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Disparities in maternity care for disabled women in the UK

MARCH 2025

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Citation: Kuper, H. and Rodríguez Gatta, D. *Disparities in maternity care for disabled women in the UK*, 2025. International Centre for Evidence in Disability, London School of Hygiene & Tropical Medicine and Missing Billion Initiative.

Executive Summary

Disabled women make up 20% of women of reproductive age (15-49 years) in the UK, equating to 2.9 million women. Emerging evidence in the UK and elsewhere shows that disabled women have worse maternity care access, experiences and outcomes. Yet, the needs of disabled women appear to be rarely considered in relevant maternity guidance. Moreover, this important issue has not previously been systematically reviewed in the UK. There is therefore an urgent need to assess the up-to-date evidence on maternity care inequities for disabled women in the UK, to inform policy, practice and research.

Consequently, the key objectives of this report are to:

1. Systematically review the scientific literature on maternity care access, experiences and outcomes for disabled women in the UK;
2. Undertake an umbrella review of the systematic reviews on maternity care access, experiences and outcomes for disabled women globally;
3. Assess the inclusion of disabled women in maternity care guidance documents in the UK;
4. Make recommendations for next priority actions, in terms of strengthening policy, programmes and research on disability-inclusive maternity care in the UK.

Key findings

UK data on maternal and neonatal outcomes for disabled women:

- Eleven quantitative studies were identified comparing maternity care access, experiences and outcomes by disability status in the UK.
- The data were relatively sparse, but showed inequalities for disabled women, including
  - Higher risk of neonatal/infant death in infants born to disabled mothers
    - Stillbirth/neonatal mortality **(44% higher odds)**
    - Postnatal death significantly more likely **(p=0.04)**
  - Caesarean birth more likely **(30% to 69% higher odds)**, and some evidence that preterm birth more likely
  - Lower levels of breastfeeding **(35% to 70% lower odds)**
  - Longer postnatal stay **(51% to 111% higher odds)**
- Eight qualitative/mixed methods studies were identified, which highlighted the range of challenges faced by disabled women when accessing maternity care, including inaccessible information and infrastructure, negative attitudes of staff, and lack of continuity of care, as well as the importance of good family and professional support.

Global data on maternal and neonatal outcomes for disabled women:

- Eight systematic reviews with meta-analyses were identified comparing maternity care access, experiences and outcomes by disability status, but almost entirely focussed on women with mental health conditions.
- Evidence showed clear inequalities compared to non-disabled women in:
  - Neonatal/perinatal mortality **(41% to 66% higher odds)**, stillbirth **(42% to 106% higher odds)** and postnatal mortality **(49% to 187% higher odds)**

- Adverse antenatal outcomes (gestational diabetes, hypertension and other adverse pregnancy outcomes)
- Poor labour and delivery outcomes (higher odds of preterm birth, low birthweight, and higher risk of caesarean)
- Worse longer-term outcomes, including infant development delays

- Twelve systematic reviews of qualitative/mixed methods papers highlighted challenges experienced by disabled women in seeking maternity care because of insufficient information, lack of experience and poor attitudes of clinicians about disability, inaccessibility of health equipment, facilities and information, lack of support groups, and overall, low satisfaction with quality of care.

Guidance review:

- Documents were reviewed for consideration of disability in guidance documents of:
  - Royal College of Obstetricians and Gynaecologists (RCOG): 67 relevant reports (and the titles of 75 Scientific Impact Papers).
  - National Institute for Health and Care Excellence (NICE): 30 guidance documents in the categories fertility, pregnancy and childbirth.
- Across the documents, there was extremely limited attention to disability:
  - None of the documents focussed specifically on disability.
  - RCOG: **2 out of 67** reports reviewed mention disability.
  - NICE: **6 out of 30** guidance documents reviewed mention disability.
  - Any mention of disability in the reports was brief, lacking specific action.
- Limited guidance on maternity care for disabled women was identified from specific UK hospitals or institutions.

Key recommendations for UK

1. Establish a **UK committee**, that is inclusive of disabled women, to review the current situation of maternity care services for disabled women, in order to define next priority actions.
2. Finance and undertake **UK-focussed research** to:
   - **a.** Estimate inequalities in maternity and neonatal care access, experiences and outcomes of disabled women.
   - **b.** Develop and test interventions to improve maternity care for all disabled women in the UK.
3. Develop **policy and programme guidance** relevant to maternity care in the UK (e.g. NICE and RCOG) that:
   - **a.** Specifically addresses maternity care of disabled women.
   - **b.** Include consideration of disability within broader guidance on maternity care.
4. Strengthen **maternity care delivery** in the UK to improve access, experiences and outcomes, for disabled women including by:
   - **a.** Training all clinical staff who deliver maternity care about disability (pre-service and in-service training).
   - **b.** Providing joined-up care throughout the maternity care pathway for disabled women (antenatal, labour and delivery, and postnatal care).
   - **c.** Ensuring the provision of reasonable adjustments and accessible facilities, equipment and information to disabled women throughout the maternity care pathway.

