



Review Article

Access to, and experiences of, maternity care for women with physical disabilities: A scoping review



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ABSTRACT

Objective: Women with physical disabilities face multiple barriers in accessing safe, respectful and acceptable healthcare. As the number of women with physical disabilities becoming pregnant rises, ensuring their access to acceptable and high-quality maternity care becomes increasingly important. This review aimed to explore the most recent evidence regarding access to, and experiences of, maternity care for women with physical disabilities in high-income countries.

Design: A scoping review was undertaken as guided by the Preferred Reporting Items for Systematic Reviews extension for scoping reviews (PRISMA-ScR). A systematic search of five online databases identified relevant articles published in English from 2000 to 2020. Reference lists of included studies were also screened, and quality was appraised using the Joanna Briggs Institute Checklists. A thematic synthesis was undertaken to develop descriptive and analytical themes.

Findings: After screening, 27 articles from eight high-income countries were included. All articles were identified as having moderate or high methodological rigour in the quality appraisal. Women with physical disabilities reported numerous barriers in accessing maternity care and described predominantly mixed and negative experiences of care. These findings were grouped under three major themes: women with physical disabilities want a “normal” pregnancy experience; the need to strengthen maternity provider’s disability knowledge and skills; and promoting enabling environments for improved access to, and experiences of, maternity care.

Key conclusions and implications for practice: This review found that for women with physical disabilities access to, and experiences of, maternity care is suboptimal. Improving maternity providers disability knowledge and awareness, increasing the availability of support services for women, and increasing person-centred care through organisational policies and provider training may help to address the inequities women with disabilities face in accessing high-quality maternity care.

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Background

Access to, and experiences of, maternity care for women with physical disabilities is a topic of increasing interest and importance as the number of pregnancies and births in this population group increases (Iezzoni et al., 2015a; Tarasoff et al., 2020). It is estimated that 12.6% of women aged 15 to 59 years in high-income countries live with a moderate or severe disability (World Health Organisation, 2011) and it has been estimated that 9.4% of women in the United Kingdom who had recently given birth had one or more conditions causing disability (Šumilo et al., 2012). The rise in inci-

dence of pregnancy for women with disabilities is thought to be the result of improved societal acceptance of people with disabilities, increased awareness of sexuality in people with disabilities, reduced practices of forced sterilisation, and improvements in, and access to, assistive reproductive technologies (Iezzoni et al., 2013).

Many women with disabilities still experience multiple forms of discrimination and barriers that restrict their ability to participate fully in society and reach their utmost potential (World Health Organisation, 2011). Barriers contributing to reduced quality of life in women with disabilities include low levels of employment, high rates of domestic violence, and reduced access to facilities including health services (Bradbury-Jones et al., 2015; Krahn et al., 2015; World Health Organisation, 2011). Physical disabilities, in particular, involve a physical impairment that alters or reduces mobility,

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strength or endurance that when combined with unaccommodating environments and societies, limits participation in everyday activities and access to healthcare (Wen and Fortune, 1999).

A social model of disability supports creating accommodating environments and societies that better support the needs of individuals with impairments. In order for improvements in care, it is critical that barriers faced by women with physical disabilities in accessing safe, high quality maternity care are identified and understood. Under the Universal Right of Childbearing Women Charter all childbearing women have the right to access safe, equitable, high quality maternity care and to be treated with dignity and respect throughout all pregnancy and birthing experiences (White Ribbon Alliance, 2011). This Charter applies equally to women with physical disabilities and is further backed by The Convention on the Rights of Persons with Disabilities (CRPD) (United Nations, 2007). Article 23 of the CRPD, "Respect for home and the family" specifies the right of persons with disabilities to access appropriate information and reproductive health services free of discrimination (United Nations, 2007). All dimensions of access (accessibility, affordability, availability, accommodation and acceptability) have the potential to impact women's experiences of maternity care and individuals belonging to one or more minority groups including disability are likely to face additional barriers in accessing care and having positive care experiences (Penchansky and Thomas, 1981; Peterson-Besse et al., 2014; World Health Organization, 2020).

An understanding of the experiences of women with disabilities in accessing maternity care is important to ensure the needs of these women are met. Nguyen et al. (2019) recently explored experiences and challenges faced by women with physical disabilities in accessing maternity care in low- and middle-income countries, however, there has not been a review in high-income countries for a number of years. The most recent review that included countries part of the Organisation for Economic Co-operation and Development (OECD) was published in 2013 (Lawler et al., 2013). Given the amount of research in the disability field has increased in recent years, this review was in need of updating. As such, the aim of this review was to identify and provide an overview of the most recent evidence regarding the access to, and experiences of, maternity care for women with physical disabilities in countries that are part of the OECD.

