



The Human Rights & 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 maintenance 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, Sumilo 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 (Sumilo 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 care giver 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, Sinclair & Clarke 2013).

A study using the sample from the UK millennium cohort (Sumilo et al 2012) was completed prior to the report from the Mid Staffordshire public inquiry (Francis 2013) and identification of the strategy of developing compassionate care (Department of Health 2012) that are 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 improve care.

Design

The study had two consecutive phases:

Phase 1 – an Initial quantitative survey to identify the health 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.

This interim report exclusively focuses on the findings of phase 1 of the study.

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 are 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, this research focuses on 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,

people with ME/CFS). 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.

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 re-ascertained in phase 2 by the researcher prior to commencing interviews.

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 offered; for example participants who were hard of hearing or dDeaf 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.

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. Interviews are currently on-going; once completed they will be analysed using inter- and intra-thematic analysis to understand the narratives of individuals and their experience in the context of human rights and dignity.

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.

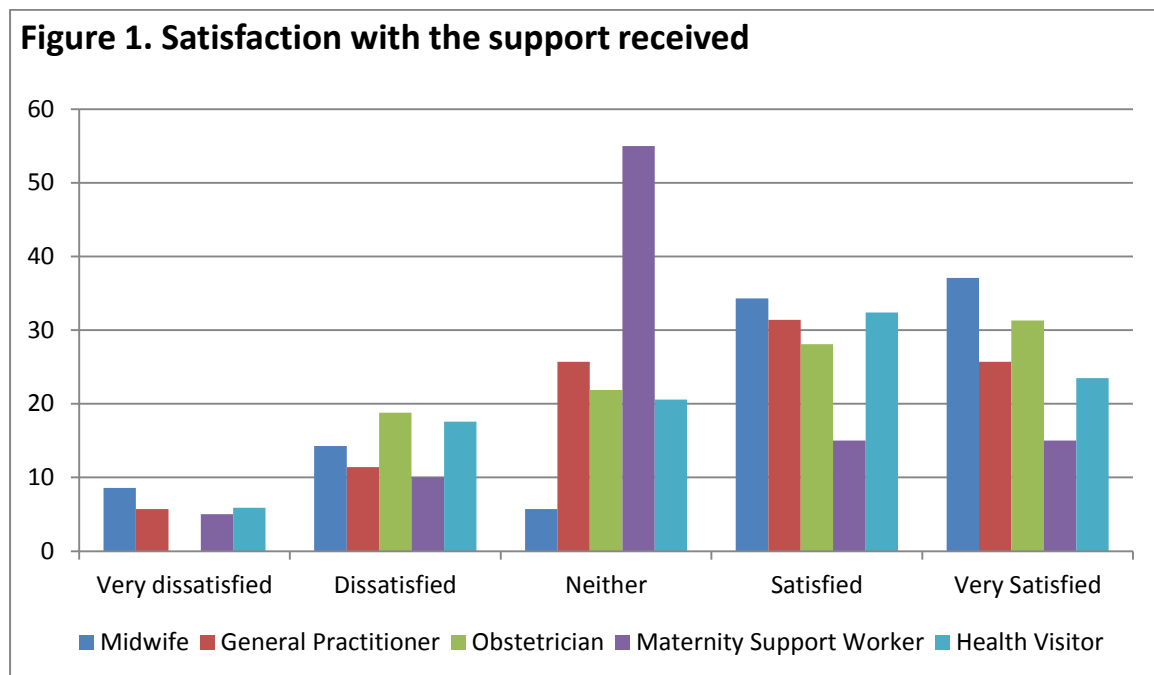
The maternity care received

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 members 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’.

