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Choices and Support on the Maternity Journey in the UK

Voices from Women with Cerebral Palsy

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ABSTRACT

Introduction: The number of disabled women, including those with cerebral palsy (CP), experiencing pregnancy and motherhood globally is increasing. This could be attributed to equality legislation, medical advancements (including assistive reproductive technologies), and strong activism and support networks of disabled women raising awareness of their rights and choices. These women, however, continue to face disadvantages and discrimination.

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Methods: The research question explored the experiences of women with cerebral palsy in relation to pregnancy and motherhood in the UK. Semi-structured qualitative interviews with mothers with CP were analyzed thematically. Digital methods ensured the research process was accessible for participants.
Findings: Women with CP experience support but also considerable challenges during pregnancy and childbirth. Less than optimal care during the maternity care journey was evident. Women felt they were not listened to or else regarded as a risk to be managed. Choice was sometimes compromised. Practitioners' lack of knowledge and understanding of disability and CP undermined women's trust in care. It also compromised safety. Supportive family relationships, including an active role of partners, offered a helpful resource, as did the women's personal agency and resilience.
Conclusion: The issues faced by women with CP could be equally applicable to other types of impairments. 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. Findings emphasize the need for sensitive and responsive care throughout the maternity journey, including deciding when and how to have children. Findings also highlight a need for training and education among healthcare professionals.

KEYWORDS
women, cerebral palsy, pregnancy, support, childbirth, postnatal, fathers, maternity care

Introduction

The number of disabled women, including those with cerebral palsy (CP), experiencing pregnancy, labour/childbirth, and motherhood globally is common and rising (Blackford et al., 2000). While global inequities exist, research suggests disabled women are experiencing pregnancy at the same rate as their non-disabled contemporaries (Iezzoni et al., 2013; Horner-Johnson, 2016; Lipson and Rogers, 2000). In the UK, it is estimated that 9.4 per cent of women who give birth have an impairment.

For context, in the UK, maternity care is provided free at the point of service (Birthrights, n.d.) and funded through general taxation. The majority of childbearing women receive maternity services from the National Health Service. Maternity care is provided by a multidisciplinary team comprising midwives, obstetricians, paediatricians/neonatologists, and anaesthetists. Care during pregnancy is provided in both hospital and community settings, predominantly by midwives, with obstetric involvement in hospital antenatal clinics for women considered at higher medical or obstetric risk. Over 98 per cent women give birth in a hospital setting, which may include an obstetric unit or birth centre, with a small number of

free-standing birth centres available nationally (Care Quality Commission, 2024). For women who plan to give birth at home, care is provided by midwives. Postnatal care for women and their babies is provided by the community midwifery team through home visits or community-based postnatal clinics, generally during the first ten days to one month. Contemporary maternity policy includes attention to personalized care, including informed decision-making, continuity of care, and supporting women's perinatal mental health (NHS England, n.d.). The content of care is supported by a suite of evidence-based national clinical guidelines developed under the auspices of the National Institute for Health and Care Excellence (NICE), for women during antenatal and postnatal care (NICE, 2021a, 2021b). NICE suggests the views, beliefs, and values of all women, their partners and families should be sought and adhered to.

Internationally, several policies have been developed to facilitate supportive maternity care for all women, including disabled women. For instance, the Respectful Maternity Care Charter (WHO, 2018) was seen as significant to promote dignity and respect for all women experiencing pregnancy and childbirth. Articles 23 and 25 of the United Nations Convention on the Rights of Persons with Disabilities (United Nations, 2006) assert that all disabled women who have the capacity have a fundamental right to choose and decide on their fertility, reproduction and family life. Further, they have a right to access maternity services and resources on par with their non-disabled peers.

However, for many disabled women, including women with CP, who consider themselves to be experts of their own bodies and capable of making decisions about their lives, the ableist gaze creates a host of multi-level barriers, inequalities and inequities across their maternity journey, including pregnancy, childbirth and postnatal care, which can lead to restriction in choice. However, there remains a dearth of international research specifically focusing on the experiences of barriers and support for women with CP during pregnancy, childbirth, and postnatal care.

According to the World Health Organisation there are currently 18 million people with CP, making them the largest cohort of people with lifelong impairments, with a global prevalence of 1 to 4 per 1000 live births and an increasingly normative life expectancy. The World Report on Disability (World Health Organisation, 2011) estimates that there are 12.6 per cent disabled women in high-income countries. This growing number of disabled women in general, coupled with the stable prevalence of CP diagnosis, indicates that the population of women with CP is increasing. For example, there are currently three times more adults than children living with CP (Bell et al., 2023; Paneth et al., 2006).

However, women with CP, alongside other disabled women, are more vulnerable to both gender inequalities and ableism, which trigger inequalities in different aspects of life, including the maternity journey, from pregnancy to early motherhood (Fine and Asch, 1988; Oh et al., 2000). Despite the growing number of disabled women who desire the opportunity to have children, this can clash with the lack of appropriate specialists to facilitate their journey (Commodari et al., 2022).

This article is influenced by a social model of disability perspective, rather than the traditional medical interpretation typically taken in relation to maternity care. It explores the social barriers experienced by women with CP, which restrict their access and utilization of good-quality, equitable healthcare across their maternity pathway. Our analytical focus, for example, is on social and systemic barriers (physical, environmental, and attitudinal), as opposed to issues around personal coping and individual risk (Thomas and Curtis, 1997). This is aligned with ideas of embodiment, which represent an important aspect of pregnancy and childbirth. Previously, personal experiences of embodied impairment have not been included in social model analysis, having been criticized for directing attention away from the social and back to the individual (Oliver, 1996; Campbell and Oliver, 1996). Disabled feminist researchers have challenged this and argued that there needs to be an understanding of (i) how impaired female bodies are created – and acted upon – by society; and (ii) strategies women use to negotiate different social institutions which favour the non-disabled body (Morris, 1998; Thomas, 1997; Zitzelsberger et al., 2005). These researchers perceive personal narratives as a valuable lens to illuminate social barriers and identify potential avenues for social change. As Thomas (1999, 8) contends, "experiential narratives offer a route to understanding the socio-structural". Establishing the connections between individual biography and disabling barriers is therefore an important task. This paper is informed by both social model and disabled feminist perspectives, as it is important to consider how both social structures and individual embodiment impacts experience of maternity care for women with CP.

Background

Research suggests that disabled women are often considered incapable of fulfilling the maternal role and undertaking the responsibilities required to be a good parent (Hayward et al., 2017; Panuccio et al., 2020). Discourses which construct disabled women as asexual, non-normative or dysfunctional are further likely to shape how healthcare providers (HCPs) perceive and treat them, potentially hindering their access to good-quality maternity care from pregnancy to the postnatal period, in addition to outcomes and care received (Finger, 1992; Waxman, 1993; Blair et al., 2022; Shakespeare et al., 1996). The prioritizing of the non-disabled body, which is regarded as the norm, introduces an undercurrent of ablism in society, especially in relation to motherhood. Consequently, disabled women are less likely to be positioned as nurturing experts of mothering. Instead, they become seen as "other" and their non-normative body associated with asexuality, risk and dependency (Malacrida, 2009; Daniels, 2019). This abelist gaze serves to complicate disabled women's pathway to motherhood by restricting their access to maternity care provision. It also impacts their confidence when performing mothering tasks and instilling a fear to ask for support (Daniels, 2019).

