



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

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Introduction

In 2013 Birthrights conducted the first large-scale maternity survey in the United Kingdom to focus exclusively on women's experience of their dignity and respect during pregnancy and childbirth. Although the *Dignity in Childbirth* survey did not set out specifically to examine the experiences of disabled women, the survey findings indicated that the small number of women who identified themselves as disabled appeared to have unequal care with less choice and control over their experience, including less information and reduced choice in pain relief (Birthrights 2013). The survey concluded that further research was needed and with this in mind Birthrights commissioned Bournemouth University to explore the experience of disabled women throughout pregnancy, childbirth and the first few post-natal weeks (the pregnancy continuum).

Background

It has previously been noted that a growing number of women living with long term conditions and disability are having children (Blackford, Richardson & Grieve 2000), exercising their desire and legitimate right to become mothers (Smeltzer 2007). However, collecting exact numbers of women who would be considered 'disabled' is challenging as information about disabled women is not specifically gathered (RCN 2007, Šumilo et al 2012). While there have been some studies examining disabled women's experiences, little research exists describing maternity care and issues experienced by women who are disabled (Malouf et al 2014). In addition, disabled women's parenting ability is often brought into question (Lipson & Rogers 2000).

Disability is frequently defined in terms of impairments, activity limitations, participation restrictions, and environmental factors (World Health Organization [WHO] 2015). However the WHO has recently revised its definition of disability from a disease focus to one that focuses on health. This change of focus is key when considering pregnancy in women with disabilities. In a biopsychosocial model of disability, providers recognise that women with disabilities are knowledgeable about their disability; full partners in decision making and the experts on how their own bodies respond; having had their own lived and individual experience (United States Public Health Service [USPHS] 2005). Several studies highlight the following problems identified by women with disabilities: access; information; communication and choice (Redshaw et al 2013; Thomas & Curtis 1997).

It is recognised that there are different perspectives on disability, broadly underpinned by differing theoretical positions – the 'models of disability' – which provide understandings of

disability as an individual or social phenomenon. Disability activists, for example, reject the WHO classification of disability and rather propose that while impairment is individual to the person, disability is understood in terms of the accessibility of the physical and social environment (Oliver 1990). Thus, a social or rights-based disability model describes a person as 'disabled' by society, a 'disabled woman' rather than a woman who *has* a disability. In recognition of the social model of disability, throughout this research, we have used the language of 'disabled woman' while recognising that some of the women may prefer the 'people-first' language more commonly used in health and social care services.

Disabled women are more likely to experience social and economic needs and have worse outcomes from birth than non-disabled women (Šumilo et al 2012). Access to services is important, but current evidence is conflicting, with some research suggesting that disabled women have less access to services (Walsh-Gallagher, Sinclair, McConkey 2012), while other research indicates that women with physical disability receive more antenatal and postnatal support, but have less choice around labour (Redshaw et al 2013). Redshaw et al identified that women with sensory impairment were more likely to have met their caregiver prior to labour than non-disabled women (2013). While more support and meeting caregivers prior to labour are initially assumed to be positive, the impact of these on equality and dignity is not known: some women describe 'special' treatment as 'othering' thus undermining their sense of dignity and equality.

There is some evidence to indicate that disabled women do not feel that staff have adequate knowledge about their needs (Walsh-Gallagher, Sinclair & McConkey 2012) and health carers have also identified a 'lack of competence, knowledge and skill' around disability as well as not recognising that they may not be providing individualised care to women (Walsh-Gallagher, et al 2013:298).

A study highlighted some poor aspects of care within the sample from the UK millennium cohort (Redshaw et al 2013) but was completed prior to the report from the Mid Staffordshire public inquiry (Department of Health (DH) 2013) and identification of the strategy of developing compassionate care (DH 2012) that is now intended to underpin nursing and midwifery practice. The recent National Maternity Services review in England (NHS England 2016) identified that women require care that is individualised to their needs; autonomy in the choices they make and continuity provided by a relationship with a known small group of midwives. Though not focused on women with disability, this highlights that current organisation of services is not meeting all women's expectations.

This two-phase, inter-professional research responds to an approach by Birthrights to investigate disabled women's experiences of childbirth and their interaction with maternity services.

Methods

The specific objectives of the study were to:

- document the lived experience and perceptions of women with physical and sensory disability during pregnancy, childbirth and early parenting;
- identify the needs of disabled women during the pregnancy continuum and use this information to describe how care could be improved.

Design

The study had two consecutive phases:

- Phase 1* – an Initial quantitative survey to identify the experiences of women in the UK and Ireland with physical or sensory impairment during the pregnancy continuum;
- Phase 2* – a follow-up qualitative study to establish in-depth views and experiences of human rights and dignity in maternity care of a self-selecting group of women.

Sample

The sample was drawn from the population of women who identify themselves as having a physical or sensory impairment. As the specific needs of women with circumstances related to emotional and psychological wellbeing would present different issues, and there is a range of specific perinatal mental health services already in place, this group was not included in this study. Similarly, there is already some research about the needs, rights and safeguarding of women with learning disabilities and so the focus is not on women with learning or intellectual disability. With a view to both focus the research and in recognition of the greatest gaps in knowledge, the concern of this research is with women with a physical or mobility impairment, sensory impairment (such as impaired vision or hearing) and people with long-term health conditions that impact on their daily life (such as chronic fatigue).

It was recognised that the population of disabled women who have experienced the pregnancy continuum is somewhat difficult to frame. Options for sampling included seeking involvement from mainstream maternity services, but it was felt that this would reveal very few participants from a large volume of contact. Instead, women were recruited through

organisations of and for disabled women / disabled parents and through social media networks. A list of organisations was compiled to include umbrella disability organisations, organisations that focus on one type of disability (e.g. Blind Mums Connect) and organisations for people with specific medical conditions (e.g. people with spinal cord injury, multiple sclerosis or with CFS/ME). These organisations were contacted by e-mail and through social media (including Twitter and Facebook) and asked to circulate the link to the online survey. Birthrights and other organisations focusing on maternity care also shared Tweets to inform potential participants of the study.

The study was specifically focused on women living in the UK and Ireland, although international responses to the online survey were received.

Phase 1 – involved a self-selecting, convenience sample of women who had given birth in the UK and Ireland and who completed an internet-based survey. Women were identified through online networks and groups of and for disabled parents.

Phase 2 – involved women from the above sample who were willing to undertake a follow-up telephone, Skype or e-mail interview to provide in-depth information about their experiences of childbirth. Participants were drawn from a wide geographical area. Additional participants who had not completed the online survey were also sought with a view to achieving greater diversity (purposive sampling approach was used).

Ethics

Ethical approval was obtained from Bournemouth University's Research Ethics Committee. Participant information was available in a range of accessible electronic formats (including large and clear print, screen-reader and assistive technology accessible text and British Sign Language videos would have been provided if required). Consent for phase 1 was obtained on the "landing page" where participants were provided with information and asked to consent by clicking either 'agree to participate' or 'don't want to participate'. Participation was voluntary, and those who did not consent were directed away from the survey to a page thanking them for their time.

To help protect confidentiality, the survey did not contain information that would personally identify participants, such as names, email or IP addresses; however participants were asked to leave their contact details if they wished to participate in phase 2. Consent was redetermined in phase 2 by the researcher prior to commencing interviews.

For the interviews, participants were contacted initially by e-mail and were asked to supply further details for contact. Arrangements were made for an experienced midwife researcher

to conduct the interviews via telephone or Skype. In addition, some student health professionals had the opportunity to contribute to interview preparation and data analysis. Participants were encouraged to seek a private space for the interviews. The full consent information was read to the participants at the start of the interview and their responses to this were recorded. The recordings of the consent were kept separate from the interviews. Procedures were in place should a participant become upset and interviews would have been terminated if participants wished it. All information was transcribed and anonymised and pseudonyms are used in this report. Due to the small population size, some details about individuals have been omitted to protect their identities.

Data collection methods

Phase 1 - Internet based survey

Data were collected using an online survey tool delivered through *Bristol online survey* (BOS). The survey was designed to be accessible for participants who use assistive technology and supplementary information on how to access the survey was provided in a range of formats. The survey link was distributed via social media sites, and through connections via email to groups and charities related to disability. The survey was also available to be answered orally if required, but no one took up this option.

The survey contained both open and closed questions relating to dignity, respect, human rights and health equality issues. Questions covered the experience of women during the antenatal, birth and early postnatal periods and related to physical, emotional and human rights experiences. Many free-text boxes were also provided to enable opportunity to respond more fully as required.

Phase 2 – Telephone or Skype interviews

Participants who left their contact details were contacted by the research team and invited to participate in a follow-up interview. Interviews were via telephone or Skype in order to gather in-depth information regarding their experiences. This method of data collection allowed participants from a wide geographical area to participate and for detailed narrative data to be collected. Various formats were available: for example participants who were hard of hearing or Deaf were offered the option for BSL interpreted Skype conversations, while participants who use augmentative communication technologies were offered asynchronous e-mail conversations. One participant specifically requested an interview via the instant messaging option using Skype but no other alternative communication methods were required.

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 5 responses were excluded because they came from women based in the USA (n=3) and Canada (n=2). A further four participants did not consider themselves to be disabled or Deaf and so these responses were also excluded. This left 37 responses for analysis.

Table 1 provides the demographic characteristics of the participants. Participants ranged between 21 and 46 years of age with the majority being aged 30-39 years. The majority of women had given birth, but for one woman this was her first pregnancy and she had not yet given birth. Participants were asked how they characterise their primary impairment; most women reported having a physical or mobility impairment.

Participants were offered the opportunity to describe their impairment using their own words. The two participants that identified as Deaf or hard of hearing simply stated, 'hearing impaired' or 'hard of hearing'. Of the seven blind/visually impaired people, two identified as totally blind with the others identifying that they are partially sighted. The majority of women who identified as having a physical impairment described what would traditionally be classified as musculoskeletal problems, such as arthritis, joint problems and conditions that cause joint hypermobility. Some of these accounts describe how pregnancy exacerbated existing disability due to body changes in pregnancy. On-going health issues were described in less detail, with one participant describing moderate ME/CFS.

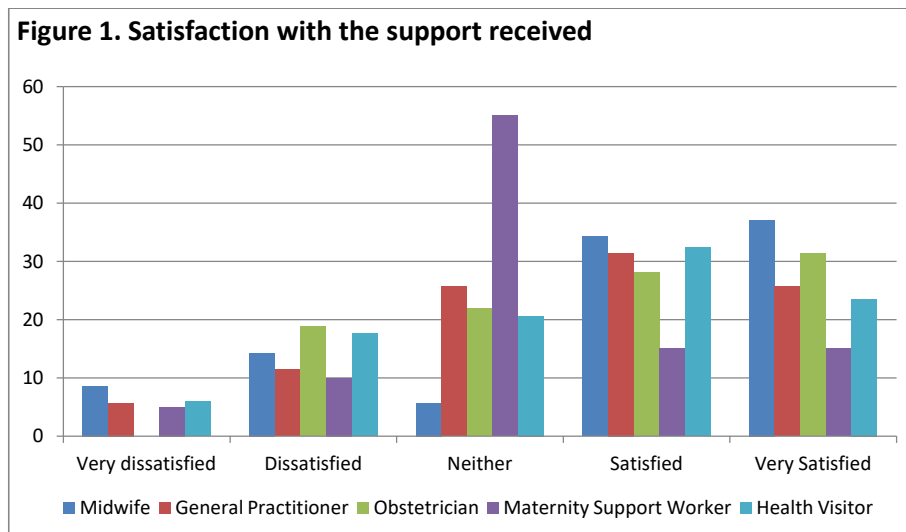
The maternity care received

The majority of participants (58%) had given birth within the last two years (Table 2). More than two thirds of women received shared antenatal care; this was most often shared between the midwife, general practitioner and obstetrician (60%). Most women reported that they gave birth in an obstetric unit (78%). All women reported receiving some form of postnatal support (participants could choose more than one option) and most indicated that they had support in hospital and in the community from a midwife, and a home visit from health visitors.

Satisfaction with support received

Participants were generally happy with the support that they received from maternity care providers (Figure 1). All women had received care from a midwife in their most recent pregnancy, and 71% were satisfied or very satisfied with that support. Most women

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.



Despite generally positive responses, just over half of the women (19/37) expressed dissatisfaction with one or more care providers.

The information from the open-ended questions about the support received broadly comprised of themes about maternity care providers' awareness and attention to the impact of disability, the need for continuity of carer, the perception of reduced choice or choices being overruled and care providers needing more information.

Many of the comments made by participants, particularly those with physical disabilities, suggested that maternity care providers seem to lack knowledge about disability and how that can influence pregnancy, childbirth and parenting.