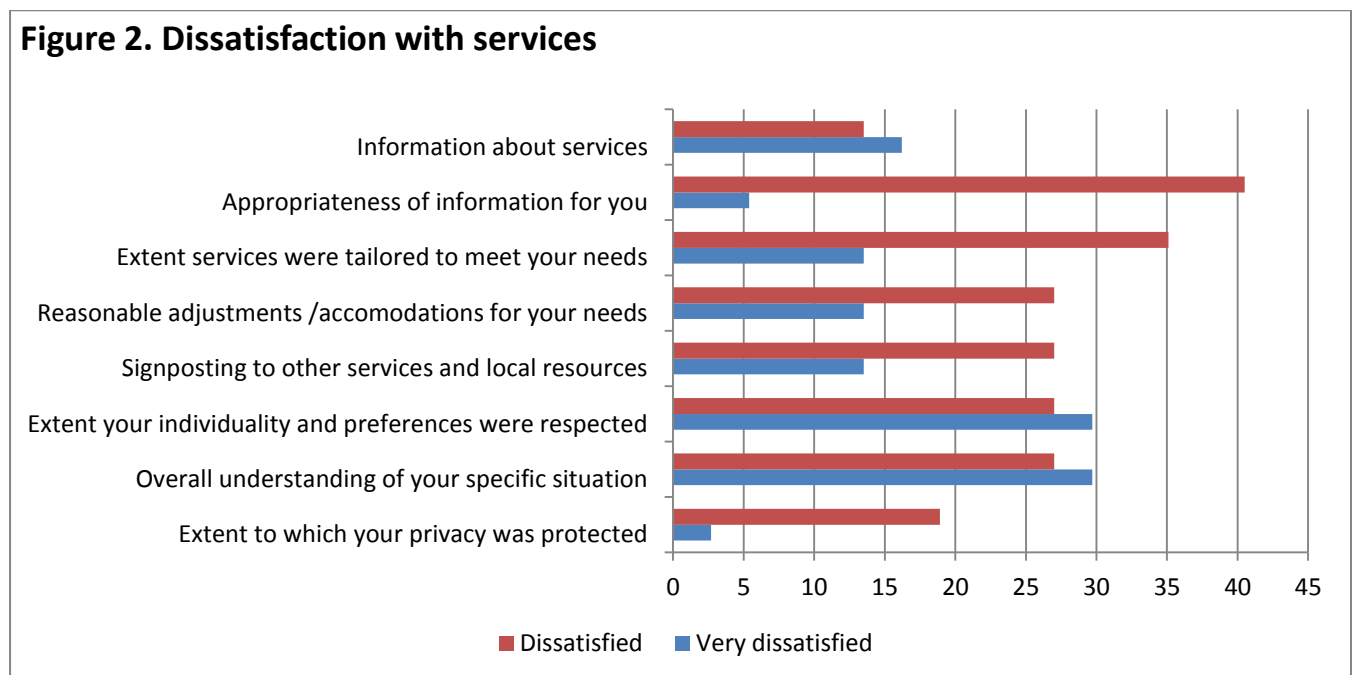
The midwives were fine but I told the obstetrician I didn't want to give birth on the delivery suite and they asked me to physically demonstrate I could get into certain positions that they considered necessary for giving birth. I found that quite insulting. It also undermined my confidence in my body.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



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 babies 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. Participants' disability 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.

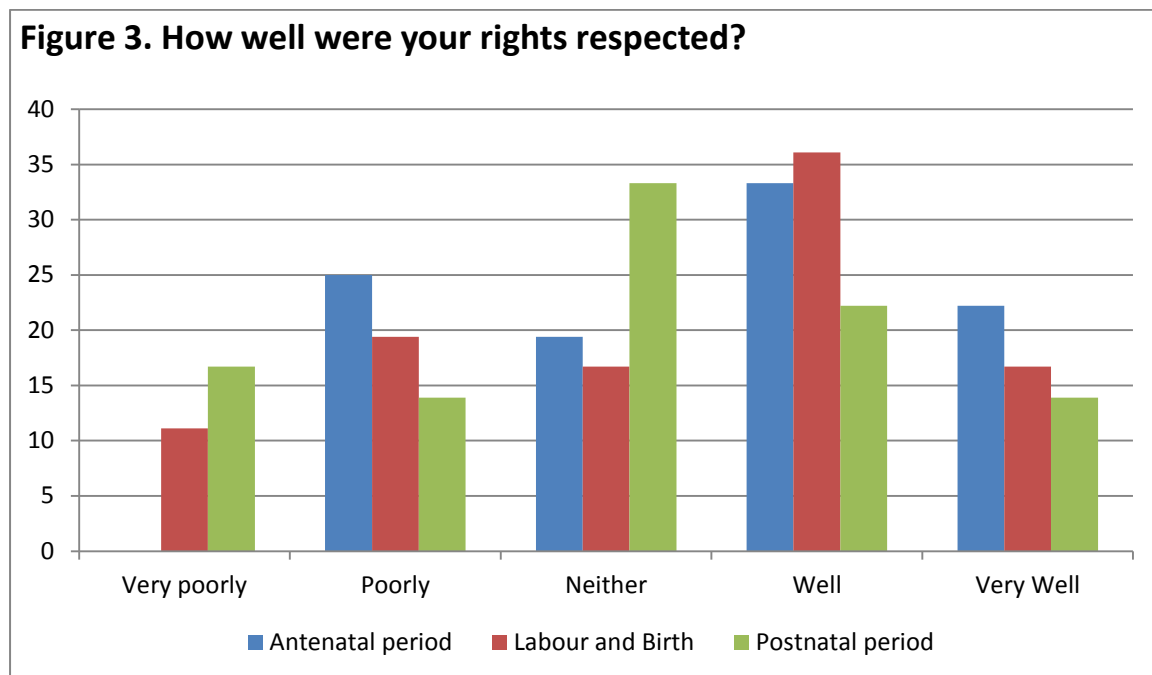
If I were not disabled none of these things would have been an issue. I feel not meeting those needs means I was treated with less favour due to my disability.

