The Human Rights and Dignity Experience of Disabled Women during Pregnancy, Childbirth and Early Parenting

Acknowledgements

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We are grateful to the women who took the time to complete the online survey in phase 1 and those who gave their time and experiences so generously during interviews for phase 2.

We also acknowledge the co-operation of the many organisations that helped us in distributing the link to the online questionnaire for women. We particularly thank Blind D µ u [• } v v (} Œ • š] u µ o š] v P }] µ • š µ Z •] } v Œ using social media, independent of the study.

We would like to thank Bethan Roberts for her assistance hen

to conduct the interviews via telephone or Skype. In a

Interviews were semi-structured and asked participants to describe their experience of maternity care, particularly focusing on their perception of if and how their rights and dignity were protected or not protected during their maternity care. The interviews were recorded and transcribed verbatim.

Data Analysis

Survey data were analysed using descriptive statistics. Thematic analysis was used for open questions, with themes from each individual question analysed as well as overall themes from all questions being analysed. The analysis of the data from phase 1 helped to inform the semi-structured format of the phase 2 interviews.

Interview transcripts were initially analysed using an open-coding method by two researchers (BC and JH), with a research student also involved. Detailed intra-thematic analysis was undertaken independently; then findings were discussed by the two researchers to promote trustworthiness of the emergent themes. Following analysis of each individual transcript, inter-thematic analysis was undertaken to understand the differences between narratives of individuals and specifically to identify findings relating to the context of human rights and dignity. Once initial overall themes had been generated, these were checked with the research team, including the researcher who had conducted the interviews. Further information on analysis may be obtained from the research team.

In this report, an overview of the themes that emerged is presented with a specific focus on how these relate to human rights and dignity. An interpretative process was used to link themes that arose from narratives with these concepts as these were rarely introduced by the women themselves in the interviews.

Findings

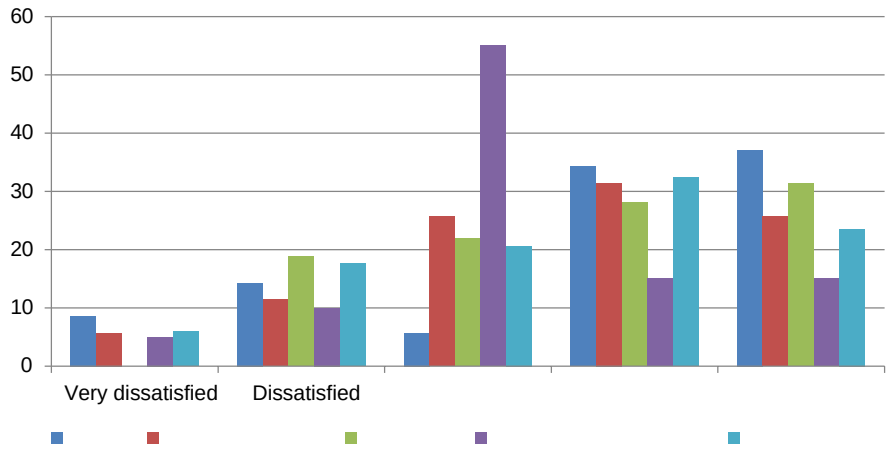
Phase 1 - the internet based survey

The participants

A total of 46 surveys were completed, however responses were excluded because they came from women based in the USA (n=3) and Canada (n=2). A further participants did not consider themselves to be disabled or Deaf and so these responses were also excluded.

reported satisfaction with general practitioner (57%), obstetrician (59%) and health visitor (56%) support. Fewer reported satisfaction with maternity support worker input, but only half of the participants (n=20) answered the question. A number of women stated that they did not know what a maternity support worker was.

