

# BMJ Open Access and quality of maternity care for disabled women during pregnancy, birth and the postnatal period in England: data from a national survey

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## ABSTRACT

**Objectives** More disabled women are becoming mothers, and yet, their care is rarely the focus of quantitative research. This study aimed to investigate access and quality of maternity care for women with differing disabilities.

**Design** Secondary analysis was conducted on data from a 2015 national survey of women's experience of maternity care. Descriptive and adjusted analyses were undertaken for five disability groups: physical disability, sensory impairment, mental health disability, learning disability and multiple disability, and comparisons were made with the responses of non-disabled women.

**Setting** Survey data were collected on women's experience of primary and secondary care in all trusts providing maternity care in England.

**Participants** Women who had given birth three months previously, among whom were groups self-identifying with different types of disability. Exclusions were limited to women whose baby had died and those who were younger than 16 years at the time of the recent birth.

**Results** Overall, 20,094 women completed and returned the survey; 1958 women (9.5%) self-identified as having a disability. The findings indicate some gaps in maternity care provision for these women relating to interpersonal aspects of care: communication, feeling listened to and supported, involvement in decision making, having a trusted and respected relationship with clinical staff. Women from all disability groups wanted more postnatal contacts and help with infant feeding.

**Conclusion** While access to care was generally satisfactory for disabled women, women's emotional well-being and support during pregnancy and beyond is an area that is in need of improvement. Specific areas identified included disseminating information effectively, ensuring appropriate communication and understanding, and supporting women's sense of control to build trusting relationships with healthcare providers.

## BACKGROUND

The number of disabled women choosing to become mothers is growing.<sup>1</sup> However, stigma still exists about such women and their care-giving and mothering capabilities.<sup>2</sup> Although all women are entitled to have

## Strengths and limitations of this study

- All organisations providing maternity care in England participated in the recent survey.
- The large size of the survey allowed for more detailed subdivisions and comparison of the experience of different disability groups than previous research.
- Data in this survey were self-reported and collected retrospectively at 3 months postpartum which may affect the quality of responses based on recall.
- The response rate was lower than previous surveys which may affect the generalisability of the findings; however, weighting for non-response was used.

access to high-quality maternity care, worldwide, half of disabled people cannot afford healthcare, compared with a third of non-disabled people, and they are more likely to find healthcare providers' skills inadequate.<sup>3</sup> This is despite disabled women's greater need for, and use of, healthcare services.<sup>4</sup> Disabled people and their families frequently experience inequalities in accessing health services, with poor communication and challenging attitudes among healthcare providers.<sup>2</sup> Furthermore, disabled people are four times more likely to report being treated badly and nearly three times more likely to be denied access to healthcare.<sup>3</sup>

Disabled women accessing maternity care may be considered unusual and problematic. Healthcare professionals may be concerned that these women will not be able to cope with pregnancy and motherhood.<sup>5</sup> However, the social model of disability suggests that disability is a social construction brought about by structural and attitudinal barriers encountered by people with impairments.<sup>6</sup> It views disabled people as socially oppressed and argues for policies and practices that facilitate full inclusion.<sup>7</sup>

Healthcare professionals may lack knowledge and experience in planning and

providing care for pregnant disabled women.<sup>8</sup> For example, antenatal information may be distributed in a manner inappropriate and insufficient for women with visual impairment.<sup>19</sup> There is some evidence that women with hearing impairment receive fewer antenatal visits and have limited access to maternity information.<sup>10 11</sup> For women with a less easily identified disability, such as those arising from mental health problems, there may be difficulties in receiving appropriate care.<sup>12</sup> For women in this group, dissatisfaction and lack of trust have been found to be the main barriers in seeking help during pregnancy.<sup>12</sup>

In the UK, maternity services are freely available for all women. A study reporting on the use of maternity services by women with disabilities in 2010<sup>13</sup> concluded that disabled women were at higher risk for adverse pregnancy outcomes; for example, they were more likely to deliver early and have low-birth-weight babies. However, it also concluded that some women, such as those with physical disabilities, appropriately received more care. In this paper, we aim to reflect predominantly on the quality of maternity care received for disabled women in England more recently.

## METHODS

The main objective of this secondary analysis was to report on access to care and the quality of care received by disabled women who used the maternity services in 2015 in England, seeking a better understanding of the maternity care issues arising for women with different types of disability. In this paper, we:

- ▶ compare the perceptions and experiences of maternity care received by women with different types of disability and women with no disability;
- ▶ identify differences or gaps in care for disabled women which could be addressed.

## Study design and survey measure

A structured cross-sectional study design was implemented by all National Health Service (NHS) trusts using a strict methodology and data collated by the Care Quality Commission (CQC) in 2015.<sup>14</sup> The CQC is an independent regulator of health and social care in England and all NHS trusts providing maternity care and was responsible for the trust-based surveys using the same survey instrument. Modifications were made to the 2010 and then the 2013 CQC survey measures following consultation, focus groups and cognitive interviews which identified additional aspects of women's maternity care to be covered. While the survey continued to cover aspects of pregnancy, labour and birth, and postnatal care, more questions asked about women's access to care, communication with healthcare providers, involvement in decision making, awareness of birth choices and support for emotional well-being and physical health. Limited data on neonatal outcomes as well as sociodemographic

characteristics including age, ethnicity, marital status and parity were also collected.

Postal surveys were sent to a minimum of 300 women from each trust who had given birth to a live baby in February 2015 (and possibly January 2015 for trusts with smaller numbers of births), 50945 women in total. Completing and returning the survey was considered as consent to take part in the study. Women who were younger than 16 years, those who had a stillbirth or whose baby died after birth, women who delivered in private settings and women without a UK postal address were excluded from the surveys. Up to two reminders were sent to non-respondents as required. A freephone language line provided translation services, and MENCAP also provided support to women with learning disabilities.<sup>14</sup> The survey, reference 07/MRE08/1, was passed by the NRES Committee North West—Haydock in February 2015.

