In recent years, people with disabilities have been challenging many of our society’s more hostile or patronising assumptions, in order to claim a more active and autonomous lifestyle. They have shown that our society’s preconceptions about what disabled people can or can’t do are based more on traditional fears, inflexibility, or unwillingness to provide practical support, than on disabled people’s own aspirations and abilities. Nowhere is this clearer than in the area of parenting.

Increasingly, people with learning or physical disabilities, or chronic ill health, are using the maternity services. Whatever the nature or extent of their disability, they are looking to midwives to provide the individualised, holistic woman-centred care that they need to enjoy their pregnancy and delivery, and make an effective transition to parenthood.

The position paper below was first published in May 1996. It aims to help midwives develop their practice by understanding and responding to the needs of all women in our increasingly diverse society. Those seeking further information or specific advice are advised to contact the agencies listed at the end of this paper.

The RCM believes that it is the responsibility of all those involved in the provision of maternity services to meet the needs of pregnant disabled women and their families. Midwives have a key role to play in meeting the particular needs of disabled women, and this position paper explores how they can prepare themselves to meet the challenge.

The RCM recognises that services that are responsive to the needs of minority groups are also more likely to meet the needs of all women satisfactorily.

The RCM supports the principle set out in Changing Childbirth that: ‘It is important that services reflect the needs of women who have disabilities and ensure that action is taken to overcome the obstacles which confront them. While physical obstructions are of course a frustrating problem, there are other equally daunting barriers resulting from the prejudice and ignorance of able-bodied professionals’ (DoH, 1993).

**Ensuring best practice**

The nature of women’s disabilities may be wide-ranging, but the principles of woman-centred care are as important in their maternity care as they are to able-bodied women.

An increasing number of women with physical or sensory disabilities are choosing to have children. Although statistics are not readily available, disabled mothers are more visible in the maternity care system. Research seems to indicate serious shortcomings in assisting them towards confident, healthy and safe childbearing and childcaring. Research also indicates
that disabled people carefully consider the potential difficulties in making the choice to have children. They seek information about, and want to learn strategies for, successful and responsible parenting. Their anxieties are like those of other expectant or new parents, but may be intensified by lack of information, exposure to negative attitudes and the absence of support services and role models.

Midwives with the interest, knowledge and understanding can play a significant and active role in changing this situation. Achieving this entails continuing contact with the disabled woman and her family. This will help form a detailed understanding of living conditions, physical surroundings and relationships as well as of the availability of local information and networks of professionals and voluntary organisations.

Service planners and commissioners need to consult people with disabilities, and involve them as full partners in decisions about service provision. This includes incorporating the needs of disabled parents and prospective parents in contracts with providers, setting targets for improvements where necessary and taking action to ensure standards are being met. Disabled parents should be involved in the setting of standards and the evaluation and monitoring of services.

**Overcoming prejudice**

The attitudes demonstrated by health professionals can greatly affect the quality of care experienced by disabled women. In a recent survey, disabled women identified insensitive, inadequate and insufficient understanding of the nature of their disability in relation to pregnancy as their chief complaint about maternity care (Maternity Alliance, 1994).

Health providers have a responsibility to address explicitly the existence of discrimination and its implications for care. Disability equality training should be provided for all levels of staff, including non-medical personnel, e.g. domestic staff, and should be facilitated by disabled people themselves. Midwives with limited experience in caring for disabled women should seek advice and guidance from better informed services, professionals and colleagues and from women themselves, who are often the best source of information.

**Informed choice**

To make informed choices disabled women need appropriate, accessible and accurate information. Midwives should be aware of local resources and work with disabled women to locate relevant information as early as possible.

Disabled women may wish to seek support from self-help and voluntary organisations. Midwives should be aware of local networks and contacts and should be ready to work with them. This is particularly important where a disabled woman chooses to use an advocate to support her.

If disabled women are to make effective choices about independent living they may need financial and practical support. Midwives should know where to go for advice on the range of benefits and service provisions and the availability of special equipment and aids.
It is particularly important that disabled women feel supported by, and able to trust, their midwife. A disabled woman should have the right to change the professional involved in her care at any time. Midwives should empower disabled women to make informed choices about all aspects of their pregnancy and delivery, including place of birth, antenatal testing, delivery position and postnatal support.

