in the home; it usually provides a non-threatening environment and 'safe place' for disabled women, although some prefer to attend clinic as any other woman would do; home visits give midwives an opportunity to see the environment and discuss concerns
- ◆ agree frequency and location (at home, GP surgery or hospital) of antenatal visits with the woman; this may be specially helpful for those who have more than one impairment or long-term medical conditions that need to be considered, particularly those with learning disabilities
- ◆ perform a detailed assessment of needs and history of the impairment from the woman's own point of view, respecting the fact that she has lived with her impairment before requiring maternity services; midwives and nurses need to

be guided by disabled people themselves about their service needs

- ◆ identify the woman's strengths, focusing on the social model and how needs can be met safely, rather than directly on the impairment
- ◆ perform risk assessment as necessary
- ◆ address complex needs by networking with the multiprofessional team (including nurses, other midwives, specialist community public health nurses, community mental health teams, learning disability teams, sensory service teams, psychiatrist, occupational therapists, social workers, occupational health nurses for working women, specialists in disability or orthopaedics, and support groups) to facilitate multi agency support and provide inclusive care; remember to engage with those currently involved with the woman and her family as they will know her situation well
- ◆ a plan of care should be discussed and written with the woman to include pregnancy, birth and postnatal care in hospital and at home; communicate this with the multi-disciplinary team
- ◆ parents are encouraged to bring aids and equipment into hospital; quality of care and safety must not be compromised but 'common sense' suggestions make a difference.

In terms of the birth:

- ◆ a home birth in their own environment may suit some women better than hospital birth; many impairments pose no increased risk.
- ◆ a bed, settee or similar are needed for partners or other carers who sleep overnight during hospital admissions
- ◆ discuss the possibility of admission the night before a planned hospital delivery; this can worry some but provide reassurance and security for others
- ◆ identify appropriate sources of equipment, aids and other support for both parents and professionals (see Appendix 2).

In terms of parenting:

- ◆ positive role models should be identified, and women and their partners enabled to access them; contact with other disabled parents can be useful, for example using support organisations (see Appendix 2)
- ◆ parent education does not usually address the specific needs of disabled parents but their right of access applies as usual; it's important that disabled parents are able to join and

contribute to mainstream services but may require more specific information related to the impairment and pregnancy and birth

- ◆ the wider determinants of health and economic influences need to be considered, recognising that long-term needs as parents go beyond any disability.

Finally, it is important to remember that midwifery care can continue for as long as necessary following the birth, instead of being confined to 28 days (NMC, 2004b). Nevertheless joint working with other members of the multidisciplinary teams is vital, for example in devising discharge plans with women.

#### 4.6 Nursing and other health care worker responsibilities

Nurses may encounter women who are pregnant, or recently delivered, in any part of the health service when other needs arise. However some nurses and health workers may have specific involvement or responsibilities.

##### Specialist community public health nurses

Specialist community public health nurses, whether district nurses, health visitors or school nurses for adolescents, may have long-term involvement supporting women.

##### Learning disability specialists

This group may include nurses, social workers, speech and language therapists, occupational therapists, physiotherapists and psychologists. As members of community learning disability teams, these specialists enable midwives and other community nurses to provide the appropriate care and support for women with learning disabilities and their families. An example of good practice in this area is the NHS Cornwall's Special Parenting Service (see Appendix 1). It should be noted, however, that learning disability specialists are not available everywhere.

##### Occupational therapy

Support may be required for assessing women's needs at home relating to pregnancy and parenting, and all disabled women are entitled to this; referral is made through GPs. Advice and support can cover equipment and loans, managing at home, baby care, and referral to social services if adaptations are required. Most women who need this support will have been already assessed well before pregnancy.

Occupational health nurses are important in ensuring the changing needs of disabled pregnant women are met in the workplace, and collaboration with midwives is important.

#### 4.7 Support for working mothers

Working pregnant women with disabilities should be able to function as normally as possible, and close liaison between midwives and occupational health nurses can resolve or overcome obstacles and difficulties these women may experience in the workplace.

Working expectant and new mothers are protected by the Management of Health and Safety at Work Regulations 1999. This legislation places a statutory duty on employers to ensure the health and wellbeing of pregnant women is protected during pregnancy and for six months after giving birth, and those who are breastfeeding. Employer failure to undertake these duties is covered under the Sex Discrimination Act 1975.

Employers should conduct risk assessments throughout the pregnancy and reasonable adjustments must be made where problems are identified. Midwives should note whether women are working, and establish whether there is occupational health provision.

Midwives may wish to discuss risk assessments and reasonable adjustments directly with the occupational health nurse. Ongoing support may focus on, for example:

- ◆ reduced mobility
- ◆ physical hazards or psychological distress
- ◆ the attitudes of fellow workers or managers regarding the pregnancy (which may take the form of bullying and harassment).

Resources relating to work related issues and potential hazards are available for both women and health professionals (see Appendix 3).

#### 4.8 Support for adults or children at risk

Health care professionals often assume that disabled people are unable to become good parents, or need help and support. People with significant learning disabilities or severe mental health issues are particularly vulnerable to being considered incapable of being good enough parents.

