

Optimum care for disabled women

This summer, as the Paralympics GB team soared to success with 147 medals in Rio, a report (Hall et al, 2016) was published which highlights that there is a long way to go in improving attitudes towards disability in the UK, including in maternity services.

Bournemouth University and human rights in childbirth charity Birthrights published the interim report of a study looking into the treatment of disabled women during pregnancy, childbirth and the postnatal period (Hall et al, 2016). The report analyses data from a survey of 37 women who identified as disabled, with disabilities including hearing impairments, visual impairments, physical/mobility-related impairments and long-term health conditions.

The key problems reported by disabled women regarding their maternity care were:

- Lack of continuity of carer
- Lack of knowledge of disability among maternity care providers
- Not being listened to
- Not feeling in control of their own care
- Having their choices reduced.

Some of these problems are common to many childbearing women; for example, the National Maternity Review (2016) highlighted the need for continuity of carer in maternity services across England. However, there are some disability-specific concerns that must be addressed if we are to ensure that disabled women receive optimum care during their pregnancy and childbirth experience.

A third (33%) of the women surveyed reported that their dignity was poorly or very poorly respected in the postnatal period, and more than half (56%) felt that maternity care providers did not have appropriate attitudes to disability. This is a complicated subject, because there is no consensus regarding what constitutes 'appropriate'. Some women said they felt ignored and should have received special treatment, while others appreciated that

they were not treated differently because of their disability. Some reported that they were given different treatment but they felt that this was a positive thing. The common theme among all respondents was that they wanted health professionals to listen to them and try to understand how their specific impairments affected them in pregnancy and birth. As one woman said (Hall et al, 2016: 24):

'I know my needs and limitations better than anyone else.'

The report's authors call for appropriate training and guidance for maternity care providers regarding disability, so that they can better understand how a woman's disability may affect her pregnancy, birth and parenting—and, therefore, how they can optimise her outcomes (Box 1).

Many of the women surveyed acknowledged that the maternity units in which they gave birth were understaffed, and that this was a contributory factor in negative experiences. But a lack of resources should not be an excuse for treating people without dignity. All midwives have a responsibility to provide the best possible

care for women, and there is evidence that care can be improved through even minor changes on an individual level. There are some positive comments about best practice in the report, including midwives advocating for the disabled women in their care and providing additional time to ensure their needs were met.

On a broader level, it is essential that maternity units consider the needs of disabled service users so that this group of women does not slip through the net when it comes to service improvement.

A follow-up qualitative study, to establish in-depth experiences of human rights and dignity in maternity care of a self-selecting group of women, is ongoing. Results will be available in January 2017.

BJM

Hall J, Collins B, Ireland J, Hundley V (2016) *Interim report: The Human Rights & Dignity Experience of Disabled Women during Pregnancy, Childbirth and Early Parenting*. Centre for Midwifery Maternal and Perinatal Health, Bournemouth University, Bournemouth
National Maternity Review (2016) *Better Births: Improving outcomes of maternity services in England. A Five Year Forward View for maternity care*. <http://tinyurl.com/NMR2016> (accessed 19 September 2016)

Box 1. Recommendations

Services should adapt to provide continuity of carer for all women, which is particularly important for disabled women

Maternity care providers should undertake additional education about the care of disabled women to ensure that women's rights are respected and dignity is promoted

Maternity care providers should seek to allow additional time, particularly at the beginning of the relationship with a disabled woman, to listen to her and discuss her specific needs, abilities, expectations and preferences

Appropriate training and guidance should be provided to maternity staff about issues relating to disability, such as breastfeeding for visually impaired women, or pain management in the context of a person who experiences ongoing pain owing to disability

Access auditing is required of maternity care environments to ensure that facilities are accessible and that, if possible, there is accommodation for a personal assistant to remain with a disabled woman

Maternity care providers should consider their communication with disabled women so that women feel listened to; alternate forms of communication should be provided for people with sensory impairments to ensure accessibility

From: Hall et al, 2016: 27

Madeleine Murphy
Editor, BJM