Figure 1. Satisfaction with the support receive



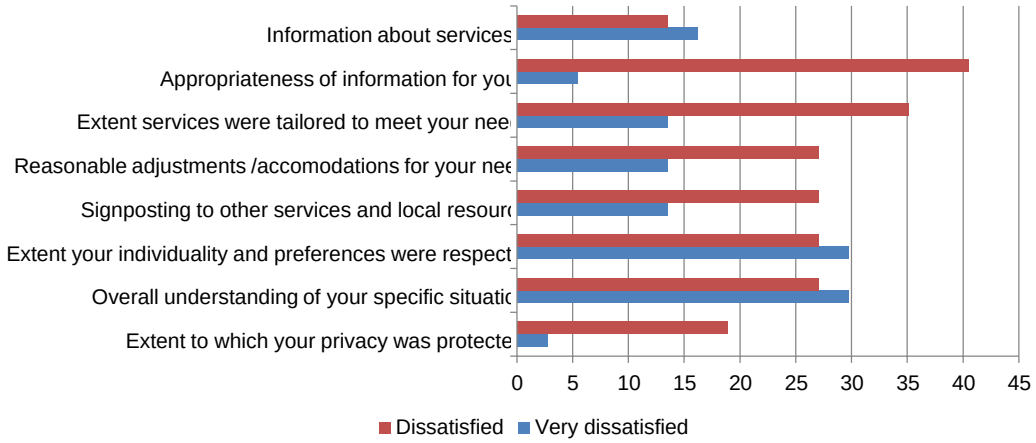
> My Disability is unseen and was not recognised by midwives when in labour. I was put under tremendous pressure to give birth naturally when I had already planned a c section. My baby was breach, I had a dislocated hip and was scared my pelvis would literally snap. This was ignored when I went in to spontaneous labour 3 weeks early. C section was safest option for both of us but midwives know best and were pushing so hard for a natural delivery.
> Participant with a physical disability

Another participant described the need to demonstrate her ability to adopt certain positions for her choice of birthplace to be possible, w hZ • Z • Œ] • • Z.] v • µ o š] v P [

> The midwives were fine but I told the obstetrician I didn't want to give birth on the delivery suite and they asked me to physically demonstrate I could get into certain positions that they considered necessary for giving birth. I found that quite insulting and also undermined my confidence in my body.
> Participant with physical disability

> My midwife antenatally and postnatally was great in community, but the midwives in hospital made me feel like they did not have time for my questions, they told me what hospital guidelines were but I didn't feel like they took into account what I wanted. They spent more time with monitors than actually supporting me. The health visitor dumped loads of leaflets that were supposed to answer my

Figure 2. Dissatisfaction with service



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Themes from the open-ended text boxes were similar to those already discussed, particularly the perception that maternity care providers had little understanding of ‰ Œ Ę š]] d ‰ abilityŽ • [eeds and participants felt that their needs were not being ‹ µ š d Ç •] Œ Ę X } u u µ v] š š}} v À Œ Ę Ç] u %] v ‰ Œ Ę šŒ Ę vš š] ‰ v š • [comments about their satisfaction with service provision, including communication with the individual, between members of the multidisciplinary team and signposting or referral to other services.

My care was between

-32 I had less information and understanding on how to cope or what to
s important to be able to feel in control of the future otherwise it can be very

Satisfaction with care during labour and birth

Satisfaction was also high for care during labour and birth, but a significant minority reported dissatisfaction with various aspects of the care (Table 5). Dissatisfaction was greatest for the extent to which women were listened to during labour and birth (39% of participants were either dissatisfied or very dissatisfied).

The comments provided reflect the scoring with many being about women feeling that they were not being listened to and their choices were not being heard.

not have somewhere to store wheelchair out of the way. They did not listen to me I advised them on the unique way my body works. They did not listen to my advocates.
Participant with physical impairment

I was talked into an induction I didn't need, and was given a sweep without warning or consent.
Participant with physical impairment