However, specific actions need to be taken to support women in developing parenting skills where appropriate and in the following situations:

- ◆ when concerns exist about parenting ability, or the child is considered to be 'at risk' of harm or neglect



- ◆ in the presence of severe mental health problems such as schizophrenia, bipolar disorder and psychosis.

Referral may be made to adult social services for support for women, or to children's services for child safeguarding issues.

### Adult social services

If referral to adult social services is necessary, the referral should be discussed, the woman's consent sought, and support offered. Many women are anxious when social services become involved; they fear that their baby will be removed even if no child protection concerns exist. It is therefore important that women are provided with information about the process and role of social services.

If consent for referral is withheld, all health professionals involved should be informed and asked to monitor, support and report concerns; the refusal to consent to referral must be documented in the case notes. Referral is then made if indications arise that the child may be at risk.

The Mental Capacity Act 2005 (England and Wales) and the Adults with Incapacity (Scotland) Act 2000 may be relevant to women unable to make decisions for themselves (see RCN, 2006).

Parents have the right to ask social services for an assessment of the full range of their needs by the adult team, under the Fair Access to Care Services framework, and this includes any need for support with parenting and caring roles. Some parents may be reluctant to contact social services, in case it is suggested that their children are in need. However the Children Act 1989 makes it clear that the children of disabled parents should not be considered vulnerable as a matter of course and that services to support parents can be provided under community care legislation for adults. Parents with disabilities have the same right as anyone else to play a full role in all aspects of their life, including bringing up their children.

### Children's social services

Referral to children's social services needs to be considered when dealing with women who have mental health issues, learning disabilities or a physical impairment that may put a child at risk of harm or neglect.

Not all women require referral, but midwives and others involved must consider the impact of the condition on parenting ability. They should seek advice from the local child protection officer. Partners who have disabilities are not considered principal carers so referral is unnecessary unless, as with women, there is potential for poor parenting, for example substance abuse.

A child is considered to be 'in need' when it appears to be at risk of not reaching its full potential and development (see Section 17 of the Children Act 1989), or of significant harm (see Section 47 of the Children Act 1989). Important points relating to the referral process include:

- ◆ consent is not required
- ◆ full information, where possible, must be provided for the parents
- ◆ a pre-birth assessment by social services (with input from all involved in care) is necessary to determine whether the child is in need
- ◆ a post assessment meeting with the parents should be undertaken to discuss individual concerns and needs, and to assess support networks at home
- ◆ a case conference may be necessary and midwives/nurses are required to attend and provide information in the best interest of the unborn, or new born child; these professionals may find this particularly difficult, especially if the possibility exists of a child being removed from the parents or if she has built up a relationship of trust with them.

It can be very distressing for disabled parents to be observed and monitored, particularly if they have lacked support. Many vulnerable adults distrust social services, especially if they have had children removed previously. It also needs to be remembered that the mother may herself be under the age of consent, or be vulnerable and at risk, and may already have social service support.

Further information on safeguarding children is available in Appendix 3.

## 5

## Case studies

Much can be learned from women's experiences. The four case studies that follow describe the typical experiences of four women, each of whom has a different disability. The stories do not relate to specific individuals, but instead reflect the experiences of several women.

Each case study begins with a patient story and is then followed by practice points related to how to remove barriers for women with the specific impairments explored within the case study itself.

### 5.1 Tracey – a woman with learning disabilities

People with learning disabilities face many challenges when becoming parents. They can often be 'good enough' parents if they receive the appropriate emotional and practical support. (Tarleton et al. 2006). The following case study highlights the challenges, prejudice and stigmatisation that many such mothers face.

#### Tracey's story

Tracey became pregnant almost immediately she and her long term partner John decided to start a family.

The local antenatal service was supportive and flexible. In particular the community midwives and her community nurse were helpful to Tracey; Tracey was treated like any other first-time mother and no assumptions were made about her parenting ability. Tracey felt uncomfortable attending antenatal classes, so midwives visited her at home and liaised with the community nurse to ensure information was provided in a way that she would understand. The resources used to achieve this included pictures of the developing foetus, anatomical models and videos.

Social services were already involved because Tracey was considered to be a vulnerable adult and there were concerns about her partner because of past violence. A social worker, who specialised in assessing parents with learning disabilities, was asked to assess Tracey and John's ability to parent and support a child physically and emotionally.

Before the birth a number of child protection case conferences were arranged with Tracey and an independent advocate. Hearing 15 people discuss their concerns about John at one case conference distressed her; Tracey wanted them to know that John was always good to her. Although her advocate requested a less intimidating way for them to be involved, she was informed that the format could not be changed because of the requirements of the child protection process.

Nevertheless the multi agency approach worked well, ensuring that midwives, community nurse and health visitor, learning disability services, advocacy and social services worked together and shared information and progress with the couple (as recommended by Tarleton et al., 2006).

Tracey gave birth to a healthy boy. A social worker took him into care unexpectedly on the second day. Tracey was then discharged home without her baby with no consideration being given to the trauma this would cause both parents, or how she would actually get home, or who would support them after this traumatic event. By chance the community nurse called in having found out that she had given birth (social services had not informed anyone) and took them home. Seeing other women with their babies in the lift also going home, Tracey asked: "I've got a baby like them, haven't I?"