Very little understanding about my condition
Participant with physical impairment

Generally there was a sympathetic attitude towards my pain and worries but no solutions were offered - just a case of sit and wait until the baby was born. Postnatal ward was not fun.
Participant with physical impairment

Very few midwives/doctors seemed to be clued up or cared about my SPD/PGP or made any allowances for my severe form during pregnancy, birth and afterwards.

Participant with physical impairment

No one understood my disability. No-one knew how to help or who to send me to for support

Participant with physical impairment and long-term health condition

Service providers had no understanding of specific needs and are only equipped for the mainstream.

Participant with visual impairment

My community midwife was amazing as was my GP. The consultant was unfamiliar with my disability and its implications. The midwife on day of delivery was beyond useless deciding she knew better than specialist of my disability. Anaesthetist was oblivious of my disability and failed to read the notes from my specialist. The labour ward were unaware I was disabled prior to arrival for induction, it took 36 hours for them to get me a toilet frame and told me it was ok because there was 1 grab rail. The registrar decided what was best for me and baby without even considering my disability and its implications. The post labour ward did not provide sufficient space for wheelchair or safe use of crutches. They had a perch stool rather than shower stool which I slipped off the moment it got wet and soapy. Postnatal ward could not meet my physical need so said I should go home. Post natal were infuriating, they wouldn't take needles out of my hands until I had walked to the toilet, I could not walk without crutches and could not walk on crutches with needles in my hands. Anaesthetist did not listen to what I had to say or to my husband or mother who were there to advocate for me when I was unable.

Participant with physical impairment

Two participants specifically highlighted the need for maternity care providers to have knowledge of breastfeeding; both of the participants were blind or partially sighted so it could be that information about breastfeeding for this group is particularly challenging.

My health visitor and most of the health visiting team I have come in to contact with could definitely do with more breastfeeding training.

Participant who is blind

Very little or no signposting to breastfeeding support groups following my recent pregnancy.

Participant with visual impairment

Participants, particularly those who experienced pelvic girdle pain or pain due to other disability, commented on how little attention was paid to their experiences of pain and its impact on pregnancy and childbirth, or listening to how they manage their disability.

I found every health care professional unsupportive in recognising my PGP, acknowledging it or treating it. I had zero pain relief offered either. The public health nurse was the only person who offered any advice or support. I never met my obstetrician.

Participant with physical impairment

In the hospital I had other midwives. One of them was very dismissive of my PGP. I also found that the obstetrician's team didn't have a clue about PGP. I asked them at the beginning as I had a previous back injury and they said it wouldn't cause a problem. They still didn't acknowledge it even when I was on crutches!

Participant with physical impairment

Some participants differentiated between different maternity care providers, and for example, found one provider more helpful than others.

Midwife and obstetrician couldn't have been better. OT was completely useless.

Participant with a physical disability

I loved my community midwife but she was the only one who wanted to know how I was feeling about things or if I needed explanations. Everyone else made assumptions, talked about guidelines or looked at monitors.

Participant with physical disability

Comments, as with some of those above, also suggested that continuity of carer and follow-through with the same provider was far better for them than if they needed to meet different maternity care providers throughout their pregnancy continuum. The responses suggest that challenges arose when different professions of maternity care providers were involved with the care of the woman.

The issues were continuity of care. For "my" midwife who knew my history she was great. When she went off work and I saw others, they appeared to neither know nor care.

Participant with a physical disability

Midwife was fantastic. Due to my disability she decided to make herself fully available to me, I saw only her, didn't have to explain my impairment repeatedly to different people. GP was generally useless, had to be reminded by me what each appointment with him was actually for, kept forgetting to do various tests. HV was fine, very 'nosy'!

Participant with visual impairment

Midwife I saw during pregnancy was amazing, midwives in hospital mixed. One who actually delivered my daughter was great, but a few before and after treated me horrendously.

Participant who is blind

See different midwife every time. No special assistance despite me asking because of having ME / CFS.

Participant who has on-going health issue

Two of the responses particularly relate to choice. One participant, who has a physical disability and mental health condition described that 'I had to fight for the birth I wanted', whereas another participant, who has a physical disability described her choice to have a caesarean section as being 'overruled'.

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, which she describes as 'insulting'.

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. It 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 questions but they didn't. If I wanted support or my baby weighed I had to go to clinics but they didn't usually have a health visitor, just a nursery nurse who didn't answer my questions.

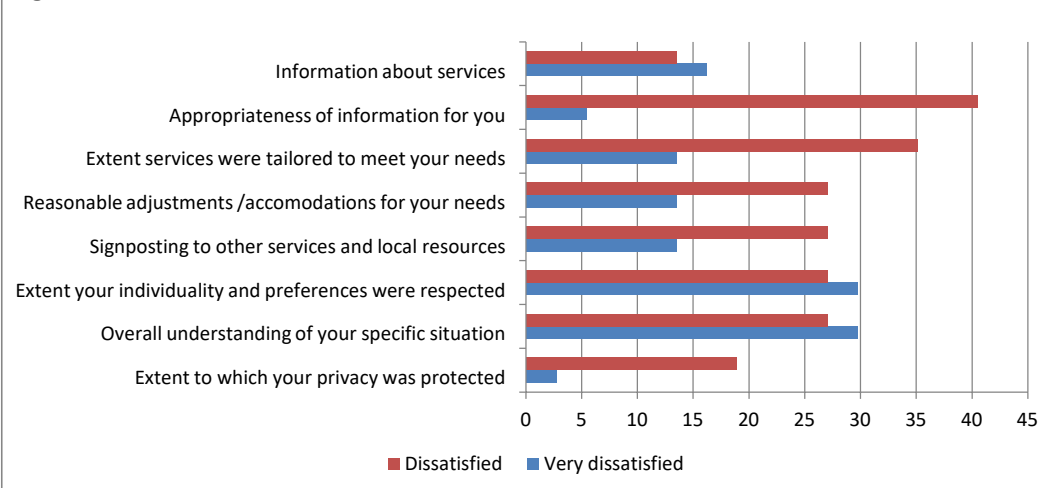
Participant with a physical disability

The quote above also highlights the need for continuity of carer and the need for staff to have information to answer women's questions, a finding repeated by other participants. One blind participant described employing an independent midwife to manage her care for her second baby due to negative experiences with her first birth.

Satisfaction with services provided

The majority of participants (59%) were happy with the information about the services available (Table 3); however there was significant dissatisfaction with other aspects of the service (Figure 1).

Figure 2. Dissatisfaction with services



Dissatisfaction was greatest for the statements “The extent to which your individuality and preferences were respected” (57%) and “The overall understanding that service providers showed of your specific situation” (57%).

Themes from the open-ended text boxes were similar to those already discussed, particularly the perception that maternity care providers had little understanding of participants’ disability needs and participants felt that their needs were not being adequately considered. Communication seemed to be very important in participants’ comments about their satisfaction with service provision, including communication with the individual, between members of the multi-disciplinary team and signposting or referral to other services.

My care was between 2 hospitals due to baby’s complications. I was never offered support outside of the hospital setting. My information was not shared between all the doctors and I had to constantly repeat myself and to do that I had to understand everything going on. I was lucky I did but information was only what I looked up myself.

Participant with visual impairment

My care post natal from some midwives was fantastic but from others there was a belief that I needed to be mobile because of DVT risk - they did not appreciate how difficult and painful being mobile was and I was made to feel as if I was overreacting by some midwives and support workers

Participant with physical impairment

My physical needs were neither enquired about, listened to or met without a great deal of Aggro on the delivery ward.

Participant with physical impairment

No signposting was done despite the fact I wanted to find out about other services. Information was shared about me without my consent because local team had never dealt with a VI [visually impaired] person before and panicked a little. My hospital experience was horrendous, no one listened to me and several people talked about me not to me.

Participant with visual impairment

From the comments relating to service provision, it seems that not being listened to affected participants in different ways. For some, it was considered insulting, for others it was frustrating. In some cases a lack of clear communication resulted in a perceived lack of choice.

Good practice was particularly described when the participant had choice and the opportunity to discuss and try out options with Maternity care providers.

Hiring IMs [Independent Midwife] and birthing at home meant my individual needs were well met and avoided difficulties of navigating hospital etc. IM had time to explain options rather than just giving inaccessible leaflets.

Participant who is blind

during my pregnancy, my midwife made sure I was 100% happy with any decisions made about my plans for labour/birth due to my disability, she even made an appointment for me to try some birthing equipment out weeks before I was due to have my baby so it was easier for me to make a decision of what I would like through labour/birth and so I was 100% that I would be comfortable with my choices due to my limits of what my body can do.

Participant with physical impairment

Challenges relating to services included that the hospital was not accessible for several participants.

Midwifery staff were very good but VERY understaffed. My husband was allowed to stay with me before & after birth & we were given the family room, however it wasn't suitable for my wheelchair. He is my main carer.

Participant with physical impairment

Other participants suggested changes to services that would have supported them, including the provision of a temporary disabled parking permit, as pregnancy caused more significant mobility issues for some women with physical disability, and the provision of more information about twins.

Satisfaction with antenatal care

Participants reported a high degree of satisfaction with all aspects of antenatal care (Table 4). Aspects with the greatest dissatisfaction were continuity of care during pregnancy (40% of participants were either dissatisfied or very dissatisfied) and the extent to which women were listened to during the antenatal period (36% of participants were either dissatisfied or very dissatisfied).

The comments made about antenatal care are far more negative than the scoring, although the themes directly reflect areas that were rated less well. The themes that emerged as important were continuity of carer, the extent to which women felt that they were being listened to and the amount of choice women felt they had in the type of antenatal care on offer. Some women described more positive experiences if they employed an independent midwife or private care.

I was never given options of home birth or community midwife lead clinics. As this was my second baby I wasn't offered antenatal classes. I had to repeat all my history at every appointment because there was no continuity of care. I was railroaded and left bewildered after a number of hospital visits and tests where I felt not listened to.

Participant with visual impairment

Because no one understood my history they didn't know what to do for the best. If they'd listened to me at any point I could have explained it further; but no one ever did

Participant with physical impairment and health condition

For some participants, antenatal care was made difficult because of inaccessibility of the hospital or venue where classes were held.

I could not attend antenatal lesson as the building is ill-equipped for wheelchairs. I would have to travel further for tests as the local location was ill-equipped for wheelchairs.

Participant with physical impairment

Annoying that doors at the maternity unit are not all able to be opened from a wheelchair

Participant with physical impairment

Some of the participants felt that there was not enough time for questions in antenatal classes or that they just did not have the information that they needed. Having information was considered important to enable a sense of choice and control.

Antenatal classes covered a lot of information in too short a time. There should have been an extra session to cover any other questions people may have had or to clarify things.

Participant with physical impairment

I felt that between weeks 24-32 I had less information and understanding on how to cope or what to expect. When in pain it's important to be able to feel in control of the future otherwise it can be very scary.

Participant with physical impairment

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.

I didn't have any control or any choice. Everything was decided for me.

Participant with physical impairment and health condition

I was highly restricted unnecessarily, bullied into having an epidural and threatened when I refused a clip on my babies head. I had a catheter and had to threaten to withdraw my permission for it to be inserted for them to remove it as it was placed wrongly... I wanted an active birth and was kept still on the bed throughout.

Participant who is blind

When I told the midwife the epidural wasn't working she didn't believe me even when using the cold spray I told her I felt it straight away

Participant with health condition

I had no control, I tried to tell my midwife five times that my back hurts and I don't want to lie down. She didn't try to help me up and I physically couldn't move. I had PGP and intense back labour and there was something wrong. I tried to tell her something is wrong with baby and she ignored me. Eventually another midwife called a doctor and we were rushed in for an emergency c-section.

Participant with physical impairment

Several things stuck with me. A consultant shouted at me and refused me a birthpool for pain relief. Just prior to going into surgery a midwife shouted. Whilst performing a forceps delivery the consultant was ordering me to push, despite the fact I was numb from the waist down. I'd had 2 epidurals that didn't work, they didn't believe me.

Participant with physical impairment

You're told to make a birth-plan and then that is not respected. So what was the point of making it?

Participant with health condition

They wanted to force me to have a section even though with my condition this should be reserved for emergencies only. They did not have bath or shower stools. They did not have toilet frames. They did

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 several midwives and my consultant deliver him with my limit of flexibility of my legs and hips due to my disability I could not had ask for better care during my labour/birth I was always made to feel comfortable and in control.

Participant with physical impairment

1st labour my little girl was in distress and a bit poorly. At no time did I feel panicked though as the midwives and doctor attending were kind caring and extremely professional. 2nd labour was totally different. Relaxing and even enjoyable. I was left alone but never felt worried.