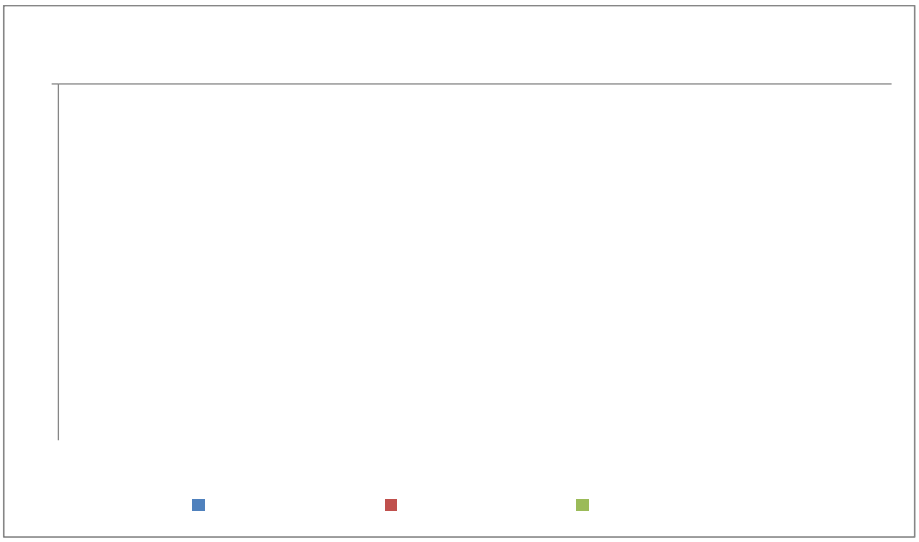
There were also some very positive stories of care during childbirth; again these seem to be related to when the women felt that they were in control and being listened to.

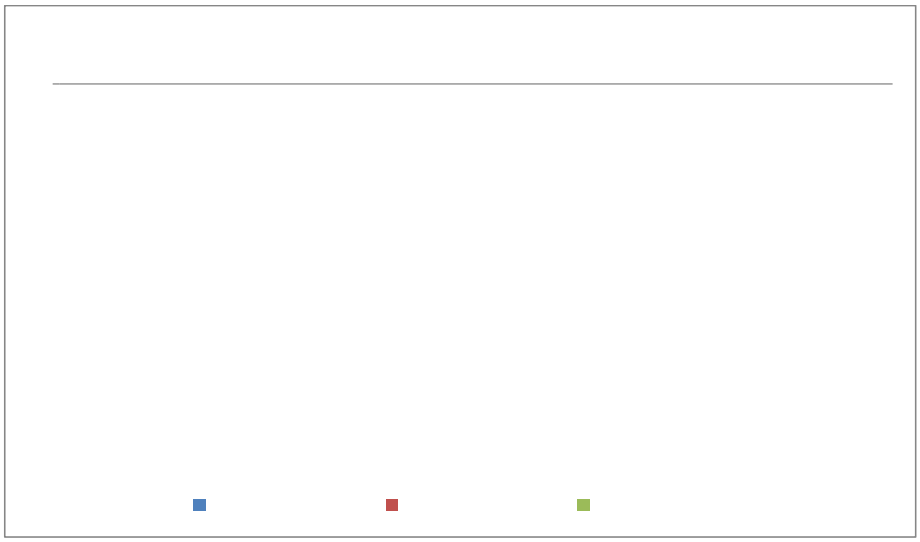
My baby was born naturally face first. I had

Dignity and respect

Participants were split over whether they were treated differently as a result of their disability (Table 7). A third of the women reported that having a disability put them in a high85 g /TT0

Some of the communication issues related to access to information, such as the way a health professional communicated with a person with a sensory impairment. Adjustments to communication would potentially have resulted in better communication with these participants.





Phase 2 - Interviews

Participants

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Freya

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Geraldine

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Accepting the label in pregnancy meant that she got some specialist help, however it did not translate into better understanding of the condition by most caregivers. Jane has one pre-school aged child with her partner and has a supportive family network nearby.