Background

Disabled people are those with a physical or mental impairment that has a 'substantial' and 'long-term' negative effect on their ability to undertake normal daily activities.[1] In the United Kingdom (UK), there are approximately 16.1 million people with a disability, making up 24% of the total population.[2] This number includes 2.9 million disabled women of reproductive age (i.e. 15-49 years), making up 20% of women in that age group. There is now strong and consistent evidence from the UK, as well as globally, that disabled people frequently experience worse health, higher mortality, and poorer healthcare access.[3-5] There is also emerging evidence that these healthcare inequalities extend to maternity care[6, 7], including in the UK,[8, 9, a] – meaning the care of women during pregnancy, labour and delivery and the postnatal period and the care of their babies. These inequities in maternity care access, experience and outcomes occur, even though there are a range of laws protecting the rights of disabled women to maternity care (Box 1).

Box 1: Rights of disabled women to maternity care are protected by law

- The UK's Equality Act 2010[1] - states that public bodies, such as the National Health Service (NHS), must take all reasonable steps to eliminate discrimination and advance equality of opportunity when providing services. Consequently, people with protected characteristics must be able to access the same maternity care as any other person, and reasonable adjustments must be offered.
- Article 14 of the European Convention on Human Rights[10] - prohibits discrimination on the grounds of disability. Therefore, everyone should have equal access to safe and appropriate maternity care that respects their dignity and autonomy.
- Article 25 of the UN Convention on the Rights of Persons with Disabilities[11] - states that States must provide persons with disabilities with the same range, quality and standard of free or affordable health care and programmes as provided to other persons, including in the area of sexual and reproductive health and population-based public health programmes.

Disabled women are not a homogenous group, and so maternity care access, experiences and outcomes will vary by factors such as disability type, socio-economic circumstances and region.[9] Nevertheless, there are several reasons why disabled women may have worse maternity care access, experiences and outcomes.[4]

- First, disabled women on average experience higher levels of poverty, and widespread discrimination and exclusion, including from education and work,[12, 13] and these **adverse social determinants of health** are known predictors of poor maternity outcomes.[14]
- Second, they may experience **diverse barriers to care**, resulting from health system failures, such as lack of skills of healthcare workers in offering them reasonable adjustments, and inaccessible health information or facilities.[15, 16] **Lack of knowledge and negative attitudes of healthcare workers around disability** may be particularly important, for instance the inappropriate assumption that disabled women are asexual or cannot/should not require maternity care.
- Third, disabled women, by definition, have an **underlying impairment or health condition**, which may directly or indirectly increase the risk of poor outcomes (e.g. resulting from urinary tract infections among women with spinal cord injuries).[17]

Yet, few policies, guidance documents, or programmes appear to be in place to close the gap in maternity care for disabled women in the UK. Indeed, there is a general lack of attention on this topic in the UK, including from key recent guidance documents such as the NHS's 2016 National Maternity Review "Better

a Pre-conception care is also an important topic, but was not considered in this report.

Births – Improving outcomes of maternity services in England" report,[18] the 2024 research briefing on "Quality and safety of maternity care (England)",[19] and the 2023 NHS report "Three year delivery plan for maternity and neonatal services".[20] The 2022 "Women's Health Strategy for England" Report acknowledges the difficulties disabled women may encounter in healthcare access and that they are an under-represented group, but does not address their maternity care needs specifically.[21] This lack of guidance exists despite the evidence on gaps in maternity outcomes and quality services for disabled women in the UK.[8, 9] Moreover, concerns were already flagged in 2017 by the Committee on the Rights of Persons with Disabilities around the UK's lack of mainstreaming of issues related to women with disabilities, inadequate policies, and multiple barriers to accessing sexual and reproductive health services, among other issues.[22]

There is therefore an urgent need to assess the evidence on maternal health inequities for disabled women in the UK, to inform policy, practice and research.[b] Consequently, the objectives of this report are to:

1. Systematically review the scientific literature on maternity care access, experiences and outcomes for disabled women in the UK;
2. Undertake an umbrella review of the systematic reviews on maternity care access, experiences and outcomes for disabled women globally;
3. Assess the inclusion of disabled women in maternity care guidance documents in the UK;
4. Make recommendations for next priority actions, in terms of strengthening policy, programmes and research on disability-inclusive maternity care in the UK.

b Points of clarification: This report focuses on disability existing prior to pregnancy, and not mental health or other conditions that emerge during pregnancy (e.g., pre/post-natal depression). Moreover, the focus is on the experience of maternity care by disabled women, not disability-related treatment impacts (e.g. psychotropic medication pregnancy impacts). We are not addressing evidence on interventions on "what works" to improve maternity outcomes for disabled women, although it is clear that there is a lack of evidence on this topic.[23, 24] The focus is on "women", meaning adults of female sex. However, we acknowledge that disabled trans-men may also require maternity care, but are likely to have additional barriers and adjustments when seeking care.

Methods

The following methods were undertaken to achieve the objectives:

Systematic review of maternity care for disabled women in the UK[c]

A search was conducted in January 2025 across three databases (EMBASE, MEDLINE and PsycINFO) to identify published peer-reviewed articles (qualitative, quantitative or mixed methods) that reported original research on maternity care access, experiences and outcomes for disabled women conducted in the UK. We restricted the search to papers published from 2010 onwards, to ensure relevance of data (Appendix 1[d] – Search terms). The following inclusion criteria were applied:

- Maternity services included antenatal care, labour and delivery, and postnatal care.
- Participants included disabled women of reproductive age (15-49 years).
- Disability was measured through functioning limitations, impairments or health conditions deemed likely to result in disability (e.g., schizophrenia) and excluded women with conditions arising during pregnancy (e.g., perinatal depression), as our focus was on outcomes for women with pre-existing disability.