As in previous surveys,<sup>15</sup> women were asked "Do you have any of the following long-standing conditions?" with seven options, including "No, I do not have a long-standing condition". Using the checklist, respondents were thus able to describe their disability and indicate if they had more than one disability. Five different disability groups were identified: physical (long-standing physical condition and long-standing illness), sensory (deafness or hearing impairment and blindness or partial sightedness), mental health problem, learning disability and multiple disabilities, that is, having two or more disabilities (see table 1).

## Statistical analysis

The data presented are grouped in relation to access to care, the clinical care received and women's perceptions about the different phases of care. The categories used were those collected, and where variables were further aggregated for conciseness, this was based on clinical or policy relevance. The cut-offs are indicated in the tables. Univariate data analyses were carried out to compare the maternal characteristics and responses of disabled women to non-disabled women.  $\chi^2$  statistics were used to compare study groups. Adjusted ORs and 95% CI were weighted for variation in response rate by the trusts and adjusted for age, parity and ethnicity using binary logistic regression. Each of the subgroups, physical, sensory, mental, learning and multiple disability, was separately compared with the referent group of non-disabled women. Maternal characteristics and reports about care were compared with women who did not self-identify with any of the conditions listed above. The analyses were carried out in STATA V.13.

## RESULTS

### Women's characteristics

Overall, 20094 women completed and returned the survey, with a usable response rate of 41.2%. Disabled women represented 9.5% (1958) of the total sample.

**Table 1** Characteristics of pregnant women with different types of disability and their babies compared with non-disabled women and their babies

Characteristics	Physical condition or illness (n=873), n (%)	Sensory disability (n=174), n (%)	Mental health disability (n=664), n (%)	Learning disability (n=127), n (%)	Multiple disability (n=120), n (%)	No disability (n=18136), n (%)
<b>Age group (years)</b>	***		***	***		
16–19	6 (0.7)	2 (1.2)	10 (1.5)	5 (3.9)	2 (1.7)	165 (0.9)
20–24	50 (5.7)	17 (9.8)	81 (12.2)	35 (27.6)	13 (10.8)	1397 (7.7)
25–29	179 (20.5)	43 (24.7)	174 (26.2)	40 (31.5)	40 (33.3)	4134 (22.8)
30–34	300 (34.4)	59 (33.9)	223 (33.6)	28 (22.1)	35 (29.2)	6550 (36.1)
35+	338 (38.7)	53 (30.5)	176 (26.5)	19 (15.0)	25 (25.0)	5890 (32.5)
<b>Ethnic group</b>			**	**		
White	736 (87.3)	120 (78.4)	614 (93.5)	110 (92.4)	98 (89.1)	15019 (85.5)
Mixed	20 (2.4)	3 (2.0)	13 (2.0)	2 (1.7)	1 (0.9)	296 (1.7)
Asian or Asian British	59 (7.0)	22 (14.4)	23 (3.5)	6 (5.0)	8 (7.3)	1538 (8.8)
Black or Black British	27 (3.2)	6 (3.9)	5 (0.8)	1 (0.8)	2 (1.8)	583 (3.3)
Arab or other	1 (0.1)	2 (1.3)	2 (0.3)	0 (0.0)	1 (0.9)	121 (0.7)
<b>Parity</b>				**		
Primiparous	426 (49.4)	78 (47.0)	298 (45.5)	76 (61.3)	59 (51.3)	8788 (48.7)
Multiparous	437 (50.6)	88 (53.0)	357 (54.5)	48 (38.7)	56 (48.7)	9248 (51.3)
<b>Gestation at birth</b>	***		**	*	***	
<37 weeks	102 (11.7)	17 (9.8)	66 (10.0)	15 (11.9)	21 (17.5)	1185 (6.6)
≥37 weeks	769 (88.3)	156 (90.2)	595 (90.0)	118 (88.1)	99 (82.5)	16902 (93.4)
<b>Plurality</b>						
Single baby	860 (98.5)	170 (97.7)	655 (98.6)	127 (100.0)	118 (98.3)	17846 (98.5)
Twins	13 (1.5)	4 (2.3)	9 (1.4)	0 (0.0)	2 (1.7)	268 (1.5)
Triplets	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	6 (0.0)
<b>Breastfeeding</b>						
Breast feeding first few days after birth	**	**	***	***	***	
Breast milk (at least some)	691 (80.0)	129 (75.4)	480 (72.6)	80 (64.5)	79 (66.4)	14858 (82.8)
Formula only	173 (20.0)	42 (24.6)	181 (27.4)	44 (35.5)	40 (33.6)	3097 (17.2)

\*p<0.05, \*\*p<0.01, \*\*\*p<0.001.

Compared with non-respondents, survey respondents were significantly more likely to be white, aged 30 years or more and primiparous<sup>14</sup> which may affect the generalisability of results. Physical and mental health disabilities were most frequently identified. Of those with a disability, almost half reported having a physical disability (45%), and a third of women identified with a mental health disability (34%). Fewer women reported having a sensory disability (8.7%), and small proportions of women reported having a learning disability (6.5%) or more than one disability, most commonly a physical condition and mental health problem (6%). More women with physical disability were 35 years and older than women with no disability (38.7% vs 32.5%); however, women with mental health and learning disability were younger than women with no disability (table 1). White women were significantly more likely to report mental health and learning disabilities compared with all other ethnic groups. Similarly, primiparous women were significantly more likely than multiparous women to report learning disabilities. All disabled women were at a higher risk for delivering preterm compared with non-disabled women, particularly those with physical disability, mental health problems, learning disability and women with multiple disability (table 1). Across all groups, babies born to disabled were significantly less likely to be breast fed at the time of hospital discharge compared with non-disabled women.