Participant with visual impairment

Satisfaction with care after the birth

Postnatal care was the area that scored least well in terms of satisfaction (Table 6). Areas of particular dissatisfaction included women's involvement in decisions about the type of postnatal care they received (40% of participants were either dissatisfied or very dissatisfied); communication between women and their maternity care providers (39% of participants were either dissatisfied or very dissatisfied), and the extent to which women were listened to during the early postnatal period (44% of participants were either dissatisfied or very dissatisfied).

The comments about the post-natal period were largely negative; continuing the themes of participants feeling that they were not listened to, a lack of continuity of carer and also that there was inadequate support or conflicting information once the baby was born. Some of the issues raised could be the same for any woman and may not be disability-specific whereas some comments were specifically about access and treatment due to disability.

My care in the hospital was poor. My baby fed well in the hour after birth but I struggled the following day and no one observed him feed. I requested to be discharged and it wasn't until my community midwife arrived that he fed again properly. I spent over 24 hours with a hungry irritable baby that went unfed. We nearly bought formula. I was crying with him. As soon as my community midwife showed me what to do, we were fine. Now I am so proud of that but so angry that I was ignored in hospital.

Participant with physical impairment

Midwives have shown no interest in my ongoing pelvic problems post birth and often fob me off with 'well it hurts to give birth' when I ask about my mobility issues post birth. I have also received conflicting advice around how to care for my baby from midwives from the same NHS trust. It's hard to know who to trust as a new parent.

Participant with physical impairment

Lots of pressure to breast feed yet no practical support to enable me to treat engorged breasts. Ward seemed understaffed and I felt pressured to go home before I was fully recovered

Participant with physical impairment

A different member of staff came to me each time, I never spoke to the same person twice. My complaints were ignored. My needs were ignored. I was injured due to them believing they knew more about disabled mobility aids than me, the user.

Participant with physical impairment

I wasn't allowed to hold my baby for long periods in case I fell asleep. I could not fetch him from the bassinet. I could not get washed for days. It was awful. I couldn't wait to get home.

Participant with physical impairment and health condition

The care at the hospital was awful. I felt decisions were made without consulting us. Some members of staff were rude and unhelpful.

Participant with visual impairment

My experience of pregnancy wasn't that bad. It was the birth and the postnatal period that were the hardest and I felt ignored/unheard

Participant with physical impairment

The postnatal ward was completely inaccessible to me. I was unable to look after myself or my baby there.

Participant with physical impairment

There were some positive comments about the post-natal period and these suggested that listening to the individual rather than 'dictating' practice was valued. While one participant described care as good, she also described being 'smothered', which she assumed was due to inexperience, suggesting that greater knowledge of disability would be helpful.

My health visitor was practical and gave helpful suggestions that would suit me rather than dictating how I should parent my child. I had different midwives visit... but all were helpful. Holding my own copy of my notes was useful.

Participant with physical impairment

Care was generally good. There were some things I would change, I felt smothered and not trusted but I realise this was more through panic and inexperience of my team rather than anything I was doing wrong.

Participant who is blind

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 high risk category. The comments also give some insight into how being treated differently was perceived. Some women saw different treatment as positive, they wanted and/or received different treatment to take account of their disability. Other participants said they did not want or expect different treatment and this could lead to them being treated less favourably.

I feel that my disability was largely ignored. I cope well but continuity of care could have been so much better last time. I had to keep going over the same things to different midwives last time. This time I have just one midwife and my consultant. They know me really well and it's so much better.

Participant with physical impairment

Only one person [treated me differently]: lady giving me epidural though I didn't understand her, and I was answering different questions as a result. In fact I do lip read, but during the procedure I couldn't lip read. She was frustrated and shouted at me. The midwife and my husband had to explain to her that I was hard of hearing. She calmed down... A little bit.

Participant who is hard of hearing

I didn't feel like I was treated any different most of the time which is good

Participant with visual impairment

I say yes [I was treated differently] in a positive way as everything was done to make my pregnancy and delivery go as smoothly as possible.

Participant with physical impairment

Yes while they do [treat me differently] they often don't know what to offer in support or even operate from charitable model which can be ostracising at times.

Participant with visual impairment

They should have treated me differently - to allow for my situation but didn't appear to.

Participant with physical impairment

At times it is right to be treated different. My disability is unseen and even when I signpost educate and explain, my needs are ignored.

Participant with physical impairment

Only 19% of women thought that reasonable adjustments or accommodations had been made for them. The disability of the participants did not increase their likelihood of being told that they would see the same care provider and just over half the women felt that communication was not good.

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.

People did not make the effort to look into my face when speaking which is what I need to fully see what they are saying

Participant who is hard of hearing

NHS letters such as scan aps all inaccessible

Participant with visual impairment

Other types of adjustments described by participants included better continuity of carer, so that participants did not need to repeat information about their disability at each visit, additional screenings if required, choice of birth options or a carer being able to stay in the hospital setting. Some participants described needing extra help to care for their baby.

My community midwife was really on top of everything and even slotted in extra visits when I went past my due date to give me extra sweeps. She was fab. No one else really asked what I wanted or presented options that weren't in guidelines.

Participant with physical disability

... midwife argued my case for a homebirth due to disability, familiarity etc, some weren't [providing reasonable adjustments] i.e. not being allowed to move in hospital

Participant with visual impairment

I did need extra help to be able to look after my baby as i couldn't get up of bed and walk. Baby's cot was too far from my bed and I had to rely on other people to help me (pass me the baby). We had to pay £120 for room with private toilet. I think this should have been given to us free of charge.

Participant with health issue

Allowed into birthing pool even though midwife believed it would slow labour down, but I knew if I could get off my knees it would help. So they felt they were humouring me but they listened to me.

Participant with physical impairment

I had my own room on post natal so my husband could stay but we'd had to travel a long way from home to get the appropriate care so this was a minor consolation

Participant with physical impairment

after giving birth I found it very difficult to stand and walk due to my disability I would not be able to do it on my own, the care I got in hospital was amazing they let my partner stay with me over night and we were put in a room with a double bed and en-suite so I would have everything I needed near me without any difficulty I could not have been any happier with the care I received

Participant with physical impairment

Continuity of midwife care antenatally. Accommodation of request for home birth.

Participant with visual impairment

When reasonable adjustments were not in place, participants' independence and dignity were undermined. For some of the participants with physical and mobility impairments, the reasonable adjustments could have been provision of accessible rooms.

None [no reasonable adjustments were provided]. I had to remain in bed because my wheel chair couldn't fit in the room. Totally removed my independence

Participant with physical impairment

Post natal should have given me a bed with wheelchair access. I should have had immediate access to toilet frame and bath or shower stool.

Participant with physical impairment

A quarter of women reported that they felt they were treated less favourably because of their disability. In addition, more than half (56%) felt that maternity care providers did not have appropriate attitudes to disability. These findings from the quantitative analysis are strongly echoed in the comments analysed, with communication and attitude or knowledge of disability being the most common and strongest themes that emerged from an analysis of all of the open-ended text.

As some of the women in the study described, the challenges that they faced were due to disability and these were not always recognised or managed appropriately. The lack of support due to disability in itself resulted in less favourable treatment.

If I were not disabled none of these things would have been an issue. I feel not meeting those needs means I was treated with less favour due to my disability.

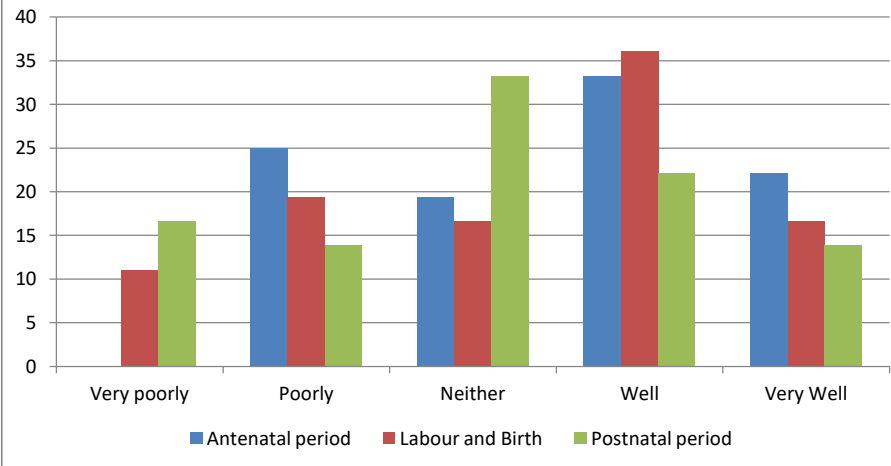
Participant with physical disability

I was told I couldn't have a water birth in case I couldn't get out of the water in a hurry despite demonstrating at 36 weeks I could do it unaided. This made me really cross as what would they do if someone collapsed in the pool anyway.

Participant with physical disability

Participants were asked how well they thought that their rights and their dignity were respected during pregnancy, labour and birth and the postnatal period. More than a quarter of women felt that their rights were either poorly or very poorly respected (Figure 3).

Figure 3. How well were your rights respected?



Participants were then asked to describe how their rights were or were not respected and several women described their choices over care being limited, that they were not listened to and that their suggested forms of support were not available. When analysing the text, it is noteworthy that the term 'allowed' is frequently used, suggesting a power differential where the service providers are in power and ultimately making decisions, allowing or disallowing women's choices.

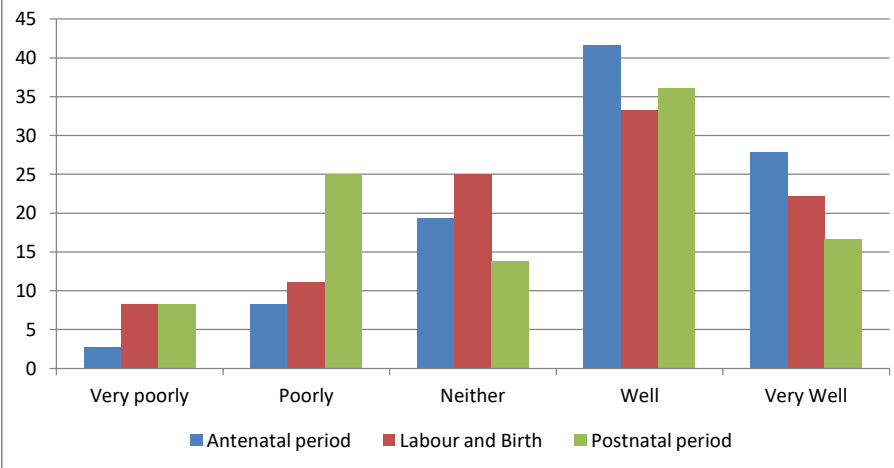
not allowed birthing ball, not allowed to walk around etc
Participant who is blind

I wasn't allowed to go to low risk centre despite my disability not affecting my capacity to give birth. Problems in pregnancy weren't addressed i saw a specialist but too late then needed my care transferring urgently but this took over a week introducing another significant delay and has left me with long term problems (daughter is fine). Because my problems were related to my disability I felt they weren't addressed with the same sense of urgency as with pregnancy related problems.
Participant with physical impairment

They would not allow my carer to stay overnight
Participant with physical impairment

Slightly fewer women felt that their dignity was either poorly or very poorly respected in the antenatal period (11%) or during labour and birth (19%); however a third felt that their dignity was either poorly or very poorly respected in the postnatal period (33%) (Figure 4).

Figure 4. How well was your dignity respected?



Dignity seemed to be interpreted as being able to make choices by some women. Other women described undignified care as when their individuality (and disability) was not respected and they were considered an ‘annoyance’ by service providers. The key themes arising from the perception of dignified care echo comments from the earlier parts of the survey: women want to be listened to, taken seriously and to have their wishes respected.

I felt that staff were annoyed by my requests, and that they behaved as if my physical limitations were an inconvenience.

Participant with physical impairment

I was treated as though I was being dramatic. The communication was poor. All of my options if there were any were not explained

Participant with physical impairment

I find being in a wheelchair means I am regularly not listened to. My husband or mum are asked questions instead of me. When the professional doesn't like what I have to say they looked to my mum or husband to put me in my place (at least that is how it felt).

Participant with physical impairment

I was told I was a health and safety risk, people didn't speak directly to me, felt smothered

Participant who is blind

How to improve services

Participants were asked to provide advice and suggestions for maternity care providers to improve the experience of disabled women during pregnancy, childbirth and early

parenting. The themes arising from this analysis again relate to the comments previously reported. Communication, particularly listening to the woman and respecting her wishes, her difference and that she knows her body and disability best were overwhelmingly the most frequent suggestions made.

Other recommendations could be themed as relating to: continuity of care, which was raised by many of the women; learning about disability and having a better understanding of a condition, particularly if it is likely to be exacerbated in pregnancy and to read women's notes. The below quotes are all from different participants in the study to provide general advice to maternity care providers.