The titles, abstracts, and full texts were independently screened by two reviewers against the inclusion criteria, and data was extracted from the eligible papers.[e]

Umbrella review of systematic reviews of disability and maternal and perinatal outcomes[f]

A search was also conducted of the global literature, in anticipation of a scarcity of evidence available on maternity care for disabled women in the UK. The search was conducted in January 2025 across three databases (EMBASE, MEDLINE and PsycINFO) to identify published systematic reviews or meta-analyses (qualitative, quantitative or mixed methods) that reported on maternity care access, experiences, and outcomes globally, published from 2010 onwards (Appendix 2 – Search terms). The same definitions of disability and maternity care of the UK systematic review were considered for the umbrella review, and the same strategy for screening papers and extracting data from eligible reviews.[3]

c PROSPERO registration number: CRD42025651898

d Appendices available online at: https://www.themissingbillion.org/reports

e Risk of bias of the included studies was not assessed, which we acknowledge as a limitation.

f PROSPERO registration number: CRD42025651950

Analysis of disability inclusion in UK guidance documents on maternal health

We reviewed the following sources of published documents for consideration of disability:

- Documents from the Royal College of Obstetricians and Gynaecologists (RCOG) website: Green-top guidelines, Consent advice, Good practice papers, Best practice papers, Scientific impact papers, and Clinical Governance Advice.
- National Institute for Health and Care Excellence (NICE) guidance in category "Fertility, pregnancy and childbirth" potentially related to maternal health.

For both sources, we searched the titles and text of relevant guidance documents for consideration of disability through search of the term "disab". We acknowledge that this search would have missed specific long-term conditions or impairment types which may have been within scope. We described the nature of any mentions of disability (restricting to disability of the woman, not infant, and not including conditions that arose during pregnancy).

Additionally, we conducted an internet search through Google to identify other maternity care guidance documents from the UK that focussed on disabled women. We also searched for disability within other key RCOG documentation and in training offered.

Recommendations for next priority actions

Recommendations for next priority actions were formulated by the two report authors (HK and DR) focussing on the areas of research and programmes. Recommendations were shared for feedback with key experts (including researchers, clinicians and people with disabilities), and revised accordingly.

Results

Systematic review of maternity care for disabled women in the UK

We searched 2206 individual titles and abstracts, of which 19 papers were deemed eligible and included in the review (PRISMA flow-chart in Appendix 3), including 11 quantitative, 7 qualitative and 1 mixed-methods study.

Quantitative studies (Appendix 4-7)

Almost half (5/11) of the studies were conducted using electronic health records (Appendix 4, 5). Studies were generally large, including more than 1000 disabled women (7/11 studies). Studies mainly focussed on women with: mental health conditions (n=5 studies); learning disability (n=2); physical impairment (n=1) or multiple/all (n=3). A broad range of maternal and neonatal outcomes were investigated, across antenatal care, labour and delivery, and postnatal care.

Key findings from quantitative studies (Table 1):

Antenatal

- **Health behaviours in pregnancy:** Four studies showed that disabled women had a greater likelihood of smoking, and single studies showed a greater likelihood of other adverse behaviours (drug use, poor diet, low exercise, or lack of folic acid supplementation). One study showed lower alcohol use among disabled pregnant women.
- **Health outcomes:** One study showed higher abortion and recurrent miscarriage among disabled women. One study showed no difference in occurrence of pre-eclampsia.
- **Health access:** One study showed better maternity care access (antenatal scans) for disabled women.

Labour and delivery

- **Maternal outcomes:** Three studies showed disabled women were more likely to have a (planned or emergency) caesarean birth **(30%-69% higher odds)**, while one study showed no difference by disability. Three studies found disabled women were up to twice as likely to have a premature birth, while two studies showed no difference.
- **Neonatal outcomes:** One study showed neonatal mortality was **44% higher** in newborns of disabled mothers. One study showed a two-fold higher risk of adverse neonatal events in infants of disabled mothers. Mixed evidence on differences in preterm birth, low birthweight or small for gestational age.

Postnatal

- **Maternal outcomes:** Clear evidence across four studies that disabled women are less likely to breastfeed **(35%-70% lower odds)**. Limited evidence, but three studies indicate significantly longer postnatal stay among disabled women **(51% to 111% higher odds)**. One study showed disabled mothers were less likely to report “being well”.
- **Infant outcomes:** One study shows significantly higher risks of postnatal deaths among children of disabled women (p=0.04). Consistent evidence on indicators for adverse development outcomes among infants of disabled women. Lack of evidence of lower child vaccination.

Two papers are of particular note – published from the Care Quality Commission Maternity Surveys - given their detailed investigation of maternal outcomes for disabled women, and disaggregation by disability type (Appendix 6).[8, 9] They echo the broad findings across the studies. They also highlighted that disabled women often faced gaps regarding their quality of care and interpersonal relations with staff (e.g., provided information appropriately, treated respectfully, involved in decision-making). Furthermore, across both studies, women with physical disability were less likely to have a choice of place of birth due to medical reasons and women with mental health conditions reported particular issues with communication and support by staff.