Methods

The scoping review methodology outlined in Arksey and O'Malley's (2005) scoping review framework and expanded by Levac et al. (2010) was used. This approach enabled us to map the evidence currently available and build an analytical summary stemming from multiple study designs (Sucharew and Macaluso, 2019). A research protocol was created a priori (available on request) in accordance with the PRISMA extension for Scoping Reviews (Tricco et al., 2018).

The Population, Concept, Context (PCC) framework was used to formulate search terms, inclusion and exclusion criteria. Multiple study designs were eligible for inclusion including qualitative studies, retrospective or prospective cohort studies, randomised controlled trials, case-control studies, cross-sectional studies, case series, and program/service evaluations. Grey literature, including commissioned reports, were also eligible for inclusion if they utilised these study designs. Editorials, commentaries, conference proceedings without primary data, and expert opinions were excluded as these generally do not follow a rigorous methodology or have usable data. Searches were restricted to research published since the year 2000 in order to be relevant to today's healthcare experiences and must be available in English.

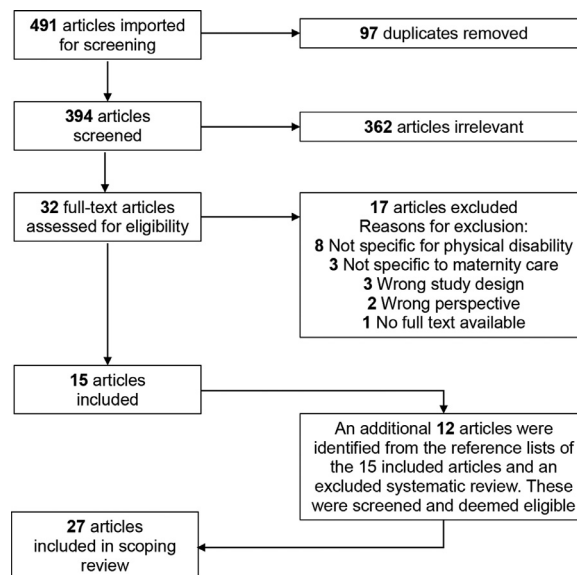


Fig. 1. PRISMA flow diagram of study selection process.

In addition to these criteria, study results had to come from the perspective of women with physical disabilities. The women's perspective was purposively chosen for two reasons. Firstly, it is integral that women remain central in conversations regarding care delivery, service evaluation and improvement (Brady et al., 2019). Secondly, the unique needs of people with disability are most authentically explained by those with lived experience of disability. The notion of 'nothing about us without us' illustrates the importance of including people with disability in research (Charlton, 1998; Smith-Merry, 2017). An overview of all inclusion and exclusion criteria can be seen in Table 1. The search was conducted on five databases: MEDLINE (Ovid), EMBASE (Ovid), CINAHL (EBSCO), SCOPUS, and Web of Science Core Collection.

A total of 491 studies were identified from the database search and imported to the review management software Covidence for screening. Initially, 97 duplicates were identified and removed leaving 394 studies. The titles and abstracts of these studies were screened independently by two reviewers (AB and JC). Any disagreements were resolved after discussion between the two reviewers. At this stage of the review, 362 of the studies were excluded. Common reasons for exclusion included the focus on disability in newborns (not the mothers) and studies not being specific to maternity care or people with a physical disability. This left 32 studies for full-text screening. Discrepancies were again discussed between the two reviewers and where required a third reviewer (CH) assisted to reach a consensus. At full-text screening, 17 studies were excluded for the following reasons: eight were not specific to physical disability, three were not specific to maternity care, three had an ineligible study design (two commentary pieces and an abstract), two were not from the woman's perspective, and one full text article was not available. Ultimately, 15 studies were identified for inclusion in the review. The reference lists of these 15 articles and one systematic review excluded during the screening process were hand searched by first author (AB), identifying an additional 12 articles. These articles were independently screened and approved by second reviewer JC leaving a total of 27 articles included in the review. The PRISMA flow diagram in Fig. 1 summarises the study selection process.

We undertook a quality appraisal to assess the quality of evidence in the included studies. The JBI Checklist for Qualitative Research was used to appraise the qualitative studies in the review, while the JBI Checklist for Analytical Cross Sectional Stud-

Table 1
Inclusion and exclusion criteria for scoping review.