John was more able than Tracey and helped her in many ways. They were always together and she enjoyed his company and the life they shared. Tracey was given the opportunity to attend a mother and baby unit with her son for assessment, but had to agree to leave her partner, who social services considered unsuitable to be a parent. Once there she was left alone to cope until she reported herself to the staff because she had shaken the baby. Tracey knew she could not care for the baby alone and unsupported, so with dignity and courage decided to have her child adopted, accepting that this was in the baby's best interests.

With the right help and support from services collaborating across service boundaries, Tracey and her partner may have been able to care for their child but such support did not exist then. Social services acted in the best interest of the child, with little attempt to identify the parents' emotional needs when he was taken for adoption. Once the child was in care, support services retreated leaving them more isolated and vulnerable than ever. Now Tracey receives a yearly letter and photograph and hopes that her son will find her when he is an adult. She is looking forward to this.

#### Working with people with learning disabilities – practice points

Practice points for meeting the needs of women with learning disabilities include:

- ◆ the person who best knows the parent should inform the midwife about most effective ways to communicate
- ◆ avoid the assumption that information is understood the first time of telling
- ◆ ensure that all information is accessible; consider using visual and tactile aids; speech therapists and language specialists can provide support (RCN, 2006)

- ◆ check that what is being said is understood by asking for feedback
- ◆ home is the best place to teach and support parenting and other new skills with new information; family members may help if appropriate
- ◆ there are many reasons for poor cooperation including lack of understanding, sensory needs, anxiety, and limited appropriate support; don't assume parents are being difficult
- ◆ don't work in isolation; learning disability services may need to support health professionals
- ◆ avoid assuming that people with learning disabilities cannot be good enough parents and do apply the same standards as you would to yourself.

Everyone has the right to respect for his or her private and family life (Human Rights Act 1998) but, according to one survey (Emerson et al., 2005), only 52 per cent of people with learning difficulties who had children looked after them.

## 5.2 Mary – a woman born with a physical impairment

There are many issues midwives, nurses and other health professionals need to consider when supporting women with physical impairments. The wider implications of care are as important as 'hands on' care, because both impact on daily life. However, there are practical issues to be addressed. Although midwives and nurses cannot always make physical changes to remove barriers to access, they need to be able to identify what the barriers are, so reasonable adjustments and appropriate and creative ways of accessing care can be put in place.

### Mary's story

Mary has spina bifida and is a long term wheelchair user. She contacted the maternity services through the Association for Spina Bifida and Hydrocephalus and her local support group. Although not yet pregnant, Mary and her partner were seeking preconceptual care.

A home visit was arranged because her own surroundings presented no problems of access for Mary. Genetic counselling was included and urine testing arranged because of fears of infection related to catheterisation, which Mary performed for herself. Other issues discussed included breathing as her uterus enlarged, her ability to care for herself, tissue viability, pregnancy changes, antenatal care provision, type of delivery, and pain relief, including epidural use. Mary had informed her specialist that she was planning a baby.

Six months later and now pregnant, Mary visited the antenatal

clinic where a needs assessment was performed alongside the booking history. Access was easy as disabled parking was provided near the entrance with level access to the building.

Antenatal screening tests were all accepted. Referrals were made at Mary's request to:

- ◆ the dietician for healthy eating advice
- ◆ the physiotherapist for a support belt
- ◆ aromatherapy for massage and relaxation
- ◆ the health visitor
- ◆ the urodynamics specialist, because of repeated infections.

Social services support was not required.

Mary expected no difficulty regarding her wheelchair when her girth and weight increased, as it was of a good size. Similarly she anticipated being able to cope with the additional weight gain as she made her own skirts using hook and loop tape.

Antenatal care was provided by the hospital and community midwife, although Mary felt safer at the hospital and found it more accessible than the surgery. Early pregnancy proceeded normally but Mary experienced some difficulties later on. She was able to perform all her normal living activities but bending forward became difficult. In addition, her increased weight and reduced mobility increased pressure on her lower back, so Mary was admitted at 28 weeks gestation for rest and help with tissue viability. She had no pressure sores but her buttocks were becoming increasingly red and tender. The tissue viability nurse visited and a special mattress was provided. Physiotherapists provided advice on exercises and taking regular periods of lying flat out of the wheelchair.

Individual antenatal classes were provided which Mary found useful, as the local classes did not meet her specific needs. Mary attended a breast feeding workshop because she wanted to breast feed her baby. In preparation for the birth appointments were made with:

- ◆ with the obstetrician to discuss the mode of delivery
- ◆ an anaesthetist to discuss analgesia and the choices available if a caesarean section became necessary.

In addition, a tour of the delivery suite and postnatal ward was arranged, and Mary was able to see the layout and size of the room and arrange for specific needs to be highlighted in her care plan:

- ◆ height and back rest adjustable bed

- ◆ height adjustable cot
- ◆ she would bring equipment from home, for example a wheelchair and other aids.