Antenatal screening should be approached sensitively, with an awareness and understanding of inherited and non-inherited disabilities. Some disabled women may need specific reassurance about fetal normality. Should an abnormality be detected, the midwife should support the woman in reaching her own informed choice over the appropriate course of action, being careful not to make assumptions or express her own views on what outcome is desirable.

Parent education should be flexible, creative and accessible. In some cases it may be more appropriate for midwives to work with women in their own homes, reflecting the woman’s abilities and the way she manages her domestic life. Disabled women should never be excluded from mainstream antenatal and postnatal groups except by choice. When participating in some groups, discussions about fetal abnormality need to be handled carefully and disabled women should be given an opportunity to raise concerns privately.

Like all women, the disabled new mother should have a choice about her length of postnatal stay. Liaison with appropriate social services and voluntary organisations should be sought as early in pregnancy as possible, they should be alerted prior to discharge to ensure access to support and resources in the community are available.

**Woman centred care**

Every disabled woman should be given the choice of lead professional who is responsible for planning and maintaining her care, and who she should be able to contact for advice and information. A named midwife gives the disabled woman a trusted carer with whom she can discuss concerns, ask questions, identify issues and experiment with adaptive and creative approaches to meeting her needs, throughout her pregnancy, delivery and postnatal period. Disabled women, like all women, need to get to know all the midwives and health professionals likely to be involved in their care at an early stage of their pregnancy.

The most effective way of conversing with a woman should be identified at her first contact with the maternity services and communicated to all staff who have contact throughout her pregnancy and delivery. It is vital that users have access to suitably qualified translators and interpreters, including sign language, without charge. This can be achieved by maintaining an up-to-date register of interpreters and signers available for staff and users. Pregnant women who are deaf should be provided with a minicom free of charge, with which they can contact their key health professional. However, women who lip read may benefit from sign language interpreters, particularly in times of stress or under the influence of analgesia.

**Capability and control**

Disabled women, like all pregnant women, should be invited to carry their own notes and take a full and an active role in decisions about the nature of their care. Women should be asked what they want included in notes about their condition so this information does not
have to be continually repeated to new carers. Decisions relating to care should be clearly documented.

Disabled pregnant women should be cared for in a holistic fashion and their pregnancy should not be separated from their disabilities. Therefore a multi-disciplinary approach to care is particularly important, with joint planning between team members to ensure that services meet individual needs and wishes. This is likely to include staff of voluntary and statutory support services, in addition to obstetric, specialist medical and midwifery staff, and any meetings should involve the disabled woman.

Adjustable equipment will increase the independence of disabled women and will reduce staff workload, therefore the right equipment and forward planning are crucial. Some time prior to admission the woman should be given an opportunity to visit the ward/hospital and check that facilities are appropriate to her needs, including familiarising her with the hospital environment and giving her an opportunity to meet other staff. A woman should be offered a single room if she would like one, and may choose to bring her own aids into hospital. Disabled women may feel humiliated and a nuisance by having to ask for help all the time; if this embarrassment inhibits them, their safety may be compromised.

All public premises are required by law to be physically accessible to disabled people, this includes people with sensory as well as motor impairments. This might require the use of flashing lights and bells in a waiting room, ramps and more extensive use of signs in Braille. Parking spaces for disabled drivers should be clearly signposted, close to public entrances and readily available. Affordable and appropriate hospital and community transport should be provided with non drivers. Disabled women should be able to use their wheelchair when being transported in health service vehicles. Hospitals should also provide details of wheelchair accessible taxis. Disabled partners and other disabled people should be offered the use of transport services when visiting or accompanying a pregnant woman or new mother.

Useful addresses

**Disability: Pregnancy and Parenthood International**
(DPPI - Information service and quarterly Journal)
5th Floor, 45 Beech Street
London EC2P 2LX
Freephone: 0800 018 4730
Text: 0207 256 8899
Fax: 0207 628 2833
Admin: 0207 628 2811
E-mail: dppi@eotw.co.uk
Website: [http://freespace.virgin.net/disabled.parents](http://freespace.virgin.net/disabled.parents)

**Disabled Parents Network**
(Campaigning and support for disabled parents and professionals)
PO Box 5876
Towcester NN12 7ZN
References


Carty E, Conine, TA, Hall, L. (1990) Comprehensive health promotion for the pregnant woman who is disabled and the role of the midwife. *Journal of Nursing and Midwifery* 35(3): 133-142


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