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).



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.

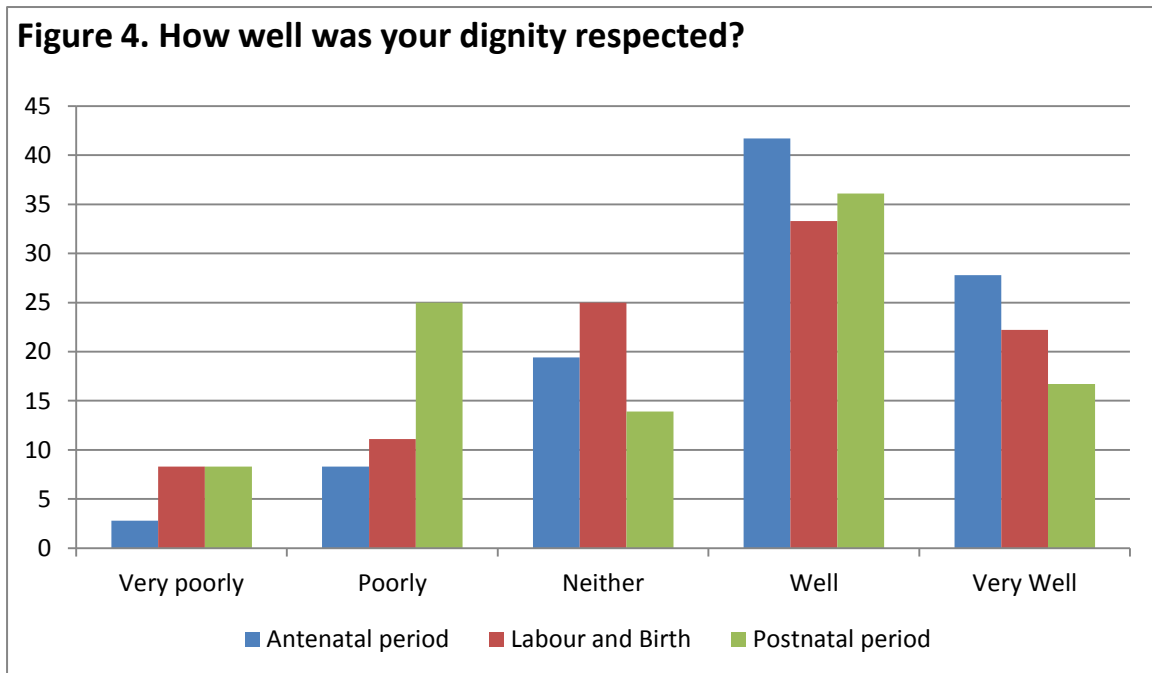
not allowed birthing ball, not allowed to walk around etc
Participant who is blind

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

The analysis is on-going and results will be available in January 2017.

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

Although the findings 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.

The particular challenges described by participants included a lack of continuity of carer. This meant that women needed 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. The most often repeated theme from the open-ended questions was that women felt that they were not being listened to and that this had the potential to reduce their choices and made them feel like they had less 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)

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 dealing with 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.

The themes from the study resonate with the findings of the recent maternity services review (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.

In conclusion, it is evident that disabled women are not generally receiving appropriate support and communication needed for individualised care. It is also evident that more consideration needs to be made to improve attitudes of midwives and other health care providers to disability and 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.

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.

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>		
<hr/>			
Number of children (n=35)			
	0	1	3%
	1	13	37%
	2	14	40%
	3	5	14%
	4	2	6%
<hr/>			
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%
<hr/>			
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%

* 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	%
<hr/>		
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%
<hr/>		