Mary remained positive throughout her pregnancy despite repeated admissions for urinary tract infections. At 34 weeks gestation Mary's large uterus was compromising her breathing so it was decided to perform a caesarean section. Mary remained awake for the delivery and her partner stayed with her throughout the procedure and afterwards.

Special arrangements needed for postnatal care included:

- ◆ her partner stayed in hospital overnight to support Mary and the baby
- ◆ following the initial postoperative period in the main ward Mary was transferred to a single room
- ◆ Mary was seen by the physiotherapist and a manual handling assessment was performed, identifying no risk issue
- ◆ a maternity care assistant helped with childcare such as nappy changing, dressing, lifting the baby out of cot when her partner was unavailable; her partner took responsibility for bathing the baby as bending was difficult for her
- ◆ Mary concentrated her efforts on breastfeeding; a five-day hospital stay helped her to establish this and gain more confidence.

The occupational therapist performed a home assessment of need before discharge and found that Mary and her partner had planned well, and nothing else was required. The community midwife visited daily at first, gradually decreasing her visits until transfer on day 21 to the health visitor who Mary already knew.

### Working with people with a physical impairment – practice points

It is best to provide as much care at home as possible. Forward planning is essential when hospital attendance and admission are anticipated and working in close partnership with other service providers is essential to support removing barriers for women with physical impairments.

#### Access

In terms of getting to facilities, and moving around them, it is advisable to ensure:

- ◆ disabled parking provision is close to building entrance and clearly signposted at an appropriate height for drivers to see; some people use rear-exit vehicles to transport wheelchairs so parking that permits both rear and side entry is useful



Height adjustable cots give women more independence and choice when caring for their babies. People who are wheelchair users may prefer to perform child care tasks sitting down, others may prefer different positions. This equipment also meets the needs of short stature or tall women and those who have had a caesarean section.

- ◆ availability of wheelchair friendly taxicabs
- ◆ access to antenatal clinic, outpatient and inpatient services includes ramps, dropped kerbs, wide and automatic doors, non-slip and tactile flooring at entrances
- ◆ voiceover on lifts and tactile buttons at a height accessible for wheelchair users or people of short stature
- ◆ escort or assistance to wards and departments is available
- ◆ adequate lighting is available day and night
- ◆ large examination and inpatient rooms are available with wide-opening doors and space for a wheelchair and other equipment such as hoists (staff must not lift).

#### Communication

In terms of communication:

- ◆ a low reception desk enables wheelchair users to communicate effectively



A low section in a reception desk avoids putting barriers in the way of people in wheelchairs or of short stature.

- ◆ there should be clear signposting which is visible from a wheelchair.

### Seating and other furniture

In terms of seating and other furniture:

- ◆ waiting areas should be accessible to all disabled people with flexible variable height seating options including; soft and firm chairs, with and without arm rests, seating for women with large frames, seating at appointment desks with enough space for wheelchair users to pull up alongside a seated companion (flexible seating is important in clinical areas also)
- ◆ wheelchairs should be available in all areas; at the main entrance and especially where corridors are long (information on long term loan of wheelchairs may be useful; primary care will facilitate this)
- ◆ height adjustable examination couches in outpatient areas, adjustable (height and back rest) electronic beds if required on wards (can be hired), height adjustable cots and incubators; steps or stools can be useful if a person is of short stature
- ◆ hoists may be needed
- ◆ large beds will be necessary for those with body mass index (BMI) above 25.

### Hospital admission

In terms of hospital admission:

- ◆ women with physical impairments may request a partner or carer be allowed to stay on the ward overnight to support her needs; the sleeping arrangements for her carer must also then be addressed
- ◆ for the 'high risk' mother, for example following caesarean section, a bed in a room with other women may be more appropriate than being alone.

### Other facilities

In terms of other facilities:

- ◆ signposted, large accessible toilets and baby changing with plenty of room for manoeuvre, with emergency cords extending to floor level
- ◆ large accessible bath and shower rooms with grab rails, non-slip floors, low shower seat, emergency cords as above.

### Equipment

Some disabled people prefer to use their own equipment (for

example bath and toilet seats). This maintains confidence and independence, reduces the risk of cross infection and should be encouraged. Help may be needed with transport to bring this equipment into hospital.

In terms of additional equipment:

- ◆ fans to cool a room are appreciated especially by women with multiple sclerosis for whom hot environments create real problems
- ◆ clocks in rooms are often appreciated, for example women with rheumatoid arthritis may be unable to tolerate wrist watches; others may not have arms
- ◆ equipment, for example, walking frames, crutches, and hoists can be provided by physiotherapists and hospital equipment banks.

### At home

Needs vary according to a person's individual impairment, and many people are unaware of what is available, or what to ask for. Providing information about available equipment benefits disabled people and maintains their autonomy over choice and cost. Many disabled people already have home aids and adaptations already; for example, a bath buddy, raised toilet seats, handrails, stairlift, wheelchair, deaf aids.

In terms of support at home:

- ◆ in addition to occupational therapy assessment (if required) midwives and nurses should focus on equipment disabled parents may require for child care and safety such as baths, changing areas, prams, baby slings and car seats
- ◆ arrange for an introduction to the health visitor early in pregnancy so that there is time for a relationship to be established before the birth.