### Access and care received

Findings on access to maternity care and the care received are shown in table 2.

Women with a physical disability accessed antenatal care similarly to those with no disability. However, those with a sensory disability were significantly less likely to see a health professional before 12 weeks' gestation and to have a later booking appointment (where a full history is taken and women are given their pregnancy notes) (table 2). There were no significant differences between the groups in continuity of care, with less than half of women in all groups seeing the same midwife for antenatal checks through the pregnancy. Choice in relation to place of birth differed for the disability groups: while only 9% of non-disabled women indicated that, for medical reasons, they had no choice about where they could have their baby, the comparable figure for women with a physical disability was 32% and for the other groups between 14% and 27%. Clinical care differed across the groups in relation to labour and birth, with women with a physical condition significantly more likely to have intervention in the form of assisted vaginal births and planned or emergency caesarean section. Shortly after the birth, women with physical disability were slightly less likely to have skin-to-skin contact with their baby, although nearly nine out of ten women did so.

While approximately a quarter of non-disabled women (26%) stayed in hospital for more than 2 days after giving birth, more women in all the different types of disability groups did so, significantly more for women with physical,

mental health, learning or multiple disabilities which may relate partly to method of delivery. Nearly half of the women with multiple disabilities (45%) stayed longer than 2 days. More than 90% of women with and without disability received at least one postnatal home visit from a midwife, although this was slightly fewer for the physically disabled women. However, women with mental health or learning disability were significantly more likely to have received a home visit or seen a midwife in a clinic five or more times in the postnatal period. Women with physical or mental disability were less likely to report that advice about infant feeding was always available at evenings and weekends.

### Perceptions of care

Women's views about the care received varied across the different groups (tables 3–5).

During pregnancy, women with physical disability, those with mental health conditions and women with more than one disability were all significantly less likely to feel that there was always time to ask questions at their appointments, to feel listened to, spoken to in a way they could understand, involved enough in decisions about their care, and if they had contacted a midwife, that they had been given the help they needed (table 3). All disabled women were significantly more likely to report negative experiences of pregnancy care, particularly in relation to always being spoken to by health professionals in a way that they could understand and, except for women with sensory loss, being involved in decisions about their care.

Perceptions of labour and birth care also differed between the groups (table 4). While 85% of non-disabled women reported that all staff who treated and examined them introduced themselves, significantly fewer women with physical disabilities and mental health conditions reported this (76% and 74%, respectively) (table 4). Significantly fewer women in with physical, mental health and learning disabilities were likely to report definitely having confidence and trust in staff, fewer women in all disability groups reported always being spoken to so they could understand, and fewer women with physical, sensory and mental health disabilities reported that they were always treated with respect at this time. Significantly fewer women with physical disabilities (65%) and mental health conditions (65%) reported that they were always involved in decisions about their care compared with 76% of those with no disability. Similarly, while 83% of non-disabled women felt that their concerns during labour and birth were taken seriously, significantly fewer women with mental health problems or learning disability perceived this to be the case (74% and 72%, respectively).

Women were asked whether they and their partner were left alone at a time when it worried them during labour or shortly after the birth and whether they received attention and help from a member of staff within a reasonable time. Feeling left alone and worried at some time was reported by a quarter of non-disabled women or with physical disability (25% and 27%, respectively)