***Table 1.** Summary findings from systematic review of maternal and neonatal characteristics and outcomes for disabled women, UK (detailed data in appendix 5).*

	No of studies reporting outcome	Worse for disabled women, Odds Ratio (95% CI)	No difference, Odds Ratio (95% CI)	Better for disabled women, Odds Ratio (95% CI)
Antenatal				
Alcohol drinking	1			1) OR 0.94 (0.90–0.08)
Smoking	4	1) OR 1.57 (1.27–1.95) 2) aOR 2.50 (1.84–3.40) 3) OR 2.5 (1.7–5.0) 4) 29.2% vs 20.8% (p < 0.001)		
Illegal/recreational drugs	1	1) OR 3.02 (2.79–3.27)		
Healthy diet	1	1) OR 0.67 (0.64–0.71)		
Exercise	1	1) OR 0.90 (0.83–0.96)		
Folic acid supplementation	1	1) OR 0.84 (0.79–0.89)		
Recurrent miscarriage	1	1) aOR 1.87 (1.11–3.17)		
Abortion	1	1) aOR 1.64 (1.11–3.18)		
Pre-eclampsia	1		1) 6.5% vs 9.9% (p = 0.09)	
Antenatal scans	1			1) aOR 2.04 (1.83–2.28)
Labour and delivery				
Caesarean	4	1) aOR 1.35 (1.19–1.52) 2) 26.6% vs 20.9% (p < 0.001) 3) *Planned*: aOR 1.34 (1.17–1.55) physical disability to aOR 1.69 (1.38–2.06) multiple disability; *Emergency*: aOR 1.30 (1.07–1.58) physical disability	1) *Planned*: aOR 0.71 (0.32–1.66) learning disability to aOR 1.40 (0.90 to 2.30) sensory disability; *Emergency*: aOR 0.81 (0.47 to 1.40) sensory disability to aOR 1.21 (0.71 to 2.06) multiple disability 2) 9.3% vs 7.5% (p = 0.32)	
Preterm birth	5	1) aOR 1.31 (1.25–1.37) 2) aOR 2.11 (1.96–2.28) 3) 9.3% vs 5.9% (p < 0.001)	4) aOR 0.83 (0.31–2.26) 5) OR 1.4 (0.6–3.0)	
Maternal morbidity	1	1) aOR 1.26 (1.01–1.57)		
Stillbirth/neonatal mortality	2	1) aOR 1.44 (1.13–1.84)	2) *Stillbirth:* 2/217 vs 346/244 790 (p = 0.34); *Neonatal mortality:* 1/215 versus 1095/243 444 (p = 0.62)	
Low birthweight	3	1) aOR 1.29 (1.21–1.38) 2) aOR 1.49 (1.10–2.00)	3) OR 1.5 (0.7–3.3)	
Small for Gestational Age	2	1) aOR 1.64 (1.51–1.79)	2) aOR 1.03 (0.59–1.80)	
Neonatal adverse outcome	1	1) aOR 1.98 (1.82–2.16)		

	No of studies reporting outcome	Worse for disabled women, Odds Ratio (95% CI)	No difference, Odds Ratio (95% CI)	Better for disabled women, Odds Ratio (95% CI)
Postnatal				
Breastfeeding	4	1) OR 0.3 (0.1–0.5) 2) aOR 0.31 (0.22–0.42) 3) aOR 0.65 (0.57–0.74) 4) 25.6% vs 33.4% (p < 0.001)		
Postnatal stay length >2 days	3	1) aOR 1.51 (1.00 –2.28) learning disability to aOR 2.11 (1.40–3.17) multiple disability 2) aOR 1.63 (1.45–1.83) 3) OR 1.9 (1–1-3.3)	1) aOR 1.15 (0.80–1.63) sensory disability	
Postnatal death	1	1) 3/214 vs 830/242 349 (p = 0.04)		
Mother reported being well	1	1) aOR 0.45 (0.27–0.78) physical disability; OR 0.29 (0.16–0.52) mental/learning disability		
Low Apgar score at 1/5 minutes	2	1) *At 1 min:* aOR 1.14 (1.10–1.19); *at 5 min:* aOR 1.23 (1.12–1.34)	1) *At 1 min:* 10% vs 9.6% (p = 0.37)	
Child vaccination	1		1) *PCV:* aOR 0.69 (0.50–0.95) *MMR:* aOR 0.79 (0.55–1.14) *DTP:* aOR 0.87 (0.62–1.21)	
Adverse infant development	1	1) *Negative child health:* OR 5.0 (2.5–10); *Fine motor delay:* OR 2.0 (1.0–4.0)		

Note: Odd ratios with 95% confidence intervals are shown; alternatively, percentages or risks with p values. An odds ratio compares the likelihood of an event occurring in one group versus another—for example, if disabled women have an OR of 2 for smoking, it means that their odds of smoking during pregnancy are twice as high as for non-disabled women. Abbreviations: aOR adjusted odds ratio; CI, confidence intervals; DTP, diphtheria, tetanus and pertussis; MMR, measles mumps and rubella; OR, odds ratio; PCV, pneumococcal; Vs, versus.

Qualitative/mixed methods

The eight qualitative/mixed methods studies were generally very small (<10 participants) and included a similar range of impairment types to the quantitative studies (mental health n=2; learning n= 2; physical n=1; neurodiversity n=1; all/multiple n=2).

Themes highlighted by qualitative literature included:

- Challenges faced during maternity care, including understanding the written and oral information provided, accessibility of infrastructure, and negative attitudes of staff.
- Moreover, some disabled women feared disclosing their condition and being seen as an “abnormal pregnant woman”.
- A key issue was lack of continuity of care – including between antenatal, labour/delivery and postnatal services.
- Disabled women expressed the desire for continuity of care, positive attitudes from staff and support, knowledge, and control and involvement in decision making.
- Good family and professional support, including from midwives, were seen as key for positive maternity care.

