

# BMJ Open

## Access and quality of maternity care for women with disability during pregnancy, birth and the postnatal period

Journal:	<i>BMJ Open</i>
Manuscript ID	bmjopen-2017-016757
Article Type:	Research
Date Submitted by the Author:	08-Mar-2017
Complete List of Authors:	Malouf, Reem; University of Oxford, Policy Research Unit in Maternal Health and Care, NPEU, Nuffield Department of Population Health Henderson, Jane; University of Oxford, Policy Research Unit in Maternal Health and Care, NPEU, Nuffield Department of Population Health Redshaw, Maggie; University of Oxford, Policy Research Unit in Maternal Health and Care, NPEU, Nuffield Department of Population Health
<b>Primary Subject Heading</b>:	Health services research
Secondary Subject Heading:	Health services research, Public health
Keywords:	maternity care, disability, maternity services, pregnancy, labour, postnatal

SCHOLARONE™  
Manuscripts

1  
2  
3  
4  
5  
6  
7  
8  
9  
10  
11  
12  
13  
14 **Access and quality of maternity care for women with disability during pregnancy, birth**  
15 **and the postnatal period**  
16

17  
18  
19 Reem Malouf

20  
21 Jane Henderson

22  
23 Maggie Redshaw\*  
24  
25  
26  
27  
28  
29  
30

31 Policy Research Unit in Maternal Health and Care

32 National Perinatal Epidemiology Unit

33 University of Oxford  
34  
35  
36  
37  
38  
39

40 \*Corresponding author:

41 Maggie Redshaw,

42 Policy Research Unit in Maternal Health and Care,

43 National Perinatal Epidemiology Unit,

44 Nuffield Department of Population Health,

45 University of Oxford,

46 Old Road Campus,

47 Oxford OX3 7LF,

48 UK

49 maggie.redshaw@npeu.ox.ac.uk  
50  
51  
52  
53  
54  
55  
56  
57  
58  
59  
60

## Abstract

**Objectives :** More women with disability 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 made with the responses of women without disability.

**Setting:** Survey data were collected on women's experience of primary and secondary 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 aged less 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 women with a disability, women's emotional wellbeing 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 health care providers.

**Keywords:** Maternity care, maternity services, disability, pregnancy, labour, postnatal.

**Strengths and limitations**

- A more detailed picture of the care experienced by women with disability is provided compared to previous surveys.
- It was possible to look at the experience of different groups, with very different types of disability.
- The findings highlight aspects of care where maternity services need to improve to provide equal services to women with disability.
- A strength of the study is that all the organisations providing maternity care in England participated
- All data in this survey were self-reported and collected retrospectively at three months postpartum which may affect the quality of responses based on recall.
- The response rate was lower than previous surveys which may affect the generalizability of the findings, however, weighting for non-response was used.

1  
2  
3 **Access and quality of maternity care for women with disability during pregnancy, birth**  
4  
5  
6 **and the postnatal period**  
7

8 **Background**  
9

10  
11 The number of women with disability choosing to become mothers is growing.(1) However, stigma  
12 still exists about such women and their care-giving and mothering capabilities.(2) Although all  
13 women are entitled to have access to high quality maternal care, worldwide half of disabled people  
14 cannot afford health care, compared to a third of non-disabled women, and they are more likely to  
15 find health care providers' skills inadequate.(3) This is despite disabled women's greater need for,  
16 and use of, health care services.(4) People with disabilities and their families frequently experience  
17 inequalities in accessing health services, with poor communication and challenging attitudes among  
18 health care providers.(2) Furthermore, people with disability are four times more likely to report  
19 being treated badly and nearly three times more likely to be denied access to health care.(3)  
20  
21

22  
23 The challenges to women with physical disabilities accessing maternity services are recognised by  
24 some health care professionals who believe that this group of women are less able to cope with  
25 pregnancy.(5) At the same time, health care professionals may lack knowledge and experience in  
26 planning and providing care for pregnant women with disability.(6) For example, antenatal  
27 information may be distributed in a manner inappropriate and insufficient for women with visual  
28 impairment. (1, 7) There is some evidence that women with hearing impairment receive fewer  
29 antenatal visits and have limited access to maternity information.(8, 9) For women with a less easily  
30 identified disability, such as those arising from mental health problems, there may be difficulties in  
31 receiving appropriate care. (10) For women in this group, dissatisfaction and lack of trust have been  
32 found to be the main barriers in seeking help during pregnancy. (10)  
33  
34

35  
36 In the UK, maternity services are freely available for all women. A study reporting on the use of  
37 maternity services by women with disabilities in 2010 (11) concluded that women with disability  
38  
39  
40  
41  
42  
43  
44  
45  
46  
47  
48  
49  
50  
51  
52  
53  
54

1  
2  
3 were at higher risk of adverse pregnancy outcomes, for example, they were more likely to deliver  
4  
5 early and have low birth weight babies. However, it also concluded that some women, such as those  
6  
7 with physical disabilities, appropriately received more care. In this paper, we aim to reflect  
8  
9 predominantly on the quality of maternity care received for women with disability in England more  
10  
11 recently.  
12

### 13 14 15 **Methods**

16  
17 The main objective of this secondary analysis was to report on access to care and the quality of care  
18  
19 received by women with disability who used the maternity services in 2015 in England, seeking a  
20  
21 better understanding of the maternity care issues arising for women with different types of  
22  
23 disability. In this paper we:  
24

- 25  
26 • compare the perceptions and experiences of maternity care received by women with  
27  
28 different types of disability and women with no disability
- 29  
30 • identify differences or gaps in care for women with disability which could be addressed  
31  
32

### 33 34 ***Study design and survey measure***

35  
36 A structured cross-sectional study design was implemented and data collated by the Care Quality  
37  
38 Commission (CQC) in 2015.<sup>(12)</sup> The CQC is an independent regulator of health and social care in  
39  
40 England and all National Health Service Trusts providing maternity care carried out trust based  
41  
42 surveys using the same survey instrument. Modifications were made to the 2010 and then the 2013  
43  
44 CQC survey measures following consultation, focus groups and cognitive interviews which identified  
45  
46 additional aspects of women's maternity care to be covered. While the survey continued to cover  
47  
48 aspects of pregnancy, labour and birth and postnatal care, more questions asked about women's  
49  
50 access to care, communication with health care providers, involvement in decision-making,  
51  
52 awareness of birth choices and support for emotional well-being and physical health. Limited data  
53  
54 on neonatal outcomes as well as socio-demographic characteristics including age, ethnicity, marital  
55  
56 status and parity were also collected.  
57  
58  
59  
60

1  
2  
3 Postal surveys were sent to 50,945 women aged 16 years or more who had given birth to a live baby  
4  
5 in February 2015. Completing and returning the survey was considered as consent to take part in the  
6  
7 study. Women who were less than 16 years, those who had a stillbirth or whose baby died after  
8  
9 birth, women delivered in private settings and women without a postal address were excluded from  
10  
11 the surveys.  
12

13  
14 Women were asked if they had any long-standing conditions with seven options, including 'No, I do  
15  
16 not have a long-standing condition'. Using the checklist, respondents were thus able to describe  
17  
18 their disability and indicate if they had more than one disability. Five different disability groups were  
19  
20 identified: physical (long-standing physical condition and long-standing illness), sensory (deafness or  
21  
22 hearing impairment and blindness or partial sightedness), mental health problem, learning disability,  
23  
24 and multiple disabilities, i.e. having two or more disabilities (see Table 1).  
25  
26

### 27 28 **Statistical analysis**

29  
30 The data presented are grouped in relation to access to care, the clinical care received and women's  
31  
32 perceptions about the different phases of care. The categories used were those collected and where  
33  
34 variables were further aggregated for conciseness this was based on clinical or policy relevance. The  
35  
36 cut-offs are indicated in the tables. Univariate data analyses were carried out to compare the  
37  
38 maternal characteristics and responses of women with disability to women without disability. Chi-  
39  
40 square statistics were used to compare study groups. Adjusted odds ratios and 95% confidence  
41  
42 interval were weighted for variation in response rate by the trusts and adjusted for age, parity and  
43  
44 ethnicity using binary logistic regression. Each of the subgroups, physical, sensory, mental, learning,  
45  
46 and multiple disability, was separately compared to the referent group of non-disabled women.  
47  
48 Maternal characteristics and reports about care were compared to women who did not self-identify  
49  
50 with any of the conditions listed above. The analyses were carried out in STATA, version 13  
51  
52  
53  
54

### 55 **Results**

56  
57  
58  
59  
60

### ***Women's characteristics***

Overall, 20,094 women completed and returned the survey, with a usable response rate of 41.2%.

Women with disability represented 9.5% (1,958) of the total sample. Compared to non-respondents, survey respondents were more likely to be White, aged 30 years or more, and primiparous(12). 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 to all other ethnic groups. Similarly, primiparous women were significantly more likely than multiparous women to report learning disabilities. All women with disability were at a higher risk of delivering preterm compared to women without disability, particularly those with physical disability, mental health problems, learning disability and women with multiple disability (Table 1). Across all groups, babies born to women with disability were significantly less likely to be breast fed at the time of hospital discharge compared to women with no disability.

### ***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



1  
2  
3 between the groups in continuity of care, with less than half of women in all groups seeing the same  
4  
5 midwife for antenatal checks through the pregnancy. Choice in relation to place of birth differed for  
6  
7 the disability groups: while only 9% of women without a disability indicated that, for medical  
8  
9 reasons, they had no choice about where they could have their baby, the comparable figure for  
10  
11 women with a physical disability was 32% and for the other groups between 14% and 27%. Clinical  
12  
13 care differed across the groups in relation to labour and birth, with women with a physical condition  
14  
15 significantly more likely to have intervention in the form of assisted vaginal births and planned or  
16  
17 emergency caesarean section. Shortly after the birth, women with physical disability were slightly  
18  
19 less likely to have skin-to-skin contact with their baby, although nearly nine out of ten women did so.  
20  
21  
22 While approximately a quarter of women without disability (26%) stayed in hospital for more than  
23  
24 two days after giving birth, more women in all the different types of disability groups did so,  
25  
26 significantly more for women with physical, mental health, learning or multiple disabilities which  
27  
28 may relate partly to method of delivery. Nearly half of the women with multiple disabilities (45%)  
29  
30 stayed longer than two days. More than 90% of women with and without disability received at least  
31  
32 one postnatal home visit from a midwife although this was slightly fewer for the physically disabled  
33  
34 women. However, women with mental health or learning disability were significantly more likely to  
35  
36 have received a home visit or seen a midwife in a clinic five or more times in the postnatal period.  
37  
38 Women with physical or mental disability were less likely to report that advice about infant feeding  
39  
40 was always available at evenings and weekends.  
41  
42  
43  
44

#### 45 ***Perceptions of care***

46  
47 Women's views about the care received varied across the different groups (Tables 3-5).

48  
49 During pregnancy, women with physical disability, those with mental health conditions and women  
50  
51 with more than one disability were all significantly less likely to feel there was always time to ask  
52  
53 questions at their appointments, to feel listened to, spoken to in a way they could understand,  
54  
55 involved enough in decisions about their care, and if they had contacted a midwife, that they had  
56  
57  
58  
59  
60

1  
2  
3 been given the help they needed (Table 3). All disabled women were significantly more likely to  
4  
5 report negative experiences of pregnancy care, particularly in relation to always being spoken to by  
6  
7 health professionals in a way that they could understand and, except for women with sensory loss,  
8  
9 being involved in decisions about their care.  
10

11  
12 Perceptions of labour and birth care also differed between the groups (Table 4). While 85% of  
13  
14 women without disability reported that all staff who treated and examined them introduced  
15  
16 themselves, significantly fewer women with physical disabilities and mental health conditions  
17  
18 reported this (76% and 74% respectively) (Table 4). Significantly fewer women in with physical,  
19  
20 mental health and learning disabilities were likely to report definitely having confidence and trust in  
21  
22 staff, fewer women in all disability groups reported always being spoken to so they could  
23  
24 understand, and fewer women with physical, sensory and mental health disabilities reported that  
25  
26 they were always treated with respect at this time. Significantly fewer women with physical  
27  
28 disabilities (65%) and mental health conditions (65%) reported that they were always involved in  
29  
30 decisions about their care compared with 76% of those with no disability. Similarly, while 83% of  
31  
32 women without disability felt that their concerns during labour and birth were taken seriously,  
33  
34 significantly fewer women with mental health problems or learning disability perceived this to be  
35  
36 the case (74% and 72% respectively).  
37  
38  
39

40  
41 Women were asked whether they and their partner were left alone at a time when it worried them  
42  
43 during labour or shortly after the birth, and whether they received attention and help from a  
44  
45 member of staff within a reasonable time. Feeling left alone and worried at some time was reported  
46  
47 by a quarter of women without disability or with physical disability (25% and 27% respectively) but  
48  
49 significantly more so by the other disability groups. However, receiving attention within a reasonable  
50  
51 time was reported by 65% of women without disability but significantly more so by women with a  
52  
53 mental health condition (69%) or a physical disability (71%).  
54  
55  
56  
57  
58  
59  
60