This equipment can be used in outpatient departments so women with physical impairments or of short stature can be examined. Women can themselves adjust the height so preserving their independence and dignity. Health carers can also adjust the height.



### 5.3 Jenny – a woman with sensory impairment

#### Jenny's story

Jenny was delighted to be pregnant and wanted the whole experience to be a good one. Jenny was deaf with speech; she had limited hearing and was able to communicate with lip reading and using British Sign Language (BSL). Her partner Peter was also deaf; he had no hearing, did not lip read and communicated with BSL only. They informed the midwife that they were deaf at the antenatal booking appointment and requested a sign language interpreter for every hospital visit and for antenatal classes.

A plan of care was written which identified communication needs for pregnancy, the birth, and the postnatal period in hospital and at home. This was coordinated with other carers and some of the resources explored included:

- ◆ an alarm mattress was needed so Jenny could hear her baby cry at night, and it was suggested they use this in hospital
- ◆ using their own Minicom for contacting relatives.

The pregnancy caused no concerns but some difficulties arose over communication. The interpreter missed appointments on two occasions; further appointments had to be made and delays occurred in providing information although the information happened not to be urgent. In addition, conflict arose in the ultrasound department as Jenny could not watch the BSL interpreter and the screen simultaneously; all she wanted was to see her baby on the scan. Extra time was given so she could see the scan and watch the interpreter.

Jenny had the support of her mother and Peter at the birth, which was straightforward. Her mother interpreted for them both while Peter supported Jenny. The baby was put to the breast straight after the birth and they were transferred to the postnatal ward soon after.

They encountered new barriers during the postnatal period. The baby had to be transferred to the neonatal unit (NNU). Unaware of this Peter became very distressed when he found his wife and son gone from the ward. Once the midwife explained where they were he was escorted to the NNU but no sign language interpreter was available. Jenny described what had happened and the paediatrician later explained everything to them both, reinforcing the information in writing. In addition, access to all areas was by intercom which caused delays and barriers. Peter requested a pass so he could visit his son on the NNU independently. This was a reasonable adjustment so a security pass to the NNU only was provided, to be collected at the hospital entrance and returned on Peter's way home. This met both his needs and the security needs of staff. Jenny was always

accompanied by staff so did not need this. When the baby was well, he was returned to the postnatal ward and was soon discharged home.

As a result of this experience, a checklist for deaf parents was developed in the unit and used to meet the needs of users and carers alike.

#### Working with people with a sensory impairment – practice points

Practice points for people with sensory impairments include providing pictorial, tactile 'Way Finder' maps and audio tapes to promote independence for people who are hearing or visually impaired. Guide dogs for the blind and dogs for deaf people should be allowed into hospitals and other health care settings. On the maternity ward, the use of baby alarms (specialist monitors that vibrate under the mother's pillow when the baby cries) may be difficult to use in an open ward as it will pick up other babies' cries; special provision may need to be made in a single room.

#### Hearing impairment

It is the responsibility of service providers to provide sign language interpreters for deaf people (DDA 1995), but some may prefer to use family members and friends to interpret. If this is the case, their choice must be documented in the notes and verbally explained that the trust is not responsible for information that may be inaccurately translated. Interpreters provided by the trust must be registered and trained to NVQ level 3 and be accountable for all information given. BSL interpreters are not always available at short notice and it is therefore essential to book this service in advance.

In an emergency situation, a staff member who has knowledge of BSL may be used to interpret but when time allows a registered sign language interpreter must be made available to reinforce information given (DDA 1995).

In terms of hearing impairment:

- ◆ alert disabled people in waiting rooms to when their name is called by using electronic displays or a ticket system
- ◆ clinic receptionists should inform midwives or nurses when a deaf person attends so they can approach the woman personally when she is called; a touch on the arm or hand sign can be used to attract her attention
- ◆ women may use BSL, sign supported speech or lip read; you should note that English may be the woman's third language, not second (BSL being the first)



To avoid barriers of communication, alternative ways of gaining access to wards and departments may be needed. This call bell is low on the wall and has a light.

- ◆ speak normally and clearly and face women so they can lip read, even if they have some hearing or an aid
  - ◆ organise suitably qualified BSL interpreters or lipspeakers where necessary, and video interpreters can be useful working via special telephone equipment; ideally learn some signs yourself (details of fingerspelling charts can be found in Appendix 3 and this is easier than BSL)
  - ◆ keep pen and paper available
  - ◆ back up information with visual material
  - ◆ ensure staff know how to use equipment like text phones and videophones
  - ◆ provide televisions with teletext and subtitles, this applies to educational videos too
  - ◆ provide or loan a Minicom or text phone, or encourage patients to bring in and use their own if unavailable; midwives and nurses can communicate using text in emergency (mobile telephones are permitted in hospital only to text a deaf person)
  - ◆ access to a fax machine may be requested occasionally
  - ◆ many wards and departments have intercom access for security purposes (which can make that area inaccessible to deaf people); organisations for the deaf suggest intercoms should include lights to alert visitors when doors are unlocked and a video-entry system can provide greater accessibility and more effective security
  - ◆ women may need single rooms to reduce background noise and improve communication; the bed should face the door and ideally have a view of the midwives' or nurses' station so the woman can signal for help if needed
- ◆ during labour
    - pain, drugs and anxiety may interfere with communication
    - lipreading is impossible when face masks are used and difficult in some labour positions or when women have their eyes closed, so a second person can help communication
    - discuss before labour begins some signs the woman would prefer to use
    - it may be difficult to book an interpreter for labour or an emergency because of its unpredictability.