Criteria	Inclusion	Exclusion
Population	Childbearing people with a physical disability	Childbearing people with other primary disability types (intellectual, mental, sensory)
Concept	Access and experiences of maternity care including: <ul style="list-style-type: none"> - Antenatal care - Ultrasound and pregnancy screening services - Planned mode of birth and place of birth - Care during labour and birth - Type of pain management in labour - Initiation of breastfeeding - Length of hospital stay - Postnatal care in hospital and the community - Healthcare providers involved 	Studies measuring other aspects of maternity care including health outcomes. <ul style="list-style-type: none"> - Services excluded: - Family planning services - Assisted reproductive technology services - Postnatal services beyond 6 weeks after birth
Context	OECD member countries as of September 2020	Non-OECD member countries.
Study types	<ul style="list-style-type: none"> - Qualitative study - Retrospective or prospective cohort study - Randomised controlled trial - Case-control study - Cross sectional study - Case series - Program/service evaluation - Grey literature including commissioned reports 	<ul style="list-style-type: none"> - Editorials - Commentaries - Conference proceedings - Case studies - Expert opinions - Previously conducted reviews
Language restrictions	Published in English	Publications not available in English
Publication dates	2000 - September 2020	Before and including 1999, and after September 2020
Perspective of results	Women with a physical disability	<ul style="list-style-type: none"> - Maternity care providers - Family members or carers of women with a physical disability

ies was used for the remaining studies (The Joanna Briggs Institute, 2017, 2020). These tools are considered to have high validity for appraisal of their respective study types (Hannes et al., 2010; Ma et al., 2020). Second reviewer (JC) appraised five randomly selected studies to check inter-rater reliability of AB who appraised all studies. As the JBI checklists do not provide minimum recommended overall quality scores, it was decided during protocol development that articles satisfying less than 60% of checklist items would be excluded from the review. All articles satisfied between 63% and 100% of checklist items (see Table 2), thus none were excluded based on quality.

A data extraction form was used to collect the following study characteristics: author, publication year, location, study aim(s), methodology, participant number and characteristics, key findings, study strengths and limitations. During data extraction 'key study recommendations' was added as an additional data field. Data extraction was performed by AB.

The thematic synthesis process developed and described by Thomas and Harden was employed for data analysis (Thomas and Harden, 2008). Thematic synthesis is primarily used for reviews in the public health and health promotion fields where topics of healthcare experiences commonly require qualitative synthesis (Finlayson et al., 2020; Harden et al., 2006, 2004). After reading all articles in full, AB first coded the data line-by-line. Next, patterns in the coding framework were recognised and became the basis for the descriptive themes. Descriptive themes were discussed with another author (CH) and revised before overarching analytical themes were formed. After further reading of the articles and discussions between the authors, the analytical and descriptive themes were finalised and supporting quotes were identified with the assistance of NVivo software. As the quantitative studies included in the review used heterogeneous outcome measures a meta-analysis could not be performed. Instead, data from all five cross-sectional studies were categorised according to the descriptive themes developed in the thematic synthesis to provide further support of the qualitative findings.

Results

Ultimately, 27 articles from 22 separate studies were included. Eight articles were generated from three study samples and all were included due to their unique and different focuses. Of the 27 articles, 22 were qualitative, including individual or focus group discussion data, whilst five were cross-sectional studies and included postal, online or telephone survey data. Articles were from the following countries: Austria ($n = 1$), Canada ($n = 4$), England ($n = 1$), Ireland ($n = 2$), New Zealand ($n = 2$), Scotland ($n = 1$), Switzerland ($n = 1$), Turkey ($n = 1$), United Kingdom ($n = 4$), United Kingdom and Ireland ($n = 1$), and United States ($n = 9$) (see Table 2). The majority of participants in the studies were urban dwelling and well-educated women. Many studies listed low ethnic diversity as a study limitation.

Thematic synthesis yielded 10 descriptive themes, assisting the development of three analytical themes (Fig. 2). In the proceeding discussion analytical themes are italicised and bolded, while descriptive themes are bolded.

Women with physical disabilities want a "normal" pregnancy experience

Overall, women reported a desire to be cared for in a similar, if not identical, manner to those without disabilities. They really **wanted to just fit in**. Some women reported feeling singled out and labelled as high-risk on account of their disability. They resented this label, particularly when it was not medically indicated as it increased their anxiety levels in regard to the health of themselves and their baby, increased appointment and screening frequency, and restricted their choice of place and mode of birth. However, some women indicated that being treated differently actually resulted in additional care and consideration provided, for example:

Table 2
Characteristics and quality appraisal scores of included articles.