Women with lived experience of lifelong physical impairments are experts of their own bodies and capable of making decisions about their lives. They are,

however, often denied their right to exercise choice due to structural barriers at macro and meso levels. A quantitative study of disabled women's use of maternity care in 2015 in England (Malouf et al., 2017) reported that they were significantly less likely to be offered choices in relation to antenatal and postnatal checks, birth plan, birth, and infant care, when compared to non-disabled women. This was also evidenced in a large UK maternity survey, conducted by Birthrights (2013), which compared the care of respondents who self-identified as disabled to non-disabled women, particularly in relation to choice and control over information and pain relief. Other studies highlighted that disabled women's experiences of pregnancy, childbirth and motherhood were interlaced with social barriers within healthcare structures and relationships with others, including being perceived as a risk or a potentially unfit mother, who required safeguarding (Thomas, 1997). Disabled women felt health practitioners (obstetricians, gynaecologists, midwives) had limited knowledge and understanding about their impairment, thus doubted their competence to meet their needs with dignity, which is important for a person-centred approach to pregnancy (Walsh-Gallagher, 2013). A case report of a woman with CP, written by a doctor in a high-risk obstetric clinic, suggests that misconceptions about disability and pregnancy can be overturned with patience and willingness to listen and learn from the disabled person (Tejani, 2004).

There is limited international literature specifically focusing on the experiences of pregnancy and childbirth of women with CP. That which exists further confirms these ableist tendencies in care. Hayward et al. (2017), who conducted one of the few studies on this, highlight that women and girls with CP are perceived as asexual and not capable of being a parent, thus influencing the quality of information and care they receive for optimal reproductive health across the life course. The researchers suggest that HCPs should have a knowledge of the CP impairment effects (including medication use, medical history, and co-morbidities) so they can ascertain in advance what accommodations, specialists and referrals women may require, to best facilitate successful outcomes. Other research suggests improvements in maternity care could be facilitated by training hospital staff to use adaptive strategies and specialized equipment when necessary for dignified, safe and successful outcomes during disabled women's journeys from pregnancy to early motherhood (Krishbaum, 1988) and modifying existing training modules to include questions about disability in general and CP in particular (Hayward et al., 2017).

More recent literature suggests that while the cerebral palsy impairment itself does not necessarily affect a woman's pregnancy or ability to give birth, there is some evidence that embodied impairment effects, such as involuntary muscle contraction, may worsen during childbirth, particularly where there is pain or psychological distress or pelvic abnormalities (Deeksha et al., 2023; Sundelin et al., 2020). Studies have reported that HCPs believe this could make a vaginal birth difficult and unsafe, and therefore, likely to recommend a caesarean section as the best plan for childbirth. A Swedish population-based study of 770 births found that mothers with CP experience a higher risk of preterm birth and caesarean delivery compared to women in a control group (Sundelin et al., 2020). They suggest reasons for the

former include a higher risk of pregnancy complications, while the latter was considered to be connected with women's pelvic abnormalities, chronic pain and spasticity during childbirth. These findings prompted Sundelin et al. (2020) to conclude that women with CP deserve more healthcare surveillance and support during the antenatal period.

However, many disabled women have experienced successful pregnancies and parenthood (Hayward et al., 2017). Positive support from their families and partners, coupled with personal self-efficacy, can facilitate successful maternity journeys, from pregnancy to performing the mothering role (Commodari et al., 2022). Self-efficacy has been considered as a protective factor which enables women to perform the required actions to meet specific goals and exercise influence over their lives (Bandura and Wessells, 1997). Other studies, exploring the challenges and successes across the lives of adults with different physical impairments, have found that those with high self-efficacy and personal agency were not deterred by aversive experiences, but demonstrated a resilience and resistance to challenges which helped them complete their goals successfully (Shah, 2005; Shah and Priestley, 2011). Further research points out that adults with lifelong impairments (such as CP) have resilience to "get on with it" and are experts in negotiating ableism, discrimination, and stigma across different parts of their life course (Shah et al., 2024; Connell and Sanford, 2001). Such learnt behaviour can have benefits for women with CP negotiating the journey from pregnancy to motherhood and the obstacles encountered by formal maternity care services.

People also live relational and interdependent lives, where families and partners are seen as important networks of support to negotiate particular life pathways and overcome challenges together (Elder, 1994). Much research has suggested that family support is viewed as vital during pregnancy for many women, and the absence of such support can have distressing outcomes for the woman and unborn baby (Mitra et al., 2015). This may be more likely for women with impairments who are often faced with multi-level barriers in relation to being disabled and pregnant. Often it is the family whose extensive insights about the women's practical, physical, and emotional needs enable them to be the women's trusted supporter and advocate (Traustadóttir and Sigurjónsdóttir, 2008). Other literature, however, has reported that family support is not guaranteed (Powell et al., 2017). For instance, women might experience negative attitudes and reactions from family, related to misconceptions about their ability to perform the mothering role.

To our knowledge, this is the first UK ethnographic study to explore the experiences of pregnancy, childbirth, and postnatal care for women with CP. This article will address a gap in current literature in both women's reproductive health and sociology of disability, illustrating the importance of maternity care in the lives of women with CP and reporting on their experiences of enabling and challenging support at different stages of the maternity journey, especially pregnancy and childbirth. The evidence reported gives particular attention to the support they experience from HCPs and their families and partners, but also to the women's personal agency and sense of resilience on their journey. Bringing the firsthand

accounts of women with CP into the public domain is important to the development of practices in maternity care and to promote an awareness and sense of empowerment for future generations of women with CP who may be considering motherhood. Consequently, it is important to adhere to the philosophy of Disabled People's Movement "Nothing About Us Without Us" (Charlton, 1998).

Methods

Research Design

This article reports on selected findings from the study: "RIghts and CHoices for women with cerebral palsy: Understanding what works in the provision of their maternity care" (aka the RICH study). RICH is (to our knowledge) the first UK study to explore the maternity healthcare experiences of women with CP, and the challenges and support available for them during the maternity journey. The study was funded by the National Institute of Health Research, Research for Patient Benefit (NIHR RfPB) between July 2022 and November 2024. The main research questions addressed by this paper include: (i) How do women with CP experience pregnancy, childbirth, postnatal care, and early motherhood? (ii) What are the factors that support this? (iii) What are the factors that make this challenging? The article reports on the findings of interviews with women with CP to generate new knowledge of the various supportive and challenging experiences over the course of their maternity care journey.

Recruitment

We used purposive sampling techniques to ensure that only individuals who met the inclusion criteria were selected for the interviews (Patton, 2002). We used the following inclusion criteria: identify as a woman with cerebral palsy; geographically based across the UK; experienced pregnancy between 2019 and 2024 (including loss); with the capacity to participate and consent. Maximum variation sampling techniques were used to capture a range of perspectives to enable an in-depth understanding of the phenomena under investigation (experiences of the maternity journey for women with CP) and explore differences and commonalities for women with different types of CP who experienced pregnancy and childbirth using different methods (i.e., vaginal, caesarean) and live in different parts of the UK.

Interview participants were recruited through various channels. Participant and study information was disseminated to different service providers and digital support and information platforms for adults with CP and individuals with CP. The project collaborator, Scope (the UK disability charity with a special interest in CP), and the project advisory group (of adult professionals with CP) were instrumental to recruitment. Scope UK shared the RICH recruitment information on the Scope Online Community, and one PPI member shared it on the UK Facebook support group she coordinates, CPAdultUK and Parents with Cerebral Palsy, both of which proved useful for recruiting the target sample. The first author (who is the project lead and the interviewer) is a woman with CP. Her impairment status gave her per-

mission to access closed Facebook groups for adults with CP so she could share the recruitment resources with them, as well as share them with UK-based members of an international support and discussion Facebook group (Women Ageing with CP), which she moderates. Snowballing techniques were also utilized, whereby existing participants shared information about the study with their own networks.

Recruitment was voluntary, so individuals interested in participating in the study contacted the research team themselves. They were then sent a recruitment questionnaire (electronically) to establish whether they met the inclusion criteria, describe their CP impairment type and the effects of their impairment (e.g., mobility, speech, coordination) and to ascertain their preferred method of interview. Individuals who met the inclusion criteria were given more detailed information about the study and a consent form. Once the research team had received completed recruitment questionnaires and signed consent forms, appointments were arranged to interview each participant.