1  
2  
3 Perceptions of hospital and community postnatal care varied, with women who had a physical or  
4  
5 mental health disability less likely to report a positive experience in both contexts (Table 5). In  
6  
7 hospital they were significantly less likely to report always being treated with kindness and  
8  
9 understanding, or that their companion or partner was able to stay with them as much as they  
10  
11 wanted. Once home, a third of those with a sensory disability would have liked to have seen  
12  
13 midwives more often (34%) as would women with learning disability (30%), compared with a fifth  
14  
15 (20%) of women with no disability. Over 70% of women without disability always felt listened to,  
16  
17 definitely had confidence and trust in the midwives providing postnatal care at this stage, and, if a  
18  
19 midwife was contacted, felt that they always received the help needed. However, for most variables,  
20  
21 women with all forms of disability, especially mental health and learning disability, were significantly  
22  
23 less likely to report so positively on these points.  
24  
25

26  
27 Similarly, regarding infant feeding, women with physical or mental health disability were significantly  
28  
29 less likely to report receiving active support and encouragement during the postnatal stay, or, in the  
30  
31 six weeks after the birth, to receive help and advice with feeding and the baby's health and progress.  
32  
33

#### 34 ***Checks and information on women's health and emotional wellbeing***

35  
36 In the antenatal period less than half of women without disability (49%) reported that during their  
37  
38 antenatal checks midwives always appeared to be aware of their medical history (Table 6). This was  
39  
40 significantly even less likely for women with a physical or mental health disability (both 44%).  
41  
42 Among the midwives providing postnatal care, awareness was greater than for antenatal care for all  
43  
44 groups. However, as with antenatal care, significantly fewer of those women with a physical or  
45  
46 mental health disability felt that midwives were always aware of their medical history. Women were  
47  
48 also asked if they had been given enough information about their physical recovery after the birth.  
49  
50 Just over only half of those without disability reported that they had definitely been given this  
51  
52 information (56%). Some disability groups reported lower frequencies than this: women with a  
53  
54 physical disability a mental health condition and multiple disability (48%, 48% and 49% respectively)  
55  
56  
57  
58  
59  
60

1  
2  
3 were all significantly less likely to have been given this information. Advice about contraception was  
4  
5 less available to all disabled women, significantly so among those with a physical, mental health or  
6  
7 learning disability.  
8

9  
10 Women with disability were more concerned that their personal circumstances had not been taken  
11  
12 into account (65% vs. 74%). Women with mental health, learning or multiple disability were less  
13  
14 likely to report being informed of the need to arrange their own postnatal check-up.  
15

16  
17  
18 All women should be asked about their emotional wellbeing during pregnancy and postnatally.(13)  
19

20 While just over half of those with no disability reported being asked about their emotional wellbeing  
21  
22 during pregnancy (56%), this was even less likely for those with a physical disability (52%). In  
23  
24 contrast, over 90% of women in all groups reported being asked about their emotional wellbeing  
25  
26 postnatally, though some groups, especially women with a physical, mental health or learning  
27  
28 disability, were still less likely to report having been asked. Women were also asked about being  
29  
30 given information about the emotional changes that might be experienced after the birth. Fewer  
31  
32 women overall (less than 60%), reported being given enough information about possible changes in  
33  
34 mood and this was even less likely for women with physical disability and those with mental health  
35  
36 problems (51% and 52% respectively). Of women without disability, 75% were told who to contact  
37  
38 for advice about any emotional changes, but only 69% of women with a physical disability reported  
39  
40 this.  
41  
42  
43  
44  
45

## 46 Discussion

47  
48  
49 This study provides further evidence that women with disability a poorer perception of care during  
50  
51 pregnancy, childbirth and in the postnatal period which need to be recognized. The conditions  
52  
53 giving rise to disability are extremely diverse and some women may need more clinical or supportive  
54  
55 care than others. Yet such women often encounter negative attitudes towards their pregnancy.(14,  
56  
57 15) Women with disability are usually classified during their pregnancy as 'high risk',(2) requiring  
58  
59  
60

1  
2  
3 more antenatal visits and more scans. Arranging these intensive appointments can be difficult for  
4  
5 some women with disability. There is a need for more specific services, and more guidance and  
6  
7 training for health care professionals caring for women with any disability during pregnancy.  
8  
9

10 This study shows that, in England in 2015, while care was more responsive in some respects for  
11  
12 women with disability, such as more home visits after hospital discharge, disabled women overall  
13  
14 perceived their care in more negative terms than non-disabled women. In particular, they felt that  
15  
16 they were not always spoken to so that they could understand, listened to, did not always have time  
17  
18 to ask questions, were not always sufficiently involved in decisions about their care, treated with  
19  
20 respect, or their concerns taken seriously. Women with sensory, mental health, learning or multiple  
21  
22 disabilities were more likely to be left alone at a time when it worried them during labour or shortly  
23  
24 after birth. It may be that these women needed more reassurance and support or had more reason  
25  
26 to be worried but their concerns were not addressed by staff. It is also possible that disabled women  
27  
28 who would, in general, have had more experience of the health service than non-disabled women,  
29  
30 were expressing their disillusionment with healthcare generally.  
31  
32

33  
34 Communication barriers, deficits in health information and a lack of knowledge and awareness  
35  
36 among health care professionals have been identified before.(16, 17) Information needs to be  
37  
38 distributed in accessible formats. Disability awareness and training for health care professionals as  
39  
40 well as allocation of additional care time and flexible postnatal visiting could have a positive  
41  
42 influence on care. In addition, the focus should be on women's abilities rather than their disabilities.  
43  
44 Support through the transition from pregnancy to motherhood should also be considered by health  
45  
46 care providers.(5) Integrated care between different services, such as mental health and obstetric  
47  
48 services, may be required to meet the needs of these groups.  
49  
50

51  
52 This data from this survey highlight particular areas where maternity services need to improve to  
53  
54 provide equal services to women with different types of disability. The greater number of questions  
55  
56 in the 2015 survey focusing on specific aspects of maternity care contribute to a broader and more  
57  
58  
59  
60

1  
2  
3 detailed picture of the care experienced by women with disability compared to previous surveys.  
4  
5 Flexible and responsive services are needed by women with different types of disability. Specifically,  
6  
7 women with physical disability are likely to need rather different personalised care and support from  
8  
9 women with mental health disability. For example, women with physical conditions may need help  
10  
11 with physical access whereas those with mental health problems may need more emotional support  
12  
13 than others. As we also concluded from our earlier study, empowering women and supporting their  
14  
15 involvement in the decision-making process during pregnancy is a key area for improvement.(11)  
16  
17 Supported decision-making may be necessary to enable some individuals to communicate their  
18  
19 needs and choices. Individual women differ and those with disability should be offered the same  
20  
21 antenatal options, choices of birth place and pain relief as non-disabled women, unless their medical  
22  
23 conditions contradict these options. Information should be accessible and in a comprehensive  
24  
25 format. An early assessment of the maternity care required is crucial to forming a care plan with the  
26  
27 women involved. Health care professionals need to plan ahead on how to meet the individual needs  
28  
29 with the women themselves and to keep the conversation open and ongoing over the pregnancy  
30  
31 and afterwards.  
32  
33  
34  
35

36 The needs of women with disability are still not fully met in the maternity services in England as  
37  
38 evidenced here, and there is a clear need to document and assess the needs of this group. In other  
39  
40 countries high rates of abortion, miscarriage, caesarean section, and low usage of contraception  
41  
42 were among the findings from a survey that was carried out in South Korea involving 410 physically  
43  
44 disabled women (18)). The WHO global disability action plan 2014-2021 requires Member States to  
45  
46 strengthen the collection of relevant and internationally comparable data on disability, and support  
47  
48 research on disability and related services.(3)  
49  
50

### 51 ***Study limitations***

52  
53  
54 All data in this survey were self-reported and collected retrospectively at three months postpartum.  
55  
56 This may call into question the validity of the responses recalled from pregnancy. However, research  
57  
58  
59  
60

1  
2  
3 into the accuracy of recall suggests that it is good. (19-21) The survey response rate was low (41%)  
4  
5 which may affect the generalizability of the findings, however, weighting for non-response was used.  
6  
7 Also, many possible associations were tested and some significant associations may have arisen by  
8  
9 chance. However, the high level of statistical significance of many of the associations reported  
10  
11 mitigate against this. Strengths of this study include the fact that all the organisations providing  
12  
13 maternity care in England participated and substantial numbers of women with different types of  
14  
15 disability responded. Moreover, we report on women's own perspective on their care. Further  
16  
17 research could focus on specific groups and involve qualitative and well as quantitative methods.  
18  
19 Studies of attitudes and knowledge of health care providers, including the way in which stereotypes  
20  
21 may operate, would also be useful in understanding the differences in care and disabled women's  
22  
23 perceptions described.  
24  
25

### 26 27 **Conclusion and implications for practice**

28  
29  
30 This study presents the findings of a 2015 maternity survey in England as they relate to disability.  
31  
32 Using recently collected data, the study objectives were to investigate access to maternity care and  
33  
34 the quality of that care as reflected in women's perceptions, exploring differences in the experience  
35  
36 of women with different types of disability.  
37  
38

39  
40 Disabled women were more critical about their maternity care, communication, and involvement in  
41  
42 decision making. Those with a physical disability or longstanding illness were more critical about the  
43  
44 care received: inadequate or inappropriate communication, limited involvement in decision-making,  
45  
46 and being able to establish a trusted and respected relationship with clinical staff are areas for  
47  
48 improvement for women in this group. For women with sensory disability, having information  
49  
50 delivered in an appropriate format was particularly important. It may be helpful for staff caring for  
51  
52 these women to allow more time to communicate effectively throughout their maternity care.  
53  
54  
55  
56  
57  
58  
59  
60

1  
2  
3 In order to provide more appropriate care for women with a mental health disability, a longer  
4 hospital stay and more frequent midwife visits may be required. In this group many aspects of  
5 maternity care were not perceived as positively as for other groups, particularly they felt that they  
6 were not always listened to, did not have time to ask questions, were not sufficiently involved in  
7 decisions about their care, treated with respect, or had their concerns taken seriously.  
8  
9

10  
11  
12  
13  
14 Similarly for women with multiple disabilities, improvements in communication and involvement in  
15 decision-making are needed. For women with a learning disability aspects of care concerning  
16 communication and involvement in decisions, feeling listened to and supported, particularly during  
17 labour and birth, were highlighted as lacking and specific efforts are needed to improve the quality  
18 of care experienced.  
19  
20  
21  
22  
23  
24

25  
26  
27 Health care professionals sometimes lack sufficient awareness and experience to respond effectively  
28 to the needs of women with disability during pregnancy and early postnatal period. To achieve  
29 satisfactory maternity care for all women, the needs and voices of women with disabilities should  
30 not only be referred to in the strategy and policy documents of health care providers but also  
31 embodied in their provision and practice.  
32  
33  
34  
35  
36  
37

### 38 **Competing interest**

39  
40  
41 We declare no competing interests  
42  
43  
44

### 45 **Author's contributions**

46  
47  
48 All three listed authors have contributed to this paper: MR designed the analysis plan, JH and RM  
49 carried out the analyses, RM drafted the main manuscript and all authors contributed to the  
50 interpretation of the findings and refining the manuscript. All three authors read and approved the  
51 final version of the manuscript.  
52  
53  
54  
55  
56  
57  
58  
59  
60



## Acknowledgements

This work reports on an independent study which was funded by the Policy Research Programme in the Department of Health (DH) in the United Kingdom. The views expressed are not necessarily those of the DH. The Care Quality Commission was responsible for the original survey and granted access to the data. We are most grateful to women who responded to the survey.

## Data sharing agreement

The women's trust based data used in this study were accessed from CQC who were responsible for the survey.

## References:

1. Blackford KA, Richardson H, Grieve S. Prenatal education for mothers with disabilities J Adv Nurs. 2000;32(4):898-904
2. Walsh-Gallagher D, Sinclair M, Mc Conkey R. The ambiguity of disabled women's experiences of pregnancy, childbirth and motherhood: A phenomenological understanding. Midwifery. 2012;28(2):156-62.
3. World Health Organization. Disability and rehabilitation 2016 [Available from: <http://www.who.int/disabilities/data/en/>]
4. Hague G, Thiara R, Mullender A. Disabled women, domestic violence and social care: the risk of isolation, vulnerability and neglect. Br J Soc Work. 2011;41(1):148-65.
5. Lawler D LJ, Begley C. Access to maternity services for women with physical: a systematic review. Int J Childbirth 2013;3(4)::203-17.
6. Lipson JG RJ. Pregnancy, birth, and disability: women's health care experiences. Health Care Women Int. 2000 21:11-26.
7. Clark L, . Accessible health information: Liverpool Central Primary Care Trust. Project Report. Liverpool2002 [Available from: <http://pf7d7vi404s1dxh27mla5569.wpengine.netdna-cdn.com/files/library/Clark-Laurence-liverpool-NHS.pdf>].
8. Steinberg EJ. Deaf Mothers and Reproductive Healthcare: Identifying Inequalities and Documenting Experiences. Presented at the Wellington Park Hotel, Belfast Conference on Equality and Social Inclusion in the 21st Century  
1 February, 2006. 2006.
9. O'Hearn A. Deaf women's experiences and satisfaction with prenatal care: a comparative study. Fam Med. 2006;38(10):712-6.
10. Jesse DE, Dolbier CL, Blanchard A. Barriers to seeking help and treatment suggestions for prenatal depressive symptoms: focus groups with rural low-income women. Issues in Mental Health Nursing. 2008;29(1):3-19.
11. Redshaw M, Malouf R, Gao H, Gray R. Women with disability: the experience of maternity care during pregnancy, labour and birth and the postnatal period. BMC Pregnancy and Childbirth. 2013;13:174-.