### Visual impairment

In terms of visual impairment:

- ◆ provide extra lighting in rooms, dimmed at night
- ◆ provide magnifying equipment
- ◆ clear signage in large font, with good background contrast and visual or pictorial symbols, or audio directions, is needed for clinics and wards; people can become confused or lost especially when attending other departments such as ultrasound (the hospital should have carried out an audit of accessibility for visually impaired people, and ensured that they are conforming to the DDA)
- ◆ adjust the layout of rooms before admission to be more appropriate for a visually impaired woman, having discussed this with her during pregnancy, enabled her to familiarise herself with the new layout and included it in her care plan; this layout should not be changed without warning her
- ◆ all literature provided to sighted women should be provided in a format accessible to those with visual impairment
- ◆ communications should all be made by telephone or other audio media
- ◆ always discuss with the woman whether any special communication or other equipment is required
- ◆ reception staff should be aware that electronic displays or ticket/number systems are not accessible to most people with a visual impairment
- ◆ blocking corridors, toilets and bathrooms with equipment creates hazards
- ◆ be aware that a visually impaired woman may need assistance at mealtimes, for instance she should always be advised of the location of drink or food, or any other items provided for her.

## 5.4 Dawn – a woman with long-term mental illness

Mental illness is the leading cause of maternal death in the UK (Lewis and Drife, 2004). Mental illness associated with childbirth is common, both in terms of new episodes and the recurrence of pre-existing conditions; 10 per cent to 15 per cent of all women experience postnatal depression (DOH, 1995).

Health services addressing the needs of this minority group are not yet well-established, and up-to-date statistics on prevalence are not readily available. Older statistics, however, paint a useful picture although this does not necessarily feature women with pre-existing conditions. For example:

- ◆ 10 per cent of new mothers suffer from a depressive illness (O'Hara et al., 1996)
- ◆ 30 per cent to 50 per cent of these will have a severe depressive illness (Cox et al., 1993)
- ◆ two percent of childbearing women will see a psychiatrist during the first year after delivery (Oates, 1996)
- ◆ four in one thousand childbearing women will be admitted to a psychiatric hospital, half of which will have puerperal psychosis (Kendell et al., 1987)
- ◆ the suicide rate is lower during pregnancy and the first year as a mother than amongst non-pregnant women (Lewis and Drife, 2004) although there are signs it may be rising.

### Dawn's story

Dawn was diagnosed with schizophrenia at the age of 19 but her mental health remained good for many years and she was supported by the community mental health team (CMHT). Dawn saw her psychiatrist and mental health nurse regularly. Her mental health deteriorated five years later; she was not complying with taking medication and was having bizarre thoughts and delusional ideation. Dawn was then sectioned under the Mental Health Act 1983 and remained an inpatient for four weeks. She was now pregnant with her third child.

Dawn visited the hospital antenatal clinic at 15 weeks gestation for a booking visit. During this visit a full history was taken recording her mental health. In addition to the usual medical and obstetric histories, details of her psychiatric hospital admission and current medication histories were also noted. The GP letter had summarised her medical and mental health history, which was recorded in her notes. Dawn had a supportive partner.

An appointment was made for Dawn to see the consultant obstetrician, who liaised with primary and secondary services to request collaboration and further information about her mental

health history and management. The frequency of antenatal appointments was discussed and no immediate concerns were identified, so Dawn received antenatal care from her community midwife, returning to the obstetrician at 34 weeks.

A follow-up letter was sent to the GP to ensure appropriate support and treatment was given during the antenatal and postnatal periods. A social service referral was made in view of the past history (one of her children was in care). The social worker completed an assessment and communicated with other services that no issues had been identified relating to this pregnancy. Dawn was very anxious about this referral, believing that making judgments and assumptions about her ability to parent was unfair. As Dawn was taking her medication and accessing services, the case was closed.

A plan of care was written by the mental health and midwifery teams and Dawn contributed to this process. Copies of this plan were put in notes retained by Dawn and her hospital records, and sent to other relevant agencies. Dawn had no particular requests for labour but she specifically mentioned that she wanted to breastfeed her baby.

Following the birth Dawn was transferred to a room with other women in the postnatal ward; she understood that a single room was unsafe because of the risk of suicide. Dawn coped well during the three days she spent there. There were no signs that her mental health was deteriorating and, following a visit from her psychiatric nurse who expressed no concerns about Dawn or her baby, she was discharged home. On discharge she was supported by the community midwife, GP, health visitor and community mental health team and had an appointment to see the psychiatrist to discuss her postnatal medication and assess her mental wellbeing.