First Author (year), location	Study aims	Study design and methodology	Participants	Key Findings	Study strengths	Study limitations	Quality appraisal score (percentage)
Begley (2010), Ireland	To explore the strengths and weaknesses of Ireland's publicly funded maternity services provided for women with disabilities	Qualitative, descriptive study. Third and final phase of a mixed methods Nation-wide study. Individual interviews with women with disability and focus groups with relevant maternity health care providers.	78 women with a disability, 18 of these had a physical disability. Most women (63%) lived in an urban setting. Physical disability causes: multiple sclerosis, cerebral palsy, spina bifida, and acquired physical disabilities.	5 main themes: - <i>Availability</i> Lack of individualised care, medicalised models of care. - <i>Accessibility</i> Physical accessibility of buildings and equipment better in new facilities. - <i>Accommodation</i> Continuity of care important. Antenatal classes not accommodating individual educational needs. - <i>Acceptability and attitudes</i> Encounters with providers varied from discriminatory, to supportive. Provider knowledge lacking. - <i>Affordability</i> Transportation costs high for women.	Women interviewed within 2 years of giving birth (probable good recall of memories and reflects on the current healthcare context). Includes detailed and actionable recommendations at the policy, organisational, and individual levels.	Possible self-selection bias.	9/10 (90%)
Bertschy (2015), Switzerland	To identify the perceived maternity service needs of women with spinal cord injury (SCI) in Switzerland and reconstruct their healthcare service utilisation.	Open qualitative research design involving four focus groups and five individual semi-structured interviews. Content analysis of data.	17 women who had given birth with paraplegia or quadriplegia.	- Identified the need for improved access to integrated care. - Women had difficulties finding providers with knowledge in both gynaecology and paraplegia. - Pre-existing patient-provider relationships helped optimise care. - Women saw no extra benefit in services specialised for women with SCI, preferring to attend local services and regular maternity hospitals.	One researcher had a lived experience with physical disability providing a unique perspective to the analysis. Small focus group sizes used to facilitate rich and personal discussions.	Some participants gave birth up to 15 years ago. This long recall time may produce less accurate data and the experiences may not reflect the current context. Self-selection bias. Highly educated sample with half employed in healthcare.	9/10 (90%)

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Table 2 (continued)

First Author (year), location	Study aims	Study design and methodology	Participants	Key Findings	Study strengths	Study limitations	Quality appraisal score (percentage)
Blackford (2000), Ontario Canada	To determine how prepared prenatal nurse educators are to meet the learning needs of mothers with disabilities.	Descriptive, exploratory study using qualitative interviews. Qualitative content analysis undertaken.	8 mothers with a disability and at least one child under the age of two. Physical disabilities included: rheumatoid arthritis, lupus and Wolf Parkinson-White Syndrome.	<ul style="list-style-type: none"> - Mothers not receiving sufficient or appropriate information from their nurse educators about their pregnancy, chronic illness, and postnatal care. - Mothers feel nurses doubt their ability to make decisions and to be responsible mothers. - Nurses not acting as advocates for special services required by mothers. 	First study in Canada to focus on prenatal education for women with disabilities.	Small sample size. Ethics approval not reported in article.	7/10 (70%)
5 Bradbury-Jones (2015), Scotland	To explore how women with a disability who are domestically abused approach maternity services and their expectations of these services.	Qualitative methodology utilising the Critical Incident Technique. Individual interviews conducted face to face, over Skype, or via email as preferred by participants.	5 women all with more than one child. Disabilities included: congenital physical impairments, acquired physical impairment, and long-term mental health conditions (results from mental health participants excluded).	<ul style="list-style-type: none"> - Four domains identified as important in shaping maternity care experiences: attitudes, knowledge, social norms, and perceived control. - Positive staff attitudes help empower women to have control of their maternity care. - Fear of judgement and loss of control negatively impact women's care experiences. - Accessible and inclusive information meeting the additional needs of these women is lacking. 	Limited prior research on this hard-to-reach population. Strong theoretical underpinning. Allowing flexibility in interview media (not only face to face) increased participation.	Difficulties in recruitment led to small sample size (50% of intended sample size).	9/10 (90%)

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Table 2 (continued)

