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"Choices and Support on the Maternity Journey: Voices from Women with Cerebral Palsy"

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Introduction

Growing numbers of disabled women, including those with cerebral palsy (CP) are experiencing pregnancy, labour, childbirth and motherhood.

However, disabled women are often considered incapable of fulfilling the maternal role and being a good parent. They are also significantly less likely to be offered choices around pregnancy, birth and infant care, when compared to non-disabled women.

Women with CP are more likely to experience a fall during their pregnancy and the effects of their impairment may worsen during childbirth. It is therefore important that maternity care clinicians have specialist knowledge of women's CP effects to meet their support needs.

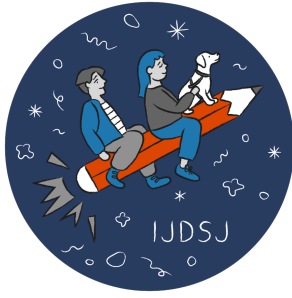
Methods

The lead author, Dr Sonali Shah who has CP herself, interviewed sixteen women, aged 27-43 who had experienced pregnancies in the UK between 2019-2024. Three women identified as having quadriplegia (4 limbs affected), six with diplegia (two limbs affected), seven with hemiplegia (one side of the body paralysed), and one with triplegia (three limbs affected). The interviewees were invited to talk about their experiences of accessing and utilising maternity care. They were also asked for their suggestions for healthcare professionals who are involved in treating disabled pregnant women, and suggestions for women with CP who were considering pregnancy.

Results

Women with CP have varied experiences of support during pregnancy and childbirth. Some women reported positive experiences where midwives and other healthcare professionals listened to their concerns and respected their preferences (for example, whether or not they wanted to have a caesarean). They described how healthcare professionals suggested adaptations and adjustments to help them during pregnancy, childbirth and early motherhood which helped to reduce their anxieties.

However, the women who were interviewed also described considerable challenges during pregnancy and childbirth. For example, one woman was asked whether she wanted to



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terminate her pregnancy because the doctor assumed that she would not be capable of caring for a child due to her disability. Women felt that they were not listened to when they expressed their concerns and that their expertise in their own bodies was disregarded. Their choices were not always respected, and women's preferences were often unmet. Some healthcare professionals appeared to have little or no knowledge and understanding of disability and CP. This undermined women's trust in the care they were receiving and also potentially their safety and sometimes led to feelings of anxiety.

Supportive family relationships, including partners playing an active role were helpful. Also, women were willing to speak up for themselves and displayed resilience. They described seeking advice and getting support from social media, e.g. Parents with Cerebral Palsy UK facebook group (<https://www.facebook.com/groups/308836423499478>). They also recommended equipment that would be helpful for women with CP during early motherhood which healthcare providers were unable to provide.

The women who were interviewed offered advice for healthcare professionals caring for disabled women during pregnancy and childbirth.

For healthcare professionals:

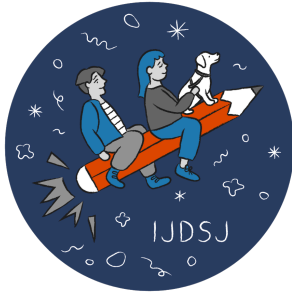
- Prepare information about pregnancy and childbirth for disabled women that is easy to read and to understand.
- All healthcare providers should listen to disabled women. They should acknowledge that women are experts in their own bodies and abilities. They should respect their choices in the pregnancy journey.
- GPs, midwives, physiotherapists and anyone else involved in a disabled woman's maternity care should share information so that the woman does not have to keep repeating her needs.

For disabled women considering pregnancy:

- Talk to healthcare professionals during your pregnancy and tell them about your condition.
- Be open and honest with your midwives if you are struggling, don't be afraid to ask for help.
- Don't listen to people who say you can't do it. Listen to your body and trust yourself.

Implications

It is two decades since the United Nations asserted that all disabled women have a right to the same access to maternity services as their non-disabled peers (UNCRPD, 2006). Our research is a reminder that disabled women continue to experience disadvantage during pregnancy and childbirth.



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The study highlights inequalities in maternity care for women with CP which can also be applicable to other disabilities.

Some of the experiences expose societal misconceptions about disabled women's abilities during pregnancy and motherhood.

There is a need for healthcare practitioners to be better informed about treating disabled women during pregnancy and childbirth. Above all, they need to listen to women because they are experts in their own bodies.

Finally, all women should have equal access to good maternity services, regardless of ability.

Author Bios

Dr Sonali Shah is Associate Professor in Disability and Life Course Research in the School of Medicine at the University of Nottingham. She leads and conducts NIHR research projects in relation to the healthcare of disabled across the life course, more recently adults with cerebral palsy. She is a qualitative researcher and is passionate about using digital methods to enable disabled people to participate in research; and develops knowledge exchange tools, using creative methods – film, animation, theatre - to share new research to non-academic audiences so it can be applied in policy and practice.

Karl Atkin is professor of sociology at the University of York. He has a particular interest in qualitative approaches, whose research focuses on health and social care in multicultural societies. This including understanding the social consequences of chronic illness and disability.

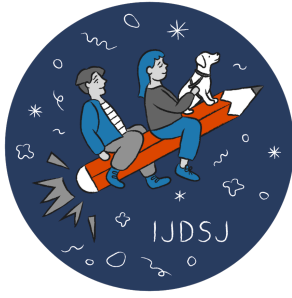
Helen Spiby is a professor of midwifery. Recent research relates to the provision of care to labouring women including its organisation; the roles of volunteer doulas in supporting disadvantaged childbearing women and further work in antenatal education.

Thomas Blackett is a PhD student at the University of Nottingham. His PhD is in microbiology, developing therapeutic bacteriophages active against *C. difficile*. He has contributed to analysis of the RICH project.

Diane Trusson is a sociology and health policy researcher with a PhD from the University of Nottingham, specializing in women's experiences post-breast cancer treatment. Her work on treatment side effects and healthcare professionals is recognized by the NIHR and featured on BBC Radio 4.

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Resources link

The evidence reported in the paper was collected for the research project Rights and Choices for women with Cerebral Palsy (RICH): A qualitative study to understand what works in the provision of their maternity care. It was used to develop an animation video and infographics for maternity care providers and disabled women, see link:

<https://www.nottingham.ac.uk/research/groups/healthofolderpeople/projects/rich-study/index.aspx>