12. Care Quality Commission. 2015 Maternity Survey: Quality and Methodology. London; 2016.
13. National Collaborating Centre for Mental Health. Antenatal and postnatal mental health. Clinical management and service guidance. London: National Institute for Health and Care Excellence; 2014.
14. Becker H, Stuijbergen A, Tinkle M. Reproductive health care experiences of women with physical disabilities: A qualitative study. *Archives of Physical Medicine and Rehabilitation*. 1997;78(12):S26-S33.
15. Gill C, Kerotoski MA, Turk NMA. Becoming visible: personal health experiences of women with disabilities. *DM women with physical disabilities: achieving and maintaining health and wellbeing*. Baltimore: Pall H. Brookes; 1996. p. 5-15.
16. Smeltzer S S-HN, Ott B, Zimmerman V, Duffin J. Perspectives of women with disabilities on reaching those who are hard to reach. *Journal of Neuroscience Nursing*. 2007;39:163-9.
17. Prilleltensky O. A Ramp to Motherhood: The Experiences of Mothers with Physical Disabilities. *Sexuality and Disability*. 2003;21(1):21-47.
18. Lee O, Oh E-K, Oh H. A wise wife and good mother: reproductive health and maternity among women with disability in South Korea. *Sexuality and Disability*. 2005;23(3):121-44.
19. Bat-Erdene U, Metcalfe A, McDonald SW, Tough SC. Validation of Canadian mothers' recall of events in labour and delivery with electronic health records. *BMC Pregnancy Childbirth*. 2013;13 Suppl 1:S3.
20. Tate AR, Dezateux C, Cole TJ, Davidson L. Factors affecting a mother's recall of her baby's birth weight. *International journal of epidemiology*. 2005;34(3):688-95.
21. Quigley MA, Hockley C, Davidson LL. Agreement between hospital records and maternal recall of mode of delivery: evidence from 12 391 deliveries in the UK Millennium Cohort Study. *BJOG : an international journal of obstetrics and gynaecology*. 2007;114(2):195-200.

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=18,136) 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)	15,019 (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)	16,902 (93.4)
<b>Plurality</b>						
Single baby	860 (98.5)	170 (97.7)	655 (98.6)	127 (100.0)	118 (98.3)	17,846 (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>Breast feeding first few days after birth</b>	**	**	***	***	***	
Breast milk (at least some)	691 (80.0)	129 (75.4)	480 (72.6)	80 (64.5)	79 (66.4)	14,858 (82.8)
Formula only	173 (20.0)	42 (24.6)	181 (27.4)	44 (35.5)	40 (33.6)	3097 (17.2)

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

**Table 2 – Access and clinical care for women with different disabilities. Odds ratios and 95% confidence intervals weighted for variation in response rates by Trust and adjusted for age, parity and ethnicity compared to women without disability.**

	Physical condition or illness		Sensory disability		Mental health disability		Learning disability		Multiple disability		No disability	
	N	%	N	%	N	%	N	%	N	%	N	%
	aOR	(95% CI)	aOR	(95% CI)	aOR	(95% CI)	aOR	(95% CI)	aOR	(95% CI)		
<b>Pregnancy</b>												
<b>First saw a HCP by 12 weeks</b>	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, 2.27)	0.47	(0.25, 0.88)	1.03	(0.66, 1.60)	0.45	(0.22, 0.92)	0.89	(0.31, 2.49)		
<b>Booking appointment &lt;13 wks</b>	753	92.1	132	84.6**	571	92.7	101	87.1	99	91.7	15,555	91.9
aOR (95%CI)	1.03	(0.80,1.34)	0.49	(0.31,0.75)	1.13	(0.83,1.54)	0.60	(0.35,1.03)	0.98	(0.49,1.94)		
<b>Contact number for a MW</b>	846	97.5	160	94.7*	633	95.9**	115	94.3	110	94.0	17,555	97.7
aOR (95% CI)	0.95	(0.59, 1.53)	0.43	(0.21, 0.90)	0.55	(0.36, 0.85)	0.55	(0.23, 1.28)	0.43	(0.18, 1.03)		
<b>Saw same MW each check</b>	286	34.2	66	40.0	231	35.8	54	45.0	50	44.6	6574	37.1
OR (95% CI)	0.90	(0.77, 1.05)	1.17	(0.82, 1.66)	0.90	(0.76, 1.07)	1.29	(0.87, 1.91)	1.23	(0.81, 1.86)		
<b>No choice for place of birth for medical reasons</b>	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, 5.59)	1.54	(0.95, 2.51)	1.85	(1.46, 2.30)	1.75	(0.99, 3.03)	3.40	(2.14, 5.40)		
<b>Birth (each mode of delivery compared with all others)</b>												
<b>Vaginal birth</b>	411	47.7***	103	61.3	376	57.1	76	61.8	61	52.1	10,704	59.6
OR (95%CI)	0.64	(0.55,0.75)	0.99	(0.69,1.42)	0.83	(0.69, 0.98)	0.97	(0.63, 1.78)	0.69	(0.46, 1.04)		
<b>Assisted vaginal delivery</b>	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, 1.29)	0.91	(0.63, 1.34)	0.86	(0.71, 1.03)	1.10	(0.66, 1.70)	1.27	(0.75, 2.14)		
<b>Planned caesarean section</b>	158	18.4***	23	13.7	77	11.7	7	5.7*	15	12.8	1983	11.0
OR (95% CI)	1.69	(1.38, 2.06)	1.40	(0.90, 2.30)	1.07	(0.83, 1.39)	0.71	(0.32, 1.66)	1.34	(1.17, 1.55)		
<b>Emergency caesarean section</b>	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, 1.58)	0.81	(0.47, 1.40)	1.20	(0.95, 1.53)	1.09	(0.64, 1.84)	1.21	(0.71, 2.06)		
<b>Postnatal care</b>												
<b>Skin to skin after birth</b>	644	89.2	139	91.4	520	91.9	102	92.7	90	90.9	14,843	91.3
OR (95% CI)	0.72	(0.56, 0.94)	0.87	(0.48, 1.58)	0.98	(0.70, 1.37)	0.83	(0.39, 1.80)	0.67	(0.32, 1.41)		
<b>Length postnatal stay &gt;2 days</b>	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, 2.18)	1.15	(0.80, 1.63)	1.89	(1.58, 2.26)	1.51	(1.00, 2.28)	2.11	(1.40, 3.17)		
<b>Home visit by midwife</b>	824	95.6**	164	97.6	642	97.0	118	95.2	112	96.6	17,440	96.9
OR (95% CI)	0.62	(0.43, 0.89)	3.42	(0.80, 14.62)	0.85	(0.65, 1.72)	0.76	(0.31, 1.94)	1.45	(0.45, 4.62)		
<b>Feeding advice always available out of hours</b>	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, 0.78)	0.90	(0.55, 1.48)	0.65	(0.50, 0.84)	1.56	(0.90, 2.72)	0.77	(0.45, 1.33)		
<b>5+ visits with MW</b>	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, 1.32)	1.40	(0.95, 2.05)	1.55	(1.28, 1.87)	1.82	(1.18, 2.79)	1.01	(0.62, 1.63)		

\* $p < 0.05$ , \*\* $p < 0.01$ , \*\*\* $p < 0.001$ ; Sensory disability: visually impaired, deaf and hearing impaired; HCP Health care professional; MW Midwife

**Table 3 – Perception of antenatal care received for women with and without disability. Number and proportion of women with and without various types of disability, odds ratios and 95% confidence intervals weighted for variation in response rates by Trust and adjusted for age, parity and ethnicity compared to women without disability**

	Physical condition or illness		Sensory loss		Mental health disability		Learning disability		Multiple disability		No disability	
	N	%	N	%	N	%	N	%	N	%	N	%
	aOR	(95% CI)	aOR	(95% CI)	aOR	(95% CI)	aOR	(95% CI)	aOR	(95% CI)		
<b>Always time to ask questions</b>	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, 0.82)	0.71	(0.49, 1.02)	0.60	(0.50, 0.71)	1.00	(0.65, 1.54)	0.61	(0.40, 0.93)		
<b>MWs always listened</b>	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, 0.73)	0.70	(0.48, 1.02)	0.50	(0.42, 0.60)	0.57	(0.38, 0.87)	0.39	(0.25, 0.59)		
<b>Always spoken to so could understand</b>	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, 0.89)	0.45	(0.30, 0.70)	0.56	(0.45, 0.71)	0.31	(0.20, 0.47)	0.40	(0.25, 0.65)		
<b>Always involved enough in decisions</b>	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, 0.70)	0.77	(0.53, 1.12)	0.62	(0.51, 0.74)	0.45	(0.31, 0.67)	0.54	(0.36, 0.82)		
<b>If MW contacted, always given help needed</b>	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, 1.04)	0.81	(0.32, 2.08)	0.90	(0.55, 1.47)	0.70	(0.45, 1.09)	1.00	(0.61, 1.64)		

\* $p < 0.05$ , \*\* $p < 0.01$ , \*\*\* $p < 0.001$       Sensory disability: visually impaired, deaf and hearing impaired

**Table 4 – Perception of labour and birth care received for women with and without disability. Number and proportion of women with and without various types of disability, odds ratios and 95% confidence intervals weighted for variation in response rates by Trust and adjusted for age, parity and ethnicity compared to women without disability**

	Physical condition or illness		Sensory disability		Mental health disability		Learning disability		Multiple disability		No disability	
	N	%	N	%	N	%	N	%	N	%	N	%
<b>All staff introduced themselves</b>	646	75.6***	130	80.2	479	73.9***	94	79.0	86	76.1	14,982	84.6
aOR (95% CI)	0.57	(0.48, 0.68)	0.90	(0.58, 1.41)	0.52	(0.43, 0.63)	0.80	(0.50, 1.28)	0.77	(0.46, 1.27)		
<b>Always spoken to in a way could understand</b>	74.4	87.1*	132	79.5***	533	81.8***	89	72.4***	92	79.3***	16,126	89.9
aOR (95% CI)	0.74	(0.59, 0.93)	0.50	(0.32, 0.77)	0.49	(0.39, 0.62)	0.39	(0.25, 0.60)	0.44	(0.27, 0.74)		
<b>Definitely had confidence and trust in staff</b>	656	75.8**	134	78.8	465	71.1***	85	69.7**	89	76.1	14,542	80.9
aOR (95% CI)	0.73	(0.62, 0.87)	0.82	(0.55, 1.22)	0.57	(0.47, 0.69)	0.58	(0.38, 0.87)	0.68	(0.43, 1.08)		
<b>Always involved enough in decisions</b>	541	65.1***	116	71.6	414	65.0***	81	68.6	84	74.3	13,357	76.2
aOR (95% CI)	0.60	(0.51, 0.70)	0.82	(0.56, 1.20)	0.59	(0.49, 0.70)	0.73	(0.48, 1.11)	1.00	(0.62, 1.61)		
<b>Always treated with respect</b>	700	81.0***	132	78.6**	503	76.7***	97	80.2	93	79.5	15,701	87.5
OR (95% CI)	0.59	(0.49, 0.71)	0.65	(0.43, 0.98)	0.47	(0.38, 0.57)	0.71	(0.44, 1.15)	0.67	(0.39, 1.14)		
<b>Concerns taken seriously</b>	450	78.9*	90	74.4*	348	73.6***	59	72.0***	67	80.7	9279	82.7
aOR (95% CI)	0.78	(0.62, 0.98)	0.55	(0.34, 0.88)	0.57	(0.46, 0.72)	0.66	(0.38, 1.13)	0.80	(0.44, 1.48)		
<b>Always received attention in reasonable time</b>	463	71.0**	101	73.2	370	69.2***	62	65.3	69	63.3	10,563	64.5
aOR (95% CI)	0.76	(0.63, 0.92)	0.95	(0.62, 1.45)	0.68	(0.56, 0.83)	0.73	(0.46, 1.16)	1.05	(0.62, 1.78)		
<b>Left alone and worried at some point</b>	231	26.7	62	36.7***	224	34.1***	57	45.6***	43	35.8***	4401	24.5
aOR (95% CI)	1.12	(0.95, 1.32)	1.32	(0.92, 1.91)	1.71	(1.43, 2.04)	1.87	(1.26, 2.76)	1.45	(0.94, 2.23)		