**Table 2** Access and clinical care for women with different disabilities

Physical condition or illness								
		Sensory disability	Mental health disability	Learning disability	Multiple disability	No disability		
Pregnancy								
First saw a HCP by 12 weeks	n (%)	833 (97.1)	153 (92.2**)	629 (96.3)	108 (92.3*)	111 (96.5)	17 117 (96.1)	
	aOR (95% CI)	1.46 (0.94 to 2.27)	0.47 (0.25 to 0.88)	1.03 (0.66 to 1.60)	0.45 (0.22 to 0.92)	0.89 (0.31 to 2.49)		
Booking appointment <13 weeks	n (%)	753 (92.1)	132 (84.6**)	571 (92.7)	101 (87.1)	99 (91.7)	15555 (91.9)	
	aOR (95% CI)	1.03 (0.80 to 1.34)	0.49 (0.31 to 0.75)	1.13 (0.83 to 1.54)	0.60 (0.35 to 1.03)	0.98 (0.49 to 1.94)		
Contact number for a MW	n (%)	846 (97.5)	160 (94.7*)	633 (95.9**)	115 (94.3)	110 (94.0)	17555 (97.7)	
	aOR (95% CI)	0.95 (0.59 to 1.53)	0.43 (0.21 to 0.90)	0.55 (0.36 to 0.85)	0.55 (0.23 to 1.28)	0.43 (0.18 to 1.03)		
Saw same MW each check	n (%)	286 (34.2)	66 (40.0)	231 (35.8)	54 (45.0)	50 (44.6)	6574 (37.1)	
	aOR (95% CI)	0.90 (0.77 to 1.05)	1.17 (0.82 to 1.66)	0.90 (0.76 to 1.07)	1.29 (0.87 to 1.91)	1.23 (0.81 to 1.86)		
No choice for place of birth for medical reasons	n (%)	278 (31.9***)	25 (14.5)	112 (17.0***)	17 (13.5)	32 (26.7***)	1660 (8.8)	
	aOR (95% CI)	4.70 (3.96 to 5.59)	1.54 (0.95 to 2.51)	1.85 (1.46 to 2.30)	1.75 (0.99 to 3.03)	3.40 (2.14 to 5.40)		
Birth (each mode of delivery compared with all others)								
Vaginal birth	n (%)	411 (47.7***)	103 (61.3)	376 (57.1)	76 (61.8)	61 (52.1)	10704 (59.6)	
	aOR (95% CI)	0.64 (0.55 to 0.75)	0.99 (0.69 to 1.42)	0.83 (0.69 to 0.98)	0.97 (0.63 to 1.78)	0.69 (0.46 to 1.04)		
Assisted vaginal delivery	n (%)	132 (15.3)	22 (13.1)	105 (15.9)	21 (17.1)	21 (18.0)	2699 (15.0)	
	aOR (95% CI)	0.61 (0.85 to 1.29)	0.91 (0.63 to 1.34)	0.86 (0.71 to 1.03)	1.10 (0.66 to 1.70)	1.27 (0.75 to 2.14)		
Planned caesarean section	n (%)	158 (18.4***)	23 (13.7)	77 (11.7)	7 (5.7*)	15 (12.8)	1983 (11.0)	
	aOR (95% CI)	1.69 (1.38 to 2.06)	1.40 (0.90 to 2.30)	1.07 (0.83 to 1.39)	0.71 (0.32 to 1.66)	1.34 (1.17 to 1.55)		
Emergency caesarean section	n (%)	160 (18.6**)	20 (11.9)	101 (15.3)	19 (15.5)	20 (17.1)	2585 (14.4)	
	aOR (95% CI)	1.30 (1.07 to 1.58)	0.81 (0.47 to 1.40)	1.20 (0.95 to 1.53)	1.09 (0.64 to 1.84)	1.21 (0.71 to 2.06)		
Postnatal care								
Skin to skin after birth	n (%)	644 (89.2)	139 (91.4)	520 (91.9)	102 (92.7)	90 (90.9)	14843 (91.3)	
	aOR (95% CI)	0.72 (0.56 to 0.94)	0.87 (0.48 to 1.58)	0.98 (0.70 to 1.37)	0.83 (0.39 to 1.80)	0.67 (0.32 to 1.41)		
Length postnatal stay >2 days	n (%)	339 (39.4***)	54 (32.5)	245 (37.6***)	46 (38.0**)	53 (45.3**)	4528 (25.6)	
	aOR (95% CI)	1.86 (1.59 to 2.18)	1.15 (0.80 to 1.63)	1.89 (1.58 to 2.26)	1.51 (1.00 to 2.28)	2.11 (1.40 to 3.17)		
Home visit by midwife	n (%)	824 (95.6**)	164 (97.6)	642 (97.0)	118 (95.2)	112 (96.6)	17440 (96.9)	
	aOR (95% CI)	0.62 (0.43 to 0.89)	3.42 (0.80 to 14.62)	0.85 (0.65 to 1.72)	0.76 (0.31 to 1.94)	1.45 (0.45 to 4.62)		
Feeding advice always available out of hours	n (%)	146 (43.3***)	47 (54.0)	132 (46.0**)	45 (65.2)	33 (49.3)	3698 (54.5)	
	aOR (95% CI)	0.61 (0.48 to 0.78)	0.90 (0.55 to 1.48)	0.65 (0.50 to 0.84)	1.56 (0.90 to 2.72)	0.77 (0.45 to 1.33)		
5+ visits with MW	n (%)	191 (23.3)	43 (26.5)	183 (29.1***)	36 (31.6**)	25 (23.4)	3645 (21.2)	
	aOR (95% CI)	1.11 (0.93 to 1.32)	1.40 (0.95 to 2.05)	1.55 (1.28 to 1.87)	1.82 (1.18 to 2.79)	1.01 (0.62 to 1.63)		

ORs and 95% CIs weighted for variation in response rates by trust and adjusted for age, parity and ethnicity compared with women without disability.

Sensory disability: visually impaired, deaf and hearing impaired.

\*p<0.05, \*\*p<0.01, \*\*\*p<0.001.

aOR, adjusted odds ratio; HCP, healthcare professional; MW, midwife.

**Table 3** Perception of antenatal care received for women with and without disability

		Physical condition or illness	Sensory loss	Mental health disability	Learning disability	Multiple disability	No disability
Always time to ask questions	n (%)	597 (68.8***)	119 (70.0)	434 (65.9***)	90 (72.6)	79 (66.9*)	13 624 (75.5)
	aOR (95% CI)	0.70 (0.59 to 0.82)	0.71 (0.49 to 1.02)	0.60 (0.50 to 0.71)	1.00 (0.65 to 1.54)	0.61 (0.40 to 0.93)	
MW always listened	n (%)	623 (71.9***)	131 (76.2)	447 (67.6***)	87 (69.0**)	77 (64.7***)	14 538 (80.7)
	aOR (95% CI)	0.62 (0.52 to 0.73)	0.70 (0.48 to 1.02)	0.50 (0.42 to 0.60)	0.57 (0.38 to 0.87)	0.39 (0.25 to 0.59)	
Always spoken to so could understand	n (%)	756 (87.2*)	138 (80.7***)	559 (84.4***)	86 (68.8***)	94 (79.0***)	16 173 (89.5)
	aOR (95% CI)	0.71 (0.57 to 0.89)	0.45 (0.30 to 0.70)	0.56 (0.45 to 0.71)	0.31 (0.20 to 0.47)	0.40 (0.25 to 0.65)	
Always involved enough in decisions	n (%)	589 (68.8***)	124 (73.8)	451 (69.8***)	73 (61.3***)	76 (65.5**)	13 830 (78.3)
	aOR (95% CI)	0.60 (0.51 to 0.70)	0.77 (0.53 to 1.12)	0.62 (0.51 to 0.74)	0.45 (0.31 to 0.67)	0.54 (0.36 to 0.82)	
If MW contacted, always given help needed	n (%)	513 (94.5)	98 (94.2)	394 (95.4)	66 (66.0)	77 (74.8)	10 629 (96.7)
	aOR (95% CI)	0.67 (0.44 to 1.04)	0.81 (0.32 to 2.08)	0.90 (0.55 to 1.47)	0.70 (0.45 to 1.09)	1.00 (0.61 to 1.64)	

Number and proportion of women with and without various types of disability, ORs and 95% CIs weighted for variation in response rates by trust and adjusted for age, parity and ethnicity compared with women without disability.