### Working with people with mental health problems – practice points

#### Pregnancy

During the pregnancy:

- ◆ the mental health history recorded by midwives should include current medication, psychiatric unit admissions, whether sectioned under the Mental Health Act or admitted voluntarily, and any family history of mental illness
- ◆ its important to know the woman's reaction to previous pregnancies; if her condition worsened she will be especially anxious and will need help
  - to identify and report signs of recurrence
  - to identify what helped her and what did not



- ◆ exploring what works best means systems can be put in place if her condition does deteriorate and she will be more prepared to cooperate
- ◆ poor cooperation from a woman may occur because of her condition, or because of lack of understanding, or feeling threatened or anxious
- ◆ the possible effects of pregnancy should be explained so the woman and her family know what to expect
- ◆ perform an assessment to identify individual risk factors and needs
- ◆ discuss the withdrawal and safe use of antidepressants and other psychiatric medicines which can harm the foetus and breastfeeding infant
- ◆ care plans should include trigger factors that may indicate deteriorating mental health so that midwives know what to observe; if concerns arise the CMHT or, if unavailable, the on-call psychiatrist should be contacted
- ◆ give the woman telephone numbers and contact details of the mental health crisis team who will support and help resolve periods of crisis; most teams are based in emergency departments
- ◆ a letter to inform the GP, community midwife and health visitor of current mental health issues is essential
- ◆ consider referral to social services, but do not assume a woman with mental health problems cannot be a good parent: it is important to apply the same standards of parenting as you would to yourself (however, referral is essential if there are safeguarding children issues)
- ◆ record names and telephone numbers of psychiatrist, mental health worker and any other services involved in care
- ◆ offer referral to the specialist disability midwife or lead midwife in special needs.

## Labour

During the labour:

- ◆ a woman transferred from a psychiatric ward in labour remains the responsibility of the mental health service and must be accompanied by a mental health nurse who will support both patient and staff; if her mental health is stable then 24 hour access to a mental health nurse may be adequate; in an emergency the duty psychiatrist can be called
- ◆ medication needs to be managed according to the psychiatric plan of care
- ◆ a risk assessment should be performed on the postnatal ward; a single room is not offered because of the risk of suicide
- ◆ CMHT members should be informed of the birth, visit the woman in hospital and perform a mental health assessment before transfer home
- ◆ a postnatal hospital stay of five days is recommended for women at high risk of exacerbation of mental health problems; transfer home should be possible if no concerns exist
- ◆ discharge arrangements involve notifying the community midwife, health visitor, GP and CMHT, and social services if there are any issues around safeguarding children
- ◆ close multidisciplinary follow-up is required in the postnatal period (Lewis and Drife, 2004).

## 6

# The Disability Equality Duty (DED) and public bodies

## 6.1 Summary

The philosophy of quality management at the centre of NHS provision embraces the needs of all people at all times, and is foundational to disability discrimination legislation. The DED places the involvement of people with disabilities at the centre of developing quality service provision to ensure barriers of communication and access are eliminated. A disability equality scheme and three-yearly review will demonstrate how this is being achieved.

In summary, the requirements of the specific DED (DDA 2005, DRC 2006a) are as follows:

- ◆ user involvement;
  - identify interested disabled people with varying disabilities and other characteristics – former, current and potential users, staff, support groups, other community members
  - develop a disability equality scheme and action plan together
  - provide risk assessment tools, audit services and develop an ethos of research
- ◆ mapping provision;
  - review current services, identifying good practice, inequalities and barriers to service provision
  - continue to monitor while developing a disability equality scheme
- ◆ develop a disability equality scheme including;
  - a statement of how disabled people are involved
  - an action plan
  - how information about disability equality performance and the impact of activities is gathered
  - arrangements for review.

Remember that disabled people's needs for access to health care must be met, even if this means treating them more favourably than others.

## 6.2 Conclusion

The aim of all staff should be to respect the diversity and individuality of people with disabilities. All health care workers are responsible for exploring and resolving negative attitudes they may have and for being prepared to meet the challenges. Midwives, nurses and other health care personnel must work in partnership with agencies and disabled people themselves to promote health, deliver care in new ways and become advocates of good practice.

A health service that meets the needs of disabled women who are pregnant will meet the needs of all childbearing women well; in effect, a health service that's built around the needs of disabled people enhances the quality of care provided in general and works more effectively. By investing a little additional effort and thought, it is possible to make a difference to the lives of disabled childbearing women. The aim is to deliver services for childbearing women that value diversity and see the woman first, and disability second.

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# Appendix 1: Examples of good practice

Here are just three examples from many that could be selected.

## 1 Liverpool Women's Hospital NHS Foundation Trust

The Liverpool Women's Hospital Disability Service has won several commendations for its well-established systems which both enable it to meet needs of individual women with disabilities, and comply with legislative and NHS requirements. A key element in the success of the establishment was the creation of the role of disability advisor.

Today, midwife Jackie Rotheram (who herself has received a number of personal awards) leads the service and, in her role as disability advisor, coordinates multi agency activities, including human resources, to work with individual women and their partners.

### Contact information

Jackie Rotheram, Disability Advisor  
Telephone: 0151 702 4012, Monday to Thursdays  
Email: jackie.rotheram@lwh.nhs.co.uk

## 2 Milton Keynes Maternity Unit, Milton Keynes General NHS Trust

Milton Keynes provides a service to pregnant women with additional needs, led by midwife Patricia Fairlamb. Guidelines, a care pathway, equipment and information resources help to support women with disabilities. The lead midwife also teaches disability awareness at Northampton University.