We integrated a number of strategies to augment the rigorous conduct of the study. As discussed, the primary researcher [SS] undertook all the interviews, but to ensure that the analysis and interpretations were grounded in the data, the transcripts and emerging interpretations were shared with the team, with additional analysis from a maternity perspective. The study design and conduct are informed by the project advisory group, who are experts by experience and provided an external scrutiny that was invaluable in checking out and verifying the findings of the study. Crucially, this increases the chances that the findings and recommendations are relevant to practice.

Ethical Approval

Ethical approval was granted by the University of Nottingham Faculty of Medicine Ethics Committee and the Nottingham University Hospitals Trust. All participants gave both written and verbal consent. The interview participants were not inpatients but volunteers telling their stories retrospectively and therefore were not subject to the same stringent ethical criteria as hospital patients. Nevertheless, the Trust considered the women as vulnerable as they identified as disabled, and therefore the team needed to resubmit the ethics paperwork several times with detailed explanations of the safeguards that would ensure that participants were not put in vulnerable positions while being involved in the study. This inevitably delayed the original timeline for the project deliverables.

Data Collection

Sixteen women volunteered to be interviewed for the RICH research study. Fieldwork took place between April and September 2024. The original target for interview participants was 25. However, despite three waves of recruitment, through the channels mentioned above, it was difficult to recruit more participants without widening the inclusion criteria, which required additional ethical approval by the University of Nottingham and Nottingham University Hospital Trust. Nevertheless, the re-

search team considered that saturation had been achieved with 16 interviews, as each interview contained substantial high-quality data, which included a range of different experiences.

An interview schedule was designed to generate information about the experiences of different stages of the maternity journey. The topic guide focused on the support and challenges experienced when considering having a child, during pregnancy, during childbirth, during the postnatal period, and during early motherhood. It also included the experiences of pregnancy loss; the changing embodied effects of CP for women during and after pregnancy and childbirth; access and utilization of maternity healthcare, including good and poor practice; and suggestions for improvement in service delivery. Interviews were conducted via Zoom, Facebook Messenger, or email. These different interview methods enabled the women to participate in research interviews without necessarily relying on others for physical or communication support. These also addressed constraints of time and geography, which would have hindered participation for some participants and put undue burden on the disabled researcher (Shah et al., 2022). It also reduced some of the inherent biases in recruiting participants with speech impairments or no verbal communication, known to compromise eligibility in communication (Parkes et al., 2012). Authors such as Rios et al. (2016) and Ison (2009) argue that the adoption of overly rigid recruitment and data collection instruments can exclude some disabled people from becoming active research participants. They suggest that time and resource constraints, and limitations in researcher knowledge and flexibility, often deter researchers from involving disabled people, including those with associated speech impairments, in health and social care research.

Analysis

In analyzing our material, we used data familiarization and open coding before generating themes. We compared these themes across the entire set of interviews to highlight potential similarities and differences (Riessman, 2007), before discursively reflecting on how these themes shaped our participants' interpretative meaning (Gubrium and Holstein, 2009). Consistent with "reflexive thematic analysis" (Braun and Clarke, 2022) that foregrounds a "meaning-based interpretive story", the analysis focused on how responses generated experiences and perceptions of maternity care and relationships. It uses their narratives to contextualize these experiences. Consequently, we reflected on how our themes shaped interpretative meaning by locating lived experience within normative expressions of maternity care. Our analysis uses a woman's life story to understand the extent to which ableism mediates their experience when accessing maternity care. This enables us to relate personalized embodied stories to the social context in which they occur. Integrating this social context enables our analysis to identify the possibilities of good practice, consistent with women's experience. The women chose their own pseudonyms, which will be used instead of their real names to preserve anonymity.

Results

The final sample of 16 women were aged between 27 and 43; most participants were in their 30s. They lived in different cities across the UK and gave birth in their local hospital. In terms of the different types of CP: three self-identified as having quadriplegia (four limbs affected), six as having diplegia (two limbs affected), seven as having hemiplegia (one side of the body paralyzed), and one described having triplegia (three limbs affected). Out of the 16 women who experienced pregnancies between 2019 and 2024, 11 had vaginal births, and five had a caesarean; one woman had both. In terms of other diversity, one of the women in the sample was Polish, but had moved to Scotland where she met her husband and gave birth to her daughter. Other women identified as White British, and this limits our attempts to offer a more intersectional analysis. All women identified as heterosexual women from birth. Data was not collected on social class. However, over three-quarters of the women were in paid employment.

Focusing on the operation of ableism, the analysis begins with exploring women's reflection of the support they received and the challenges they faced in having their "disabled" voice heard. Good practice is also explored as a counter to these challenges. The second theme explores the more informal support received by women (i.e., from family and partners) and the extent to which this provides a resource able to facilitate their personal agency, as they negotiate a resilience and determination to have their choices heard and met. Our final theme explores women's reflections on what changes are required from healthcare providers to deprioritize the normative power of ableist bodies. It includes the advice they would give to the next generation of mothers.

Theme 1: Support and Challenges of Formal Healthcare Provision

Women reflected on the support they experienced during their encounters with healthcare practitioners. We begin by exploring women's positive experiences, as this demonstrates that maternity care is able accommodate the disabled body. Positive experiences, however, remain the exception rather than the rule, and women continually negotiated abelist barriers and assumptions, which undermined their opportunity to exercise choice. Analysis of these barriers, however, helps identify the types of support valued by women, particularly as they connect to women's accounts of good practice. Active listening, understanding impairment effects, and providing continuity of care are priorities for women with CP, and if implemented would help challenge the ableist assumptions implicit in their current experience of care.

Hannah recalled the support she received from her physiotherapist during her pregnancy. Out of all the practitioners Hannah engaged with across the course of her maternity journey, she felt that it was only her physio who had an understanding of the effects of her impairment and how it may impact her pregnancy:

> *I self-referred myself to physio at about eight weeks. And she was a really, really positive person in my pregnancy experience. If I had any aches or pains or anything like that, she was thinking about it from*

> *a "this person is hemiplegic and pregnant", and "it's probably her being hemiplegic that's causing these issues". She was the only one; everybody else, you could see they just didn't understand how to deal with it, and to be honest didn't want to deal with it* (Hannah,36, hemiplegia).

Other women also reported several positive experiences during their pregnancies. This demonstrates the potential of care to be responsive. Ursula had five pregnancies; four resulted in live births. Here she refers to her fourth pregnancy, where she was happy with the care:

> *I was met with lots of positivity for my choices and was really well looked after. They were worried how my body would cope. So, I had lots of extra care* (Ursula, 32, hemiplegia).

Jenny, who was over 40 when she had her first child, was nervous about being older as well as having hemiplegia. However, she did feel that, on the whole, formal care in hospital was positive. She especially recalls the care she received from the anaesthetist:

> *[…] most of the support I received when I was pregnant was quite positive […] I was supported when I said I would like to have a caesarean. I spoke to an anaesthetist to see if there was any special treatment that I needed, if I'd be able to have the same anaesthetic [during childbirth]*

Rachel, who was 34 and was not really planning to have a child, became pregnant when she discontinued contraception. As well as having hemiplegia, she also has a diagnosis of anxiety, so she was nervous about how both would impact her first pregnancy and vice versa. However, like Jenny, she recalled positive examples of the care she received while in hospital, especially in terms of being listened to regarding her concerns and choices, and making reasonable adjustments where and when required:

> *I absolutely cannot fault my care in pregnancy […] The care I received from midwives and the consultant was so thorough. We discussed all possibilities. How labour might go? Would I be strong enough to give birth naturally? What did I want/not want? I knew I didn't want a caesarean section. The doctor really knows her stuff and did all she could to help me feel at ease. Offering me extra scans to help ease my anxiety […] I was given extra midwifery appointments. I saw the parent education midwives and they helped me to prepare for the early weeks post birth as we knew I'd perhaps struggle with changing nappies and dressing baby. I also saw an occupational therapist to look at challenges in my house and baby carrying and wearing. I also saw a physio as I struggled with pain in late pregnancy, but amazingly was still walking albeit slowly the week before I gave birth* (Rachel, 34, hemiplegia).