Sensory disability: visually impaired, deaf and hearing impaired.

\* $p < 0.05$ , \*\* $p < 0.01$ , \*\*\* $p < 0.001$ .

aOR, adjusted odds ratio; MW, midwife.

but significantly more so by the other disability groups. However, receiving attention within a reasonable time was reported by 65% of non-disabled women but significantly more so by women with a mental health condition (69%) or a physical disability (71%).

Perceptions of hospital and community postnatal care varied, with women who had a physical or mental health disability less likely to report a positive experience in both contexts (table 5). In hospital, they were significantly less likely to report always being treated with kindness and understanding or that their companion or partner was able to stay with them as much as they wanted. Once home, a third of those with a sensory disability would have liked to have seen midwives more often (34%) as would women with learning disability (30%), compared with a fifth (20%) of non-disabled women. Over 70% of non-disabled women always felt listened to, definitely had confidence and trust in the midwives providing postnatal care at this stage, and, if a midwife was contacted, felt that they always received the help needed. However, for most variables, women with all forms of disability, especially mental health and learning disability, were significantly less likely to report so positively on these points.

Similarly, regarding infant feeding, women with physical or mental health disability were significantly less likely to report receiving active support and encouragement during the postnatal stay or, in the 6 weeks after the birth, to receive help and advice with feeding and the baby's health and progress.

### Checks and information on women's health and emotional well-being

In the antenatal period, less than half of non-disabled women (49%) reported that during their antenatal checks, midwives always appeared to be aware of their medical history (table 6). This was significantly even less likely for women with a physical or mental health disability (both 44%). Among the midwives providing postnatal care, awareness was greater than for antenatal care for all groups. However, as with antenatal care, significantly fewer of those women with a physical or mental health disability felt that midwives were always aware of their medical history. Women were also asked if they had been given enough information about their physical recovery after the birth. Just over only half of those without disability reported that they had definitely been given this information (56%). Some disability groups reported lower frequencies than this: women with a physical disability a mental health condition and multiple disability (48%, 48% and 49%, respectively) were all significantly less likely to have been given this information. Advice about contraception was less available to all disabled women, significantly so among those with a physical, mental health or learning disability.

Women with disability were more concerned that their personal circumstances had not been taken into account (65% vs 74%). Women with mental health, learning or

**Table 4** Perception of labour and birth care received for women with and without disability

	Physical condition or illness		Sensory disability		Mental health disability		Learning disability		Multiple disability		No disability
	n (%)	aOR (95% CI)	n (%)	aOR (95% CI)	n (%)	aOR (95% CI)	n (%)	aOR (95% CI)	n (%)	aOR (95% CI)	
All staff introduced themselves	646 (75.6***)	0.57 (0.48 to 0.68)	130 (80.2)	0.90 (0.58 to 1.41)	479 (73.9***)	0.52 (0.43 to 0.63)	94 (79.0)	0.80 (0.50 to 1.28)	86 (76.1)	0.77 (0.46 to 1.27)	14 982 (84.6)
Always spoken to in a way could understand	74.4 (87.1*)	0.74 (0.59 to 0.93)	132 (79.5***)	0.50 (0.32 to 0.77)	533 (81.8***)	0.49 (0.39 to 0.62)	89 (72.4***)	0.39 (0.25 to 0.60)	92 (79.3***)	0.44 (0.27 to 0.74)	16 126 (89.9)
Definitely had confidence and trust in staff	656 (75.8**)	0.73 (0.62 to 0.87)	134 (78.8)	0.82 (0.55 to 1.22)	465 (71.1***)	0.57 (0.47 to 0.69)	85 (69.7**)	0.58 (0.38 to 0.87)	89 (76.1)	0.68 (0.43 to 1.08)	14 542 (80.9)
Always involved enough in decisions	541 (65.1***)	0.60 (0.51 to 0.70)	116 (71.6)	0.82 (0.56 to 1.20)	414 (65.0***)	0.59 (0.49 to 0.70)	81 (68.6)	0.73 (0.48 to 1.11)	84 (74.3)	1.00 (0.62 to 1.61)	13 357 (76.2)
Always treated with respect	700 (81.0***)	0.59 (0.49 to 0.71)	132 (78.6**)	0.65 (0.43 to 0.98)	503 (76.7***)	0.47 (0.38 to 0.57)	97 (80.2)	0.71 (0.44 to 1.15)	93 (79.5)	0.67 (0.39 to 1.14)	15 701 (87.5)
Concerns taken seriously	450 (78.9*)	0.78 (0.62 to 0.98)	90 (74.4*)	0.55 (0.34 to 0.88)	348 (73.6***)	0.57 (0.46 to 0.72)	59 (72.0***)	0.66 (0.38 to 1.13)	67 (80.7)	0.80 (0.44 to 1.48)	9 279 (82.7)
Always received attention in reasonable time	463 (71.0**)	0.76 (0.63 to 0.92)	101 (73.2)	0.95 (0.62 to 1.45)	370 (69.2***)	0.68 (0.56 to 0.83)	62 (65.3)	0.73 (0.46 to 1.16)	69 (63.3)	1.05 (0.62 to 1.78)	10 563 (64.5)
Left alone and worried at some point	231 (26.7)	1.12 (0.95 to 1.32)	62 (36.7***)	1.32 (0.92 to 1.91)	224 (34.1***)	1.71 (1.43 to 2.04)	57 (45.6***)	1.87 (1.26 to 2.76)	43 (35.8***)	1.45 (0.94 to 2.23)	4 401 (24.5)

Number and proportion of women with and without various types of disability, ORs and 95% CIs weighted for variation in response rates by trust and adjusted for age, parity and ethnicity compared with women without disability.