\*p<0.05, \*\*p<0.01, \*\*\*p<0.001      Sensory disability: visually impaired, deaf and hearing impaired

**Table 5 – Perception of postnatal care received for women with and without disability. Number and proportion of women with and without various types of disability, odds ratios and 95% confidence intervals weighted for variation in response rates by Trust and adjusted for age, parity and ethnicity compared to women without disability**

	Physical condition or illness		Sensory disability		Mental health disability		Learning disability		Multiple disability		No disability	
	N	% (95% CI)	N	% (95% CI)	N	% (95% CI)	N	% (95% CI)	N	% (95% CI)	N	%
<b>Postnatal care in hospital</b>												
<b>Always able to get attention in reasonable time</b>	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, 0.83)	0.85	(0.60, 1.20)	0.69	(0.58, 0.82)	0.85	(0.58, 1.26)	0.73	(0.49, 1.10)		
<b>Always treated with kindness and understanding</b>	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, 0.76)	0.70	(0.49, 0.99)	0.62	(0.52, 0.73)	0.64	(0.43, 0.96)	0.63	(0.42, 0.97)		
<b>Partner or companion stayed as long as woman wanted</b>	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, 0.82)	0.73	(0.52, 1.04)	0.63	(0.53, 0.75)	1.12	(0.75, 1.66)	0.84	(0.55, 1.27)		
<b>HCPs gave active support and encouragement about feeding the baby</b>	438	54.0***	93	58.1	327	52.4***	76	64.4	61	56.0	10,732	63.5
aOR (95% CI)	0.66	(0.57, 0.78)	0.82	(0.58, 1.15)	0.64	(0.54, 0.76)	1.25	(0.84, 1.87)	0.77	(0.69, 0.87)		
<b>Postnatal care at home</b>												
<b>If MW contacted, always given help needed</b>	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, 0.88)	0.80	(0.51, 1.25)	0.72	(0.58, 0.91)	0.55	(0.35, 0.88)	0.84	(0.50, 1.40)		
<b>Would have liked to see a MW more often</b>	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, 1.61)	1.94	(1.34, 2.80)	1.22	(0.98, 1.51)	1.89	(1.25, 2.87)	1.61	(0.99, 2.63)		
<b>MWs always listened</b>	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, 0.87)	0.54	(0.38, 0.76)	0.56	(0.46, 0.66)	0.92	(0.59, 1.43)	0.56			
<b>Definitely had confidence and trust in MW</b>	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, 0.83)	0.65	(0.46, 0.92)	0.64	(0.54, 0.76)	0.69	(0.46, 1.03)	0.62			
<i>In the 6 weeks since the birth, definitely received help and advice about...</i>												
<b>Feeding the baby</b>	444	58.6***	89	60.1	327	56.9***	70	59.8	61	56.0	10,000	65.2
aOR (95% CI)	0.73	(0.62, 0.85)	0.83	(0.57, 1.19)	0.73	(0.61, 0.88)	0.94	(0.63, 1.40)	0.70			

<b>Baby's health and progress</b>	561	67.9*	100	65.8	420	67.3*	90	75.6	78	69.0	11,943	71.1
aOR (95% CI)	0.81	(0.69, 0.95)	0.69	(0.46, 0.96)	0.78	(0.65, 0.94)	1.19	(0.76, 1.88)	0.73			

\*p<0.05, \*\*p<0.01, \*\*\*p<0.001 Sensory disability: visually impaired, deaf and hearing impaired; HCP Health care professional; MW Midwife

**Table 6 – Physical and emotional well-being for women with and without disability. Number and proportion of women with various types of disability, odds ratios and 95% confidence intervals weighted for variation in response rates by Trust and adjusted for age, parity and ethnicity compared to women without disability**

	Physical condition or illness		Sensory loss		Mental health disability		Learning disability		Multiple disabilities		No disability	
	N	%	N	%	N	%	N	%	N	%	N	%
	aOR	(95% CI)	aOR	(95% CI)	aOR	(95% CI)	aOR	(95% CI)	aOR	(95% CI)		
<b>Antenatal period</b>												
<b>MW always aware of medical history</b>	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, 0.97)	0.95	(0.67, 1.34)	0.83	(0.70, 0.99)	1.28	(0.87, 1.87)	1.02	(0.68, 1.52)		
<b>MW definitely asked how feeling emotionally</b>	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, 0.95)	1.19	(0.84, 1.68)	1.16	(0.97, 1.37)	1.23	(0.83, 1.84)	1.03	(0.68, 1.57)		
<b>Postnatal care after discharge home MW always aware of medical history</b>	542	69.0***	114	74.0	438	71.5***	88	75.2	77	71.3	12,855	78.0
aOR (95% CI)	0.63	(0.54, 0.75)	0.83	(0.56, 1.23)	0.73	(0.60, 0.88)	1.00	(0.63, 1.58)	0.71	(0.44, 1.15)		
<b>MW took personal circumstances into account</b>	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, 0.82)	0.60	(0.42, 0.87)	0.59	(0.49, 0.71)	0.59	(0.39, 0.90)	0.61	(0.39, 0.97)		
<b>Women informed of need to arrange own PN check</b>	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, 1.05)	0.74	(0.42, 1.31)	0.73	(0.55, 0.97)	0.55	(0.31, 0.99)	0.73	(0.21, 0.65)		
<b>MW/HV asked how feeling emotionally</b>	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, 0.74)	0.57	(0.27, 1.21)	0.56	(0.38, 0.83)	0.39	(0.19, 0.77)	1.15	(0.40, 3.29)		
<b>Definitely given enough information about emotional changes</b>	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, 0.89)	0.90 (0.64, 1.28)	0.77 (0.65, 0.91)	0.99 (0.67, 1.47)	0.84 (0.56, 1.27)						
<b>Told who to contact about emotional changes</b>	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, 0.90)	0.92 (0.61, 1.38)	0.84 (0.69, 1.03)	0.84 (0.55, 1.30)	0.98 (0.60, 1.61)						
<b>Definitely given advice about physical recovery</b>	409	48.1***	98	60.1	311	47.9***	66	54.1	55	48.7***	10,066	56.1
		0.72 (0.62, 0.84)	1.20 (0.83, 1.67)	0.64 (0.54, 0.76)	0.90 (0.61, 1.32)	0.74 (0.67, 0.82)						
<b>Given information/advice about contraception</b>	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, 0.83)	0.84 (0.50, 1.41)	0.54 (0.42, 0.69)	0.56 (0.32, 0.99)	0.55 (0.30, 1.01)						

\*p<0.05, \*\*p<0.01, \*\*\*p<0.001      Sensory disability: visually impaired, deaf and hearing impaired

## STROBE Statement—checklist of items that should be included in reports of observational studies

	Item No	Recommendation	Page
<b>Title and abstract</b>	1	(a) Indicate the study's design with a commonly used term in the title or the abstract	2
		(b) Provide in the abstract an informative and balanced summary of what was done and what was found	
<b>Introduction</b>			
Background/rationale	2	Explain the scientific background and rationale for the investigation being reported	3-4
Objectives	3	State specific objectives, including any prespecified hypotheses	3
<b>Methods</b>			
Study design	4	Present key elements of study design early in the paper	4
Setting	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection	4
Participants	6	(a) <i>Cohort study</i> —Give the eligibility criteria, and the sources and methods of selection of participants. Describe methods of follow-up <i>Case-control study</i> —Give the eligibility criteria, and the sources and methods of case ascertainment and control selection. Give the rationale for the choice of cases and controls <i>Cross-sectional study</i> —Give the eligibility criteria, and the sources and methods of selection of participants	5
		(b) <i>Cohort study</i> —For matched studies, give matching criteria and number of exposed and unexposed <i>Case-control study</i> —For matched studies, give matching criteria and the number of controls per case	
Variables	7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable	5
Data sources/ measurement	8*	For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group	5
Bias	9	Describe any efforts to address potential sources of bias	5
Study size	10	Explain how the study size was arrived at	5
Quantitative variables	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why	5
Statistical methods	12	(a) Describe all statistical methods, including those used to control for confounding	5
		(b) Describe any methods used to examine subgroups and interactions	
		(c) Explain how missing data were addressed	
		(d) <i>Cohort study</i> —If applicable, explain how loss to follow-up was addressed <i>Case-control study</i> —If applicable, explain how matching of cases and controls was addressed <i>Cross-sectional study</i> —If applicable, describe analytical methods taking account of sampling strategy	
		(e) Describe any sensitivity analyses	

Continued on next page

**Results**

Participants	13*	(a) Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed (b) Give reasons for non-participation at each stage (c) Consider use of a flow diagram	6  Fig 1
Descriptive data	14*	(a) Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders (b) Indicate number of participants with missing data for each variable of interest (c) <i>Cohort study</i> —Summarise follow-up time (eg, average and total amount)	Table 1
Outcome data	15*	<i>Cohort study</i> —Report numbers of outcome events or summary measures over time <i>Case-control study</i> —Report numbers in each exposure category, or summary measures of exposure <i>Cross-sectional study</i> —Report numbers of outcome events or summary measures	Tables 2-6
Main results	16	(a) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95% confidence interval). Make clear which confounders were adjusted for and why they were included (b) Report category boundaries when continuous variables were categorized (c) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period	Tables 2-6
Other analyses	17	Report other analyses done—eg analyses of subgroups and interactions, and sensitivity analyses	

**Discussion**

Key results	18	Summarise key results with reference to study objectives	11
Limitations	19	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias	13
Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence	12
Generalisability	21	Discuss the generalisability (external validity) of the study results	12
<b>Other information</b>			
Funding	22	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based	15

\*Give information separately for cases and controls in case-control studies and, if applicable, for exposed and unexposed groups in cohort and cross-sectional studies.

**Note:** An Explanation and Elaboration article discusses each checklist item and gives methodological background and published examples of transparent reporting. The STROBE checklist is best used in conjunction with this article (freely available on the Web sites of PLoS Medicine at <http://www.plosmedicine.org/>, Annals of Internal Medicine at <http://www.annals.org/>, and Epidemiology at <http://www.epidem.com/>). Information on the STROBE Initiative is available at [www.strobe-statement.org](http://www.strobe-statement.org).

# 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

Journal:	<i>BMJ Open</i>
Manuscript ID	bmjopen-2017-016757.R1
Article Type:	Research
Date Submitted by the Author:	17-Apr-2017
Complete List of Authors:	Malouf, Reem; University of Oxford, Policy Research Unit in Maternal Health and Care, NPEU, Nuffield Department of Population Health Henderson, Jane; University of Oxford, Policy Research Unit in Maternal Health and Care, NPEU, Nuffield Department of Population Health Redshaw, Maggie; University of Oxford, Policy Research Unit in Maternal Health and Care, NPEU, Nuffield Department of Population Health
<b>Primary Subject Heading</b>:	Health services research
Secondary Subject Heading:	Health services research, Public health
Keywords:	maternity care, disability, maternity services, pregnancy, labour, postnatal

SCHOLARONE™  
Manuscripts

1  
2  
3  
4  
5  
6  
7  
8  
9  
10  
11  
12  
13  
14  
15  
16  
17  
18  
19  
20  
21  
22  
23  
24  
25  
26  
27  
28  
29  
30  
31  
32  
33  
34  
35  
36  
37  
38  
39  
40  
41  
42  
43  
44  
45  
46  
47  
48  
49  
50  
51  
52  
53  
54  
55  
56  
57  
58  
59  
60

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

Reem Malouf

Jane Henderson

Maggie Redshaw\*

Policy Research Unit in Maternal Health and Care

National Perinatal Epidemiology Unit

University of Oxford

\*Corresponding author:

Maggie Redshaw,

Policy Research Unit in Maternal Health and Care,

National Perinatal Epidemiology Unit,

Nuffield Department of Population Health,

University of Oxford,

Old Road Campus,

Oxford OX3 7LF,

UK

maggie.redshaw@npeu.ox.ac.uk

1  
2  
3 **Abstract**  
4  
5

6 **Objectives:** More disabled women are becoming mothers and yet their care is rarely the focus of  
7  
8 quantitative research. This study aimed to investigate access and quality of maternity care for  
9  
10 women with differing disabilities.  
11

12 **Design:** Secondary analysis was conducted on data from a 2015 national survey of women's  
13  
14 experience of maternity care. Descriptive and adjusted analyses were undertaken for five disability  
15  
16 groups: physical disability, sensory impairment, mental health disability, learning disability, and  
17  
18 multiple disability, and comparisons made with the responses of non-disabled women.  
19

20 **Setting:** Survey data were collected on women's experience of primary and secondary care in all  
21  
22 Trusts providing maternity care in England.  
23

24 **Participants:** Women who had given birth three months previously, among whom were groups self-  
25  
26 identifying with different types of disability. Exclusions were limited to women whose baby had died  
27  
28 and those who were aged less than 16 years at the time of the recent birth.  
29