Ashika, also a first-time mother with hemiplegia aged 34, remembered the good hospital care she experienced during her pregnancy:

> *They were really, really good in fairness. The only reference they made to the CP was that they said from the off they'll put me down as consultant-led just to err on the side of caution, so like you may not even need any extra assistance, but we'd rather you be under the consultant just in case.*

The participants felt especially reassured when healthcare professionals demonstrated an understanding of CP and impairment effects in adulthood, as Sheila's experience demonstrates:

> *[The consultant] did seem to understand what cerebral palsy was, and had thoroughly read things on my file already to have an understanding of how my cerebral palsy affects me […] The only thing the consultant was talking to me about was potential delivery options in terms of whether to have a caesarean or a natural birth. The consultant was just wondering how much my hips would move in order to allow a natural birth, which I guess is fair enough. So, the fact that they gave that explanation put me more at ease.*

Nehir was 30 when she gave birth to her daughter. She did have a fear of childbirth stemming from her own birth story: the foetal maternal transfusion that caused her cerebral palsy. She was given space to express her fears to the maternity care team, who listened, adapted procedures and kept her carefully monitored:

> *The care I received was fantastic, every single time I thought there was something not quite right, they'd take me seriously, and I'd be brought in for testing, and be put on the monitors and stuff […] The lactation consultant I had was fantastic, and the first thing she told me was "I told a woman with cerebral palsy how to tandem feed twins". And I was like, okay, I'm in good hands, you can definitely teach me* (Nehir, 30, hemiplegia).

She remembers how her request for her partner to be allowed in the labour suite during the birth of their baby was considered a reasonable adjustment and put in place to accommodate her support needs.

Other women also expressed satisfaction at how HCPs really listened to what they needed and wanted. Julie, who has quadriplegic CP (affecting her mobility, coordination, and [slightly] her speech), had her first baby in 2023. Her narrative indicates a continuity of care, where she saw the same midwife once a month during her pregnancy, who listened to concerns and choices and tried to accommodate these:

> *I had a great midwife who listened to what I needed, not – like what I wanted, and was really good. And she listened, if I told her I couldn't do something, she would work out how to do it in a different way […] unfortunately she didn't make the birth of my daughter, so I didn't have her at the end, but she was really good* (Julie, 27, quadriplegia).

Julie was pleased that her request for her partner to stay with her after the birth was accommodated:

> *I felt very scared, but I felt reassured. Cos they obviously knew what they were doing, and, yeah, I felt quite safe, and my partner was with me* (Julie, 27, quadriplegia).

Similarly, Heidi, also quadriplegic, reported that during her second delivery, she felt listened to and valued:

> *On the day I was going to have my daughter, a female anaesthetist came in to see me and enquired what disabilities I had and my concerns with regard to moving while they injected my spine. She listened, and we agreed that it would be better to have a general anaesthetic* (Heidi, 42, quadriplegia).

As a first-time mother-to-be with CP, Claire felt she needed support around her decision to have a caesarean. Her journey through pregnancy was difficult. Although she felt several healthcare practitioners she met on the way had little or no understanding about cerebral palsy and the possible impact a vaginal birth could have on her body, she did recall one midwife who was supportive and understanding. The midwife gave Claire time and space to discuss her worries in a way she had not been able to with other healthcare practitioners:

> *[…] when I arrived at the clinic, I met with a really, really lovely midwife who just chatted through all this stuff, and she was so lovely. And one of the things that I'd been thinking about for a while, is I'd read that women with CP […] it'd just been suggested that sometimes C-sections could be the better option […] and I'd had it in my head, right I wanna have a C-section, cos although I'd love a natural birth, I knew that it would be quite stressful on my body for many reasons. So, I talked about that with the midwife, and she'd said something like, "yeah, I think C-section'd be good for you", you know, really understanding, really lovely […]* (Claire, 34, quadriplegia).

Hannah, who had her first child in 2024, really wanted a vaginal birth. She recalls how, although her choices and concerns were not accommodated by one consultant, she later visited a consultant who really listened to what she wanted:

> *[The consultant] said, "because we don't know how your hips are aligned and how the strength is in your pelvic region, you can't have a vaginal birth; it would be unsafe for you and baby". So, I was like, okay then, fine, that makes sense. That's what you think. That makes sense […] But then when I went back for my 20-week scan, I talked to a different consultant for my C-section, and he said, "oh is that what you want?" And I said, "well I've been told that's what I have to have for the safety of my baby". And he said, who's told you that? And I said, the consultant who I've seen before. And he went, "you can have a vaginal birth if you wish". And I went, oh. And then he went back in his notes, and had a look, then went away for a bit, for a good 10 minutes. Comes back, and he actually said, which I've never had in my life, he said, "I formally apologize on behalf of the NHS, you've been given the wrong information"* (Hannah, 36, hemiplegia).

Continuity of care was also variable for mothers and their babies. Some women were fortunate enough to have the same midwife or maternity health practitioners throughout their maternity journey, but others were not. Sally, for example, spoke very fondly of a midwife who provided good care to her and her baby from the start to the end:

> *I think the most positive thing, other than having my beautiful baby girl, was the midwife that I had in the end, the one that I had all the way through, she was amazing, I mean, everyone said to me, don't you find it weird that she's so young and you're an older mum, and I said no because she knows what she's talking about. And she was brilliant all the way through and even after […] when baby was newborn she wasn't feeding very well […] she wasn't putting on weight, so midwife would come more often and […] she was really helpful through that […]* (Sally, 41, quadriplegia).

Women, however, recalled social barriers which led to sub-optimal care. Some recalled not being listened to by practitioners. Many mentioned that no reasonable accommodations were being made for them. A lack of continuity in the care caused problems too, as women had to repeat what they had previously explained to other practitioners. They found this exhausting, but perhaps more importantly, it generated a lack of trust in the care they received. Such challenges also made some women feel unsafe, especially as they felt practitioners did not listen to them and demonstrated little knowledge of disability and the interplay between their CP effects and pregnancy and childbirth:

> *[…] in terms of continuity of care, I would say there's not really continuity of care that you're technically under the same people and the same midwife team, but because of rotas and things like that you would often end up seeing different people. So, I wouldn't say I saw the same people very often. So, I'd often have to explain what I needed, like for example with scans each time* (Brooke, 36, triplegia).

Concerns about the variability of care added to the women's anxieties and contributed to the sense of precarity. This precarity was also influenced by women not being listened to by healthcare professionals and the limited knowledge and understanding they seemed to have of CP. Ursula, a mother of four, had five pregnancies. She recalls feeling unsafe during three of her childbirths because she felt she was not being listened to and supported appropriately. She recalls that the variability in care contributed to this during her fifth pregnancy in 2024:

> *I would definitely say the first one [labour] I wasn't listened to. I don't know if that was CP-related or just the fact first-time mums don't normally labour fast like I did. In all the others, I was listened to apart from number 4 […] Also, the care the fifth time round wasn't great. I had a different consultant each week who clearly didn't understand me or my baby* (Ursula, 32, hemiplegia).

Heidi, a mother of two, recalled how healthcare practitioners persuaded her to have an epidural during the birth of both of her children, but failed to listen to her concerns about the effects it would have on her impairment. Their lack of understanding and knowledge about CP worried her and added to the anxiety she was already feeling about it all:

> *With my first child the professionals only gave me a choice of having an epidural, so I did. I said that due to my CP I jump whenever my back is touched; they said don't worry. I had to have about five nurses/doctors trying to hold me still while they injected in my spine. I still moved due to my CP […] For my most recent pregnancy, I saw a male anaesthetist two days before I was due to go in hospital. He said that I would recover quicker if I had another epidural and didn't really hear my concerns about my body moving, even with people holding me still. I reluctantly agreed, as he was saying I'd be okay. I didn't feel like he listened to my concerns, so I was worried* (Heidi, 42, quadriplegia).