Sensory disability: visually impaired, deaf and hearing impaired.

\* $p < 0.05$ , \*\* $p < 0.01$ , \*\*\* $p < 0.001$ .

**Table 5** Perception of postnatal care received for women with and without disability

		Physical condition or illness		Sensory disability		Mental health disability		Learning disability		Multiple disability		No disability	
Postnatal care in hospital													
Always able to get attention in reasonable time	n (%)	373 (46.5***)	84 (53.2)	287 (46.4***)	62 (51.7)	55 (50.5)	9421 (54.6)						
	aOR (95% CI)	0.71 (0.61 to 0.83)	0.85 (0.60 to 1.20)	0.69 (0.58 to 0.82)	0.85 (0.58 to 1.26)	0.73 (0.49 to 1.10)							
Always treated with kindness and understanding	n (%)	530 (62.1 ***)	105 (64.8)	402 (61.9***)	74 (61.7*)	74 (64.3)	13114 (71.1)						
	aOR (95% CI)	0.65 (0.59 to 0.76)	0.70 (0.49 to 0.99)	0.62 (0.52 to 0.73)	0.64 (0.43 to 0.96)	0.63 (0.42 to 0.97)							
Partner or companion stayed as long as woman wanted	n (%)	451 (53.6***)	87 (53.7)	334 (52.1***)	70 (59.3)	62 (54.9)	11367 (62.8)						
	aOR (95% CI)	0.70 (0.60 to 0.82)	0.73 (0.52 to 1.04)	0.63 (0.53 to 0.75)	1.12 (0.75 to 1.66)	0.84 (0.55 to 1.27)							
HCPs gave active support and encouragement about feeding the baby	n (%)	438 (54.0***)	93 (58.1)	327 (52.4***)	76 (64.4)	61 (56.0)	10732 (63.5)						
	aOR (95% CI)	0.66 (0.57 to 0.78)	0.82 (0.58 to 1.15)	0.64 (0.54 to 0.76)	1.25 (0.84 to 1.87)	0.77 (0.69 to 0.87)							
Postnatal care at home													
If MW contacted, always given help needed	n (%)	428 (73.0**)	87 (71.9)	360 (73.3*)	62 (65.3**)	70 (74.5)	8934 (78.4)						
	aOR (95% CI)	0.72 (0.58 to 0.88)	0.80 (0.51 to 1.25)	0.72 (0.58 to 0.91)	0.55 (0.35 to 0.88)	0.84 (0.50 to 1.40)							
Would have liked to see an MW more often	n (%)	194 (23.1*)	56 (33.5***)	131 (20.4)	36 (29.8**)	28 (24.6)	3678 (19.9)						
	aOR (95% CI)	1.35 (1.12 to 1.61)	1.94 (1.34 to 2.80)	1.22 (0.98 to 1.51)	1.89 (1.25 to 2.87)	1.61 (0.99 to 2.63)							
MWs always listened	n (%)	595 (70.7***)	110 (66.7**)	428 (66.2***)	92 (76.0)	78 (69.0*)	14404 (77.8)						
	aOR (95% CI)	0.74 (0.63 to 0.87)	0.54 (0.38 to 0.76)	0.56 (0.46 to 0.66)	0.92 (0.59 to 1.43)	0.56							
Definitely had confidence and trust in MW	n (%)	538 (64.5***)	106 (64.6*)	413 (64.2***)	79 (65.8)	74 (66.1)	13423 (72.8)						
	aOR (95% CI)	0.71 (0.61 to 0.83)	0.65 (0.46 to 0.92)	0.64 (0.54 to 0.76)	0.69 (0.46 to 1.03)	0.62							
In the 6 weeks since the birth, definitely received help and advice about													
Feeding the baby	n (%)	444 (58.6***)	89 (60.1)	327 (56.9***)	70 (59.8)	61 (56.0)	10000 (65.2)						
	aOR (95% CI)	0.73 (0.62 to 0.85)	0.83 (0.57 to 1.19)	0.73 (0.61 to 0.88)	0.94 (0.63 to 1.40)	0.70							
Baby's health and progress	n (%)	561 (67.9*)	100 (65.8)	420 (67.3*)	90 (75.6)	78 (69.0)	11943 (71.1)						
	aOR (95% CI)	0.81 (0.69 to 0.95)	0.69 (0.46 to 0.96)	0.78 (0.65 to 0.94)	1.19 (0.76 to 1.88)	0.73							

Number and proportion of women with and without various types of disability, ORs and 95% CIs weighted for variation in response rates by trust and adjusted for age, parity and ethnicity compared with women without disability.

Sensory disability: visually impaired, deaf and hearing impaired.

\*p<0.05, \*\*p<0.01, \*\*\*p<0.001.

aOR, adjusted OR; HCP, healthcare professional; MW, midwife.