30 **Results:** Overall, 20,094 women completed and returned the survey; 1958 women (9.5%) self-  
31  
32 identified as having a disability. The findings indicate some gaps in maternity care provision for  
33  
34 these women relating to interpersonal aspects of care: communication, feeling listened to and  
35  
36 supported, involvement in decision-making, having a trusted and respected relationship with clinical  
37  
38 staff. Women from all disability groups wanted more postnatal contacts and help with infant  
39  
40 feeding.  
41  
42

43 **Conclusion:** While access to care was generally satisfactory for disabled women, women's emotional  
44  
45 wellbeing and support during pregnancy and beyond is an area that is in need of improvement.  
46  
47 Specific areas identified included disseminating information effectively, ensuring appropriate  
48  
49 communication and understanding, and supporting women's sense of control to build trusting  
50  
51 relationships with health care providers.  
52  
53

54  
55  
56  
57 **Keywords:** Maternity care, maternity services, disability, pregnancy, labour, postnatal.  
58  
59  
60

1  
2  
3 **1 Strengths and limitations**  
4

- 5 2 • All organisations providing maternity care in England participated in the recent survey.  
6  
7 3 • The large size of the survey allowed for more detailed sub-divisions and comparison of the  
8  
9 4 experience of different disability groups than previous research.  
10  
11 5 • Data in this survey were self-reported and collected retrospectively at three months  
12  
13 6 postpartum which may affect the quality of responses based on recall.  
14  
15 7 • The response rate was lower than previous surveys which may affect the generalizability of  
16  
17 8 the findings, however, weighting for non-response was used.  
18  
19

20  
21 9  
22  
23  
24  
25  
26  
27  
28  
29  
30  
31  
32  
33  
34  
35  
36  
37  
38  
39  
40  
41  
42  
43  
44  
45  
46  
47  
48  
49  
50  
51  
52  
53  
54  
55  
56  
57  
58  
59  
60

1  
2  
3 1 **Access and quality of maternity care for disabled women during pregnancy, birth**  
4  
5  
6 2 **and the postnatal period in England: data from a national survey**  
7

8  
9 3 **Background**

10  
11 4 The number of disabled women choosing to become mothers is growing.(1) However, stigma still  
12  
13 5 exists about such women and their care-giving and mothering capabilities.(2) Although all women  
14  
15 6 are entitled to have access to high quality maternity care, worldwide half of disabled people cannot  
16  
17 7 afford health care, compared to a third of non-disabled people, and they are more likely to find  
18  
19 8 health care providers' skills inadequate.(3) This is despite disabled women's greater need for, and  
20  
21 9 use of, health care services.(4) Disabled people and their families frequently experience inequalities  
22  
23 10 in accessing health services, with poor communication and challenging attitudes among health care  
24  
25 11 providers.(2) Furthermore, disabled people are four times more likely to report being treated badly  
26  
27 12 and nearly three times more likely to be denied access to health care.(3)  
28  
29  
30

31  
32 13 Disabled women accessing maternity care may be considered unusual and problematic. Health care  
33  
34 14 professionals may be concerned that these women will not be able to cope with pregnancy and  
35  
36 15 motherhood.(5) However, the social model of disability suggests that disability is a social  
37  
38 16 construction brought about by structural and attitudinal barriers encountered by people with  
39  
40 17 impairments.(6) It views disabled people as socially oppressed and argues for policies and practices  
41  
42 18 that facilitate full inclusion.(7)  
43  
44  
45

46  
47 19 Health care professionals may lack knowledge and experience in planning and providing care for  
48  
49 20 pregnant disabled women.(8) For example, antenatal information may be distributed in a manner  
50  
51 21 inappropriate and insufficient for women with visual impairment. (1, 9) There is some evidence that  
52  
53 22 women with hearing impairment receive fewer antenatal visits and have limited access to maternity  
54  
55 23 information.(10, 11) For women with a less easily identified disability, such as those arising from  
56  
57 24 mental health problems, there may be difficulties in receiving appropriate care. (12) For women in  
58  
59  
60



1  
2  
3 1 this group, dissatisfaction and lack of trust have been found to be the main barriers in seeking help  
4  
5 2 during pregnancy. (12)  
6  
7

8  
9 3 In the UK, maternity services are freely available for all women. A study reporting on the use of  
10  
11 4 maternity services by women with disabilities in 2010 (13) concluded that disabled women were at  
12  
13 5 higher risk of adverse pregnancy outcomes, for example, they were more likely to deliver early and  
14  
15 6 have low birth weight babies. However, it also concluded that some women, such as those with  
16  
17 7 physical disabilities, appropriately received more care. In this paper, we aim to reflect  
18  
19 8 predominantly on the quality of maternity care received for disabled women in England more  
20  
21 9 recently.  
22  
23

## 24 10 **Methods**

25  
26  
27 11 The main objective of this secondary analysis was to report on access to care and the quality of care  
28  
29 12 received by disabled women who used the maternity services in 2015 in England, seeking a better  
30  
31 13 understanding of the maternity care issues arising for women with different types of disability. In  
32  
33 14 this paper we:

- 34  
35  
36 15 • compare the perceptions and experiences of maternity care received by women with  
37  
38 16 different types of disability and women with no disability
- 39  
40 17 • identify differences or gaps in care for disabled women which could be addressed  
41  
42

## 43 18 ***Study design and survey measure***

44  
45  
46 19 A structured cross-sectional study design was implemented by all NHS Trusts using a strict  
47  
48 20 methodology and data collated by the Care Quality Commission (CQC) in 2015.(14) The CQC is an  
49  
50 21 independent regulator of health and social care in England and all National Health Service Trusts  
51  
52 22 providing maternity care and was responsible for the trust based surveys using the same survey  
53  
54 23 instrument. Modifications were made to the 2010 and then the 2013 CQC survey measures following  
55  
56 24 consultation, focus groups and cognitive interviews which identified additional aspects of women's  
57  
58  
59  
60

1  
2  
3 1 maternity care to be covered. While the survey continued to cover aspects of pregnancy, labour and  
4  
5 2 birth and postnatal care, more questions asked about women's access to care, communication with  
6  
7 3 health care providers, involvement in decision-making, awareness of birth choices and support for  
8  
9 4 emotional well-being and physical health. Limited data on neonatal outcomes as well as socio-  
10  
11 5 demographic characteristics including age, ethnicity, marital status and parity were also collected.  
12  
13  
14  
15 6 Postal surveys were sent to a minimum of 300 women from each Trust who had given birth to a live  
16  
17 7 baby in February 2015 (and possibly January 2015 for trusts with smaller numbers of births), 50,945  
18  
19 8 women in total. Completing and returning the survey was considered as consent to take part in the  
20  
21 9 study. Women who were less than 16 years, those who had a stillbirth or whose baby died after  
22  
23 10 birth, women delivered in private settings and women without a UK postal address were excluded  
24  
25 11 from the surveys. Up to two reminders were sent to non-respondents as required. A Freephone  
26  
27 12 language line provided translation services, and MENCAP also provided support to women with  
28  
29 13 learning disabilities.(14) The survey, reference 07/MRE08/1, was passed by the NRES Committee  
30  
31 14 North West – Haydock in February 2015.

32  
33  
34  
35 15 As in previous surveys(15), women were asked '*Do you have any of the following long-standing*  
36  
37 16 *conditions?*' with seven options, including '*No, I do not have a long-standing condition*'. Using the  
38  
39 17 checklist, respondents were thus able to describe their disability and indicate if they had more than  
40  
41 18 one disability. Five different disability groups were identified: physical (long-standing physical  
42  
43 19 condition and long-standing illness), sensory (deafness or hearing impairment and blindness or  
44  
45 20 partial sightedness), mental health problem, learning disability, and multiple disabilities, i.e. having  
46  
47 21 two or more disabilities (see Table 1).

## 51 **Statistical analysis**

52  
53  
54 23 The data presented are grouped in relation to access to care, the clinical care received and women's  
55  
56 24 perceptions about the different phases of care. The categories used were those collected and where  
57  
58  
59  
60

1 variables were further aggregated for conciseness this was based on clinical or policy relevance. The  
2 cut-offs are indicated in the tables. Univariate data analyses were carried out to compare the  
3 maternal characteristics and responses of disabled women to non-disabled women. Chi-square  
4 statistics were used to compare study groups. Adjusted odds ratios and 95% confidence interval  
5 were weighted for variation in response rate by the trusts and adjusted for age, parity and ethnicity  
6 using binary logistic regression. Each of the subgroups, physical, sensory, mental, learning, and  
7 multiple disability, was separately compared to the referent group of non-disabled women.  
8 Maternal characteristics and reports about care were compared to women who did not self-identify  
9 with any of the conditions listed above. The analyses were carried out in STATA, version 13

## 10 **Results**

### 11 ***Women's characteristics***

12 Overall, 20,094 women completed and returned the survey, with a usable response rate of 41.2%.  
13 Disabled women represented 9.5% (1,958) of the total sample. Compared to non-respondents,  
14 survey respondents were significantly more likely to be White, aged 30 years or more, and  
15 primiparous(14) which may affect the generalisability of results. Physical and mental health  
16 disabilities were most frequently identified. Of those with a disability almost half reported having a  
17 physical disability (45%) and a third of women identified with a mental health disability (34%). Fewer  
18 women reported having a sensory disability (8.7%), and small proportions of women reported having  
19 a learning disability (6.5%), or more than one disability, most commonly a physical condition and  
20 mental health problem (6%). More women with physical disability were 35 years and older than  
21 women with no disability (38.7% vs. 32.5%), however, women with mental health and learning  
22 disability were younger than women with no disability (Table 1). White women were significantly  
23 more likely to report mental health and learning disabilities compared to all other ethnic groups.  
24 Similarly, primiparous women were significantly more likely than multiparous women to report  
25 learning disabilities. All disabled women were at a higher risk of delivering preterm compared to

1  
2  
3 1 non-disabled women, particularly those with physical disability, mental health problems, learning  
4  
5 2 disability and women with multiple disability (Table 1). Across all groups, babies born to disabled  
6  
7 3 were significantly less likely to be breast fed at the time of hospital discharge compared to non-  
8  
9 4 disabled women.

### 5 ***Access and care received***

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

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

20 While approximately a quarter of non-disabled women (26%) stayed in hospital for more than two  
21 days after giving birth, more women in all the different types of disability groups did so, significantly  
22 more for women with physical, mental health, learning or multiple disabilities which may relate  
23 partly to method of delivery. Nearly half of the women with multiple disabilities (45%) stayed longer  
24 than two days. More than 90% of women with and without disability received at least one postnatal  
25 home visit from a midwife although this was slightly fewer for the physically disabled women.

1  
2  
3 1 However, women with mental health or learning disability were significantly more likely to have  
4  
5 2 received a home visit or seen a midwife in a clinic five or more times in the postnatal period. Women  
6  
7 3 with physical or mental disability were less likely to report that advice about infant feeding was  
8  
9 4 always available at evenings and weekends.  
10

### 11 5 *Perceptions of care*

12 6 Women's views about the care received varied across the different groups (Tables 3-5).

13  
14  
15 7 During pregnancy, women with physical disability, those with mental health conditions and women  
16  
17 8 with more than one disability were all significantly less likely to feel there was always time to ask  
18  
19 9 questions at their appointments, to feel listened to, spoken to in a way they could understand,  
20  
21 10 involved enough in decisions about their care, and if they had contacted a midwife, that they had  
22  
23 11 been given the help they needed (Table 3). All disabled women were significantly more likely to  
24  
25 12 report negative experiences of pregnancy care, particularly in relation to always being spoken to by  
26  
27 13 health professionals in a way that they could understand and, except for women with sensory loss,  
28  
29 14 being involved in decisions about their care.  
30  
31  
32  
33

34  
35  
36 15 Perceptions of labour and birth care also differed between the groups (Table 4). While 85% of non-  
37  
38 16 disabled women reported that all staff who treated and examined them introduced themselves,  
39  
40 17 significantly fewer women with physical disabilities and mental health conditions reported this (76%  
41  
42 18 and 74% respectively) (Table 4). Significantly fewer women in with physical, mental health and  
43  
44 19 learning disabilities were likely to report definitely having confidence and trust in staff, fewer  
45  
46 20 women in all disability groups reported always being spoken to so they could understand, and fewer  
47  
48 21 women with physical, sensory and mental health disabilities reported that they were always treated  
49  
50 22 with respect at this time. Significantly fewer women with physical disabilities (65%) and mental  
51  
52 23 health conditions (65%) reported that they were always involved in decisions about their care  
53  
54 24 compared with 76% of those with no disability. Similarly, while 83% of non-disabled women felt that  
55  
56  
57  
58  
59  
60

1 their concerns during labour and birth were taken seriously, significantly fewer women with mental  
2 health problems or learning disability perceived this to be the case (74% and 72% respectively).

3 Women were asked whether they and their partner were left alone at a time when it worried them  
4 during labour or shortly after the birth, and whether they received attention and help from a  
5 member of staff within a reasonable time. Feeling left alone and worried at some time was reported  
6 by a quarter of non-disabled women or with physical disability (25% and 27% respectively) but  
7 significantly more so by the other disability groups. However, receiving attention within a reasonable  
8 time was reported by 65% of non-disabled women but significantly more so by women with a  
9 mental health condition (69%) or a physical disability (71%).