Kate

Kate was diagnosed with MS shortly after getting married. This news made her and her husband wait longer than they had planned to have their first child. She chose to have an

Overarching themes relating to human rights and dignity

The prominent overarching theme that emerged from the full analysis of the interviews was
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The participants described how their disability experience influenced what they want in terms of their care and also their birth that they felt would be most appropriate for them. These differed between the women, highlighting the difference and individual needs of small group. The common feature among all of the narratives is that the women wanted and needed to be supported through the process of making decisions about the care that would be most appropriate for them. They wanted to be listened to and have their needs respected.

Ante-natal care

The women described their needs in relation to antenatal care. The common theme is that

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my midwife is Œ] o oŕ Á v•šv Ų š u Œ Á Z š Z Œ µ o P š v } Œ } • µ } š Z š µ Œ o Œ Ç v ( ] P Œ
nearer the time umm to go out and try the water birth at the water birth pool with a member of staff at the maternity hospital to see that I was comfortable there and I could comfortably get in and out. They were brilliant, I went for it and it was fine (Louise)

natural birth because I know what I cannot tolerate, I have never been able to tolerate any sort of umm [medication]really and yeah, I feel a bit, asking more questions, explain to me about the drug, itès annoying that I cant think of it, but umm literally even taking a moment to explain this would umm rule out all sorts of things. (Jane)

The women, particularly those with physical disability, also described the importance that they could choose the right position for birth. For several, this choice was not respected and the women describe not being listened to and the impact of their disability on their choice of position was not appropriately acknowledged by health care providers.

So during the birth I had asked that um if possible I would like to give birth on all fours um or on my •] µ u[µ•/ (}µšZ}•‰}•]š]}ÁvµoŒ[Ç}u(}ŒšÆošœ€rUat least OK to u v Pµ u Y Ív µ‰vuÇ l]šZo]šZ}š‰u}•Ç]šÁ}hvmy legs in stirrups um they actually told me that um well just prior to that I was kind of kneeling over the end of the bed that was working well for me I thought itwas working well enough for the labour [: um] They disagreed. They said they -6 (o)7 (u)-848 disagreed.

Being treated as an individual

Another overarching theme that relates both to women having choice and good communication is the importance of women being treated as individuals. This was unanimous in the narratives. Much of what the women described they wanted in terms of individualised treatment is disability related, and again, they highlighted that to enable this individualisation, they needed to feel that they are being listened to.

> [illegible] ng each woman as an individual and they see 5 women in the same clinic with [illegible] really worried, one may be just mentioning it because she thinks she should present with what [illegible] or not, or [illegible]

> she took the time to understand me as an individual and not necessarily [illegible] yes I think because my midwife really took time to understand em sort of what I wanted, that my baby was growing fine that the pregnancy was that a home birth was a good idea and that me being in hospital was a sort of negative so the risks of me being stressed were actually higher yes she really understood that (Freya)

Holly described the need for proactive care, that for her, being treated as an individual was recognising her needs (and potential needs) based on her disability and mental health issues. For her, having the support potentially in place would have assisted her greatly. However, she explained that support was not put in place proactively because that was not [illegible] practice Tr 8 0 t in

Maternity care providers should À o } ‰ ų (v ž] •] o] š Ç Z u ‰] } v • [Á Z will be the source of information for all practitioners and to develop appropriate resources for women to be able to understand and make choices related to their particular needs.

Further work is required to provide appropriate training and guidance for maternity care providers specifically about issues relating to disability, such as breastfeeding for blind or visually impaired women and the management of pregnancy and childbirth pain in the context of a person who experiences ongoing pain due to disability.

A national study should be undertaken to identify areas of good practice that may be acknowledged.

Access auditing is required of maternity care environments to ensure that facilities, including antenatal facilities and post-natal wards are accessible for wheelchair users and, if possible, that accommodation can be made for a personal assistant to remain with a disabled woman.

Maternity care providers should consider their communication with disabled women, to ensure that women feel listened to and more particularly that information and communication is accessible, providing alternate formats or adapting communication style to enable a person with a sensory impairment.

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