**Table 6** Physical and emotional well-being for women with and without disability

Antenatal period								
	Physical condition or illness	Sensory loss	Mental health disability	Learning disability	Multiple disabilities	No disability		
MW always aware of medical history	n (%)	378 (44.1*)	80 (48.8)	238 (43.5*)	67	54.5	60 (50.8)	8523 (48.7)
	aOR (95% CI)	0.84 (0.72 to 0.97)	0.95 (0.67 to 1.34)	0.83 (0.70 to 0.99)	1.28 (0.87 to 1.87)	1.02 (0.68 to 1.52)		
MW definitely asked how feeling emotionally	n (%)	438 (52.0**)	105 (63.3)	392 (60.2)	73 (60.8)		70 (60.3)	9882 (56.4)
	aOR (95% CI)	0.81 (0.70 to 0.95)	1.19 (0.84 to 1.68)	1.16 (0.97 to 1.37)	1.23 (0.83 to 1.84)	1.03 (0.68 to 1.57)		
Postnatal care after discharge home								
MW always aware of medical history	n (%)	542 (69.0***)	114 (74.0)	438 (71.5***)	88	75.2	77 (71.3)	12855 (78.0)
	aOR (95% CI)	0.63 (0.54 to 0.75)	0.83 (0.56 to 1.23)	0.73 (0.60 to 0.88)	1.00 (0.63 to 1.58)	0.71 (0.44 to 1.15)		
MW took personal circumstances into account	n (%)	482 (65.4***)	94 (63.9**)	379 (64.7***)	68 (63.0*)		67 (65.7)	11 071 (74.3)
	aOR (95% CI)	0.69 (0.58 to 0.82)	0.60 (0.42 to 0.87)	0.59 (0.49 to 0.71)	0.59 (0.39 to 0.90)	0.61 (0.39 to 0.97)		
Women informed of need to arrange own PN check	n (%)	731 (90.2)	150 (90.4)	549 (89.3**)	100 (85.5**)		91 (82.0***)	15 825 (92.3)
	aOR (95% CI)	0.80 (0.62 to 1.05)	0.74 (0.42 to 1.31)	0.73 (0.55, 0.97)	0.55 (0.31 to 0.99)	0.73 (0.21 to 0.65)		
MW/HV asked how feeling emotionally	n (%)	804 (94.9***)	159 (95.2)	623 (95.1**)	115 (92.0**)		114 (96.6)	17 295 (97.2)
	aOR (95% CI)	0.52 (0.37 to 0.74)	0.57 (0.27 to 1.21)	0.56 (0.38 to 0.83)	0.39 (0.19 to 0.77)	1.15 (0.40 to 3.29)		
Definitely given enough information about emotional changes	n (%)	421 (51.2***)	93 (57.8)	330 (52.0**)	71 (58.2)		63 (56.3)	9689 (57.6)
	aOR (95% CI)	0.76 (0.66 to 0.89)	0.9 (0.64 to 1.28)	0.77 (0.65 to 0.91)	0.99 (0.67 to 1.47)	0.84 (0.56 to 1.27)		
Told who to contact about emotional changes	n (%)	520 (69.1***)	102 (72.9)	428 (71.7)	81 (69.8)		81 (75.0)	11 603 (75.3)
	aOR (95% CI)	0.76 (0.64 to 0.90)	0.92 (0.61 to 1.38)	0.84 (0.69, 1.03)	0.84 (0.55 to 1.30)	0.98 (0.60 to 1.61)		
Definitely given advice about physical recovery	n (%)	409 (48.1***)	98 (60.1)	311 (47.9***)	66 (54.1)		55 (48.7***)	10 066 (56.1)
	aOR (95% CI)	0.72 (0.62 to 0.84)	1.20 (0.83 to 1.67)	0.64 (0.54 to 0.76)	0.90 (0.61 to 1.32)	0.74 (0.67 to 0.82)		
Given information/advice about contraception	n (%)	740 (88.0***)	143 (88.8)	558 (86.8***)	100 (85.5*)		93 (86.9)	16 237 (92.0)
	aOR (95% CI)	0.66 (0.52 to 0.83)	0.84 (0.50 to 1.41)	0.54 (0.42, 0.69)	0.56 (0.32 to 0.99)	0.55 (0.30 to 1.01)		

Number and proportion of women with various types of disability, ORs and 95% CIs weighted for variation in response rates by trust and adjusted for age, parity and ethnicity compared with women without disability.

Sensory disability: visually impaired, deaf and hearing impaired.

\*p<0.05, \*\*p<0.01, \*\*\*p<0.001.

aOR, adjusted OR; MW, midwife.

multiple disability were less likely to report being informed of the need to arrange their own postnatal check-up.

All women should be asked about their emotional well-being during pregnancy and postnatally.<sup>16</sup> While just over half of those with no disability reported being asked about their emotional well-being during pregnancy (56%), this was even less likely for those with a physical disability (52%). In contrast, over 90% of women in all groups reported being asked about their emotional well-being postnatally, although some groups, especially women with a physical, mental health or learning disability, were still less likely to report having been asked. Women were also asked about being given information about the emotional changes that might be experienced after the birth. Fewer women overall (less than 60%) reported being given enough information about possible changes in mood, and this was even less likely for women with physical disability and those with mental health problems (51% and 52%, respectively). Of non-disabled women, 75% were told who to contact for advice about any emotional changes, but only 69% of women with a physical disability reported this.

## DISCUSSION

This study provides further evidence that disabled women have a poorer perception of care during pregnancy, childbirth and in the postnatal period which need to be recognised. The conditions giving rise to disability are extremely diverse, and some women may need more clinical or supportive care than others. Yet, such women often encounter negative attitudes toward their pregnancy.<sup>17 18</sup> Disabled women are usually classified during their pregnancy as 'high risk',<sup>2</sup> requiring more antenatal visits and more scans, as found in other studies.<sup>19</sup> Arranging these intensive appointments can be difficult for some disabled women. There is a need for more specific services and more guidance and training for healthcare professionals caring for women with any disability during pregnancy.

