



The maternity information gap for physically disabled people

A UK study on physically disabled parents' experiences of maternity services reveals that physically disabled people embarking on parenthood face a number of challenges. In addition to working to provide the best start for their babies before and during pregnancy, through birth and into parenthood, they often also face a challenge in getting appropriate information and support to enable them to plan and prepare for birth.

The study was carried out by the UK information charity for disabled parents, Disability, Pregnancy and Parenthood International, as part of Empowering Parents, a three year initiative funded by the Department of Health.

In the study, we aimed to develop understanding of the information needs of physically disabled parents who use maternity services, and also to investigate the scope of existing provision.

We use the term "physically disabled" in the widest sense to include those with mobility problems and other physical impairments, and also people with neurological conditions such as cerebral palsy, multiple sclerosis or epilepsy who experience physical access barriers. This may include people who are not generally considered by themselves or others to be physically disabled.

Participants in the study were gathered from people attending the launch meeting of the Empowering Parents Initiative, parents and professionals taking part in the steering group of the initiative, as those responding to questionnaires on pregnancy, birth and early baby care for physically disabled parents, which were circulated widely to parents and through a number of networks of health professionals. The following is based on contributions from 19 health professionals (including midwives, occupational therapists, antenatal teachers, and breastfeeding advisors) and 11 physically disabled parents.

Parents

Physically disabled parents were asked to describe their experiences of maternity services and their access to appropriate and timely information. The following is a summary of the comments received. What they revealed was a lack of awareness and knowledge among many maternity and health professionals on integrating disabled parents' need for information and access to maternity services with their information and support needs as disabled people.

Lack of awareness and knowledge

Parents noted that many professionals knew little about the specific needs arising from their disability. They found it difficult to obtain information on how their medication might affect their baby. Hidden disabilities were often overlooked, with assumptions being made that people had no access needs. In addition, lack of continuity of care by midwives during the antenatal and postnatal periods often meant disabled mothers-to-be had to keep repeating themselves, in order to ensure their specific needs were taken into account.

Lack of knowledge of how, for example, particular birth positions might impact on parents with physical disabilities was also highlighted. A mother with scoliosis noted,

“I wanted to have an active birth, but I ended up in stirrups, flat on my back on the bed. As a result my back pain was much worse afterwards.”

Negative attitudes still persist

“Why do you want a child if you are disabled?”;

Some disabled parents reported some startlingly negative attitudes expressed by maternity professionals. These included:

- pressure to terminate a pregnancy because of health problems;
- pressure to have tests to assess if the baby had any disabilities;
- insensitivity of staff who refused to consider the access needs of disabled fathers.

Others reported patronising attitudes from their midwives who dismissed their concerns:

“everything will be OK”.

This closed down any discussion of concerns or additional needs.

Information gap

Parents highlighted a glaring gap in information relating to pregnancy and disability. While disability organisations provide information on particular conditions, and maternity services give information relating to pregnancy, parents often found it difficult to find information that bridged these two areas. Some disability organisations had pregnancy-specific information available, others would put parents in touch with other parents with the same condition, some would refer parents to the dedicated information service provided by Disability, Pregnancy & Parenthood International, but some had no information on pregnancy and parenthood and did not refer parents to appropriate sources of information. In many cases parents have to turn to the internet, in particular online communities, for their information and peer support. Additional difficulties were noted around access to culturally appropriate information and information in languages other than English.

Normalising birth

Some physically disabled women found choices limited in terms of how they would deliver and care for their baby, with the assumption being made that they would have a Caesarean section and pressure applied to do so. Assumptions were sometimes made that physically disabled mothers would not breastfeed, or that they would have no additional needs when it came to breastfeeding.

Disabled mothers might also have additional support needs on the labour and post natal wards which a husband or partner may be keen and able to provide. Rigid rules about when fathers can visit wards created additional stress to some physically disabled mothers.

Access

A disabled mother, acting as a user representative, carried out an audit of local maternity services, where she observed barriers to disabled people first hand. Problems she identified included: lack of accessible toilets and bathing facilities, inadequate space to manoeuvre wheelchairs, and lack of accessible equipment such as variable height cots. She also noted that improving such services for disabled women often also benefits all women in the later stages of pregnancy.

Professionals

Maternity professionals and health professionals working with physically disabled parents/mothers-to-be were asked to describe the main issues they faced or to highlight good practice.

Health and maternity professionals were invited to contribute their experiences of working with physically disabled parents.

Time

One midwife noted:

“Due to lack of time it was difficult to spend more time with disabled mums teaching them normal mothering skills like feeding, holding.”

If the needs of disabled parents are to be met effectively, more time needs to be provided for their appointments. Catering well for disabled parents requires a flexible appointment system. Planning in advance can also help to minimise the amount of extra time required.

Assessing individual needs and wants

An antenatal teacher noted that physically disabled parents are often labelled as ‘high risk’ simply because of their disability. She went on to add:

“The implications for labour and birth should be examined in partnership between the disabled mother, their midwife or other health care professionals on an individual basis and without an assumption of high risk as the starting point.”

A midwife noted,

“Delivery options were minimised with analgesia choices.”

This indicates that physically disabled mothers are, in some cases, being prevented from taking a full part in the decision-making about their birth because of assumptions about risk and inadequate time and attention being paid to allow for additional needs.

It was also noted that:

“Disabled people are often expert in their own situation and its medical implications, and well aware of what they can and cannot do, physically, so often (as with other expectant parents) the main role of professionals is in building confidence and providing specific information on what to expect.”

Addressing the need

All expectant parents want to be able to make choices about how they bring their child into the world and care for them, but it seems that in many cases there are still many barriers preventing disabled people from doing this.

Through the feedback received from disabled parents and health professionals, this study shows that these barriers include negative attitudes from some health professionals, a lack of knowledge and information available for both parents and professionals, as well as poor communication between disabled parents and professionals. These factors, along with pressures of time and inaccessible environments, have led to inappropriate and inadequate care being given to physically disabled parents during pregnancy, childbirth and early parenthood.

Disability, Pregnancy & Parenthood International is seeking to address some of these issues through the development of two guides for physically disabled parents – one on pregnancy and birth and the other on early baby care. The aim of the guides is to provide information to parents, including where to go for further help, in order to empower them to make choices about their pregnancy, birth and caring for their new baby. While aimed at the parents themselves it is anticipated that these guides can be shared between the parents and professionals to help increase awareness and understanding amongst professionals of the needs of disabled parents.

These guides are being drafted with input from physically disabled parents as well as maternity and other health professionals. Contact DPPI if you would like to be involved in this project. The guides are scheduled to be published in October 2010.

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