Other women were also worried about the lack of knowledge healthcare professionals seem to have about disability in general and CP in particular. This made

them anxious and fearful about being misunderstood. In some cases, women were subjected to the ableist gaze where practitioners disapproved of them becoming pregnant, and considered them to be a risk and unfit for motherhood. Such a context made some women reluctant to articulate their needs and ask for support. For instance, Ursula recalls that, although she needed and was offered support for her mental health needs, after her five pregnancies, she was afraid of being honest about her health issues:

> *I was always offered mental health support with each baby because I do have a history with my mental health but I feel I was scared to actually say how I actually felt because I was scared they would take my baby away from me if they knew I was struggling both mentally and physically* (Ursula, 32, hemiplegia).

Contrary to Ursula, Hannah did ask for her partner or parents to be able to stay with her in the postnatal ward after her first baby was born. They knew her needs and could provide the extra support for her instead of the overnight postnatal care team. Her request should have been accommodated as a reasonable adjustment, but was denied. Subsequently, Hannah had to stay alone in hospital with her newborn baby, and with limited support from the overnight maternity care team:

> *[…] my son's howling away cos he's that hungry. No one ever came, I kept ringing and ringing and ringing. And in the end a midwife assistant came, and I said where's the midwife. And she went, oh she's dealing with somebody. And I said, get me some milk and get it now. I was broken, I was absolutely broken, I was in floods of tears. They had left me for nearly two hours, and nobody came to help* (Hannah, 36, hemiplegia).

Hannah's experiences highlight how her extra support needs were considered as an unnecessary burden and a personal problem as opposed to a social concern. They also highlight how denying a disabled woman reasonable accommodations can have a negative impact on their physical and mental well-being. However, it suggests that, to the midwives (looking through their medical/individual model lens), Hannah's situation highlighted her difficulties in performing normative motherhood roles. This was illustrated by the following reflection:

> *She [midwife] sat at the end of my bed, and said to me, I'll never forget these words, "Hannah, have you thought about how you're going to take care of your baby? Have you thought about how you're going to live with your baby?" […]* (Hannah, 36, hemiplegia).

Sapphire recalls that, like Hannah, she was not allowed a companion to support her overnight in the postnatal unit despite outlining her support needs. This caused her care to be variable and compromised, and left her feeling unsafe:

> *If my partner wasn't there, I would say I was very rarely visited in my room, and when I did ask for help it felt very – like they didn't want to be there. So, I asked for feeding help twice, and then I asked for help to go to the toilet once because I was still wobbly. And it was just – there was one nice one, but it varied from shift to shift […] I felt unsafe* (Sapphire, 32, diplegia).

The women felt a lack of insight, understanding and knowledge of disability and impairment contributed to HCPs' continued focus on risk, which further undermined their experience of care. Women felt like a burden, who continually had to justify their pregnancy.

> *Well, it was quite interesting because I spoke to my midwife about it, and then we had to go to hospital to discuss it with a doctor whose first question was "when did you catch your cerebral palsy?" […] He didn't know that you can have it from birth! My partner was listening to this and just thought, that's a bit weird. And then he sent me to a neurological specialist who literally looked at me and said why have they sent you here, because you can do exactly what you've said you can do. But they sent me there to tick boxes, literally for their safety* (Julie, 27, quadriplegia).

Claire reflected on how her consultant had zero knowledge of her CP and the accommodations she would need for a safe childbirth. They failed to listen to Claire and consider the view of the expert by experience:

> *[…] we did have a meeting with a consultant, it was very weird because there was a student nurse there and this consultant. And when we walked in, she said, so, do you know why you're here? And I was just like, well, I'm pregnant, and I have CP and, and you know, obviously I just want to talk about that. And the meeting was literally the most awkward thing. Like it was, it was really upsetting, because it didn't feel like she was listening to what I was saying. So, I opened up by saying all the reasons that I wanted to have a C-section, and they were things like I get fatigued very easily, because we [women with CP] use four times more energy to do things, so I was saying I'm worried I will get exhausted. My pelvic floor isn't very strong, so I was worried that I'd be more susceptible to tears. You know, if I had an epidural and I was numb from the waist down, and then people were moving me around, it could be that I get stretched in a weird way during pregnancy and damage something or tear something […] Summarizing, she said something like, I don't have any experience of CP. She did say that. She said I have no experience, but then she said but I think you'll be fine. And I was like, well great. I do have experience of CP, and I don't think I'll be fine* (Claire, 32, quadriplegia).

When women felt they were not being listened to, they had little confidence that their choices or support needs would be considered and taken seriously. Sally explained:

> *I think I was about 35 weeks […] I wanted an epidural birth, so they said you need to go and see an anaesthetist to see whether it's possible and all this. So, I went and – this is a strange one because for me, I found it hard, but my husband, he thought it was a good thing. And so we went to see the anaesthetist, they checked me over, they said yep that's not a problem, can I suggest, from a medical point of view, we would really recommend that you have a planned caesarean. And I said, well, I really don't want that, that's not what I've ever wanted, I've always wanted an epidural birth. And she was like, I'm really worried that if you start labour in the middle of the night, and you get brought in, there might not be an anaesthetist on standby to assist you. So, this really upset me* (Sally, 41, quadriplegia).

Sheila, like several of the disabled women, felt HCPs regarded her as the problem because she was put under continuous surveillance, more than would be the

case for non-disabled mothers. She felt surprised at being seen as a risk just because of her impairment, and realized that they did not actually have prior knowledge of CP, and unfortunately did not really listen to her:

> *[…] I sort of made a joke that it was a long read (my notes), and she said, oh actually, I think you're gonna need loads of appointments. I said oh, why? I said, is it cos of my weight? I didn't really think about my cerebral palsy affecting my pregnancy, but I knew that if you had a higher BMI then that can have implications as well. And she said, oh no, because of your cerebral palsy. I said, okay, but why would I need more appointments? And she said, oh, you know I think you'd need more supervision and keeping an eye on you, etc. I was a little bit put out cos I kind of felt like a bit of a problem like first off. And she said that she thought that I might need some extra scans because she wondered how the baby would grow because of my cerebral palsy. And I was just a bit confused by that really, but I got the impression that she didn't really understand what cerebral palsy was and how it affects me […] But I think in terms of the midwife, I think if you don't have full understanding of what you're talking about and how cerebral palsy affects somebody, maybe it's best not to comment. Because I think she scared me a little bit, and I think it was unnecessary […]* (Sheila, 30, triplegia)

Theme 2: *Family Support and Personal Agency*

Family support and personal agency are important aspects of the maternity journey, irrespective of disability. Attempts to realize this provide further insights into the impact of ableist assumptions on their maternity journey, in addition to identifying important sources of support and resilience. Understanding the dynamic this creates provides further insights into how care, consistent with women's choices, can be facilitated. Many of the women in the sample recalled how their parents (especially their mother) and their husbands were highly supportive during the whole maternity journey. They supported the women to negotiate the challenges they experienced with the formal care. Heidi said:

> *We were supported on our choice to have a child by my mum* (Heidi, 42, quadriplegia).

Ursula related a similar experience, although, like several other mothers, families did have concerns:

> *This was met with positivity from my family. They were anxious about how my body would cope with the actual pregnancy, but they never doubted my abilities as a mother* (Ursula, 32, hemiplegia).

Hannah explained how her mother was a valued source of practical support during the birth of her son, helping to keep her and the baby safe by double-checking that the midwife was carefully undertaking the correct precautionary procedures. and not making assumptions based on her perceptions around disability:

> *That midwife, she just didn't help […] The only reason she realized my son's heart rate had dropped is because my mum went, "is this pain because of Hannah's arm, or are these contractions?" She went, "oh they're contractions". And then my mum went, "well how far dilated is she?" She went, "she's three". And my mum went, "but she was three when she came in". And then she looked under and that's when*

> *she apparently banged the buzzer. So, again, she [midwife] wasn't even really paying attention. But again, she just thought my pain was a bit of "hemi arm" and "oh well these are just normal contractions, and because she's so weak on her left side she just can't hack it"* (Hannah, 36, hemiplegia).