First Author (year), location	Study aims	Study design and methodology	Participants	Key Findings	Study strengths	Study limitations	Quality appraisal score (percentage)
Guerin (2017), New Zealand	To seek consensus from women with disabilities on priority strategies to improve pregnancy, childbirth and early childcare health outcomes.	Third and final phase of a mixed methods study (the qualitative first and second phases are described under Payne et al. 2014). Using a Modified Delphi Technique participants were asked over email to rank the 11 recommendations about improving maternity care for women with disabilities derived from the Payne, 2014 findings. The mean ranking for each recommendation was achieved by calculating an average of the ranks allocated by participants. The top seven ranked recommendations were reported.	20 women with a sensory disability (excluded from review) or physical disability. This was a sub-set of the sample from Payne, 2014's phase one cohort. All phase one participants were invited to participate. Physical disabilities included: multiple sclerosis, muscular dystrophy, rheumatoid arthritis, spinal cord injury, epilepsy, paraplegia, motor neurone disease, and severe traumatic brain injury. Urban and rural living women were represented in line with New Zealand's population distribution.	The seven recommendations ranked highest by women: <ol style="list-style-type: none"> 1 Make relevant information more accessible for women and health professionals. 2 Address professional knowledge deficits. 3 Address home help provision. 4 Ensure appropriate funding to reduce inequity. 5 Foster better inter-sectorial communication and improved cohesion of services. 6 Address professional attitudinal behaviours. 7 Address physical barriers. 	Provides a prioritised list of actionable recommendations.	Only 53% of phase one participants went on to participate in phase 3 representing a low response rate. Possibility of self-selection bias. Low ethnic diversity.	7/10 (70%)
Payne (2014), New Zealand	To investigate the maternity care experiences of women with physical or sensory disabilities in New Zealand, alongside the experiences of maternity care providers, to identify strategies to facilitate improvements in maternity care.	Phases 1 and 2 of a 3-part mixed method study. Post-positivist, qualitative descriptive study involving individual semi-structured interviews and focus groups.	62 women with a sensory (results excluded from review) or physical disability. 22 women participated in interviews, 26 in focus groups. Purposive sampling used with recruitment via key disability organisations and maternity providers. Urban and rural living women were represented in line with New Zealand's population distribution. Physical disability types included as for Guerin, 2017 with the addition of stroke, brain tumour, brain stem injury, cerebral palsy, and spina bifida.	Two overarching themes identified, with multiple sub-themes. Theme 1: <i>Service provision issues</i> <ul style="list-style-type: none"> - <i>Becoming an educator</i> Women needing to educate their providers. - <i>Encountering disabling environments</i> Lack of accessible equipment and supportive providers. <ul style="list-style-type: none"> - <i>Disabling attitudes</i> Negative provider attitudes. Theme 2: <i>Taking it into account</i> <ul style="list-style-type: none"> - <i>Becoming informed</i> Women wanting maternity and disability providers to increase their knowledge. <ul style="list-style-type: none"> - <i>Problem solving</i> Women appreciate providers using innovative solutions to issues that arise during their care. <ul style="list-style-type: none"> - <i>Thinking ahead</i> Foreseeing issues in advance and planning for these.	Relatively large qualitative sample size. Two phases allowed confirmation of phase one findings. Included member checking.	Participants were self-selected and therefore those with particularly strong and/or negative experiences may have been more inclined to participate (self-selection bias).	9/10 (90%)

Table 2 (continued)

First Author (year), location	Study aims	Study design and methodology	Participants	Key Findings	Study strengths	Study limitations	Quality appraisal score (percentage)
Gul (2019), Turkey	To determine fertility characteristics and problems experienced by women with disabilities in two districts of Turkey.	Descriptive study. Answers to closed, quantitative questions collected via face-to-face interviews.	181 women with different disability types, 103 with an orthopedically disability. For all participants: 88.4% lived in rural areas 51.4% were over 35 years of age Average age at first pregnancy 22.7 years 86.2% were not employed 77.9% were married Average parity 3.2 children. This sample represents a more rural and less employed demographic compared to the remaining studies in review.	67% of women with an orthopaedic disability reported problems during pregnancy due to their disability. The two most common causes of problems were: <ul style="list-style-type: none"> - Restricted mobility requiring dependence on other people. - Lack of communication with healthcare personnel. 59.1% of women with an orthopaedic disability encountered problems during delivery/birth. The most common problems were: <ul style="list-style-type: none"> - Inappropriate physical conditions in the healthcare facility. - Inability to use disabled part of the body requiring support from someone else. - Lack of communication with healthcare personnel. 	Participant characteristics different to the other studies included in review, providing a different perspective for an OECD country.	Reporting of methodology (sampling, recruitment, data collection methods) brief or missing.	5/8 (63%)
Hall (2018), United Kingdom and Ireland	To explore the experiences of dignity and respect in childbirth for women with a disability.	Exploratory design using an accessible internet-based survey with open and closed questions.	37 women with a disability, 19 of these with a physical disability. 60% received shared antenatal care between a midwife, general practitioner and/or obstetrician). 78% birthed in an obstetric unit. Physical disabilities described by most women as musculoskeletal problems including arthritis, joint problems and hypermobility. 77% had 1 or 2 children (parity range 0–4)	Only qualitative findings included here as quantitative results were not separated by type of disability. Key themes: <ul style="list-style-type: none"> - <i>Lack of maternity care provider awareness and attention to the impact of disability on pregnancy.</i> - <i>The need for continuity of care.</i> - <i>Perception of reduced care choices (women's choices overruled by care providers).</i> - <i>Care providers need for increased information on disability.</i> - <i>Dignity and respect.</i> 	First known study to directly look at dignity and respect in pregnancy/childbirth for women with disability.	Self-selected, convenience sample can may lead to selection bias with the authors suspecting over-representation of women with negative maternity care experiences. Quantitative data not separated by disability type.	7/10 (70%)