### Contact information

Patricia Fairlamb, Midwife (Special Needs)  
Telephone: 01908 660 033 extension 3162  
Email: pafairlamb@yahoo.co.uk

## 3 The Special Parenting Service, Cornwall Partnership NHS Trust

Founded and led by Dr Sue McGaw, this regionally funded NHS specialist service sits alongside the Children's And Maternal Health Service. It provides specialist parenting assessments and support through interventions, teaching and parents groups.

The service's Initial screening tool is available for download from the service's website ([www.cornwall.nhs.uk/specialparentingservices](http://www.cornwall.nhs.uk/specialparentingservices)) where the complete Parent assessment manual can also be ordered online.

### Contact information

Dr. Sue McGaw, Head of Special Parenting Services  
Telephone: 01872 356 040  
Email: sue.mcGaw@cpt.cornwall.nhs.uk

## Appendix 2: Support, advocacy and information organisations

### Disability Pregnancy and Parenthood International (DPPi)

A small UK-based registered charity, controlled by disabled parents, which promotes better awareness and support for disabled people during pregnancy and as parents. Its services include a quarterly journal for parents and professionals, a staffed UK information service and resources, including books and DVDs.

#### Contact information

Voice: Freephone 0800 018 4730  
Text: Freetext 0800 018 9949  
Fax: 020 7263 6399  
Email: [info@dppi.org.uk](mailto:info@dppi.org.uk)

Website: [www.dppi.org.uk](http://www.dppi.org.uk)

### Disabled Parents Network (DPN)

The DPN is a national organisation of and for disabled people who are parents or who hope to become parents, and their families, friends and supporters.

It provides a wide range of support, information and advice, including a newsletter, a helpline and training for health care professionals. It has around 500 disabled parents on its contact register and organises local networks of disabled parents to provide peer support.

#### Contact information

Helpline: 0870 410 450  
or [e-help@disabledparentsnetwork.org.uk](mailto:e-help@disabledparentsnetwork.org.uk)

Email (for general enquiries):  
[information@disabledparentsnetwork.org.uk](mailto:information@disabledparentsnetwork.org.uk)

Website: [www.disabledparentsnetwork.org.uk](http://www.disabledparentsnetwork.org.uk)

### Royal National Institute for the Blind (RNIB)

This membership organisation and charity provides support, information and advice to over two million people with sight problems. The RNIB produces aids and publications aimed at visually impaired people and others and can provide information on both environmental and literature design. Its guidance for health professionals, *Patient focus: how to provide a good service*, can be ordered via the website, or by contacting RNIB Customer Services on 0845 702 3152. The factsheet *Information for blind and partially sighted parents* is available from the RNIB helpline. The RNIB runs Talk and Support Parent Network Groups which can be contacted on 0845 330 3723 or via the RNIB website.

#### Contact information

Main office and resource centre:  
105 Judd Street, London WC1H 9NE  
Telephone: 020 7388 1266  
Helpline: for enquiries, call 0845 766 9999  
Fax: 020 7388 2034

Website: [www.rnib.org.uk](http://www.rnib.org.uk)

### Royal National Institute for the Deaf (RNID)

This support and campaigning organisation provides an extensive range of information, services and training to support deaf and hard of hearing people, families, employers and professionals. The website contains information on all services and publications available. The RNID also provides a variety of communication support services, including British Sign Language/English interpreters and Electronic Notetakers. There is an online booking form for these services.

#### Contact information

Information line: Freephone 0808 808 0123  
Text: Freetext 0808 9000  
Fax: 020 7296 8199  
Email: [informationline@rnid.org.uk](mailto:informationline@rnid.org.uk)

Website: [www.rnid.org.uk](http://www.rnid.org.uk)

# Appendix 3: Other resources and further reading

## Websites

### [www.direct.gov.uk](http://www.direct.gov.uk)

This government site for service users and professionals contains detailed resources and information on a wide variety of topics, including health during pregnancy, and mental health. The site contains links to partner services, online services and also contains links to government legislation which is available online.

### [www.equalityni.org](http://www.equalityni.org)

The Equality Commission for Northern Ireland website contains information about equality legislation, together with reports and news releases.

### [www.dcalni.gov.uk](http://www.dcalni.gov.uk)

Additional information relating to equality legislation and legal duties in Northern Ireland can be found here on the Department of Culture, Arts and Leisure's (DCAL) website.

### [www.fairforalldisability.org](http://www.fairforalldisability.org)

The NHS disability network is a Fair for all partnership initiative, developed by the Scottish Executive Health Department and the Disability Rights Commission staff for those who lead on equality within the NHS in Scotland.

### [www.saifscotland.org.uk](http://www.saifscotland.org.uk)

The Scotland Accessible Information Forum works to improve accessible information for disabled people by producing and promoting standards and guidelines.

### [www.scotland.gov.uk](http://www.scotland.gov.uk)

Access information on disability equality resources.

## Additional reading and resources

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