However, family support was not guaranteed. Andrea was brought up in Poland. She never expected to be a mother, socialized by her own mother and grandmother to believe, from an early age, that she would not follow the life course expected of non-disabled women:

> *I never thought I would be a mum […] I was brought up by my mum or my grandma they were saying that you need to be good and study, and you're going to be a nun because nobody would marry you* (Andrea, 34, hemiplegia).

Nonetheless, Andrea defied family and societal expectations when she moved to the UK in her 20s to study, met a partner, married and had a child. Seeing that her disabled daughter could indeed follow what is seen as a normative life course for Western women triggered an attitudinal change from her Polish family.

Jenny also highlighted how her mother focused on the risk of her having a baby as a disabled mother, and her ability to perform the nurturing responsibilities viewed as typical of the motherhood role. Instead of being happy and excited about Jenny being pregnant, her mother was actually upset and afraid, therefore possibly not quite as supportive of Jenny as would have been expected:

> *Most of the negative problems I've had connected to my condition have been when I've been younger […] I think my mother was quite concerned, think she thought that it would be difficult for me, and that I wouldn't be able to carry the baby, and it'd be too much work […] and me being older as well, I think initially her reaction wasn't very positive, she was quite – out of concern for me she was quite upset when she found out I was pregnant* (Jenny, 43, hemiplegia).

Conversely, Hannah reflects how, when she was growing up, she was socialized to believe she could pursue a normative adult life for a Western woman:

> *My parents are like oh yeah, you'll have a baby one day, and you'll have a husband and a house and a job and things like that. It was just normal life* (Hannah, 36, hemiplegia).

The analysis revealed that husbands played a critical role in supporting their disabled wives during the maternity journey. This included making decisions about appropriate healthcare with their wives, locating or actually building adaptive equipment so the women could attend to the baby safely, and sometimes playing an advocacy role while negotiating ablism within formal healthcare settings. For example, as highlighted above, Hannah was denied extra support the night after childbirth and was subsequently interrogated about her physical ability to look after their baby. The below quote illustrates how Hannah's husband stepped in and corrected the midwife's misconceptions:

> [Midwife] *said, "Have you thought about how you're going to take care of your baby? Have you thought about how you're going to live with your baby?" And I looked at her, and my husband looked*

> *at her, and he went, "[Hannah] works in childcare". And she changed her attitude* (Hannah, 36, hemiplegia).

Similarly, Claire's husband supported her decision to have a caesarean and ensured practitioners listened to their choices and concerns:

> *And like, in one way it was – like my husband said to me, you know, it's encouraging in a way because they all think you can handle labour. Yep. But if you want a C-section you, you know, we go for it. And he thought that was the best option as well. But I knew they didn't understand, because they're saying they have no experience of CP* (Claire, 34, quadriplegia).

Ashika explained how her partner acted as an advocate, which she found reassuring given her lack of trust in formal care:

> *[…] I'm very lucky I've got a very outspoken stern partner, so he was a really good advocate. If there was ever anything they weren't doing, he was like "hang on now, come on". So, he was very, very good, I think if it wasn't for him kind of giving a nudge sometimes when it was needed, then maybe it would've felt a lot more difficult than it was* (Ashika, 27, diplegia).

In some cases, the husbands/partners were the main carers for their wives, and they needed to stay with them in hospital after the birth of their baby. As pointed out above, this should have been considered as part of the reasonable adjustment policy adopted in all hospitals. However, the women's experiences highlighted how this was not standard policy, and its implementation often depended on the protocol of the individual hospital. In 2024, Hannah gave birth in a hospital which did not have this policy, and did not listen to Hannah or her family about them being her carers:

> *[…] And my partner did explain, and so did my mum […] they said, could one of us stay, cos Hannah will need help. And they [midwives] went, "no you can't, it's policy you can't. Someone will help her if she needs help". And that didn't happen. I had the worst night of my life* (Hannah, 36, hemiplegia).

However, when it was implemented, some women felt safe and happy:

> *I said [to the nurses] I really wanna be in a room with my husband, because my husband is one of my main carers. So, they said, "yeah, that's fine", and then, there were a few things that happened that I thought were really good* (Sally, 41, quadriplegia).

Women's stories evidenced how personal agency and resilience were determining factors in achieving their choices and overcoming the structural and organizational challenges when facing motherhood, especially for the first time. Having a lifelong impairment meant they had developed a resilience and learnt how to negotiate ableism and social barriers, and to develop strategies to manage difficult situations across their life course. Hannah explained:

> *It was kind of more, well, I've learnt how to do things differently to everybody else in my life, I'll learn how to take care of a baby my way* (Hannah, 36, hemiplegia).

For some women, this self-determination emerged earlier in the pregnancy. Nehir was an expert on her own body and knew that a vaginal birth could exacerbate her impairment effects, so she was determined to have a caesarean section:

> *I was a very strong advocate for myself from the off. Like, my very first midwife appointment at 6 weeks, I was like, "I'm going to have a C-section", and she was like, "are you sure?" And I was like "absolutely", because I don't want to end up in a situation that I could've prepared myself for. Primarily because I know my own limits and I didn't want to put myself through it all, and then "end up" in inverted commas with a C-section, so that's what I had* (Nehir, 30, hemiplegia).

Claire reflected on the importance of being assertive, which she gradually learnt over the course of her pregnancy when she realized that the HCPs were not listening to her choices and had very little insight into her impairment effects. She reflects on a meeting with an obstetrician about her birth plan, and a meeting with a young mother with CP:

> *In the meeting with this consultant I got a bit upset, cos I almost wanted someone to say, okay you can have a C-section, this is what's best for you, but no one was saying that! […] After that meeting, I kind of got a bit of a fire lit within me, and I just thought, right I'm gonna do as much research as I can and find out for myself and decide […]* (Claire, 34, quadriplegia).

Saphire chose to use private care, as she felt this provided her with more options. Her contact with the NHS was less positive. As the other women mentioned, Saphire was a strong self-advocate and had developed a strong sense of determination and resilience to ensure her needs and choices were met during her maternity journey. She had two children and worked in social services in child protection, so she was very aware of her rights as a disabled woman and a mother. Saphire had her first child in 2020 during COVID-19 in a NHS hospital. The ableism she encountered triggered her decision to go to a private hospital in 2024 for her second child:

> *Healthcare providers weren't too supportive, I don't think many wanted to deal with me, but yeah, the exception to that was when I went private. When I went private, the attitude changed a lot. They come to your home, and they'll take your word for it, so often in first readings, I get high blood pressure because I get white coat syndrome because I'm a walking ball of anxiety. And they just took my word for that rather than being like that oh you've got to go to hospital because you've got high blood pressure, it was like alright let's give it five minutes, go get a cuppa, let's have a chat and I'll redo it in a bit, and surprise, surprise when they did it that way it would just come straight down. It meant that I didn't have to worry about dealing with accessibility issues, as well, because maternity is not accessible. In hospital I had to basically write my own reasonable adjustment plan. And we had a big meeting and some of it was kind of standard […] Theoretically, the consultant midwife there was supportive, but all my feedback that I put forward (for reasonable adjustments) didn't really get done. It's things like they'd locked the double doors to the easy entrance to the antenatal clinic. Because I still had to have blood tests on the NHS because I'm rhesus negative, I still had to go there. So I had to walk 5–400 metres round. And also, there was only two disabled parking spaces, which, more than once, would be taken up by consultants […] and that was included in my complaint to PALs* (Saphire, 32, diplegia).