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Table 2 (continued)

First Author (year), location	Study aims	Study design and methodology	Participants	Key Findings	Study strengths	Study limitations	Quality appraisal score (percentage)
Hayward (2017), United States	To determine if pregnancy rates and discussions about pregnancy with healthcare providers for women with cerebral palsy are related to their functional levels.	Cross sectional survey implemented predominantly online with paper and telephone options available.	375 women diagnosed with cerebral palsy of varying severity. Only 76 of these reported current or previous pregnancies (results from women who had never been pregnant are excluded from this review). For women who had been pregnant: All had completed high school with 88% attending/completing a higher degree 48.7% were employed or self-employed 16.6% were unable to work.	<p>During pregnancy:</p> <ul style="list-style-type: none"> - 71% of women reported decreased mobility however referrals to physiotherapists and occupational therapists were rare (15.9% and 7.9% respectively). - Most frequently offered referrals were to nutrition programs (39.5%) and genetic screening (30.3%). - Only 11.8% were offered mental health services. <p>Postpartum services offered:</p> <ul style="list-style-type: none"> - Breastfeeding education (69.2%). - Family planning options (47.7%). - Physiotherapy (4.6%). - Support groups for mothers with disabilities (3.1%). - No services offered (15.4%). <p>Overall, higher functioning and higher educated women were offered services more frequently.</p>	Multiple accessibility options of completing survey allowed women with varying severities of cerebral palsy to participate.	Older participants (up to 66 years) likely recalling maternity experiences from 15+ years ago. This may not reflect the current context and memories may not be accurate. Possible response bias when survey completed with assistance from carer, however this allowed those requiring assistance to participate and have their voice heard.	7/8 (88%)
Iezzoni (2015b), United States	To gather experiences women with mobility disabilities have with prenatal services' physical accessibility and equipment.	Qualitative, descriptive study involving in-depth, semi-structured telephone interviews.	22 women with a physical disability. Mean age 34.8 years. All women used mobility assistive devices or had limited arm/hand movement at the time of pregnancy. Disability types included: arthrogryposis, cerebral palsy, Charcot-Marie-Tooth disease, congenital myasthenia, muscular dystrophy, osteogenesis imperfecta, spina bifida, incomplete spinal cord injury with mitochondrial disease, congenital absence of multiple limbs, and trauma related bone injuries. Highly educated, 20 of the 22 women having started or complete a college or graduate degree.	<ul style="list-style-type: none"> - Less than half of the women's obstetricians had access to height adjustable examination tables. - Women found being lifted onto non-adjustable tables, scary and humiliating, particularly when done by staff. - Some women were not physically examined or were examined in their wheelchair. - No women were weighed routinely throughout pregnancy due to a lack of accessible scales. This caused anxiety in many women and made medication dosage calculations difficult/inaccurate during labour. 	Uncovered an important finding that women in wheelchairs are not being routinely weighed during pregnancy. This represents substandard care requiring urgent rectification.	Low ethnic diversity represented. Possible self-selection bias. Authors believe women with negative experiences more inclined to participate. Some women had their youngest child up to 10 years ago. Recall of memories possibly inaccurate.	7/10 (70%)

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Table 2 (continued)

First Author (year), location	Study aims	Study design and methodology	Participants	Key Findings	Study strengths	Study limitations	Quality appraisal score (percentage)
leozoni (2017), United States	To determine what new mothers with a mobility disability would recommend to their peers considering pregnancy in the future about the various aspects of the pregnancy experience.	See leozoni, 2015.	See leozoni 2015.	<p>Women had five main recommendations for other women considering pregnancy:</p> <ul style="list-style-type: none"> - <i>Recognising the possibility of giving birth</i> <p>Pregnancy and motherhood is achievable with formal and informal supports.</p> <ul style="list-style-type: none"> - <i>Advocacy and support</i> <p>Self-advocating for maternity care preferences and support needs required.</p> <ul style="list-style-type: none"> - <i>Being informed and information sources</i> <p>Educating oneself to facilitate informed care decisions. A lack of information increased women's anxiety. Peers are a trusted source of information.</p> <ul style="list-style-type: none"> - <i>Approaches toward obstetrical practitioners</i> <p>Seek providers/facilities that consider and accommodate individual needs. Those with prior experience caring for women with disability preferred.</p> <ul style="list-style-type: none"> - <i>Managing fears about losing custody of their child.</i> 	Unique perspective of women with disability providing recommendations to their peers.	See leozoni, 2015.	7/10 (70%)

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Table 2 (continued)