Umbrella review of systematic reviews of disability and maternal and perinatal outcomes

We searched 3071 individual titles and abstracts, of which 21 papers were deemed eligible and included in the umbrella review (Appendix Figure 8), including six reviews with meta-analyses, two systematic reviews, four qualitative reviews, and nine mixed methods reviews.

The meta-analyses and systematic reviews were moderate in size (5 included 10-19 papers; 3 included 20 or more papers), and only one included studies from outside of high-income settings (Appendix 9-12). Six reviews focussed on women with mental health conditions, one on physical impairments and one on all conditions.

Key findings from the umbrella review (Tables 2 and 3):

The meta-analysis of systematic reviews clearly shows worse outcomes for disabled women (Table 2), including:

Antenatal

- Consistent evidence of higher prevalence of gestational diabetes, hypertension, and pre-eclampsia **(generally 50%-100% higher odds)**.
- Relatively consistent evidence of greater likelihood – generally twice as high - of adverse pregnancy conditions, including antepartum haemorrhage and placental complications.

Labour and delivery

- Eight studies show significantly higher risk of neonatal/perinatal mortality **(41%-66% higher odds)** and stillbirth **(42%-106% higher odds)**.
- Clear evidence of negative neonatal outcomes, including preterm birth, low birthweight and small for gestational age.
- Five studies show significantly higher risk of caesarean birth.
- Evidence on higher risk of foetal distress, but not other adverse delivery outcomes (e.g. instrumental delivery).

Postnatal

- Four studies show significantly higher risk of infant death – and postnatal mortality **(49%-187% higher odds)**.
- Clear evidence that children have higher risk of developmental delay or disability (e.g. congenital malformations, low Apgar score).
- Lack of data on other postnatal outcomes.

Table 2. Summary findings from umbrella review of meta-analyses from systematic reviews of maternal and neonatal outcomes for disabled women, globally (detailed data in appendix 10).

	No of meta-analyses reporting outcome	Worse for disabled women, Odds Ratios or Relative Risk (95% CI)	No difference, Odds Ratios or Relative Risk (95% CI)	Better for disabled women, Odds Ratios or Relative Risk (95% CI)
Antenatal				
Gestational diabetes	3	1) OR 1.46 (1.06–2.03) 2) OR 1.74 (1.17–2.57) 3) OR 2.35 (1.57–3.52)		
Gestational hypertension	4	1) OR 1.19 (1.02–1.40) 2) OR 1.45 (1.16–1.82) 3) OR 1.55 (1.02–2.36)	4) OR 1.26 (0.80–1.99)	

	No of meta-analyses reporting outcome	Worse for disabled women, Odds Ratios or Relative Risk (95% CI)	No difference, Odds Ratios or Relative Risk (95% CI)	Better for disabled women, Odds Ratios or Relative Risk (95% CI)
Pre-eclampsia/ eclampsia	3	1) OR 1.20 (1.05–1.36) 2) OR 1.85 (1.52–2.25) 3) OR 1.95 (1.10–3.45)		
Antepartum haemorrhage	3	1) OR 2.02 (1.30–3.13) 2) OR 2.28 (1.58–3.29)	3) OR 2.14 (0.66–6.88)	
Threatened preterm labour	2	1) OR 2.91 (1.57–5.40)	2) OR 1.74 (0.79−3.83)	
Placental complications	4	1) RR 1.36 (1.14–1.63) 2) OR 1.75 (1.34–2.30) 3) OR 2.20 (2.02–2.39)	4) OR 1.44 (0·97−2·14)	
Rupture of membrane	2	1) OR 1.29 (1.06–1.58)	2) OR 1.04 (0.88–1.23)	
Placenta previa	1		1) OR 0.95 (0.63–1.42)	
Thromboembolic disease	1	1) OR 2.00 (1.44–2.78)		
Labour and delivery				
Neonatal mortality	3	1) OR 1.41 (1.03–1.94) 2) OR 1.58 (1.02–2.44) 3) RR 1.66 (1.27–2.16)		
Perinatal mortality (stillbirth & neonatal deaths)	1	1) OR 1.51 (1.28–1.79)		
Stillbirth	4	1) OR 1.42 (1.20–1.69) 2) RR 1.62 (1.30–2.02) 3) OR 2.06 (1.83–2.31)	4) OR 1.14 (0.99−1.30)	
Preterm birth	4	1) RR 1.41 (1.30–1.53) 2) OR 1.49 (1.29–1.72); very preterm OR 1.84 (1.32–2.57) 3) OR 1.53 (1.32–1.78) 4) OR 1.79 (1.62–1.98); very preterm OR 2.31 (1.78–2.98)		
Low birthweight	4	1) RR 1.46 (1.28–1.66) 2) OR 1.54 (1.19–1.99) 3) OR 1.75 (1.46–2.11) 4) OR 1.80 (1.66–1.94)		
Small gestational Age	4	1) RR 1.28 (1.17–1.39) 2) OR 1.28 (1.14–1.45) 3) OR 1.63 (1.48–1.80)	4) OR 2.05 (0.67–6.32)	
Large gestational age	4		1) OR 0.84 (0.60−1.18) 2) OR 0.93 (0.59–1.46) 3) OR 1.13 (0.96–1.33) 4) RR 1.20 (0.92–1.56)	
Caesarean	5	1) RR 1.19 (1.11–1.28) 2) OR 1.21 (1.01–1.45) 3) OR 1.31 (1.02–1.68) 4) OR 1.33 (1.22–1.45) 5) OR 1.35 (1.26–1.45)		
Malpresentation	2		1) RR 1.07 (0.89–1.28) 2) OR 0.96 (0.78–1.17)	