10 Perceptions of hospital and community postnatal care varied, with women who had a physical or  
11 mental health disability less likely to report a positive experience in both contexts (Table 5). In  
12 hospital they were significantly less likely to report always being treated with kindness and  
13 understanding, or that their companion or partner was able to stay with them as much as they  
14 wanted. Once home, a third of those with a sensory disability would have liked to have seen  
15 midwives more often (34%) as would women with learning disability (30%), compared with a fifth  
16 (20%) of non-disabled women. Over 70% of non-disabled women always felt listened to, definitely  
17 had confidence and trust in the midwives providing postnatal care at this stage, and, if a midwife  
18 was contacted, felt that they always received the help needed. However, for most variables, women  
19 with all forms of disability, especially mental health and learning disability, were significantly less  
20 likely to report so positively on these points.

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

24 ***Checks and information on women's health and emotional wellbeing***

1  
2  
3 1 In the antenatal period less than half of non-disabled women (49%) reported that during their  
4  
5 2 antenatal checks midwives always appeared to be aware of their medical history (Table 6). This was  
6  
7 3 significantly even less likely for women with a physical or mental health disability (both 44%).  
8  
9 4 Among the midwives providing postnatal care, awareness was greater than for antenatal care for all  
10  
11 5 groups. However, as with antenatal care, significantly fewer of those women with a physical or  
12  
13 6 mental health disability felt that midwives were always aware of their medical history. Women were  
14  
15 7 also asked if they had been given enough information about their physical recovery after the birth.  
16  
17 8 Just over only half of those without disability reported that they had definitely been given this  
18  
19 9 information (56%). Some disability groups reported lower frequencies than this: women with a  
20  
21 10 physical disability a mental health condition and multiple disability (48%, 48% and 49% respectively)  
22  
23 11 were all significantly less likely to have been given this information. Advice about contraception was  
24  
25 12 less available to all disabled women, significantly so among those with a physical, mental health or  
26  
27 13 learning disability.  
28  
29 14 Women with disability were more concerned that their personal circumstances had not been taken  
30  
31 15 into account (65% vs. 74%). Women with mental health, learning or multiple disability were less  
32  
33 16 likely to report being informed of the need to arrange their own postnatal check-up.  
34  
35  
36  
37  
38  
39 17  
40 18 All women should be asked about their emotional wellbeing during pregnancy and postnatally.<sup>(16)</sup>  
41  
42 19 While just over half of those with no disability reported being asked about their emotional wellbeing  
43  
44 20 during pregnancy (56%), this was even less likely for those with a physical disability (52%). In  
45  
46 21 contrast, over 90% of women in all groups reported being asked about their emotional wellbeing  
47  
48 22 postnatally, though some groups, especially women with a physical, mental health or learning  
49  
50 23 disability, were still less likely to report having been asked. Women were also asked about being  
51  
52 24 given information about the emotional changes that might be experienced after the birth. Fewer  
53  
54 25 women overall (less than 60%), reported being given enough information about possible changes in  
55  
56 26 mood and this was even less likely for women with physical disability and those with mental health  
57  
58  
59  
60

1  
2  
3 1 problems (51% and 52% respectively). Of non-disabled women, 75% were told who to contact for  
4  
5 2 advice about any emotional changes, but only 69% of women with a physical disability reported this.  
6  
7  
8  
9

#### 10 4 **Discussion**

11  
12 5 This study provides further evidence that disabled women have a poorer perception of care during  
13  
14 6 pregnancy, childbirth and in the postnatal period which need to be recognized. The conditions  
15  
16 7 giving rise to disability are extremely diverse and some women may need more clinical or supportive  
17  
18 8 care than others. Yet such women often encounter negative attitudes towards their pregnancy.(17,  
19  
20 9 18) Disabled women are usually classified during their pregnancy as 'high risk', (2) requiring more  
21  
22 10 antenatal visits and more scans, as found in other studies.(19) Arranging these intensive  
23  
24 11 appointments can be difficult for some disabled women. There is a need for more specific services,  
25  
26 12 and more guidance and training for health care professionals caring for women with any disability  
27  
28 13 during pregnancy.  
29  
30  
31

32 14 This study shows that, in England in 2015, while care was more responsive in some respects for  
33  
34 15 disabled women, such as more home visits after hospital discharge, disabled women overall  
35  
36 16 perceived their care in more negative terms than non-disabled women. In particular, they felt that  
37  
38 17 they were not always spoken to so that they could understand, listened to, did not always have time  
39  
40 18 to ask questions, were not always sufficiently involved in decisions about their care, treated with  
41  
42 19 respect, or their concerns taken seriously. Women with sensory, mental health, learning or multiple  
43  
44 20 disabilities were more likely to be left alone at a time when it worried them during labour or shortly  
45  
46 21 after birth. It may be that these women needed more reassurance and support or had more reason  
47  
48 22 to be worried but their concerns were not addressed by staff. It is also possible that disabled women  
49  
50 23 who would, in general, have had more experience of the health service than non-disabled women,  
51  
52 24 were expressing their disillusionment with healthcare generally.  
53  
54  
55  
56  
57  
58  
59  
60



1  
2  
3 1 Communication barriers, deficits in health information and a lack of knowledge and awareness  
4  
5 2 among health care professionals have been identified before(20, 21) and represent some of the  
6  
7 3 attitudinal barriers faced by disabled women. Information needs to be distributed in accessible  
8  
9 4 formats. Disability awareness and training for health care professionals as well as allocation of  
10  
11 5 additional care time and flexible postnatal visiting could have a positive influence on care. In  
12  
13 6 addition, the focus should be on women's abilities rather than their disabilities. Previous research  
14  
15 7 has indicated that, whilst some staff were excellent, others provided 'unhelpful help', taking over,  
16  
17 8 leading to feelings of disempowerment.(22) Support through the transition from pregnancy to  
18  
19 9 motherhood should also be considered by health care providers.(5) Integrated care between  
20  
21 10 different services, such as mental health and obstetric services, may be required to meet the needs  
22  
23 11 of these groups.  
24  
25  
26  
27 12 These data from this survey highlight particular areas where maternity services need to improve to  
28  
29 13 provide equal services to women with different types of disability. The greater number of questions  
30  
31 14 in the 2015 survey focusing on specific aspects of maternity care contribute to a broader and more  
32  
33 15 detailed picture of the care experienced by disabled women compared to previous surveys. Flexible  
34  
35 16 and responsive services are needed by women with different types of disability. Specifically, women  
36  
37 17 with physical disability are likely to need rather different personalised care and support from women  
38  
39 18 with mental health disability. For example, women with physical conditions may need help with  
40  
41 19 physical access whereas those with mental health problems may need more emotional support than  
42  
43 20 others. As we also concluded from our earlier study, empowering women and supporting their  
44  
45 21 involvement in the decision-making process during pregnancy is a key area for improvement.(13)  
46  
47 22 Supported decision-making may be necessary to enable some individuals to communicate their  
48  
49 23 needs and choices. Individual women differ and those with disability should be offered the same  
50  
51 24 antenatal options, choices of birth place and pain relief as non-disabled women, unless their medical  
52  
53 25 conditions contradict these options. Information should be accessible and in a comprehensive  
54  
55 26 format. An early assessment of the maternity care required is crucial to forming a care plan with the  
56  
57  
58  
59  
60

1 women involved. Health care professionals need to plan ahead on how to meet the individual needs  
2 with the women themselves and to keep the conversation open and ongoing over the pregnancy  
3 and afterwards.

4 The needs of disabled women are still not fully met in the maternity services in England as evidenced  
5 here, and there is a clear need to document and assess the needs of this group. Research from  
6 Korea involving 410 physically disabled women points to high rates of abortion, miscarriage,  
7 caesarean section, and low usage of contraception (23). In Switzerland, there are few guidelines and  
8 little regular assessment for women with psychiatric problems in the perinatal period.(24) In  
9 qualitative studies in the USA and Canada, women with physical impairments reported numerous  
10 barriers to reproductive health services.(17, 25, 26) However, an Australian study illustrated the  
11 positive care experience possible for women attending a specialised childbirth and mental health  
12 antenatal clinic.(27) The WHO global disability action plan 2014-2021 requires Member States to  
13 strengthen the collection of relevant and internationally comparable data on disability, and support  
14 research on disability and related services.(3)

### 15 ***Strengths and limitations***

16 Strengths of this study include the fact that all the organisations providing maternity care in England  
17 participated and substantial numbers of women with different types of disability responded.  
18 Moreover, we report on women's own perspective on their care. All data in this survey were self-  
19 reported and collected retrospectively at three months postpartum. This may call into question the  
20 validity of the responses recalled from pregnancy. However, research into the accuracy of recall  
21 suggests that it is good.(28-30) The survey response rate was low (41%) which may affect the  
22 generalisability of the findings, however, weighting for non-response was used. Also, many possible  
23 associations were tested and some significant associations may have arisen by chance. However, the  
24 high level of statistical significance of many of the associations reported mitigate against this.

1  
2  
3 1 Analyses were limited to the data collected by CQC. Unfortunately data were not collected on level  
4  
5 2 of education, marital status, income level, or urban/rural setting.  
6  
7

### 8 3 **Conclusion and implications for research and practice**

9

10  
11 4 This study presents the findings of a 2015 maternity survey in England as they relate to disability.  
12  
13 5 Using recently collected data, the study objectives were to investigate access to maternity care and  
14  
15 6 the quality of that care as reflected in women's perceptions, exploring differences in the experience  
16  
17 7 of women with different types of disability.  
18  
19

20  
21 8 Disabled women perceived greater problems regarding their maternity care, communication, and  
22  
23 9 involvement in decision making than non-disabled women. Those with a physical disability or  
24  
25 10 longstanding illness perceived problems regarding inadequate or inappropriate communication,  
26  
27 11 limited involvement in decision-making, and being able to establish a trusted and respected  
28  
29 12 relationship with clinical staff are areas for improvement for women in this group. For women with  
30  
31 13 sensory disability, having information delivered in an appropriate format was particularly important.  
32  
33 14 It may be helpful for staff caring for these women to allow more time to communicate effectively  
34  
35 15 throughout their maternity care.  
36  
37  
38

39  
40 16 In order to provide more appropriate care for women with a mental health disability, a longer  
41  
42 17 hospital stay and more frequent midwife visits may be required. In this group many aspects of  
43  
44 18 maternity care were not perceived as positively as for other groups, particularly they felt that they  
45  
46 19 were not always listened to, did not have time to ask questions, were not sufficiently involved in  
47  
48 20 decisions about their care, treated with respect, or had their concerns taken seriously.  
49  
50

51  
52 21 Similarly for women with multiple disabilities, improvements in communication and involvement in  
53  
54 22 decision-making are needed. For women with a learning disability aspects of care concerning  
55  
56 23 communication and involvement in decisions, feeling listened to and supported, particularly during  
57  
58  
59  
60

1 labour and birth, were highlighted as lacking and specific efforts are needed to improve the quality  
2 of care experienced.

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

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

#### 14 **Competing interest**

15 We declare no competing interests

#### 16 **Author's contributions**

17 All three listed authors have contributed to this paper: MR designed the analysis plan, JH and RM  
18 carried out the analyses, RM drafted the main manuscript and all authors contributed to the  
19 interpretation of the findings and refining the manuscript. All three authors read and approved the  
20 final version of the manuscript.

#### 21 **Acknowledgements**

1  
2  
3  
4  
5  
6  
7  
8  
9  
10  
11  
12  
13  
14  
15  
16  
17  
18  
19  
20  
21  
22  
23  
24  
25  
26  
27  
28  
29  
30  
31  
32  
33  
34  
35  
36  
37  
38  
39  
40  
41  
42  
43  
44  
45  
46  
47  
48  
49  
50  
51  
52  
53  
54  
55  
56  
57  
58  
59  
60

1 This work reports on an independent study which was funded by the Policy Research Programme in  
2 the Department of Health (DH) in the United Kingdom. The views expressed are not necessarily  
3 those of the DH. The Care Quality Commission was responsible for the original survey and granted  
4 access to the data. We are most grateful to women who responded to the survey.