This need to continuously negotiate disabling barriers and develop her own management strategies was exhausting and heightened Saphire's anxiety. This was especially the case when her capacity to take care of her children was questioned:

> *Avery was almost 4 years old […] and they were like […] you know that they're going to start climbing soon, and are you going to be there to catch them? Like critiquing whether we were keeping our children safe […] It was slightly stressful because they tried to put in a referral to children's services, so we had to fight that a little bit. If I have support, if I have these aids, it's not going to be a problem, but they don't want to spend money on the aids. They'd rather spend a fortune on introducing my child to children's social services, which costs a lot more money* (Saphire, 32, diplegia).

Several of the women used their personal agency and initiative to seek out equipment and resources they would need to take care of their baby. Some women, together with partners and/or family, designed and built the resources they needed to take care of their babies. Such provision or information was not available or offered by maternity care providers. As Jenny recalls:

> *[…] eventually, after I gave birth, I was referred to adult services, but I didn't find them very helpful to be honest. They referred me to a Facebook support group which has been very helpful, and they said oh you can go on Mumsnet, and try social media, but I thought they were really pushing me off, I didn't really think it was a very good […] they didn't offer me any therapy, they just said there's not really anything they could do to help me […] I was worried I would have difficulty holding my daughter, be more difficult to hold her if she got bigger, and wanted to know if there was any special cots or things like that that I could benefit from. I mean, I have actually found some equipment that could help just from doing my own research, but it seems that there weren't any professionals that could help me there* (Jenny, 43, hemiplegia).

In fact, most women in the study did their own research and worked with their families to get the information and equipment they required for early motherhood. As mentioned above, people with CP are familiar with adapting to manage and negotiate disabling barriers, so they could do the same when they had their baby. As Julie said:

> *As normal, I've adapted it myself. We have an anti-roll mat, which doesn't really work because she crawled off it straight away. And she's been doing that for ages now, so that can be challenging to change her nappy. But all I have to remember is take my time […]* (Julie, 27, quadriplegia).

Claire and Sheila described the importance of online and offline peer support groups for adults and/or specifically women with CP. From these groups, they found support, information and encouragement about the journey to disabled motherhood. The knowledge that there were other women in their position who were successful mothers gave them the confidence to self-advocate and challenge the decisions of healthcare practitioners, but also to find out what resources and equipment they needed and where to find them.

> *I got in touch with a woman with CP from America who has worked with disabled women and their babies at a charity called Looking Glass. She introduced me to one of her friends who was quite*

> *similar to me, and we had a chat […] It immediately made me feel a lot more confident, and they were like, you have a choice to say what you want to do* (Claire, 34, quadriplegia).

> *When I first came home, it was very difficult to transfer her from the bassinet to be able to feed, like, just, even though she was only a little tiny, I just couldn't pick her up. So, in one of the Facebook groups, I can't remember which one of them it was, probably the parenting group, somebody recommended a snuggle bundle or something, I think it's called? That was a complete game-changer* (Bella, 32 quadriplegia).

> *I don't know anyone with cerebral palsy, so I did make a post on the 'Parents with Cerebral Palsy' online support group […] Cos I was concerned that obviously with my mobility and getting around that carrying a baby as well, I didn't want to put the baby at risk or anything like that so I did ask for some suggestions and some of the girls did come up with some helpful things* (Sheila, 30, triplegia).

Fortunately, the women in the study had the financial means and support to buy or make the equipment that was required to enable their performance of motherhood safely and successfully. However, this is not always the case. Such provisions should be available through the NHS, to lease or at a subsidized rate. Furthermore, maternity teams and rehabilitation teams should be able to advise women and their families about suitable equipment and where to locate it.

Theme 3: Advice for HCPs and for Future Mothers with CP

To end each research interview, we asked participants (a) what advice they would give to HCPs to improve maternity care for women with CP; and (b) what advice they could offer women with CP considering pregnancy. This further enabled our analysis to explore the embedded ableist assumptions faced by women when accessing appropriate maternity care by asking them what future support should look like. Their reflections provide valuable insights into how healthcare organizations can begin to dismantle the ableism barriers experienced by women, which, by deprioritizing their concern with the non-disabled body, can provide the basis for a more inclusive care, consistent with women's choices and preferences. The advice for HCPs mostly centred on listening to patients and having knowledge of CP:

> *I would just tell all staff to listen to what every woman wants, regardless of disability status* (Ursula, 32, hemiplegia).

Women associated listening with choice:

> *I would really encourage the Maternity team to keep listening to women and taking their choices into account and offering individualized care. I feel BRI do this already, but with funding issues, this will likely become harder* (Rachel Black, 34, diplegia).

To further facilitate listening, participants expressed a need for HCPs in maternity care to have a knowledge of CP and its different effects in adult women:

> [HCPS should] *Get their knowledge and check in regards to cerebral palsy, because if you don't understand that, then you're not gonna be able to fully support the individual* (Sally, 41, quadriplegia).

Such knowledge would participants believe generate trust and confidence in the provision:

> *Just be a bit more aware of what certain disabilities are or you know, if you're not aware then do a little bit of research beforehand, just to help instil a bit more confidence in the ladies that are coming to you for support* (Ashika, 27, diplegia).

Some women suggested that it would be helpful if disabled mothers could be given information and practical advice by HCPs, during their maternity care, about adaptive equipment they may need to help look after their babies. Jenny's words echo the thoughts of almost all of the women interviewed:

> *I would've liked an OT to give advice on strategies to help carry baby, or even provision of aids and equipment to help lift her in and out of the pram or the cot […] if there was any special cots or things like that that I could benefit from. I mean, I have actually found some equipment that could help just from doing my own research, but it seems that there weren't any professionals that could help me there* (Jenny, 43, hemiplegia).

Participants also offered advice to women with CP who may be considering pregnancy. The women felt it was important to have open and honest conversations with healthcare practitioners in relation to the maternity care journey from the start, including how CP could affect pregnancy and childbirth and vice versa.

> *I never sought advice before getting pregnant, but see a GP before trying to conceive and [speak to someone] regarding maternity care and options* (Rachel, 34, hemiplegia).

The importance of talking was emphasized throughout the journey:

> *Talk to medical professionals during your pregnancy to tell them about your condition* (Brooke, 36, triplegia).

As we have seen, women worried about being judged, although with experience, they had learnt the value of open conversations.

> *Make sure that you're open and honest with your midwives if you are struggling* (Bella, 32, diplegia).

Women said it was important for women like them to be strong enough to speak up for themselves and have confidence in their abilities to do what they wanted and not be persuaded that their choices were wrong. They were experts by experience. Their lived experience of negotiating ablism across different stages of their life course would have equipped them with confidence and skills to overcome challenges during this part of their lives. Women needed to take confidence in this.

> *People might tell you, "Oh don't go for it, it will be hard, it will damage your body, you're not able to do it", just don't listen to anyone. Listen to your body* (Andrea, 34, hemiplegia).

This included preparing for possible challenges:

> *I would just say that you know you the best so, if you think something's going to be an issue you tell the people who can help you that it will be an issue and even if they push it to a side don't stop […]*

> *and make sure that you have a plan for if that happens cos it probably will happen, like when I had that anaesthetist say to me, oh you might not spasm up. I knew it would, I knew it would, so I made a plan for when that was going to happen* (Hannah, 36, hemiplegia).

Women felt it was important to have confidence in their own judgement and understand they could make choices:

> *Trust yourself, you know what's best for you. Like breastfeeding was the big thing that like everybody said to me, "you don't have to", and I know that's true, but I really, really wanted to […] They [HCPs] were like "you know you don't have to; you can take formula with you to the hospital". That's absolutely fine, if that's what you want to do for yourself, but I don't want to do that, so if I'm asking for breastfeeding support, that's what I want* (Nehir, 30, hemiplegia).