Listen to what women tell you about what they want and ask them if they can do things, don't request them to. Don't tell them what the policies are without explaining how you can adapt them or why they are recommended in that way.

Listen to the patient - we know our bodies better than anyone else

Listen to patients who know their history and their bodies. Not everyone follows the rules of a textbook.

Listen to the individual. I know my needs and limitations better than anyone else

Ask on first visit what supports are required and put a plan in place to meet needs that is on file and reviewed and updated regularly which will be available to all health care professionals at the front of file. This will ensure that people with a disability are not constantly explaining their needs. Staff also need to be trained in equality and a rights based model to disability.

Remember every mum is different whether disabled or not.

Each woman is different as is each baby. If a woman says she's in pain she invariably is. Just because the general advice following a section is to be as mobile as possible that doesn't mean it is possible for everyone and just because some women feel very little pain post section doesn't mean that those who do suffer are weak or less deserving of your support. Please tailor your care accordingly and listen to what you are being told

Research medical conditions before you try to treat. If you are told something about the individual's needs/condition, make a note of it and ensure all are aware. Do not say you know what someone feels or needs unless you have been in the exact same position as them.

If a patient has a syndrome please have a quick google or look at the charity website associated with the condition. In 2 minutes you'll be able to see the main issues associated with the condition, which aren't always what you would expect. Patients know you are unlikely to be an expert in their condition, but they do expect you to know what it is.

They need to have more detailed understanding of the variety of disabilities or even have some equality champions who can be called upon to liaise with mum

Put yourself in my shoes and figure out how to help rather than follow the standard path. Make an effort to understand how my disability affects me - I'm not asking for extra assistance to be awkward but to try and create a circumstance I can cope with.

Think 'can do' rather than can't!

Some participants also noted that the staffing levels meant that there was not enough time to meet their needs and that for disabled women, additional support and appointments may be needed.

I think if the mother is experiencing any kind of difficulty they should automatically be offered extra midwife appointments and more emotional support.

To allow women to labour in their own time and accept that refusing drugs is not about being stoic but more about accepting sensitivities to chemicals.

Phase 2 - Interviews

Ten semi-structured interviews were undertaken with women with a range of disability experience. Pseudonyms are used and some detail about each participant has been omitted in these results to help to protect the women's identities. The results are presented by first introducing each of the participants and then describing the overarching themes from the women's narratives.

Participants

Ella

Ella is visually impaired and describes her experiences with the pregnancy and birth of her two girls. The second born died soon after birth due to a complex medical condition. It was not related to the condition which caused Ella's visual impairment.

Freya

Freya has a two year old son and works full time. She has a medical condition which is characterised by fatigue and she also suffered severe pelvic girdle pain from about 20 weeks' gestation. She is visually impaired and uses a guide dog.

Geraldine

Geraldine described her experiences of having her third baby at home for the purposes of this study (just a few months old when we spoke). She is totally blind. She booked late in the pregnancy to avoid having to decline features of care which she didn't want. She wanted to give birth at home.

Holly

Holly described her experience with her first child. She had experienced anxiety before she became pregnant and had a mobility impairment, describing pain with pelvic girdle dysfunction around the 20 week point of her pregnancy and received little and late support. She found she was unable to walk outside with her new baby son (now one and a half), which she described as causing depression.

Immy

Immy has had an arthritic condition since early childhood. She is very aware, from living with the condition about how it can affect childbirth (and she has some professional knowledge). She has a partner and they have a child of 2 and a half.

Jane

Jane has hypermobility of her joints and doesn't generally like to think of herself as 'disabled'. 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 elective caesarean section and was very fatigued in the early days after childbirth. She found pregnancy and breastfeeding to have a good effect on the MS and fed her son for nine months. She commented that care between the obstetric and neurology team was not 'joined up'.

Louise

Louise and her partner have three children, 2 boys and a girl (two of school age when most recent baby was born). Her second born child had heart surgery at six weeks old for a condition which was not related to her own disability. Her condition appears to affect only girls and starts around puberty. Louise has a physical disability but can walk and drive. She uses a buggy to support herself when walking and has an adapted car.

Mandy

Mandy had her first baby by emergency caesarean section and had to be transferred to a larger hospital for special baby care. She suffered badly from pelvic girdle pain and had crutches to get around for the last month of pregnancy. Unfortunately the PGP did not improve postnatally and she was unable to walk up the stairs in her home until she'd had several months of alternative treatment. She attends a Pilates class and a positive birth group regularly now and feels empowered by the knowledge she has gained should she decide to have another baby.

Naomi

Naomi and her husband are both disabled. Her husband works full time and the couple had a stillborn baby a few years ago. Naomi uses a wheelchair when she needs to due to pain and fatigue but can usually get around the house and upstairs. When her second child was born she found the social care system worked very differently from the first time. She was dismayed that she had to move in with her parents so that they could supervise her and her husband with their baby boy. He was then taken in to foster care. At the time of the interview he was back home with Naomi and her husband but it took a long time for bonding to be established because of the restrictions on visiting him during the foster care placement.

Comment [RB1]: from

Overarching themes relating to human rights and dignity

The prominent overarching theme that emerged from the full analysis of the interviews was that women's rights and dignity are maximised when they were listened to and their specific needs were understood and acknowledged. This is drawn from a range of sub-themes, which will be described below. These sub-themes include that good communication is essential and should be genuine and purposeful. Women need to be enabled to know what they want in terms of care; disability impacts on what women want for care and despite knowing what they wanted, women's wishes were not always acknowledged or implemented. Women most wanted to be understood and treated as individuals and there was much discussion about the longer-term impact of care – be it positive or negative – on women, well after the birth of their child.

While on the surface, many of these themes may resonate with non-disabled women, the participants of this research clearly articulated the difference that disability makes. For example, while listening is important for any woman, they explained how a lack of appropriate listening was specifically exacerbated by disability. Similarly, while they acknowledged that every woman may have specific requests during childbirth, they highlighted that their needs typically related to or are impacted by disability and so may be different from those of other women. Their views varied about whether they should be treated differently because of disability.

Listening and communication

All of the participants described the importance of being listened to. They wanted the option to discuss their situation, their hopes for their pregnancy, birth and parenting and to understand the options available to them. Women described examples of when they felt that they could communicate well with care providers and also the challenges and repercussions of when communication was not effective.

Some participants described the expectation that they would be able to communicate with care providers and that they would be listened to. Immy, for example, assumed that she would be listened to and treated respectfully, knowing that she has experience with her own disability, having experienced arthritis and the consequent limitations on mobility for most of her life: she feels that she often knows what is best for her body.

[My] expectation was that I would be listened to. I have had my disability all my life and know how my body works. (Immy)

However, Immy's experience was not as she expected. Rather, she was asked to physically demonstrate her ability to move in particular ways and get into positions in a manner that felt like it was just to make the care providers satisfied, rather than being for her own

benefit. Immy felt that she needed to demonstrate that she could get into certain positions to be accepted to have her child in the birth centre that she felt was the most appropriate place for her to give birth. She describes finding that this experience undermined her dignity. Immy also felt that she knew her body and had made a choice about the care she wanted, based on her understanding of the facilities available and what would enable her to be most comfortable. She described the conversation about her wishes and that this sense of not being listened to made her feel like she was incapable of making a sensible choice.

I think I left the room thinking 'is that the way you speak to everyone? Because it wasn't kind. I didn't find her kind, I didn't think she listened to me and I do think those things are important. Not just to women, to everyone. You want to be listened to; you want your healthcare professionals to listen. Like I was prepared to make reasonable adjustments for them if they could point out good reasons why I shouldn't go to the midwife-led unit, like that was fine. I would have accepted... the only reason that I wanted to go to the midwife-led unit was because I felt that it would be a good environment for me and I'd be comfortable (Immy)

Holly describes a similar experience to Immy: she felt that no matter what she asked for and no matter how rational her request was that it would be ignored by the midwives and she would be asked to adopt the position that they wanted rather than what she wanted for the birth of her child. The feeling was that she did not have control or choice in the decisions, and, like Immy, she felt that her dignity and knowledge of her own body was being undermined.

So and er you kind of think they're, they're the midwives they should know but certainly I did not feel respected, I did not feel erm that you know my that my wishes were being respected, that my dignity was being respected, that my erm physical limitations were being respected. And it seemed that they had their agenda, and I could have said... I wanted to give birth you know hanging upside down from the ceiling, whatever you know even if the latest research had said that that was the best position to give birth in, but they had the opinion that lithotomy in stirrups was best and it was as if I could have gone in asking for anything and that wouldn't have mattered. I would have ended up in that position anyway (Holly)

Several of the women described the feeling that their care providers did not give adequate time or attention to listening to them or hearing their information about their disability and the impact of disability on pregnancy, childbirth and parenting. While some participants acknowledged that some care providers were a bit sensitive or reluctant to discuss disability with them, others, particularly Geraldine, Immy, Jane and Ella specifically describe that it is more important that disability is discussed and an attempt is made by care providers to understand the women and the impact of disability.

though I think there wasn't an attempt to fully understand me you know? (Jane)

Kate described in some detail the wish that she had more opportunity to discuss the impact of her condition, MS, on pregnancy. She felt that she was listened to but the communication seemed to be with limited understanding of the potential impact of her physical disability. A challenge experienced by Ella was a lack of continuity of carer, meaning that she needed to explain herself, her eye condition and her medical history repeatedly. She describes that the health care providers did not even read her files so she needed to repeat herself multiple times, which was especially stressful as she was living with the knowledge that her unborn second baby had been diagnosed with a syndrome and she was being treated in three different hospitals/care centres. While she explicitly stated that she did not mind explaining about her visual impairment, she felt the focus on her visual impairment at every appointment was inappropriate when her priority in antenatal appointments was on her pregnancy and the baby. Thus it felt like the conversation was to satisfy a care provider's curiosity or to compensate for their not reading her medical notes rather than to meet her needs.

When care providers avoid discussing disability, this also causes problems because for most of the participants in this study, disability is ever-present. Geraldine is blind and has been blind all of her life. She describes how it would be better if she were just asked about her blindness, but instead she was told that a risk assessment was needed, with inadequate explanation of why this was being done, whether it was because she is blind (which is what she suspected) and what it was aiming to achieve. She felt that she needed to call the Supervisor of Midwives to seek clarification on the process, when she would have preferred an open, honest conversation with the care providers.

To be honest, by that point, well I would [have preferred to discuss being blind and coping strategies] if it had set people's minds at rest. Rather than having to make phone calls saying, well why am I having a risk assessment, what is going on? It would have been much nicer to just to be able to sit down and talk about things I think. (Geraldine)

Several of the women described not feeling like they were being listened to and really 'heard'. Geraldine was surprised to find that care providers seemed to be more interested in the paperwork than listening to her or asking how she was. She felt confident in her own abilities and decision-making as this was not her first pregnancy and so wondered if care providers assumed that she did not need or want any help, support or to be listened to. While she recognises that she chose to book very late in her pregnancy (to avoid the need to decline treatment or monitoring that she didn't want), she was still surprised with how little care or compassion was evident.

[I] was amazed at the amount of paperwork and the lack of care time that I got. Obviously it was my choice to book very late, but I was amazed that there was no "how are you feeling" none of that, and that really shocked me if I'm honest. So the midwife as I say she did the blood tests and so on and so

forth, but I thought “my goodness, no wonder people complain that there is no care anymore!” She really didn’t have the time beside the paperwork, it seems a shame... It was all a bit odd actually. She said they’d come and wanted to do the new-born check, and again there was no feeling of, we’ve come to see how you’re doing or how are you or congratulations, there was no niceness. They really didn’t sell NHS care my midwives! It was not good! They weren’t unkind or anything, and they did the new-born check and everything the care was perfectly good, but there was just no niceness. No “ooh how is everybody getting on” or “do you need anything” or “how are you feeling” or anything like that at all... None of them actually said “wow how are you doing after such a speeding birth” or anything because it was quite a big thing to have such a speedy labour, you know. My best friend lives at the other end of the road and she missed it! So it was quite breathe taking, and it was never acknowledged at all. (Geraldine)

Jane’s experience was slightly different. While she did not feel that she was being listened to or understood, she did feel that she had some control. She described the feeling that the midwives were just ‘humouring’ her by enabling her to have what she felt was needed for her care. When, in the course of the interview, she was asked how she felt about being ‘humoured’ she described not really minding, because at the end, she could access the care that she wanted.

was a bit lucky I think I got the ones I knew, you could tell they were humouring me because obviously they all knew how long my first labour was and then they actually broke the waters for me and then I got into the pool and even that they were saying ‘we’re doing this just to make you feel a bit better’ (Jane)

For some of the participants, the communication was confusing because it lacked purpose. Freya describes her experience below:

Well I was confused, I didn’t really see the benefit of her [Health Visitor’s] visit. It was generic, although she did probe a lot about personal things, nothing came out of it that was helpful advice, she just kind of went off with it. There were suggestions, again they were specific things about a baby which I already knew. (Freya)

Some of the communication that the women were seeking is quite basic, for example information on examinations or tests that would be undertaken during pregnancy or childbirth.

certainly, it sounds so simple, being listened to, so even when I, when I spoke with the specialist midwife and she was talking about the vaginal examinations and I said, you know, no-one has even explained how they are carried out (Holly)

Some of the women describe feeling let down when their understanding of the plans to discuss things of importance to them were dismissed or ignored. Holly gives an example below:

Even, even things like the birth plan and I, I remember saying to the midwife, oh you know, see for this week we're scheduled to go through birth plan and she was kind of, "oh you can if you want, it doesn't end up getting followed anyway". And it's kind of well it's, it's not so much about me saying I want to be wearing my pink pyjamas and having [music] playing in the background, it's really about the different pain killers and not only their effect at the time... it's I guess it's going through things one to one in more detail than the antenatal classes have time for. (Holly)

A point made by Freya, Geraldine and others is that communication needs to be meaningful and supportive of the women. Some of the participants felt that questions were being asked out of interest of the care provider rather than to support them.