#### 5 **Funding**

6 This study was funded by the Policy Research Programme in the Department of Health (DH) in the  
7 United Kingdom.

#### 8 **Data sharing agreement**

9 The women's trust based data used in this study were accessed from CQC who were responsible for  
10 the survey.

11

1 **References:**

- 2 1. Blackford KA, Richardson H, Grieve S. Prenatal education for mothers with disabilities. *J Adv*  
3 *Nurs*. 2000;32(4):898-904
- 4 2. Walsh-Gallagher D, Sinclair M, Mc Conkey R. The ambiguity of disabled women's experiences  
5 of pregnancy, childbirth and motherhood: A phenomenological understanding. *Midwifery*.  
6 2012;28(2):156-62.
- 7 3. World Health Organization. Disability and rehabilitation 2016 [Available from:  
8 <http://www.who.int/disabilities/data/en/> Accessed 11/4/17.
- 9 4. Hague G, Thiara R, Mullender A. Disabled women, domestic violence and social care: the risk  
10 of isolation, vulnerability and neglect. *Br J Soc Work*. 2011;41(1):148-65.
- 11 5. Lawler D LJ, Begley C. Access to maternity services for women with physical disabilities: a  
12 systematic review. *Int J Childbirth* 2013;3(4)::203-17.
- 13 6. Thomas C. Medicine, gender, and disability: disabled women's health care encounters.  
14 *Health Care Women Int*. 2001;22(3):245-62.
- 15 7. Thomas C. Disability: getting it "right". *J Med Ethics*. 2008;34(1):15-7.
- 16 8. Lipson JG RJ. Pregnancy, birth, and disability: women's health care experiences. *Health Care*  
17 *Women Int*. 2000 21:11-26.
- 18 9. Clark L, . Accessible health information: Liverpool Central Primary Care Trust. Project Report.  
19 Liverpool2002 [Available from: [http://pf7d7vi404s1dxh27mla5569.wpengine.netdna-  
21 cdn.com/files/library/Clark-Laurence-liverpool-NHS.pdf](http://pf7d7vi404s1dxh27mla5569.wpengine.netdna-<br/>20 cdn.com/files/library/Clark-Laurence-liverpool-NHS.pdf). Accessed 11/4/17.
- 22 10. Steinberg EJ. Deaf mothers and reproductive healthcare: identifying inequalities and  
23 documenting experiences. Presented at the Wellington Park Hotel, Belfast Conference on Equality  
24 and Social Inclusion in the 21st Century. 1 February, 2006.
- 25 11. O'Hearn A. Deaf women's experiences and satisfaction with prenatal care: a comparative  
26 study. *Fam Med*. 2006;38(10):712-6.
- 27 12. Jesse DE, Dolbier CL, Blanchard A. Barriers to seeking help and treatment suggestions for  
28 prenatal depressive symptoms: focus groups with rural low-income women. *Issues Ment Heal Nurs*.  
29 2008;29(1):3-19.
- 30 13. Redshaw M, Malouf R, Gao H, Gray R. Women with disability: the experience of maternity  
31 care during pregnancy, labour and birth and the postnatal period. *BMC Pregnancy Childbirth*.  
32 2013;13:174-.
- 33 14. Care Quality Commission. 2015 Maternity Survey: Quality and Methodology. London; 2016.
- 34 15. Care Quality Commission. National findings from the 2013 survey of women's experiences of  
35 maternity care. London: CQC; 2013.
- 36 16. National Collaborating Centre for Mental Health. Antenatal and postnatal mental health.  
37 Clinical management and service guidance. London: National Institute for Health and Care  
38 Excellence; 2014.
- 39 17. Becker H, Stuijbergen A, Tinkle M. Reproductive health care experiences of women with  
40 physical disabilities: A qualitative study. *Arch Phys Med Rehabil*. 1997;78(12):S26-S33.
- 41 18. Gill C, Kerotoski MA, Turk NMA. Becoming visible: personal health experiences of women  
42 with disabilities. *DM women with physical disabilities: achieving and maintaining health and*  
43 *wellbeing*. Baltimore: Pall H. Brookes; 1996. p. 5-15.
- 44 19. Mitra M, Clements KM, Zhang J, Iezzoni LI, Smeltzer SC, Long-Bellil LM. Maternal  
45 characteristics, pregnancy complications, and adverse birth outcomes among women with  
46 disabilities. *Med Care*. 2015;53(12):1027-32.
- 47 20. Smeltzer S S-HN, Ott B, Zimmerman V, Duffin J. Perspectives of women with disabilities on  
reaching those who are hard to reach. *J Neurosci Nurs*. 2007;39:163-9.

- 1  
2  
3 1 21. Prilleltensky O. A ramp to motherhood: the experiences of mothers with physical disabilities.  
4 2 Sex Disabil. 2003;21(1):21-47.  
5 3 22. Thomas C, Curtis P. Having a baby: some disabled women's reproductive experiences.  
6 4 Midwifery. 1997;13(4):202-9.  
7 5 23. Lee O, Oh E-K, Oh H. A wise wife and good mother: reproductive health and maternity  
8 6 among women with disability in South Korea. Sex Disabil. 2005;23(3):121-44.  
9 7 24. Amiel Castro RT, Schroeder K, Pinard C, Blöchlinger P, Künzli H, Riecher-Rössler A, et al.  
10 8 Perinatal mental health service provision in Switzerland and in the UK. Swiss Med Wkly. 2015(Feb  
11 9 21):145.  
12 10 25. Blackford KA, Richardson H, Grieve S. Prenatal education for mothers with disabilities. J Adv  
13 11 Nurs. 2000;32(4):898-904.  
14 12 26. Iezzoni LI, Wint AJ, Smeltzer SC, Ecker JL. Physical accessibility of routine prenatal care for  
15 13 women with mobility disability. J Womens Health (Larchmt). 2015;24(12):1006-12.  
16 14 27. Hauck Y, Allen S, Ronchi F, Faulkner D, Frayne J, Nguyen T. Pregnancy experiences of  
17 15 Western Australian women attending a specialist childbirth and mental illness antenatal clinic.  
18 16 Health Care Women Int. 2013;34(5):380-94.  
19 17 28. Bat-Erdene U, Metcalfe A, McDonald SW, Tough SC. Validation of Canadian mothers' recall  
20 18 of events in labour and delivery with electronic health records. BMC Pregnancy Childbirth. 2013;13  
21 19 Suppl 1:S3.  
22 20 29. Tate AR, Dezateux C, Cole TJ, Davidson L. Factors affecting a mother's recall of her baby's  
23 21 birth weight. Int J Epidemiol. 2005;34(3):688-95.  
24 22 30. Quigley MA, Hockley C, Davidson LL. Agreement between hospital records and maternal  
25 23 recall of mode of delivery: evidence from 12 391 deliveries in the UK Millennium Cohort Study.  
26 24 BJOG. 2007;114(2):195-200.  
27  
28  
29  
30  
31  
32  
33  
34  
35  
36  
37  
38  
39  
40  
41  
42  
43  
44  
45  
46  
47  
48  
49  
50  
51  
52  
53  
54  
55  
56  
57  
58  
59  
60

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=18,136) 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)	15,019 (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)	16,902 (93.4)
<b>Plurality</b>						
Single baby	860 (98.5)	170 (97.7)	655 (98.6)	127 (100.0)	118 (98.3)	17,846 (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>Breast feeding first few days after birth</b>	**	**	***	***	***	
Breast milk (at least some)	691 (80.0)	129 (75.4)	480 (72.6)	80 (64.5)	79 (66.4)	14,858 (82.8)
Formula only	173 (20.0)	42 (24.6)	181 (27.4)	44 (35.5)	40 (33.6)	3097 (17.2)

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



Table 2 – Access and clinical care for women with different disabilities. Odds ratios and 95% confidence intervals weighted for variation in response rates by Trust and adjusted for age, parity and ethnicity compared to women without disability.

	Physical condition or illness		Sensory disability		Mental health disability		Learning disability		Multiple disability		No disability	
	N	%	N	%	N	%	N	%	N	%	N	%
	aOR	(95% CI)	aOR	(95% CI)	aOR	(95% CI)	aOR	(95% CI)	aOR	(95% CI)		
<b>Pregnancy</b>												
First saw a HCP by 12 weeks	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, 2.27)	0.47 (0.25, 0.88)	1.03 (0.66, 1.60)	0.45 (0.22, 0.92)	0.89 (0.31, 2.49)						
Booking appointment <13 wks	753	92.1	132	84.6**	571	92.7	101	87.1	99	91.7	15,555	91.9
	aOR (95%CI)	1.03 (0.80, 1.34)	0.49 (0.31, 0.75)	1.13 (0.83, 1.54)	0.60 (0.35, 1.03)	0.98 (0.49, 1.94)						
Contact number for a MW	846	97.5	160	94.7*	633	95.9**	115	94.3	110	94.0	17,555	97.7
	aOR (95% CI)	0.95 (0.59, 1.53)	0.43 (0.21, 0.90)	0.55 (0.36, 0.85)	0.55 (0.23, 1.28)	0.43 (0.18, 1.03)						
Saw same MW each check	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, 1.05)	1.17 (0.82, 1.66)	0.90 (0.76, 1.07)	1.29 (0.87, 1.91)	1.23 (0.81, 1.86)						
No choice for place of birth for medical reasons	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, 5.59)	1.54 (0.95, 2.51)	1.85 (1.46, 2.30)	1.75 (0.99, 3.03)	3.40 (2.14, 5.40)						
<b>Birth (each mode of delivery compared with all others)</b>												
Vaginal birth	411	47.7***	103	61.3	376	57.1	76	61.8	61	52.1	10,704	59.6
	aOR (95%CI)	0.64 (0.55, 0.75)	0.99 (0.69, 1.42)	0.83 (0.69, 0.98)	0.97 (0.63, 1.78)	0.69 (0.46, 1.04)						
Assisted vaginal delivery	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, 1.29)	0.91 (0.63, 1.34)	0.86 (0.71, 1.03)	1.10 (0.66, 1.70)	1.27 (0.75, 2.14)						
Planned caesarean section	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, 2.06)	1.40 (0.90, 2.30)	1.07 (0.83, 1.39)	0.71 (0.32, 1.66)	1.34 (1.17, 1.55)						
Emergency caesarean section	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, 1.58)	0.81 (0.47, 1.40)	1.20 (0.95, 1.53)	1.09 (0.64, 1.84)	1.21 (0.71, 2.06)						
<b>Postnatal care</b>												
Skin to skin after birth	644	89.2	139	91.4	520	91.9	102	92.7	90	90.9	14,843	91.3
	aOR (95% CI)	0.72 (0.56, 0.94)	0.87 (0.48, 1.58)	0.98 (0.70, 1.37)	0.83 (0.39, 1.80)	0.67 (0.32, 1.41)						
Length postnatal stay >2 days	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, 2.18)	1.15 (0.80, 1.63)	1.89 (1.58, 2.26)	1.51 (1.00, 2.28)	2.11 (1.40, 3.17)						
Home visit by midwife	824	95.6**	164	97.6	642	97.0	118	95.2	112	96.6	17,440	96.9
	aOR (95% CI)	0.62 (0.43, 0.89)	3.42 (0.80, 14.62)	0.85 (0.65, 1.12)	0.76 (0.31, 1.94)	1.45 (0.45, 4.62)						
Feeding advice always available out of hours	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, 0.78)	0.90 (0.55, 1.48)	0.65 (0.50, 0.84)	1.56 (0.90, 2.72)	0.77 (0.45, 1.33)						
5+ visits with MW	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, 1.32)	1.40 (0.95, 2.05)	1.55 (1.28, 1.87)	1.82 (1.18, 2.79)	1.01 (0.62, 1.63)						

\*p<0.05, \*\*p<0.01, \*\*\*p<0.001; Sensory disability: visually impaired, deaf and hearing impaired; HCP Health care professional; MW Midwife

**Table 3 – Perception of antenatal care received for women with and without disability. Number and proportion of women with and without various types of disability, odds ratios and 95% confidence intervals weighted for variation in response rates by Trust and adjusted for age, parity and ethnicity compared to women without disability**

	Physical condition or illness		Sensory loss		Mental health disability		Learning disability		Multiple disability		No disability	
	N	%	N	%	N	%	N	%	N	%	N	%
	aOR	(95% CI)	aOR	(95% CI)	aOR	(95% CI)	aOR	(95% CI)	aOR	(95% CI)		
<b>Always time to ask questions</b>	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, 0.82)	0.71	(0.49, 1.02)	0.60	(0.50, 0.71)	1.00	(0.65, 1.54)	0.61	(0.40, 0.93)		
<b>MWs always listened</b>	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, 0.73)	0.70	(0.48, 1.02)	0.50	(0.42, 0.60)	0.57	(0.38, 0.87)	0.39	(0.25, 0.59)		
<b>Always spoken to so could understand</b>	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, 0.89)	0.45	(0.30, 0.70)	0.56	(0.45, 0.71)	0.31	(0.20, 0.47)	0.40	(0.25, 0.65)		
<b>Always involved enough in decisions</b>	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, 0.70)	0.77	(0.53, 1.12)	0.62	(0.51, 0.74)	0.45	(0.31, 0.67)	0.54	(0.36, 0.82)		
<b>If MW contacted, always given help needed</b>	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, 1.04)	0.81	(0.32, 2.08)	0.90	(0.55, 1.47)	0.70	(0.45, 1.09)	1.00	(0.61, 1.64)		

\* $p < 0.05$ , \*\* $p < 0.01$ , \*\*\* $p < 0.001$       Sensory disability: visually impaired, deaf and hearing impaired

**Table 4 – Perception of labour and birth care received for women with and without disability. Number and proportion of women with and without various types of disability, odds ratios and 95% confidence intervals weighted for variation in response rates by Trust and adjusted for age, parity and ethnicity compared to women without disability**