This study shows that, in England in 2015, while care was more responsive in some respects for disabled women, such as more home visits after hospital discharge, disabled women overall perceived their care in more negative terms than non-disabled women. In particular, they felt that they were not always spoken to so that they could understand, listened to, did not always have time to ask questions, were not always sufficiently involved in decisions about their care, treated with respect, or their concerns taken seriously. Women with sensory, mental health, learning or multiple disabilities were more likely to be left alone at a time when it worried them during labour or shortly after birth. It may be that these women needed more reassurance and support or had more reason to be worried, but their concerns were not addressed by staff. It is also possible that disabled women who would, in general, have had more experience of the health service than non-disabled women were expressing their disillusionment with healthcare generally.

Communication barriers, deficits in health information and a lack of knowledge and awareness among healthcare professionals have been identified before<sup>20 21</sup> and represent some of the attitudinal barriers faced by disabled women. Information needs to be distributed in accessible formats. Disability awareness and training for healthcare professionals as well as allocation of additional care time and flexible postnatal visiting could have a positive influence on care. In addition, the focus should be on women's abilities rather than their disabilities. Previous research has indicated that, while some staff were excellent, others provided 'unhelpful help', taking over, leading to feelings of disempowerment.<sup>22</sup> Support through the transition from pregnancy to motherhood should also be considered by healthcare providers.<sup>5</sup> Integrated care between different services, such as mental health and obstetric services, may be required to meet the needs of these groups.

These data from this survey highlight particular areas where maternity services need to improve to provide equal services to women with different types of disability. The greater number of questions in the 2015 survey focusing on specific aspects of maternity care contributes to a broader and more detailed picture of the care experienced by disabled women compared with previous surveys. Flexible and responsive services are needed by women with different types of disability. Specifically, women with physical disability are likely to need rather different personalised care and support from women with mental health disability. For example, women with physical conditions may need help with physical access, whereas those with mental health problems may need more emotional support than others. As we also concluded from our earlier study, empowering women and supporting their involvement in the decision-making process during pregnancy is a key area for improvement.<sup>13</sup> Supported decision making may be necessary to enable some individuals to communicate their needs and choices. Individual women differ, and those with disability should be offered the same antenatal options, choices of birth place and pain relief as non-disabled women, unless their medical conditions contradict these options. Information should be accessible and in a comprehensive format. An early assessment of the maternity care required is crucial to forming a care plan with the women involved. Healthcare professionals need to plan ahead on how to meet the individual needs with the women themselves and to keep the conversation open and ongoing over the pregnancy and afterwards.

The needs of disabled women are still not fully met in the maternity services in England as evidenced here, and there is a clear need to document and assess the needs of this group. Research from Korea involving 410 physically disabled women points to high rates of abortion, miscarriage, caesarean section and low usage of contraception.<sup>23</sup> In Switzerland, there are few guidelines and little regular assessment for women with psychiatric problems in the perinatal period.<sup>24</sup> In qualitative studies in the USA and

Canada, women with physical impairments reported numerous barriers to reproductive health services.<sup>17 25 26</sup> However, an Australian study illustrated the positive care experience possible for women attending a specialised childbirth and mental health antenatal clinic.<sup>27</sup> The WHO global disability action plan 2014–2021 requires member states to strengthen the collection of relevant and internationally comparable data on disability and support research on disability and related services.<sup>3</sup>

### Strengths and limitations

Strengths of this study include the fact that all the organisations providing maternity care in England participated and substantial numbers of women with different types of disability responded. Moreover, we report on women's own perspective on their care. All data in this survey were self-reported and collected retrospectively at 3 months postpartum. This may call into question the validity of the responses recalled from pregnancy. However, research into the accuracy of recall suggests that it is good.<sup>28–30</sup> The survey response rate was low (41%) which may affect the generalisability of the findings; however, weighting for non-response was used. Also, many possible associations were tested, and some significant associations may have arisen by chance. However, the high level of statistical significance of many of the associations reported mitigates against this. Analyses were limited to the data collected by CQC. Unfortunately, data were not collected on level of education, marital status, income level or urban/rural setting.

### Conclusion and implications for research and practice

This study presents the findings of a 2015 maternity survey in England as they relate to disability. Using recently collected data, the study objectives were to investigate access to maternity care and the quality of that care as reflected in women's perceptions, exploring differences in the experience of women with different types of disability.

Disabled women perceived greater problems regarding their maternity care, communication and involvement in decision making than non-disabled women. Those with a physical disability or long-standing illness perceived problems regarding inadequate or inappropriate communication, limited involvement in decision making, and being able to establish a trusted and respected relationship with clinical staff are areas for improvement for women in this group. For women with sensory disability, having information delivered in an appropriate format was particularly important. It may be helpful for staff caring for these women to allow more time to communicate effectively throughout their maternity care.

In order to provide more appropriate care for women with a mental health disability, a longer hospital stay and more frequent midwife visits may be required. In this group, many aspects of maternity care were not perceived as positively as for other groups, particularly they felt that they were not always listened to, did not have time

to ask questions, were not sufficiently involved in decisions about their care, treated with respect or had their concerns taken seriously.

Similarly for women with multiple disabilities, improvements in communication and involvement in decision making are needed. For women with a learning disability, aspects of care concerning communication and involvement in decisions, feeling listened to and supported, particularly during labour and birth, were highlighted as lacking, and specific efforts are needed to improve the quality of care experienced.

Further research could focus on specific groups and involve qualitative and quantitative methods. Studies of attitudes and knowledge of healthcare providers, including the way in which stereotypes may operate, would also be useful in understanding the differences in care and disabled women's perceptions described.

Healthcare professionals sometimes lack sufficient awareness and experience to respond effectively to the needs of disabled women during pregnancy and the early postnatal period. As reported elsewhere,<sup>22</sup> disabled women want to be assisted to do things themselves, rather than having things done for them. To achieve satisfactory maternity care for all women, the needs and voices of women with disabilities should not only be referred to in the strategy and policy documents of healthcare providers but also embodied in their provision and practice, allowing more time for appointments and additional support staff and equipment as required.

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