First Author (year), location	Study aims	Study design and methodology	Participants	Key Findings	Study strengths	Study limitations	Quality appraisal score (percentage)
Smeltzer (2017), United States	To explore the labour, birth, and anaesthesia experiences of women with physical disabilities with the aim of guiding improvements in their obstetrical care.	See Iezzoni, 2015.	See Iezzoni 2015.	<p>Four key themes regarding labour and birth:</p> <ul style="list-style-type: none"> - <i>Women's preferences for type of delivery</i> <p>Birth choices often made in consultation with care providers. Fear of being pressured into decisions that are not medically indicated.</p> <ul style="list-style-type: none"> - <i>Clinician's and some women expecting no labour pain</i> <p>Incorrect provider assumptions of what women will feel during labour.</p> <ul style="list-style-type: none"> - <i>Fears prompting active advocacy</i> <p>Women educating themselves to facilitate self-advocacy due to a fear of lack of provider disability knowledge.</p> <ul style="list-style-type: none"> - <i>Positive experiences</i> <p>For women with providers who answered questions and provided trusted input. Four themes regarding anaesthesia:</p> <ul style="list-style-type: none"> - <i>Importance of consultation with the anaesthesia team</i> <p>Discussing options, fears and preferences. Decisions about epidural/spinal vs general anaesthesia. Not always made in consultation with the woman.</p> <ul style="list-style-type: none"> - <i>Failed epidural with repeated efforts.</i> <p>Frightening and painful</p> <ul style="list-style-type: none"> - <i>Fear of injury related to anaesthesia.</i> 	Focus on only one segment of maternity care (labour and anaesthesia) allows the authors to delve into great detail.	See Iezzoni, 2015.	7/10 (70%)

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Table 2 (continued)

First Author (year), location	Study aims	Study design and methodology	Participants	Key Findings	Study strengths	Study limitations	Quality appraisal score (percentage)
Lipson (2000), United States	To examine the pregnancy, labour, birth, and postpartum experiences of women living with mobility-limiting disability and to understand their satisfaction with healthcare services during these periods.	Exploratory and descriptive qualitative study involving semi-structured interviews.	12 women with mobility-limiting disabilities who had given birth over the past two years. Disability types included: cerebral palsy, spina bifida, dwarfism, multiple sclerosis, and permanent injuries from accidents.	<p>Women's experiences were influenced by personal and healthcare system factors including:</p> <ul style="list-style-type: none"> - <i>The specific disability</i> <p>Women with invisible disabilities felt less supported.</p> <ul style="list-style-type: none"> - <i>Resource availability</i> <p>Low access to relevant pregnancy and baby care information.</p> <ul style="list-style-type: none"> - <i>Individual approach to pregnancy and childbirth</i> <p>Assertive women who advocated their care preferences had more satisfying care experiences.</p> <ul style="list-style-type: none"> - <i>Structural and political factors</i> <p>Experiences negatively impacted by lack of communication between maternity and disability providers, and low referral rates to allied health services.</p> <ul style="list-style-type: none"> - <i>Negative provider attitudes towards women with disability, and a lack of disability knowledge.</i> 	One member of the research team has a lived experience with a physical disability providing a unique perspective. Positive and negative maternity care experiences acknowledged, recognising both types of experiences can assist in planning service improvements.	Recruitment and sampling methods not reported. Ethics approval not stated.	8/10 (80%)

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Table 2 (continued)