	No of meta-analyses reporting outcome	Worse for disabled women, Odds Ratios or Relative Risk (95% CI)	No difference, Odds Ratios or Relative Risk (95% CI)	Better for disabled women, Odds Ratios or Relative Risk (95% CI)
Fetal distress	2	1) RR 1.12 (1.04–1.21) 2) OR 1.80 (1.43–2.26)		
Induction of labour	3	1) RR 1.30 (1.10–1.52)	2) OR 1.14 (0.94–1.38) 3) OR 1.14 (0.90–1.44)	
Prolonged labour	1		1) RR 0.93 (0.79–1.11)	
Instrumental delivery	2		1) OR 0.82 (0.62–1.08) 2) RR 0.98 (0.79–1.22)	
Postnatal				
Post-neonatal/infant death	4	*Post-neonatal* 1) RR 2.10 (1.04–4.26) 2) OR 2.87 (2.11–3.89) *Infant* 3) OR 1.49 (1.20–1.85) 4) OR 1.77 (1.01–3.13) 5) OR 2.33 (1.81–3.01)		
Adverse child development/disability	3	1) OR 1.29 (1.09–1.53) 2) OR 1.39 (1.17–1.66) 3) OR 1.86 (1.71–2.03)		
Low Apgar score at 1/5 min	3	*At 1 min:* 1) RR 1.41 (1.22–1.63) 2) OR 1.59 (1.20–2.11) *At 5 min:* 1) RR 1.67 (1.27–2.20) 2) OR 1.93 (1.25–2.96)	*At 5 min:* 3) OR 1.33 (0.54–3.27)	
Postpartum haemorrhage	4	1) OR 1.14 (1.04–1.24) 2) OR 1.39 (1.20–1.62)	3) OR 0.95 (0.79–1.15) 4) RR 1.03 (0.90–1.18)	

Abbreviations: CI, confidence intervals; OR, odds ratio; RR, relative risk

The systematic review (Table 3) supports the findings from the meta-analyses.

The 12 systematic reviews of qualitative/mixed methods studies were broader in distribution of geography (with 4 not only focussed on high income settings) and disability type (learning=3; all/multiple=3; physical=2; hearing=2; mental health=1; neurodiverse=1; vision=1).

Themes highlighted by qualitative literature included:

- Need for improved health information received, choice and involvement in decision making.
- Concerns about clinicians inexperienced about disability, with negative attitudes (deficient empathy and limited respect) and lack of coordination between different teams.
- Inaccessibility of health equipment, facilities and information.
- Unmet need for information and peer support groups.
- Fear of losing custody of their child.
- Reliance on family/partner to negotiate care.
- Overall, poor satisfaction with quality of care.

Table 3. ***Summary findings from umbrella review of systematic reviews of maternal and neonatal outcomes for disabled women, globally (detailed data in appendix 10).***

	No of systematic reviews reporting outcome	Worse for disabled women	No difference	Better for disabled women
Antenatal				
Gestational diabetes	1	1) No difference (3/15 studies) and higher risk (2/15 studies)		
Gestational hypertension	2	1) Higher risk (4/15 studies) and no difference (1/15 studies) 2) Higher risk (2/16 studies) for spinal cord related and diagnosed physical disabilities but no difference (1/16 studies) among those with self-reported disabilities		
Antepartum haemorrhage	1	1) More prevalent (2/15 studies) and no difference (1/15 studies)		
Threatened preterm labour	1	1) Higher risk (2/15 studies) and no difference (1/15 studies)		
Maternal infection	1	1) Higher risk (3/6 studies)		
Labour and delivery				
Preterm birth	2	1) Higher risk (7/15 studies) and no difference (2/15 studies) 2) Higher risk (5/6 studies) and no difference (1/6 studies)		
Low birthweight	2	1) No difference (4/15 studies) and more prevalent (3/15 studies) 2) Higher risk (3/3 studies)		
Small gestational Age	1	1) Higher risk (3/15 studies)		
Large gestational age	1		1) No difference (3/15 studies)	
Caesarean	1	1) Higher risk (6/7 studies) and no difference (1/7 studies)		
Instrumental delivery	1	1) Higher risk (2/15 studies) and no difference (1/15 studies)		
Postnatal				
Infant death	1		1) No difference (3/15 studies)	
Adverse child development/ disability	1	1) Higher risk (2/15 studies) and no difference (1/15 studies)		
Low Apgar score at 1/5 min	1		1) No difference (3/15 studies) and more prevalent (2/15 studies)	
Postnatal stay length	1	1) Longer hospital stay (2/17 studies) and (1/17 studies) no difference		
Satisfaction with care	1	1) Lack of satisfaction with current care (6/17 studies)		

Analysis of disability inclusion in UK guidance documents on maternal health

Royal College of Obstetricians and Gynaecologists

There is very limited focus on maternal disability within the guidance of the Royal College of Obstetricians and Gynaecologists (Table 4; Appendix 13). There is no specific focus on disability in the titles of reports addressing: guidance on the care for women, identification of good or best practices, scientific impact, or clinical governance.