Discussion

International legislation asserts that all disabled women, with capacity, have the right to make decisions around fertility and pregnancy and receive high-quality, safe and dignified maternity care of the same quality as that of non-disabled women (United Nations, 2006). However, our study highlights a number of factors that increase inequalities in maternity care for women with CP, in addition to examples of good practice. As other studies have reported, there is limited knowledge and understanding of disability in general, and CP in particular, among healthcare professionals. (-Shah et al., 2022; Shah et al., 2024). Our paper specifically highlights how little insight healthcare professionals have when considering the bidirectional relationship between CP impairment effects and pregnancy and childbirth. A failure to understand this relationship can increase inequalities in care during pregnancy, childbirth and the postnatal period. Further, our findings suggest that the right of women to have choice and control over important decisions regarding pregnancy and childbirth was not always respected. For example, knowledge of impairment effects such as spasticity and adduction of the legs, and chronic pain is required when planning the mode of childbirth for women with CP (Hayward et al., 2017), to enable their informed decision-making.

Through analysis of maternity care stories from women with CP who had babies between 2019 and 2024, this paper indicates variable support from maternity care providers at individual and organizational levels. Some women identified individual practitioners along their maternity journey, who did listen to their concerns and tried to support their choices through respecting their views and their expert knowledge of their condition, while also providing reasonable accommodations to ensure safe and dignified care during pregnancy and childbirth. Good practice is, therefore, possible. Some of the women, however, felt they had to constantly prove their ability to be a good mother. For some, this became a fear of having their children taken into care if they could not demonstrate this sufficiently. This may have been influenced by the cultural and social ableist practices disabled women experience as mothers, which raise doubts about the extent to which disabled women can be good

mothers (Thomas and Curtis, 1997; Rogers, 2005). These experiences reflect broader discursive challenges, with some women saying how they were made to feel a "burden" as their impairment was seen to present an inconvenient problem for healthcare agencies. This explains why some women felt they had to continually struggle to remind healthcare organizations of their responsibilities and obligations. Women found this emotionally exhausting. It introduced uncertainty, too, as women were unsure about when they would be required to challenge healthcare professionals. It also meant women may be reluctant to ask for support or admit other difficulties, such as concerns about their mental health, in case their material competency is questioned.

Our findings echo those of previous studies (Hayward et al., 2017; Panuccio et al., 2020; Schildberger et al., 2017). For instance, in an Austrian study, pregnant women with physical disabilities who perceived that their skills and competence to cope with motherhood were in doubt reported feeling reluctant to admit that they needed more support (Schildberger et al., 2017). Findings suggest variability in HCPs' knowledge about CP and the amount and types of support offered to pregnant women with disabilities. 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 (UN, 2006). The experiences of many of our participants suggest this is yet to be realized fully. To counter this, participants offered suggestions for HCPs when caring for women with CP. These suggestions have since been used to create infographics, with the aim to improve care (https://www.nottingham.ac.uk/research/groups/healthofolderpeople/projects/rich-study/index.aspx).

Advice from our participants for women with CP aspiring to be mothers, centred on the importance of understanding one's own body and being assertive about their needs. Several of our participants were recruited from online support groups focusing on adult CP, and therefore, were perhaps more knowledgeable about disability rights and sources of support. Through these groups, they were possibly more empowered to know their rights and articulate their needs. Not all women with CP are likely to have these assets, and some may not have people willing to advocate for them. This suggests a potential role for services in encouraging confidence among women.

Implications from our findings emphasize the importance of establishing continuity of care, in which women have access to a familiar healthcare professional or a small team of professionals who understand their personal circumstances. Disabled women also require practitioners to respect their lived experience and recognize that they are experts about their own bodies. This should be the starting point of any consultation, rather than ableist assumptions about disabled bodies. To further facilitate this, pre and post-registration education could help healthcare professionals understand the impairment effects of pregnancy and childbirth, along with challenging the common myths associated with CP and disability encountered by women during the maternity journey. This includes encouraging greater knowledge of the

potential impact of CP on women's lives, particularly across the life course. Greater use of adaptive strategies and specialized equipment when necessary for equitable, dignified and safe outcomes during the journeys from pregnancy to early motherhood is an important feature of good practice. Postnatal care for disabled women could also be improved, particularly as women feel current support is inflexible and inadequate. In terms of breastfeeding support, more general information about that could help new mothers who experience impairments, and professional advice and assessment on the impact of giving birth on impairment would be especially valuable. Many disabled women rely on partners and other family members to advocate for them, and although this may require sensitive negotiation, greater recognition of this could improve some women's experiences.

Strengths and Limitations

Recruitment strategies are a potential limitation of the current research. Many of the women who volunteered to participate had already sought peer support from private Facebook groups for people with CP and parenting, and also had personal agency and familial support to be able to articulate their choices and rights. Not all disabled women who are pregnant will have such support. Consequently, future research could purposively seek the views of women with CP who do not have social and familial support to explore their experiences of pregnancy and childbirth. Nonetheless, a strength of the research is that women with CP spoke candidly about both the barriers they encountered and their positive experiences, giving a rounded description of their maternity journey. This may be because the primary researcher and interviewer shared some life experience (of gender, impairment effects and ablism) with the interviewees, which, methodological research suggests, can enhance rapport and elicit rich data (e.g., Finch, 1993; Råheim et al., 2016).

The issues faced by women with CP could be equally applicable to other types of impairments, highlighting a need for training and education as suggested by our participants. This is not to suggest that all HCPs should have expertise in all disabilities, but this study shows the value of asking disabled women about their abilities (Tejani, 2004). This facilitates opportunities to discuss ways of accommodating any difficulties that they might have during pregnancy, childbirth and postnatally to ensure they feel comfortable and safe at all stages of the maternity journey.

Our focus on the maternity journey explored the experiences of women who gave birth. There are, however, important considerations which further research could explore, such as pregnancy loss or miscarriage. Although women were asked about pregnancy loss during the interviews, no one offered any responses. Further research on pregnancy loss may be especially important, given the current lack of research in these important areas. Our sampling strategy also made it difficult for us to explore intersectional inequalities associated with socioeconomic disadvantages and ethnicity. Our research could be developed by exploring how a woman's social context further mediates their experience.

Conclusion

This is the first UK study which explores the experiences of women with CP as they negotiate pregnancy and childbirth. Their experiences confirmed examples of less than optimal care, including various barriers to accessing appropriate maternity care, such as a lack of insight shown by healthcare professionals when considering the impairment effects of pregnancy and the prioritizing of non-disabled bodies. This suggests that the discrimination faced by women with CP is similar to that faced by women with other impairments. Our research, however, provides further contextual details which foreground the life stories of disabled women, while locating their experiences within more conceptual debates about social models of disability and abelism. In doing so, the systemic disadvantages faced by women with CP become clear, along with suggestions about how to generate care, consistent with the needs of the women. This again has relevance beyond CP and offers further insights into how an inclusive care, respectful of disabled bodies, is possible. Many women with CP, for example, feel they are not listened to or regarded as a risk to be managed rather than a woman who is pregnant. Choice, therefore, could be compromised. This added to the anxieties women may be feeling about their pregnancy. Women felt they continually had to justify their competence as a mother, which they believed was questioned because of their disability. Women were also reluctant to raise problems with practitioners, such as concerns about their mental health, as this would further question their competence. Many women, however, describe supportive family relationships, including an active role of partners, which offers a helpful resource with whom NHS practitioners can work. Nonetheless, they believed some health care practitioners were reluctant to use this resource. Women also identified a lack of knowledge and understanding on the part of health care professionals, which undermined their trust in care and raised concerns about safety. Reassuring women and regarding them as experts on their bodies would help establish this trust, in addition to providing continuity of care, which few women said they experienced. To this extent, the reactive nature of many practitioners frustrated many women, and this is why proactive and knowledgeable practitioners were so highly valued. Women felt they were required to develop a strong sense of agency and resilience to negotiate their maternity journey successfully. This could be an area that could be developed and facilitated further by the NHS. To support this, the research identified many examples of good-quality care, and it is important to learn from these, as they are a reminder that healthcare can and does meet the needs and expectations of these women. Our research is also a reminder that pregnancy is a journey, and that women require sensitive care throughout the process. This includes deciding when and how to have children and support immediately after the birth.

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Declaration of interest statement

The authors report no declaration of interests.

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