When the health visitors, on the first two occasions they came to my house, and it was very much an inquisition I felt. It was lot of questions about... 'Was I capable of looking after a baby?' The questions were then quite invasive about other issues, em, alcohol and diet and..... I see why they ask those questions because in some situations the answers are something you need to be concerned of but it felt like a questionnaire that was there for everybody... That was really quite stressful and there wasn't anything I could do to make things better, I was in this mess and you know I kept trying to make contact and I didn't feel like that the appointments were beneficial to us emm on the whole (Freya)

Immy described an example of good communication, where she did feel listened to, respected and supported. The key element of this seems to be that the care provider took time to be with her and respected her – the language, as quoted in full below of 'she didn't fob me off' highlights her (and the other women's) need to be taken seriously and respected.

She sat with me, she did a full feed with me, she wasn't called away. She didn't fob me off, she came round straight away and she really listened to me. I said 'I don't think he's feeding' and she said 'well I trust you...let's have a look at him.' He didn't have his latch properly. She gave me that time, because she was listening to me, she encouraged me to move him a little bit and it sussed everything. I felt comfortable around her as well. I think a lot of the time....I have been in that environment where you've got a lot of different time pressures but actually feeling that someone is listening to youthat makes a massive difference. (Immy)

While there were some positive aspects to communication, many of the women described communication as being difficult, potentially due to a mismatch between their expectation that they would be listened to and their expertise and experience with their own disability being respected on the one hand and the reality of the communication that they experienced on the other. The narratives of the participants of this study show a frequent lack of caring or compassionate communication, where women didn't feel listened to or respected and where they felt helpless in the decision-making. However, there were also examples of where communication was described as positive, which are presented in the sections below, including when there was some continuity of carer.

Continuity of carer enables women to be listened to

As with the results from the questionnaires in Phase 1 of this research, continuity of carer arose again as a major theme from the interviews. It was particularly highlighted as an enabler of communication. When there was one carer, women did not feel that they needed to repeat themselves and explain their disability repeatedly – the antithesis of Ella's situation where she felt that she spent more time discussing visual impairment than her pregnancy. The women described that their human rights and dignity were better respected when they had continuity of carer.

Many of the women describe challenges with continuity of carer. While continuity of carer was not common in the area for Freya, one midwife enabled this.

I didn't have one midwife which was assigned to me but as soon as I met her on the first meeting and I explained about my eye condition. She was wonderful and she said, 'it's not normal in this area to have one midwife throughout but I want to be your midwife so you don't have to explain it every single time.' That was fantastic because it meant that I was assigned to her. She understood the condition and what it might mean. So that was great... I think it was against the norm and she was quite junior at the time, she has since moved to a more senior position, she just kind of went out of her way. I knew that. She was extremely busy and stretched with other patients, her phone was ringing off the hook, she had to be in different places at different times but she did actually make sure that locations were OK for me to get to so em she kind of tried to understand: could I get on buses?; how far could I walk?; she came to my house quite a few times. (Freya)

When asked about the impact of the one midwife, Freya describes her as essential and that the whole experience would have been less positive without that midwife doing something that was not the norm to accommodate her and her needs.

Yes, she was instrumental yes she was. I think if I hadn't have had that continuity, things may have been different. (Freya)

Others were not as fortunate as Freya. Lack of continuity of carer, as experienced by Kate, meant that there seemed to be less follow-through with any issues that she raised during appointments and few people took the time to understand or explain the impact of disability on pregnancy. She needed to explain her own situation and disability repeatedly, a situation similar to Ella's.

It was hard seeing a different obstetrician every single time. I think I saw 4 different obstetricians and some were more experienced than others, I mean a lot of them didn't really have much experience of MS at all because obviously not come across necessarily. There was one that was really good, he was really helpful and explained everything more. (Kate)

As highlighted above by Kate, another issue, alongside the lack of continuity of carer was the level of knowledge that the health care providers had of the impact of her multiple sclerosis on pregnancy, childbirth and early parenting. She described communication as being challenging because the neurologist and obstetricians did not seem to speak to each other. Thus, she did not feel that her care was 'joined up'.

The most challenging aspect of care for the women seemed to be post-natal care, where all of the women describe negative experiences, including a lack of continuity of carer – not only seeing different care providers after the birth but seeing different providers at each visit.

Some things are improving but just on continuity for afterwards I didn't have one health visitor, I didn't have one midwife or breast feeding person. I probably saw about 20 people in the first two weeks and that was just chaos... Very haphazard yeah. Very disappointing, frustrating,. With everything else you have to deal with em, hormonal. You just need a system that works, not one that is painful and, and frustrating to get to, so I think, I am a patient person and I did what I could to find help for myself while appreciating that the system was limited but it really failed me in the end. Well it didn't because I didn't let it but if I hadn't have gone elsewhere I would probably have stopped breastfeeding at about three weeks. Just by not having the knowledge of how it could be improved.(Freya)

Freya and others highlighted the 'chaos' that having a range of carers after the birth caused. The significant finding – which should be a warning to health professionals – is that this range of carers meant that some women felt that it was not worth raising any issues or concerns with care providers because they may never meet them again and because the visits were so short. This must raise questions of safety of practice, particularly when the women in the study are disabled.

absolutely and there's really no point telling them for just that 5 minute appointment and they've not got time and you'll never see them again. (Freya)

There was limited understanding of disability and this can cause problems and exclude women.

Several of the women described a lack of understanding of disability and its impact on pregnancy, childbirth and parenting (and the impact of pregnancy on pre-existing disability). All of the women described being happy to discuss disability, but some also wanted the care providers to have information to support them. Some women, such as Kate, felt that she needed to find out about disability and she needed to make decisions and had inadequate knowledgeable support for this. Geraldine discusses the importance of meeting or talking to other disabled mothers so that advice and experiences can be shared. Jane and others describe that they felt that the lack of understanding of disability made her feel that the

care providers were unaware or did not adequately acknowledge disability and its potential impact.

have more advice instead of being left up to you, as opposed to making up your own decision and not giving you a lot of advice sometimes (Kate)

umm I think that they just maybe, not as such I don't think they truly understood that I had a condition... I don't think anyone working with... I don't think it is still very well understood. I think it's seen as double jointedness you know sort of thing, it was like get in any position you want, the problem is that it is not a thing position really. I don't have the strength to cope with that... I think they just didn't understand how limited in movement I was umm I couldn't really make much of a fuss really because I didn't really move very well (Jane)

It's a very rare condition and I don't think they quite understand what means it and the main symptom for me is tiredness That's what they were most worried about. Not being able to sleep during labour. I need more sleep than most people due to how the condition affects me. That's another reason I wanted to be in my own space, in my own home because that's where I sleep the best. I couldn't visualise being somewhere that I wouldn't be able to sleep. (Freya)

Kate suggested that there should be someone specifically who has a knowledge of both pregnancy and her condition, and she made the point that multiple sclerosis is relatively common and so there should be a level of knowledge about it.

... to have someone with more knowledge of MS in pregnancy so you can say is this normal or why am I feeling like this or what is this and someone can say well yes most women with MS find that, it's like what should I do, am I better off with a caesarean or should I try a natural labour, it's like everyone is different, do you know what I mean, they tell you what they think.. they could look at your symptoms and what sort of problems you have, like I've got leg weakness and fatigue they will say that because of that I would suggest having a section, someone to give you an honest view really in about what they know from other women that have had MS and had babies. Someone really who could be like a port of call, like a font of knowledge who would have more experience, and tell you about other people maybe... some tried to discourage me from having a caesarean completely without appreciating with what symptoms I have to put up with and actually physically being able to do it. It was hard with the whole MS thing, it would have been useful to see someone with more experience in this than actual childbirth, no one could say to me those that have MS are ok and I think in my experience all the women that I spoke to... because you know, it's not that rare a condition but I didn't seem to meet many people that had known a lot of women who had actually had MS... I find it strange that MS is such a common condition, that women have pregnancies, that there isn't more stuff out there about how it affects women when they're pregnant (Kate)

The lack of knowledge or understanding of disability by staff sometimes seemed to have negative implications for participants. Several participants described negative attitudes or assumptions about how they would be able to manage pregnancy, childbirth and parenting. As Geraldine described, this can be any member of the multi-disciplinary team and is often due to not even being asked about disability.

midwives tend not to be the ones with concerns about our ability to cope if we are blind or visually impaired, but having said that, I think sometimes there is that unspoken thing, and as I said, she never actually asked me about it. She never asked me about my blindness, as far as I know. I think she might have asked me how long I've been blind, but I can't remember now you know. (Geraldine)

When health care providers did ask about how women will manage parenting, particularly when this is done in an open and supportive manner, it could be really helpful for women. For Louise, this was done early in the pregnancy and additional equipment for home was provided.

I think it was my tenth week, my first booking err I had to explain about the disability and they did ask then if I needed any extra aids or what would make me happier umm to feel safe when the baby was born at home that's when I mentioned it then... yes, yes I was very happy with it err because obviously, they were making sure that I felt safer in the house and if I didn't know who to ask then obviously I spoke to them and made sure it was done for me (Louise)

But I did find it a positive for the midwife from the cottage hospital, after my eldest was born, none of them were in doubt about my ability to manage. But when I was panicking, they were very much like "oh no you'll get the hang of everything, do not worry" They were very very encouraging. (Geraldine)

Geraldine's advice was for health care providers to listen to disabled people as experts while at the same time recognising that people are often new mums and so don't know how to care for a baby. She also highlighted the importance of reassurance.

I think they really need to be, they need to be looking to the parents themselves as the first, listening point, if you like... at the end of the day, particularly someone who is long term disabled they know more about what their needs are, than, you know the people who are going to be coming into quite brief contact with them. So I think always refer to what they need. What else would I give by way of [advice]? I think to offer reassurance, even though you're not the expert, so I think one of the things I definitely found was an issue with my first baby, and I've heard other mums say since, is when you, so my midwife was very good support, very nice but she was the first to say, 'I don't know anything about blindness, you know, you'll have to tell me what you need, you'll have to tell me how to do things'. Now there is kind of a feeling though amongst those of us having a first baby, that especially with anxiety being raised during pregnancy, will you just go "but I don't know how to do anything! How do I know when I've not had a baby before" and there is almost a real frustration there, so even when health professionals are doing that thing of saying, you're the expert, you tell us how to do things, there's actually a bit of a sense of "hang on though, I haven't done this before, I need some input from you" Actually some reassurance is really great, you know. I think my cottage hospital was the first time around, I remember saying "I can't go home, I haven't been taught how to bath him" and the senior midwife laughed and said "you'll be fine, you don't need to be taught, there's not one way of bathing a baby you know" Now for me **now, that is stating the blinking obvious, but, you know, that was new at the time!** (Geraldine)

Disability influences what women want

The participants described how their disability experience influenced what they want in terms of their care and also the birth that they felt would be most appropriate for them. These differed between the women, highlighting the difference and individual needs of our 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 antenatal care should be tailored to women's needs and not just about giving birth but also about looking after a baby as a disabled parent. The participants had mixed experiences of antenatal care and classes.

those classes were really around birth and one on breastfeeding. Certainly those were good classes. I was very much included in those, but they didn't include anything on actually looking after baby which was the main concern. (Geraldine)

Some of the women, particularly those with low vision, described the need for antenatal classes to be in accessible locations that can be accessed by public transport. Other women described the physical inaccessibility of buildings as limiting their access to antenatal care, particularly classes.