There is little mention of disability within specific documents. **Only one of the 64** green-top guidelines assessed considers disability (upholding rights of women with epilepsy). None of the eight guidance documents on consent advice specifically mentions disability. However, reference may be made within specific documents (e.g. report on planned caesarean birth states that translators must be available for those unable to understand the information, and that large print/Braille versions for those with impaired vision). None of the seven guidance documents on good practice mentions disability, and **only one of the four** best practice guidance does (telemedicine in abortion care – acknowledging the additional transport and safeguarding considerations for disabled women).

Table 4. Review of the inclusion of disability in RCOG documentation (excluding archived) (full details in Appendix 13)

Category	Description	Number of reports assessed	Title indicates focus on disability or disabled women	Mentions of disability in report
Green-top guidelines	Recommendations which assist clinicians and patients in making treatment decisions	48	0	1
Consent advice	Ensure patients are given consistent and adequate information on consent	8	0	0
Good practice papers	Practical guidance to clinicians and managers on workplace issues	7	0	0
Best practice papers	Synthesis of evidence-based guidance developed by organizations (e.g. World Health Organization)	4	0	1
Scientific impact papers	Opinion papers produced by Scientific Advisory Committee	75	0	Individual studies not assessed[g]

Disability also appears to be under-represented in other written material from RCOG. For instance, the RCOG's 2019 report "better for women" identifies "simple and cost-effective solutions to prevent girls and women falling through the cracks of our health system". This 83-page report makes only four references to disability – identifying their need to access information they need to stay healthy and recognising their additional challenges in accessing cervical screening. Moreover, there is a limited focus in disability in RCOG training[h], safeguarding policy, framework for maternity service standards, or equality and diversity policy.

g Beyond scope/time capacity of current report.

h **Core Curriculum Capability (Practice 13):** Supports healthcare professional to promote non-discriminatory practice, as he/she is able to perform consultations addressing the specific needs of a disabled person and being mindful that not all disabilities are visible.

Knowledge Area 1 Clinical Skills: Capability in Practice: Information covered includes the models of disability, key provisions and implications of disability discrimination legislation, recognition of how health systems can discriminate against patients from diverse backgrounds (including disability), and how to work to minimise this discrimination.

NICE guidance

We reviewed 30 NICE Guidance documents within the category "Fertility, pregnancy and childbirth" that were considered related to maternity care (Appendix 14). Of these documents, none focussed specifically on disability. Furthermore, **only six made any mention of disability** in the text, and in general these were limited in number (often only one mention per document) and brief. For instance:

- Antenatal care (2 mentions): information should meet the needs of the woman, including those with learning disabilities; women with intellectual disabilities may benefit from peer support.
- Intrapartum care for women with existing medical conditions or obstetric complications and their babies (1 mention): encouraging clinicians to *"explore sensitively any possible vulnerability or safeguarding concerns including "maternal learning disability""*.
- Antenatal and postnatal mental health: clinical management and service guidance (1 mention): *"When assessing or treating a mental health problem in pregnancy or the postnatal period, take account of any learning disabilities or acquired cognitive impairments, and assess the need to consult with a specialist when developing care plans".*

Surprisingly, the report on Pregnancy and complex social factors: a model for service provision for pregnant women with complex social factors – makes no apparent mention of disability.

Other NHS guidance

Limited other NHS guidance was identified on maternity care for disabled women (Appendix 15). The majority of relevant reports identified focussed on the needs of women with learning disabilities (e.g. NHS Wales, 2020: Caring for a pregnant client with a learning disability; Public Health England, 2020: How to help women with learning disabilities access antenatal and newborn screening; University Hospitals of Leicester, 2016: Management of care for pregnant women with a learning disability; Homerton University Hospital, 2015: Learning disabilities maternity and early years practice guidelines). Few focussed more broadly on disabled women and maternity care (Nursing and Midwifery Council, 2024: Disability and accessibility; Milton Keynes University Hospital, 2023: Supporting women with disabilities and special needs through pregnancy).

Summary of Key findings

UK systematic review

The data from the UK is limited, but indicates that disabled women have more adverse maternal and neonatal outcomes, including higher neonatal/infant mortality. However, in general the data is lacking, in particular for certain disability types (e.g. sensory: hearing and vision impairment). More high-quality data is needed in the UK, particularly for maternal and neonatal outcomes of women with visual, hearing or physical disability. Electronic health records and national maternity datasets may be an important and efficient resource to fill this gap, as well as including detailed disability markers within maternity surveys.

Global umbrella review

There is more extensive data globally, showing consistently that disabled women have worse maternity outcomes, including higher infant mortality, although this data is mostly focussed on women with mental health conditions. Again, data is lacking for all disability types (perhaps excepting mental health conditions). Further systematic reviews are needed specifically investigating maternity services for women with physical, learning or sensory disabilities worldwide.

Guidance review

The guidance in the UK from RCOG and NICE is extremely limited with respect to disability, either documents specifically focussed on disability or those including consideration of disability. Some relevant guidance was identified produced by specific hospitals or institutions.

Interventions to improve maternity care for disabled women

The systematic reviews show that disabled women experience inequities in maternity care, and the documentary review highlights that this gap is not considered within guidance documents on maternity care in the UK. This information points to a need to make holistic improvements in maternity care to improve access, experience and outcomes for disabled women.