	Physical condition or illness		Sensory disability		Mental health disability		Learning disability		Multiple disability		No disability	
	N	%	N	%	N	%	N	%	N	%	N	%
<b>All staff introduced themselves</b>	646	75.6***	130	80.2	479	73.9***	94	79.0	86	76.1	14,982	84.6
aOR (95% CI)	0.57	(0.48, 0.68)	0.90	(0.58, 1.41)	0.52	(0.43, 0.63)	0.80	(0.50, 1.28)	0.77	(0.46, 1.27)		
<b>Always spoken to in a way could understand</b>	74.4	87.1*	132	79.5***	533	81.8***	89	72.4***	92	79.3***	16,126	89.9
aOR (95% CI)	0.74	(0.59, 0.93)	0.50	(0.32, 0.77)	0.49	(0.39, 0.62)	0.39	(0.25, 0.60)	0.44	(0.27, 0.74)		
<b>Definitely had confidence and trust in staff</b>	656	75.8**	134	78.8	465	71.1***	85	69.7**	89	76.1	14,542	80.9
aOR (95% CI)	0.73	(0.62, 0.87)	0.82	(0.55, 1.22)	0.57	(0.47, 0.69)	0.58	(0.38, 0.87)	0.68	(0.43, 1.08)		
<b>Always involved enough in decisions</b>	541	65.1***	116	71.6	414	65.0***	81	68.6	84	74.3	13,357	76.2
aOR (95% CI)	0.60	(0.51, 0.70)	0.82	(0.56, 1.20)	0.59	(0.49, 0.70)	0.73	(0.48, 1.11)	1.00	(0.62, 1.61)		
<b>Always treated with respect</b>	700	81.0***	132	78.6**	503	76.7***	97	80.2	93	79.5	15,701	87.5
OR (95% CI)	0.59	(0.49, 0.71)	0.65	(0.43, 0.98)	0.47	(0.38, 0.57)	0.71	(0.44, 1.15)	0.67	(0.39, 1.14)		
<b>Concerns taken seriously</b>	450	78.9*	90	74.4*	348	73.6***	59	72.0***	67	80.7	9279	82.7
aOR (95% CI)	0.78	(0.62, 0.98)	0.55	(0.34, 0.88)	0.57	(0.46, 0.72)	0.66	(0.38, 1.13)	0.80	(0.44, 1.48)		
<b>Always received attention in reasonable time</b>	463	71.0**	101	73.2	370	69.2***	62	65.3	69	63.3	10,563	64.5
aOR (95% CI)	0.76	(0.63, 0.92)	0.95	(0.62, 1.45)	0.68	(0.56, 0.83)	0.73	(0.46, 1.16)	1.05	(0.62, 1.78)		
<b>Left alone and worried at some point</b>	231	26.7	62	36.7***	224	34.1***	57	45.6***	43	35.8***	4401	24.5
aOR (95% CI)	1.12	(0.95, 1.32)	1.32	(0.92, 1.91)	1.71	(1.43, 2.04)	1.87	(1.26, 2.76)	1.45	(0.94, 2.23)		

\*p<0.05, \*\*p<0.01, \*\*\*p<0.001      Sensory disability: visually impaired, deaf and hearing impaired

1  
2  
3  
4  
5 1 Table 5 – Perception of postnatal care received for women with and without disability. Number and proportion of women with and without various types of disability, odds  
6 2 ratios and 95% confidence intervals weighted for variation in response rates by Trust and adjusted for age, parity and ethnicity compared to women without disability  
7  
8

	Physical condition or illness		Sensory disability		Mental health disability		Learning disability		Multiple disability		No disability	
	N	%	N	%	N	%	N	%	N	%	N	%
	aOR	(95% CI)	aOR	(95% CI)	aOR	(95% CI)	aOR	(95% CI)	aOR	(95% CI)		
<b>Postnatal care in hospital</b>												
<b>Always able to get attention in reasonable time</b>	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, 0.83)	0.85	(0.60, 1.20)	0.69	(0.58, 0.82)	0.85	(0.58, 1.26)	0.73	(0.49, 1.10)		
<b>Always treated with kindness and understanding</b>	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, 0.76)	0.70	(0.49, 0.99)	0.62	(0.52, 0.73)	0.64	(0.43, 0.96)	0.63	(0.42, 0.97)		
<b>Partner or companion stayed as long as woman wanted</b>	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, 0.82)	0.73	(0.52, 1.04)	0.63	(0.53, 0.75)	1.12	(0.75, 1.66)	0.84	(0.55, 1.27)		
<b>HCPs gave active support and encouragement about feeding the baby</b>	438	54.0***	93	58.1	327	52.4***	76	64.4	61	56.0	10,732	63.5
aOR (95% CI)	0.66	(0.57, 0.78)	0.82	(0.58, 1.15)	0.64	(0.54, 0.76)	1.25	(0.84, 1.87)	0.77	(0.69, 0.87)		
<b>Postnatal care at home</b>												
<b>If MW contacted, always given help needed</b>	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, 0.88)	0.80	(0.51, 1.25)	0.72	(0.58, 0.91)	0.55	(0.35, 0.88)	0.84	(0.50, 1.40)		
<b>Would have liked to see a MW more often</b>	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, 1.61)	1.94	(1.34, 2.80)	1.22	(0.98, 1.51)	1.89	(1.25, 2.87)	1.61	(0.99, 2.63)		
<b>MWs always listened</b>	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, 0.87)	0.54	(0.38, 0.76)	0.56	(0.46, 0.66)	0.92	(0.59, 1.43)	0.56			
<b>Definitely had confidence and trust in MW</b>	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, 0.83)	0.65	(0.46, 0.92)	0.64	(0.54, 0.76)	0.69	(0.46, 1.03)	0.62			
<i>In the 6 weeks since the birth, definitely received help and advice about...</i>												
<b>Feeding the baby</b>	444	58.6***	89	60.1	327	56.9***	70	59.8	61	56.0	10,000	65.2
aOR (95% CI)	0.73	(0.62, 0.85)	0.83	(0.57, 1.19)	0.73	(0.61, 0.88)	0.94	(0.63, 1.40)	0.70			

<b>Baby's health and progress</b>	561	67.9*	100	65.8	420	67.3*	90	75.6	78	69.0	11,943	71.1
aOR (95% CI)	0.81	(0.69, 0.95)	0.69	(0.46, 0.96)	0.78	(0.65, 0.94)	1.19	(0.76, 1.88)	0.73			

\* $p < 0.05$ , \*\* $p < 0.01$ , \*\*\* $p < 0.001$  Sensory disability: visually impaired, deaf and hearing impaired; HCP Health care professional; MW Midwife

**Table 6 – Physical and emotional well-being for women with and without disability. Number and proportion of women with various types of disability, odds ratios and 95% confidence intervals weighted for variation in response rates by Trust and adjusted for age, parity and ethnicity compared to women without disability**

	Physical condition or illness		Sensory loss		Mental health disability		Learning disability		Multiple disabilities		No disability	
	N	%	N	%	N	%	N	%	N	%	N	%
	aOR	(95% CI)	aOR	(95% CI)	aOR	(95% CI)	aOR	(95% CI)	aOR	(95% CI)		
<b>Antenatal period</b>												
<b>MW always aware of medical history</b>	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, 0.97)	0.95	(0.67, 1.34)	0.83	(0.70, 0.99)	1.28	(0.87, 1.87)	1.02	(0.68, 1.52)		
<b>MW definitely asked how feeling emotionally</b>	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, 0.95)	1.19	(0.84, 1.68)	1.16	(0.97, 1.37)	1.23	(0.83, 1.84)	1.03	(0.68, 1.57)		
<b>Postnatal care after discharge home MW always aware of medical history</b>	542	69.0***	114	74.0	438	71.5***	88	75.2	77	71.3	12,855	78.0
aOR (95% CI)	0.63	(0.54, 0.75)	0.83	(0.56, 1.23)	0.73	(0.60, 0.88)	1.00	(0.63, 1.58)	0.71	(0.44, 1.15)		
<b>MW took personal circumstances into account</b>	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, 0.82)	0.60	(0.42, 0.87)	0.59	(0.49, 0.71)	0.59	(0.39, 0.90)	0.61	(0.39, 0.97)		
<b>Women informed of need to arrange own PN check</b>	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, 1.05)	0.74	(0.42, 1.31)	0.73	(0.55, 0.97)	0.55	(0.31, 0.99)	0.73	(0.21, 0.65)		
<b>MW/HV asked how feeling emotionally</b>	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, 0.74)	0.57	(0.27, 1.21)	0.56	(0.38, 0.83)	0.39	(0.19, 0.77)	1.15	(0.40, 3.29)		
<b>Definitely given enough information about emotional changes</b>	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, 0.89)	0.90 (0.64, 1.28)	0.77 (0.65, 0.91)	0.99 (0.67, 1.47)	0.84 (0.56, 1.27)						
<b>Told who to contact about emotional changes</b>	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, 0.90)	0.92	(0.61, 1.38)	0.84	(0.69, 1.03)	0.84	(0.55, 1.30)	0.98	(0.60, 1.61)		
<b>Definitely given advice about physical recovery</b>	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, 0.84)	1.20	(0.83, 1.67)	0.64	(0.54, 0.76)	0.90	(0.61, 1.32)	0.74	(0.67, 0.82)		
<b>Given information/advice about contraception</b>	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, 0.83)	0.84	(0.50, 1.41)	0.54	(0.42, 0.69)	0.56	(0.32, 0.99)	0.55	(0.30, 1.01)		

\*p<0.05, \*\*p<0.01, \*\*\*p<0.001      Sensory disability: visually impaired, deaf and hearing impaired

## STROBE Statement—checklist of items that should be included in reports of observational studies

	Item No	Recommendation	Page
<b>Title and abstract</b>	1	(a) Indicate the study's design with a commonly used term in the title or the abstract	2
		(b) Provide in the abstract an informative and balanced summary of what was done and what was found	2
<b>Introduction</b>			
Background/rationale	2	Explain the scientific background and rationale for the investigation being reported	4-5
Objectives	3	State specific objectives, including any prespecified hypotheses	5
<b>Methods</b>			
Study design	4	Present key elements of study design early in the paper	5
Setting	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection	5-6
Participants	6	(a) <i>Cohort study</i> —Give the eligibility criteria, and the sources and methods of selection of participants. Describe methods of follow-up <i>Case-control study</i> —Give the eligibility criteria, and the sources and methods of case ascertainment and control selection. Give the rationale for the choice of cases and controls <i>Cross-sectional study</i> —Give the eligibility criteria, and the sources and methods of selection of participants	6
		(b) <i>Cohort study</i> —For matched studies, give matching criteria and number of exposed and unexposed <i>Case-control study</i> —For matched studies, give matching criteria and the number of controls per case	
Variables	7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable	6
Data sources/ measurement	8*	For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group	6
Bias	9	Describe any efforts to address potential sources of bias	7
Study size	10	Explain how the study size was arrived at	6
Quantitative variables	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why	6
Statistical methods	12	(a) Describe all statistical methods, including those used to control for confounding (b) Describe any methods used to examine subgroups and interactions (c) Explain how missing data were addressed (d) <i>Cohort study</i> —If applicable, explain how loss to follow-up was addressed <i>Case-control study</i> —If applicable, explain how matching of cases and controls was addressed <i>Cross-sectional study</i> —If applicable, describe analytical methods taking account of sampling strategy	6-7
		(e) Describe any sensitivity analyses	

Continued on next page

<b>Results</b>			
Participants	13*	(a) Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed (b) Give reasons for non-participation at each stage (c) Consider use of a flow diagram	7  Fig 1
Descriptive data	14*	(a) Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders (b) Indicate number of participants with missing data for each variable of interest (c) <i>Cohort study</i> —Summarise follow-up time (eg, average and total amount)	Table 1
Outcome data	15*	<i>Cohort study</i> —Report numbers of outcome events or summary measures over time <i>Case-control study</i> —Report numbers in each exposure category, or summary measures of exposure <i>Cross-sectional study</i> —Report numbers of outcome events or summary measures	Tables 2-6
Main results	16	(a) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95% confidence interval). Make clear which confounders were adjusted for and why they were included (b) Report category boundaries when continuous variables were categorized (c) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period	Tables 2-6
Other analyses	17	Report other analyses done—eg analyses of subgroups and interactions, and sensitivity analyses	
<b>Discussion</b>			
Key results	18	Summarise key results with reference to study objectives	12,15
Limitations	19	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias	14
Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence	14
Generalisability	21	Discuss the generalisability (external validity) of the study results	14
<b>Other information</b>			
Funding	22	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based	17

\*Give information separately for cases and controls in case-control studies and, if applicable, for exposed and unexposed groups in cohort and cross-sectional studies.

**Note:** An Explanation and Elaboration article discusses each checklist item and gives methodological background and published examples of transparent reporting. The STROBE checklist is best used in conjunction with this article (freely available on the Web sites of PLoS Medicine at <http://www.plosmedicine.org/>, Annals of Internal Medicine at <http://www.annals.org/>, and Epidemiology at <http://www.epidem.com/>). Information on the STROBE Initiative is available at [www.strobe-statement.org](http://www.strobe-statement.org).