Freya wanted to be in familiar surroundings both for her antenatal care and also for the birth of her child because her visual impairment meant that she was less comfortable in different places and also needed to use public transport to get to appointments. She also considered the importance of locations being easy, due to fatigue being exacerbated by the need to travel. If she were to describe 'perfect' maternity care, she recommends more appointments at home.

Throughout my life I have used different visual aids but it's not the kind of condition which they seem to help its manage my own tiredness really. I suppose the only thing would be transport issues to have future appointments at home, that would be the only thing that would help really – the travel basics. (Freya)

Jane described how she was actively excluded from pregnancy yoga because of her hypermobility and the class leader's inability to cater for her.

I went to pregnancy yoga you know you're recommended to do all these things err since I was doing some stretches, I remember this so clearly, she was freaking out. I think it was a midwife led sort of physio thing umm she asked me not to come back umm because she said it wasn't for me and I think

what it was that I over stretched and was worried about me injuring myself. Rather than saying that to me, she could have given me some advice really and given me some exercises that would have strengthened you know the joints that were at risk. I think it was just a misunderstanding about what it [hypermobility] is (Jane)

Jane didn't go back to future classes and felt that she was missing out on social networks and opportunities to meet other pregnant women as a result. Jane described that she felt singled out and made to feel different.

Ella and others describe a lack of attention to her specific needs, or even a lack of questioning of what may help her. Despite her visual impairment, she was not offered information in an alternate format, such as large print, or any support ante-natally for either of her pregnancies.

if they had offered, you know if they had said to me – do you want, emm, what, do you need any facilities, do you need any different access to paperwork or whatever. On your first appointment they give you a folder full of leaflets for different things. They didn't ask me did I need it in large print, or on CD or anything like that. They just kind of give it to you. If they'd said to me 'do you need this in large print?' I would have said, I would have liked that, there wasn't an acknowledgement that I was an individual person (Ella)

Ella linked this lack of asking for what she needed in terms of access to not treating her as an individual. Throughout Ella's narrative there is a constant explanation that she felt like she was a 'body' and not treated as a person or as an individual, this was particularly in her ante-natal care.

As has already been described, Immy felt that her antenatal care was undignified because of the way care providers communicated with her and particularly because she was asked to demonstrate her ability to get into particular positions.

that particular doctor, wouldn't take my word for it and actually called me back for another one just to make sure that it wasn't like 'a fluke' on the day that I could do it and I just found that I said, I remember saying 'I'm a grown woman' (laughs) I know how my body works. I just felt I wasn't being very well respected at that particular moment in time. I was being asked to demonstrate things (Immy)

Louise had a different experience. She was thinking about what options were available to her in childbirth and was unsure of what would work for her, given her physical disability. She describes having a conversation with her midwife and then being facilitated to find out whether she could physically use different facilities, such as the birthing pool. This, she feels, enabled her to make an informed choice for herself. It contrasts sharply with Immy's experience: rather than being asked to demonstrate her abilities, Louise was provided with the opportunity to try out and decide for herself what may work for her.

my midwife is brilliant, I wasn't sure whether I could get in or out so she actually arranged for me 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 if I could comfortably get in and out. They were brilliant, I went for it and it was fine (Louise)

For Louise, antenatal care also was more than just consideration of how she would give birth. She was also enabled to consider how she would parent and if there were any adaptations to her home that would help her once her baby was born. This enabled her to feel more prepared. It was also one of the narratives that described multidisciplinary team members (an occupational therapist in this case) being involved.

I have an occupational therapist that put an extra banner [bannister] in for me on my stairs because err to make it safe going down and they made sure that was done before the baby was born as well (Louise)

'Risk' and monitoring

I have realised now how much we are, em that we're not ALLOWED that's the word that keeps cropping up. That we're not allowed to have the birth that we want to have and if you add genetic histories or if you add disability you are funnelled off into this controlled sort of manner, you know, and it's 'oh no' you're pushed off and it's, in other words 'we don't know what to do with you... you're a bit different to what we're used to dealing with so we are going to put you automatically into a high risk category' (Ella)

As Ella describes above, some women were concerned that disability automatically resulted in their being treated as 'high risk', a feeling that was echoed by other participants and indeed one of the reasons why Geraldine decided to book late for her care.

However, the idea of 'risk' seemed to be confusing to participants. While some women felt that they were being categorised as 'high risk' they were not necessarily clear about what this was or meant and some underwent risk assessments either during pregnancy or after the birth of their child without understanding why these were being done.

my named midwife, wanted to do a risk assessment, and I am assuming that that is because I am totally blind. But I never got a straight answer as to why she wanted to do that risk assessment or what that would have involved. I never really found out what this risk assessment should have entailed, but I'm assuming that it was because I was blind, but I didn't ever get a straight answer. And she came out and made a point of telling me that, were we aware that it was illegal not to call them, which obviously I'm aware is not the case, but I hadn't said at any point that that was what I intended to do anyway. So the whole conversation was a little bit odd, I must say. (Geraldine)

Kate also described having her risk assessed and additional monitoring of her baby, which she assumed was due to her disability. She seemed unclear about what risk was being assessed and just makes the assumption that, because of her medical condition, she needed to be more careful. What is striking about her narrative about risk is that she was unclear, she didn't know what risks were and nothing had been explained to her.

Yeah, I guess I saw it as a bit of a medical thing, I don't know, it isn't really is it, its natural thing that tends to happen at home and stuff, but when you have a medical condition you need to be more sensible sometimes, I don't know really. Everyone is different, someone else with MS may not be so bothered by it if they don't suffer from fatigue... (Kate)

In a previous pregnancy, Louise had a child with a heart condition. She described that this meant that she was offered additional monitoring for the pregnancy and the risk was higher. For Louise, this was highly positive, she wanted additional input and support, she remained in control and was glad that this monitoring was available.

I had the choice umm right from the beginning and I always got asked if I was happy with the decisions and I was the one that actually asked for the close monitoring because obviously I didn't get that with the second child and they didn't actually tell me but as soon as I told my midwife about the condition of my second child umm she gave me the options and umm discussed with me that she would like me to have close monitoring and I was very happy with that... [It made me feel] much more relaxed umm knowing that if I had any worries then they will always be on the other end of the phone. I didn't have to wait around for any answers or anything (Louise)

As Ella's second child had significant health issues (and died at 12 days), she had significant monitoring and this was very different from Louise's experience. She felt that treatment was undignified and that she was not treated as an individual.

While Louise's experience was due to her older child's health issue, it differs significantly from Geraldine's choice. She deliberately booked late to avoid monitoring and intervention that she did not want. Thus, with our small group of women, their needs and wishes were markedly different, the common factor is that women wanted to be asked what they want and for their choices to be respected.

Giving birth

Disability may affect where women want to have their baby. For some (e.g. Freya, Geraldine), a homebirth was thought to be a better option due to disability and feeling comfortable in one's own surroundings. Others wanted to leave the hospital setting earlier than normal to get back into their own home and surroundings (e.g. Immy and Mandy), whereas others (e.g. Kate and Louise) asked to stay in hospital for a longer time to use the support available to recover.

All of the women described ideas that they had for the birth of their babies. These related to whether or not to have a caesarean section and if they were planning a vaginal birth, what position would be most suitable. They also considered the place of birth. For some women, disability made it more likely that they would have a caesarean section, for example, Kate was concerned about fatigue during labour and Ella was advised that pushing could cause an increased risk of detached retinas. The women described that while they wanted to know about risks, they still wanted to make their own decisions about childbirth and Ella described being aware of the risks but deciding to have a vaginal birth for her first baby. She described this choice as being difficult and the power as being with the care providers: in the narrative, she repeatedly used the word 'allowed' to describe options.

Near the end of my first pregnancy... I had a doctor ask me about my general medical history. I know a lot about the genetics of my condition, there's a lot of family history, it's quite prevalent visual impairment in my family and deafness, by the way, with my husband. On my charts it was mentioned that we had, you know different disabilities in the families and he asked me 'was I going to push?' and I said 'what do you mean by that?' He said, 'well, you have [eye condition], are you going to have this baby yourself? That's the plan I said, I would hope so... and I said 'why?' And he said: 'In my country' (we would have an awful lot of different nationalities of doctors) he said, 'you have [eye condition], in my country, you wouldn't be allowed to have a natural delivery'. What do you mean 'allowed' I don't like that

Interviewer: That's an interesting word, isn't it?

He said, you are too much at risk of having a detached retina. Pushing would put too much pressure on your eyes.. It was noted on my file, basically that I was going to go ahead and have a natural delivery if I could and that this risk had been explained to me but it never crossed my mind up to that point, it wasn't something that I had been even aware of. I checked it out and yeah, there would have been a small risk but as I said that didn't end up being the, he was the only one during the time that ever brought it up. (Ella)

Many of the participants described the impact of disability on their sensitivity to medication. For some, they felt that this was not well recognised by staff and that they were considered 'difficult' or just wanting an ideal birth without taking their possible reaction to medication seriously. Jane described how she would not have accepted medication if she had understood its effect, suggesting that she was not fully informed to give consent.

I took the umm [medication] I nearly threw it back up but then because I wouldn't allow to go into the pool because I can't go into the pool within twelve hours of having this medication, now if that had been made clear to me, I never would have taken it (Jane)

they very much treated me as someone who was very stubborn really and I think the thing about your first time you know is that you did a lovely birth plan, you bring the music that you want and everything and it rarely would happen and I think that is the kind of attitude, it was that they felt that I had this kind of complete birth plan in my head of how I wanted a natural birth. Well I wanted a

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, it's annoying that I can't 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 side um 'cause I found those positions I wouldn't say comfortable exactly, but um at least OK to manage um... I ended up on my back in the lithotomy position with my 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 and that was working well for me. I thought it was working well enough for the labour [I: um]. They disagreed. They said they thought it was a terrible position and that being on my back was the best position... I needed to choose the position that best suited me, but I wasn't listened to (Holly)

Jane needed to be treated differently because her physical disability meant that she couldn't get into the positions that were needed, she wanted the opportunity to discuss options and for the staff to understand the potential impact of disability on her ability to give birth.

we need more awareness that this condition affects pregnancy really but also the different kinds of umm I think people with that condition need a little bit more aware that they are at a disadvantage they need to ask you know (Jane)

Increased monitoring or intervention during labour was perceived differently by the women: for Louise, she felt that because she was always asked if she consented to monitoring, she felt in control and more confident, Immy, on the other hand, felt that it limited her mobility and caused her problems but didn't feel that she could withdraw consent.

Post-natal care

Following the birth of their babies, women described different experiences. For those with a physical disability, such as Louise, she needed to have a room where her partner could stay so that he could provide support with her personal care. Some of the women who gave birth in a hospital or birthing centre needed en suite facilities or accessible rooms; this was not always possible. Another common feature was that women described the need to ask for what they wanted and needed, and sometimes these requests were not thought to be well received.

umm no, all I would just say is that if you feel like you need the extra help or anything that you need just make sure the staff know because I had to tell them when after I gave birth umm if I had to stay

in, I wouldn't because with my disability there is no way I would have been able to get up and walk to the toilet and being in my own room on my own and after I gave birth they actually let my partner stay with me because umm I needed his care after birth because obviously it was very difficult for me to walk and they made sure I had an en-suite room with the baby and my partner to stay in one room and which is absolutely fantastic and if I didn't tell them I wouldn't have got that (Louise)

Yeah, I think, not that I made a fuss, because they weren't too bad but they were a bit begrudging about letting me stay in longer I was a bit annoyed but I was like "tough" really because I knew that it would be better for everyone... because of my little boy and my husband if I could just stay there a bit longer it just, you know, it's a big op to get over, and having the breastfeeding support there as well I really needed that because that was really, you know, that was hard work, because not having someone, luckily my mum was really helpful, but not everyone has that, when I got home she helped me with that. If I had come home sooner, if I hadn't had her there I would have probably given up breastfeeding because it was really hard. (Kate)

Parenting

Several of the women, most notably Geraldine, described the importance of seeking advice from other disabled people about parenting skills, rather than asking health care providers who may have unhelpful attitudes towards disabled people being parents.

you're not always having to re-invent the wheel. So sometimes it's just easier to ask another VI [visually impaired] parent how they do things. It is just quicker to ask another VI parent what pushchair to buy if you want to pull one, that is much quicker. (Geraldine)

Some participants described specific support that they needed, notably, as with the survey results in Part 1, the women who are blind or visually impaired described needing support with breastfeeding, some of the women with physical disability described needing – but not always receiving – support to enable them to physically manage, such as additional rails or support for feeding their babies.

Social support was important for many of the women. This was highlighted by Kate. She describes not receiving enough information about what support is available. Likewise, Holly also describes a need for additional social support, particularly when physical or sensory disability means that it is more difficult to access the typical new mum activities.