There are complex reasons why disabled women in the UK experience worse maternal access, experiences and outcomes, including adverse socio-demographic circumstances, negative attitudes and lack of knowledge and skills of healthcare workers, and underlying impairments.[4] There will therefore be no single “magic bullet” that closes the equity gap, but a range of health system

strengthening activities are needed (Table 5). However, improving the capacity of healthcare providers to deliver disability-inclusive maternity care services is an essential component, which will require training on effective communication, respect and dignity, and availability of physical resources.[25] Interventions must always be developed and tested in partnership with disabled women and must consider the full range of types of disability. A scoping review of existing interventions will be important to guide future action.

Table 5. Health system strengthening interventions to improve maternity care access, experiences and outcomes for disabled women in the UK

Component	Purpose	Good practice example
1 **Governance**	Development and implementation of laws and policies that outlaw discrimination against disabled women in maternity care and mandates the provision of reasonable adjustments.	Guidance by Milton Keynes University Hospital (2023): Supporting women with disabilities and special needs through pregnancy.
2 **Leadership**	Spearhead and lead action on this issue within the National Health Service.	National Clinical Programme for People with Disability within the Ministry of Health (Ireland).
3 **Health financing**	Support the provision of reasonable adjustments and accessibility.	Funding within NHS of sign language interpretation during maternity care.
4 **Data and evidence**	Highlight inequities in maternal health for disabled women and what works to overcome these gaps.	National Research Centre for Parents with Disabilities (Brandeis University) creates evidence, data and resources.
5 **Autonomy and awareness**	Ensure disabled women are knowledgeable of their rights and how to access quality maternity care.	The Together Project – supporting maternity care for women with learning disabilities. Birthrights factsheet on rights of disabled women and maternity care.
6 **Affordability**	Ensure disabled women can afford to access maternity care.	Healthcare travel costs scheme
7 **Human resources**	Train healthcare workers so that they are aware, knowledgeable, and skilled in the provision of maternity care for disabled women.	Nursing and Midwifery Council - training midwives on additional care for women with learning disabilities.
8 **Health facilities**	Ensure accessibility of facilities, information and equipment for disabled women.	Accessible Maternity Resources for women with intellectual disabilities.
9 **Rehabilitation services, assistive technology and products**	Provide additional services or products, when required, to women with particular impairment types during pregnancy.	Helpful products for parents with disabilities (e.g. adapted slings, nursing pillows, baby clothing).

Key recommendations:

1. Establish a **UK committee**, that is inclusive of disabled women, to review the current situation of maternity care services for disabled women, in order to define next priority actions.
2. Finance and undertake **UK-focussed research** to:
   - **a.** Estimate inequalities in maternity and neonatal care access, experiences and outcomes of disabled women.
   - **b.** Develop and test interventions to improve maternity care for all disabled women in the UK.
3. Develop **policy and programme guidance** relevant to maternity care in the UK (e.g. NICE and RCOG) that
   - **a.** Specifically addresses maternity care of disabled women.
   - **b.** Include consideration of disability within broader guidance on maternity care.
4. Strengthen **maternity care delivery** in the UK to improve access, experiences and outcomes, for disabled women including by:
   - **a.** Training all clinical staff who deliver maternity care about disability (pre-service and in-service training).
   - **b.** Providing joined-up care throughout the maternity care pathway for disabled women (antenatal, labour and delivery, postnatal care).
   - **c.** Ensuring the provision of reasonable adjustment and accessible facilities, equipment and information to disabled women throughout the maternity care pathway.

Conclusion

Maternity care services in the UK are currently leaving behind disabled women, with gaps existing in outcomes, data available and policy guidance. This neglect occurs even though one in five women in the UK of childbearing age are disabled, and the existing evidence from the UK and globally indicates that there are consistent inequalities in maternal and neonatal outcomes, including in infant mortality. Urgent action is needed from all parties, government and healthcare professionals, with the involvement of maternity stakeholders and disabled women, to address and improve maternity care provision for disabled women in the UK.

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Appendices (available online at https://www.themissingbillion.org/reports)

Appendix 1. EMBASE search strategy UK Systematic review

Appendix 2. EMBASE search strategy Umbrella Review

Appendix 3. Figure - PRISMA flow diagram of study selection and identification for UK studies

Appendix 4. Table - Description of studies included in the UK systematic review

Appendix 5. Table Summary of studies identified from systematic review of maternal care for disabled women in the UK

Appendix 6. Table - Two papers from England based on the Care Quality Commission Maternity Survey about access to maternity care among disabled women

Appendix 7. References of UK Systematic Review

Appendix 8. Figure - PRISMA flow diagram of study selection and identification for umbrella review of systematic reviews of maternal care

Appendix 9. Table Study description of systematic reviews included in umbrella review

Appendix 10. Table Summary of studies identified from umbrella review of maternal care for disabled women worldwide

Appendix 11. Table Detailed summary findings of a meta-analysis about maternal disability and risk for pregnancy, delivery, and postpartum complications

Appendix 12. References of Umbrella Review

Appendix 13. Table - Green-top Guidance (not including archived)

Appendix 14. Table - NICE Guidance documents in category "Fertility, pregnancy and childbirth" related to maternal health

Appendix 15. Table - Other UK guidance on maternal care for disabled women


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