And it is frustrating because I can't physically do like, I can't just rush here, rush there, put him in the car, go off here, take him to this place, that place, I just haven't got the stamina or energy to do it all, so yeah it has like impacted on what I thought it would have been like (Kate)

A recurrent theme is that women felt that the care providers were inadequately informed about disability and that the women themselves were not listened to or understood. Naomi's narrative focuses largely on her experiences after the birth of her child (who was taken into care). She described not being listened to by social workers who made

assumptions about her and her husband's ability to manage, due to disability. She described being asked how she planned to manage her child in years to come, which she does not think would happen for a non-disabled couple. She called for women to be listened to rather than judgements being made about parenting ability.

the first thing they can do is actually listen to the parents, not listen with their agenda. Listen to what they have planned and what they are going to do because the parents know and have worked it out. They have looked at the fact that they can't do X, Y and Z. As a disabled person, everything in your life is planned out, you don't just jump or am gonna go such and such a place but think I would like to do such and such but when is a good thing to do, you have to plan things out in a much bigger way... Not once did they listen to a word we said and I always went in with an agenda they haven't told us about. You've showed them everything you think they want to see and you think they are happy, oh bloody hell, you didn't say that before what you were looking for, I would have showed that to you when you were around! Now, you weren't around and you didn't tell us what you were looking for and now you pretend you didn't see it! It's really crazy the way they work the system... we had gone to the pram shop ourselves, if we could have chosen the pram that we could actually use, handle and manipulate. We spent three hours in a second hand shop and we got one that is suitable for us. You don't just go into a pram shop and just buy a pram when you're disabled, you go into a pram shop thinking can I manipulate the handles or not, can take this off or not, is it easy enough for me and then does it stretch too far? You check every single thing when you're disabled (Naomi)

Women need to know what they want and need

Many of the participants described the importance of knowing what they wanted in terms of care during pregnancy, childbirth and early parenting. Some described the process by which they came to understand what they wanted. For some women, this was based on their previous experience (e.g. Geraldine) and others describe doing a lot of preparation including seeking information on the internet (e.g. Freya). A common theme across the narratives is that for the human rights and dignity of women to be respected, women need to be empowered, informed and enabled to know what they want, make choices and then be supported to enact those choices. This theme links very closely with the initial overarching theme: to enable women to make informed decisions, good communication between women and the health providers is essential. Some of the women described the need to be pro-active and even fight for what they think is right for them.

I think a lot of that was due to my own attitude towards what I wanted, and being aware of what I wanted. It wasn't necessarily always emm offered (Freya)

Yeah it's getting to a point of unless you are going to fight, for. first of all you have to know what you want. I think certainly for the first pregnancy the majority, I want a normal, natural birth. We're so heavily medicalised that my local hospital has the highest c/s rate in the country for first time mothers. Over 30%, add a disability to that and you are almost certain to end up with a section. So

yeah, I think it's a lot of: you need to know what you want before you get pregnant and then you need to have it all lined up. It's constant pushing for choice when we shouldn't have to. (Ella)

Some of the women described needing appropriate information to make choices; they needed to know what was available. A lack of information seemed common among the women. Ella emphasised that it is important to have choice, and that means having someone to explain all of the options.

I'm 'pro-choice' let people have the choice. That goes across the system though. To have the choice to have the care that you want, to have the choice of having the same midwife or the same doctor if that's the way it's going to be. Em to, like, I remember my first pregnancy ... it was never said to me like 'do you know you can have a home birth?' (Ella)

Knowing what they wanted enabled women to clearly articulate their wants and needs and have confidence to ask for what they want. Women did this differently, and describe what they feel were negative reactions as a result of their attempts to articulate their desires. Geraldine probably is the starkest example of how she made it possible for her to have the pregnancy she wanted. She deliberately booked late, purely to avoid the need to refuse interventions that she did not want.

I booked at 32 weeks, because I didn't really want standard antenatal care, and I felt like the easiest, and I was very well, I had obviously had 2 very straight forward pregnancies before, so I kind of, there were no health issues, and I felt like, it was easier to book late, than book early on and then start declining care here there and everywhere, so I didn't have to decline each scan that I didn't want to have. I was very much of the view that I would see how it went and if I had any concerns at all I would go in, I only had 1 scan in the end, which was very early on. And I would have gone in if I had had a concern but I didn't, so it seemed to me what I thought I would try doing, is just book very late, so I didn't spend my entire pregnancy saying "thank you, I understand and know you recommend it but I don't want it" just didn't have the energy to argue the toss. I didn't feel strongly enough about it to make a point, I didn't want to argue the rights or wrongs of doing scans or anything, I just didn't want to have to buy into that, so that's why I decided to book very late. (Geraldine)

Ella and Kate described the need for some form of advocate. For Kate it is someone who understands disability and pregnancy, for Ella, it is just someone to provide support in the 'fight' for what she wanted.

it's like there's no one there to hold your hand for want of an expression. There's nobody there in your corner, it's up to you. If you are a strong enough person you can fight it but if you're not, you're just going to roll over and let whatever happen and that's only during pregnancy. I mean it gets worse when you get to the hospital to have the actual baby. I mean, you know it's a very confusing, lonely sort of a time unless you have a perfect...picture perfect sort of a pregnancy when you can stay with kind of not having to go near the consultant. (Ella)

Some women had had more than one pregnancy and so it was easier to know what they wanted on a second or subsequent pregnancy and birth.

I was a lot more sure of what I would allow and wouldn't allow basically having had previous caesarean and umm so when I had my second child my labour was very different in that umm I was so much in control of it (Jane)

Previous experience enabled women to be stronger and more able to articulate what they did and did not want, e.g. Jane and Geraldine. Jane asked for the pool and was more aware of the impact of certain medications.

Despite knowing what they wanted and how best to manage their body and disability, some women didn't feel like they were listened to, which again relates to the need to be strong-willed, to 'fight' and again highlights the need for good communication.

yes, I think that in any situation, I think that sometimes, unless you do search around though, it's easy to maybe not get what you think you should have, like the staying in hospital thing or deciding, you know, I think I could easily been swayed into not having a caesarean, because that was what they were trying to lead me towards not doing, I think like if someone is not a bit strong willed or something they might easily end up doing something that they are not 100% comfortable with (Kate)

I was so adamant because I wasn't going to have a baby in a big hospital you know, I fought so hard even when I got there it was just like okay will see how far you go you know you almost have that ambulance on speed dial (Jane)

Freya described needing to stand her ground to get the homebirth that she wanted – and she recognised that there were staffing issues that jeopardised her want for this. Freya described a feeling of pride at being able to have the birth that she wanted, because she could stand her ground and stay calm.

when it came to being in labour the practicalities meant that, for an awful a long time the hospital couldn't actually send any midwives out because they were over-stretched on the unit so If I hadn't been so clued up and calm myself, about the hypnobirthing techniques that could have been a bit of a stress because I would have had to go against everything I'd wanted and the reasons for wanting that. the area was affected by such huge resource issues - they did actually send one in the end. They told me to come in but I stood my ground and said 'I'm not coming in, there's no reason for me to - I want a home birth and you knew this in advance, so if we have to do it on our own then that's what we'll do'. I think that, I don't know, it felt right in the end... I'm really proud that I ended up with the birth that I wanted and even if there had been changes to what I had planned in my head I think I would have still be comfortable with it. But I'm glad I had confidence in my decisions and that I wasn't afraid to tell people that that was what I wanted. Even at that hat last minute, when it looked like no one was going to come to my house. (Freya)

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.

So I think, I think it's a kind of basic treating each woman as an individual and they see 5 women in the same clinic with oedema, they're all, you know, one may not be bothered about it, one may be really worried, one may be just mentioning it because she thinks she should, they present with what to you may seem the same symptom, but unless you find out if they're concerned or not, or whatever, then you don't know how to respond (Holly)

she took the time to understand me as an individual and not necessarily just 'go through the motions', 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 pro-active 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 pro-actively because that was not 'standard' practice. When she then needed additional support after the birth of her baby, there was a waiting list and the support was less effective. As described by Freya, Holly described challenges with support or plans being due to financial restrictions or shortages.

I think it would have been a case of we're going to put these things in place for you. If you don't need them, that's great, but they're going to be there if you do. And then that would have been an individualised approach, it certainly would have been patient-centred. And not,. I felt very much like, you know the financial part who decides things are just not only are they nameless and faceless to patients, but patients are completely nameless and faceless to them. (Holly)

Some of the narratives describe good care, with the perception that all women, regardless of disability were treated as individuals, which is described as the ideal situation.

the staff were brilliant and they just treated everybody as individual and how they were (Louise)

In some of the narratives, there was discussion about whether individualised care means 'different' treatment for disabled women, and there were a variety of views expressed. For Ella, she felt that having a disability meant that she was immediately seen as different and, as she explained below, 'seen as less of a person'.

if you have a disability, I think it makes it worse because you can be seen as less of a person, you know when you have a disability. First of all you're seen different obviously I would say you're seen different but then for whatever reason they make assumptions and they assume that you are higher risk or that you are, that was a silly thing you did – and got pregnant. How could you put your, how could you put any child through that? (Ella)

Ella raised a concern that if she declined support that was intended for a person with low vision (such as provision of information in large print) that the assumption would be made that this is not useful for any woman with low vision, so she felt that she would need to accept additional support just so that it could be considered for other women in the future. So, she highlights a situation where she feels that all people with low vision are considered similar and she felt a duty to accept support – whether or not it was actually useful to her – because of concern for others. While this was not described in detail in any other narratives, it is a common topic of debate in blind and disability communities.

I might decline them and say 'no, thanks that's OK'. Or, I might take them up on it because it would be, if I don't take them up on it are they going to not have that facility any more for somebody else coming behind me? That's often what they do – they do 'trial runs' of things and if there's not enough uptake they drop it. (Ella)

Longer-term impacts of experiences

The women described the longer term impact of their pregnancy, childbirth and early parenting experiences. Those who were primarily recalling their second or subsequent pregnancy for this research, did describe the impact of their first experience and how they wanted to change things to enable them to have a better experience the second or subsequent time.

Mandy described her experience as being so negative that she feels that she would not be 'brave enough' to have another baby, and if she were to, she would want to avoid a hospital setting.

if I am ever brave enough to have another one, I think my mother and my husband would kill me but I would rather a home birth because I just don't want to be on that postnatal ward again and that's the best hospital and it's got the special baby care unit in it you know err the thought of giving birth there doesn't necessarily scare me but the thought of being there and being stuck there again and now this time not being able to have my husband stay with me and being at the mercy of whether or not I get you know, a compassionate midwife or not is not my idea of fun (Mandy)

Jane too had a challenging first pregnancy where she did not feel that she was treated well, but she reflects on her second pregnancy. Because she had her previous experience, she was able to advocate for herself and that feeling of self-advocacy was positive for her long after the birth of her child. It seems similar to Freya's feeling of pride that she could be in control and make decisions.

It seems that, from a psychological perspective, the women that felt that they had control and made choices and decisions could take some strength and pride from their experiences, which were positive after the birth of their child. Those who felt that their rights, dignity and decisions were undermined describe that feeling of being undermined as lasting for a longer time after the birth of their child.

For some of the women, the experience of their physical disability and the reactions to it during pregnancy and particularly childbirth also had longer-term effects. Jane describes that following her first experience, she felt the need to re-evaluate her attitude towards her own body and her disability following childbirth, she describes needing to take more care. She describes losing confidence in her body. This was partially regained in a more positive second experience, but the impact of her first birthing experience and a loss of confidence in her physical abilities remains. She has also changed her attitude to seeking assistance, when she is now more likely to ask for support.

it [first pregnancy] totally affected my confidence but I think it also made me realise that because am quite a people person [and did not consider myself as 'disabled' you know, I don't like to cause stuff or anything but I think it did really make me feel that, no, I have to actually acknowledge you know that this is the way that my body works and be a bit more careful (Jane)

So, she had entered her first pregnancy not really considering herself to be 'disabled' (despite having a very recognised disabling medical condition, and through this experience, she realised that she did need some things to be done differently and that she needed to self-advocate, regardless of the consequences of this. Jane's second experience was much more positive.

absolutely, I thought I could do anything after that... Well to be honest I felt this one well I would like to come here again if I did have another one, never having slept on my back as well, I still felt typically there should be some bit of caution really you know and I felt like for other than that, it was a completely positive experience. It was very good because they rang me up straight away after the birth which was had lavender or something in it. It was all very very gentle and it's what my body needed (Jane)

Holly felt that she had underestimated the impact of childbirth on her body and the limitations in her mobility. She feels that she was inadequately prepared for this. The greater impact for her also seems to be that the physical limitations also constrained her social involvement, which caused problems 'emotionally and mentally'.

he was born end of April so going into the summer, and I had had naïve visions of this motherhood. Well they're not naïve at all, you know, taking my baby for a walk in the pram. I couldn't. So and an that also made me miss out even when we moved, when he was you know 7, 8 months and trying to make new friends, meet up with other mums and they'd say ooo we'll go for a walk So not only was

there the kind of after-effects physically but it extended socially and therefore emotionally and mentally. (Holly)

Ella described her attitude towards the health services changing. She has lost confidence in doctors but that since her experience, particularly her second pregnancy, she questions healthcare more.

Since having (second baby) my view on birth in general has changed an awful lot. I used to be very much 'I'll do what the doctors tell me'. I'd be a good little patient. If they say 'jump' I'd say 'how high Doctor do I need to go?' Not any more, I question everything now... It has affected me in lots of different ways. What it has affected is my view of the system [crying] more than anything because that's what it is. It's a system and it's a conveyor belt, and you're just the next body, You're not a pregnant woman you're just a body, Because if I was a person to them, if I was a pregnant woman they would have read my file. (Ella)

Discussion

Although the findings from both phases relate to a small sample that cannot be generalised to the population of disabled women, it is clear from this sample that despite high rates of general satisfaction with services women experienced challenges in relation to their dignity.

It is evident that the need to be listened to and appropriate communication are the central points to promoting a positive experience for disabled women; indeed the importance of good communication is highlighted in the Maternity Services Review for all women (NHS England 2016). Communication and being listened to were the most often repeated themes from the open-ended questions and the interviews: poor communication had the potential to reduce women's choices and made them feel like they had less control. The women are happy to discuss disability – and welcome it – as long as their experience and knowledge of their own bodies are respected. There were situations where women were requested to 'prove' their physical abilities in a disrespectful manner which affected their perception of the whole experience.

Provision of individualised care and continuity of carer led to a more positive experience and better communication overall. Others were challenged by the need to repeat themselves again and again and their wishes, as discussed and agreed with one maternity care provider, were not followed through by another. Participants also criticised the lack of knowledge that maternity care providers had about disability and its impact on pregnancy, childbirth and parenting, highlighting that this was, for some, offensive and made them feel less confident in themselves. It is evident that the support needed is more psychological and around decision-making and needs to be someone with understanding of the potential impact of disability on pregnancy and childbirth. The interview participants highlighted their need for more information, and also understanding, specific to the impact of disability on pregnancy, childbirth and parenting to enable them to make appropriate choices and gain control.

These findings echo previous research about the experience of disabled women, particularly the work of Walsh-Gallagher, Sinclair and McConkey (2012) but there was limited evidence from our sample of women of improved continuity of carer or more ante-natal care found by Redshaw et al (2013).

In the survey more than a quarter of women felt that their rights were poorly or very poorly respected; a quarter felt they were treated less favourably because of their disability and more than half (56%) felt that maternity care providers did not have appropriate attitudes to disability. This finding, supported by the narrative provided by women, highlights the

urgent need for maternity care providers to develop better understanding and approaches when providing care for disabled women. This is particularly important when only 19% of women described having the reasonable adjustments that they are legally entitled to receive. Reasonable adjustments suggested included continuity of carer and use of accessible facilities and information. Similarly, a third reported that their dignity was poorly or very poorly respected in the post-natal period, with examples of their choices being undermined and inadequate information and support. Poor postnatal support was further highlighted by women who were interviewed. It is apparent from these women that, when the experience is negative, it has longer-term impacts for the women, and subsequently, their baby

The themes from the study resonate with the findings of the recent maternity services review, 'Better births' (NHS England 2016), which highlighted the importance of personalised care, which is woman-centred, with opportunity for choice and control, and continuity of carer. In addition the women in our sample highlighted postnatal care as particularly challenging. The current developments under the Maternity Transformation programme to instigate the recommendations of 'Better births' will go some way to provide the care our sample wanted which is individualised. However, though there is some focus on mental health and learning disability needs, there is limited recognition apparent of the specific requirements for those with physical or sensory disability.

Our participants described some areas that clearly improved women's satisfaction, which need further exploration to see if they can be adopted as good practice more generally. Other areas resonated with good practice recommendations in the maternity review; for example, care providers taking time to listen to women and understand their perspective. Here the knowledge should be shared, and practices celebrated, in order to act as guidance for others to provide better care.

Limitations

This was a self-selecting sample and as a consequence it is open to selection bias. That is, it could be argued that women who responded to the call had previously experienced poor maternity services and therefore were more motivated to provide feedback. Self-selection bias is a particular problem experienced with online surveys where a link is circulated to interested groups. The small sample size and the fact that it contained a high proportion of women with certain types of physical disability means that it is unlikely to be representative of the population of disabled women as a whole. Although the findings may not be generalisable, the accounts clearly point to aspects of service provision that could be

improved. In future, more specific sampling of a smaller population – for example, women with specific impairment types – may yield more representative results.

The apparently high overall satisfaction with maternity care despite significant dissatisfaction with certain aspects of care is not unusual in maternity surveys (Teijlingen et al, 2003).

Conclusions and recommendations

In conclusion, it is evident that, though some disabled women are satisfied with some aspects of care, they are not generally receiving appropriate support and communication needed for individualised care. This is impacting on their ability to make appropriate choices. It is also evident that more consideration needs to be made to improve the attitude and knowledge of midwives and other health care providers to and of disability and disabled women. This includes promotion of wellbeing, dignity and respect and value of human rights. As an aspect of this, services need to adapt to provide reasonable adjustments to accommodate disability, including improving continuity of carer.

Recommendations:

Services should adapt to provide continuity of carer for all women, but this is particularly important for disabled women during pregnancy, childbirth and parenting to ensure that appropriate accommodations and supports are in place.

Maternity care providers should undertake additional education about the care of disabled women to ensure that women's rights are respected and dignity is promoted. This education should also include information about different approaches to disability and highlight the need to listen to the woman to understand her unique disability experience.

Maternity care providers should seek to allow additional time, particularly at the beginning of the relationship with a disabled woman to listen to her and discuss and document her specific needs, abilities, expectations and preferences. These should be followed through at all stages of the service provided.

Maternity care providers should consider the development of 'disability champions' who 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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Tables

Table 1. Participants

		n	%
<hr/>			
Age (n=36)			
	20-29	7	19%
	30-39	19	51%
	40-49	10	27%
	<i>mean 35.64 (SD 6.1.88)</i>		
Number of children (n=35)			
	0	1	3%
	1	13	37%
	2	14	40%
	3	5	14%
	4	2	6%
Primary impairment (n=37)			
	Deaf / hard of hearing	2	5%
	Blind / visual impairment	7	19%
	Physical or mobility impairment	19	51%
	On-going health issue that affects daily life	6	16%
	Mental health or emotional issue	3	8%
Additional impairment (n=37)			
	Deaf / hard of hearing	1	3%
	Blind / visual impairment	0	
	Physical or mobility impairment*	5	14%
	On-going health issue that affects daily life	9	24%
	Mental health or emotional issue	7	19%
	Specific learning difficulties (such as dyslexia)	1	3%
<hr/>			

* Includes two women who had a primary physical impairment (that is they identified both primary and secondary) therefore total with any physical impairment = 22

Table 2. Maternity care received

	n	%
<i>Antenatal care</i>		
What kind of antenatal care did you receive? (n=37)		
Community midwife only	6	16%
Community midwife and GP	3	8%
Community midwife, GP, and obstetrician	22	60%
Other	6	16%
(specialist perinatal mental health midwife, consultant only, consultant and GP only, GP and hospital midwife, independent midwives, specialist needs team)		
<i>Birth</i>		
Place of birth (n=36)		
Home	2	5.5%
Stand-alone midwifery-led unit	3	8%
Alongside midwifery-led unit	1	3%
Obstetric unit	28	78%
Theatre	2	5.5%
How long ago did you last give birth (in years)? (n=36)		
0-2	21	58%
3-5	6	17%
6-10	7	19%
>10	2	5%
Which country were you in when you gave birth? (n=36)		
England	20	55%
Scotland	2	6%
United Kingdom	12	33%
Ireland	2	6%
<i>Postnatal care</i>		
What kind of postnatal care did you receive? (n=37)		
Care in hospital	22	60%
Home visit – midwife	27	73%
Home visit – maternity support worker	8	22%
Home visit – Health worker	20	54%
Other	3	8%
(day care, mental health team)		

Table 3. Satisfaction with childbirth experience

	<i>Very Dissatisfied</i>	<i>Dissatisfied</i>	<i>Neither</i>	<i>Satisfied</i>	<i>Very Satisfied</i>
Information about services available	16%	14%	11%	43%	16%
Appropriateness of information for you	5%	40.5%	13.5%	24%	16%
Extent services were tailored to your needs	13.5%	35%	19%	19%	13.5%
Reasonable adjustments for you needs	13.5%	27%	27%	13.5%	18.9%
Signposting to other services/local resources	22%	36%	17%	19%	6%
Extent to which your individuality/preferences were respected	30%	27%	11%	24%	8%
Overall understanding that service providers showed of your specific situation	30%	27%	13%	19%	11%
Extent to which your privacy was protected	3%	19%	24%	35%	19%

Table 4. Satisfaction with experience of antenatal care (ANC)

	<i>Very Dissatisfied</i>	<i>Dissatisfied</i>	<i>Neither</i>	<i>Satisfied</i>	<i>Very Satisfied</i>
Your involvement in decision-making over type of ANC you received	3%	22%	19%	31%	25%
Your choice in how ANC was provided	8%	22%	19%	31%	19%
Information you received about antenatal screening	0	8%	6%	53%	33%
Communication of those offering screening	6%	6%	3%	61%	25%
Antenatal education available to you	8%	19%	25%	33%	14%
Communication between you and those providing ANC	11%	9%	14%	49%	17%
Accessibility of the environment for ANC	17%	8%	14%	36%	25%
Continuity of care throughout pregnancy	23%	15%	12%	32%	18%
Extent to which you were listened to	11%	25%	17%	33%	14%
Control you had in decisions about your pregnancy	11%	17%	19%	33%	19%

Table 5. Satisfaction with experience of labour and birth

	<i>Very Dissatisfied</i>	<i>Dissatisfied</i>	<i>Neither</i>	<i>Satisfied</i>	<i>Very Satisfied</i>
Your involvement in planning your baby's birth	11%	17%	11%	36%	25%
Your choice in where you gave birth	19%	14%	6%	28%	33%
Your involvement in deciding type of care you received	17%	20%	9%	34%	20%
Communication between you and those providing care	9%	17%	20%	31%	23%
Accessibility of the environment for labour/birth	14%	19%	11%	33%	22%
Continuity of care during labour/birth	11%	17%	19%	28%	25%
Extent to which you were listened to	14%	25%	14%	33%	14%
Control you had in decisions about labour/birth	14%	25%	14%	33%	14%

Table 6. Satisfaction with experience of postnatal care (PNC)

	<i>Very Dissatisfied</i>	<i>Dissatisfied</i>	<i>Neither</i>	<i>Satisfied</i>	<i>Very Satisfied</i>
Your involvement in decision making over type of PNC you received	14%	26%	17%	29%	14%
Communication between you and those providing PNC	8%	31%	14%	28%	19%
Information and support you received about feeding your baby	14%	17%	14%	22%	33%
Accessibility of the environment for PNC	14%	22%	22%	31%	11%
Continuity of care during PNC	19%	17%	14%	28%	22%
Extent to which you were listened to in early postnatal period	22%	22%	17%	19%	19%
Control you had in decisions about early parenting	8%	22%	28%	14%	28%

Table 7. Dignity and respect

	n	%
Do you think that your disability, impairment or health issue led to people treating you differently (n=37)		
Yes	17	46%
No	16	43%
Don't Know	4	11%
Do you feel that your disability, impairment or health issue automatically placed you at high risk (n=37)		
Yes	11	30%
No	21	57%
Don't Know / Other	5	13%
Do you think that reasonable adjustments or accommodations were made for you (n=36)		
Yes	7	19%
No	24	67%
Don't Know / Other	5	14%
Were you told that you were more likely to meet the same health care provider at each of your appointments because of your disability, impairment or health issue (n=37)		
Yes	4	11%
No	30	81%
Don't Know / Other	3	8%
Do you feel that communication was good throughout your experience (n=37)		
Yes	11	30%
No	19	51%
Don't Know / Other	7	19%
Do you feel that you experienced less favourable treatment because of your disability (n=37)		
Yes	10	27%
No	19	51%
Don't Know	8	22%
Do you feel that health care providers had appropriate attitudes to disability (n=36)		
Yes	9	25%
No	20	56%
Don't Know	7	19%