First Author (year), location	Study aims	Study design and methodology	Participants	Key Findings	Study strengths	Study limitations	Quality appraisal score (percentage)
Long-Bellil (2017), United States	To explore the pain relief experiences of women with physical disabilities during labour and childbirth with the goal to inform future care.	Descriptive qualitative approach as part of a larger mixed methods study (alongside Mitra, 2016, and Smeltzer, 2016). Semi-structured interviews conducted over telephone	25 mothers with a physical disability. Disability types included: dwarfism, muscular dystrophy, spinal muscular atrophy, osteogenesis imperfecta, cerebral palsy, amputation, spinal cord injury, stroke, spina bifida, and multiple sclerosis. 72% used assistive technology devices. 60% had planned pregnancies. 80% had present in their child's lives. 92% had started or complete a college or graduate degree.	Pain relief experiences varied greatly. Some women were able to choose their method of relief, while others faced systemic barriers to explore pain relief options. Many anaesthesiologists encountered lacked experience and knowledge in treating women with disabilities. Being able to plan pain relief options in conjunction with healthcare providers in advance increased positive labour experiences for women.	Previous studies regarding pain relief focus on clinical outcomes rather than the experiences of women as this study does.	Some women gave birth up to ten years ago, long recall time may affect accuracy of memories and experiences may not reflect the current context. Possible self-selection bias. Those with high social media presence/more support likely over-represented due to recruitment method. Low ethnic diversity.	8/10 (80%)
Mitra (2016), United States	To examine the unmet healthcare needs of women with physical disabilities around the time of pregnancy and provide recommendations to similar women who are contemplating pregnancy.	See Long-Bellil, 2017.	See Long-Bellil, 2017.	Three key themes: - <i>Clinician knowledge and attitudes</i> Lack of awareness of the effect disability has on pregnancy. Attitudes varied greatly from supportive to disrespectful. - <i>Physical accessibility of healthcare facilities and equipment.</i> - <i>The need for information regarding pregnancy and postpartum supports.</i>	Participants contributed their own recommendations providing an important perspective to improve maternity care services.	Self-selection bias possible with convenience sampling. Women with more social-media connections/ support likely overrepresented due to recruitment methods. Low ethnic diversity.	7/10 (70%)
Smeltzer (2016), United States	To explore the perinatal experiences women with physical disabilities have with their maternity care providers	See Long-Bellil, 2017.	See Long-Bellil, 2017.	Three main themes: - <i>Clinicians' lack of knowledge about pregnancy related needs of women with physical disabilities</i> Women appreciate rectify knowledge gaps through education. - <i>Clinicians' failure to consider women's knowledge, experience, and expertise about their own disabilities.</i> - <i>Clinicians' lack of awareness of the reproductive concerns of women with physical disabilities.</i>	Women provided recommendations to improve the quality of care aimed at the level of the individual clinicians.	Possible self-selection bias. Women on social-media with more supports possibly over-represented. Up to 10 year recall for some participants.	7/10 (70%)

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Table 2 (continued)

First Author (year), location	Study aims	Study design and methodology	Participants	Key Findings	Study strengths	Study limitations	Quality appraisal score (percentage)
Malouf (2017), England	To investigate access to and quality of maternity care for women with various disabilities and to identify differences and/or gaps in care to be addressed.	Secondary analysis of National postal survey data as part of a structured cross-sectional study design. Survey repeated every few years, previous survey results reported in Redshaw 2013 study.	20,094 new mothers in total, 1958 of whom had some type of disability (9.5%), of which 873 had a physical disability (4.8%). Women with a physical disability were more likely to be 35 years or older compared to women with no disability (38.7% compared to 32.5%).	Women with a physical disability compared to women with no disability were <u>less</u> likely to: Be spoken to in a way they could understand during antenatal appointments. - Be involved in care decisions during appointments and during labour. - Have trust in the staff caring for them during labour. - Feel they were treated with respect by staff. - Have a choice in the place they gave birth. - Be given support and advice regarding feeding the baby postnatally. Women with a physical disability were <u>more</u> likely compared to women with no disability to receive attention from providers in a reasonable amount of time during labour (but not postnatally).	Large sample size, increasing generalisability of results. Participant's gave birth within the past three months (short recall time). Repeated study with modifications allows comprehensive assessment of maternity care and tracking of changes over time.	Low survey response rate (41.2%). Women using private care settings excluded.	7/8 (88%)
McKay-Moffat (2006), United Kingdom	To explore the views and experiences of childbirth for mothers with disabilities, alongside the experiences of the midwives who care for them.	Qualitative design forming the first of a two-stage mixed-methods study. Active interview process utilised. Themes generated from data from the interviews with women with disability were compared to themes generated from interviews with midwives. Only results from the women with disability included in this review.	5 women with physical disabilities who had given birth to their youngest child within the past 3. Disability types included: arm paralysis post road accident, below knee amputation due to vascular disease, cerebral palsy, multiple sclerosis, and abnormal pelvis/gait pattern. All women were employed and had complete secondary school or more. Three women were married, one divorced, and one single. 80% of pregnancies were planned.	Five themes from the mother's data: - <i>The quest for normality and independence</i> Not wanting disability to be the focus of maternity care. - <i>The disability as paramount</i> Some women self-conscious about disability leading to decreased participation in parenting classes. - <i>Midwives' lack of disability knowledge</i> Leading to inadequate care and support. - <i>The need for midwives to have disability awareness and positive attitudes</i> Interactions with midwives varied from respectful to insensitive. - <i>The importance of effective communication</i> Clear communication between midwives and women reduces anxiety and increases satisfaction.	Interviewing both mothers and midwives allowed for a comparison, and in this case confirmation, of themes.	Small sample size.	9/10 (90%)

Table 2 (continued)

First Author (year), location	Study aims	Study design and methodology	Participants	Key Findings	Study strengths	Study limitations	Quality appraisal score (percentage)
Mercerat (2020), Quebec Canada	To understand the experiences and needs of parents with physical disabilities in relation to public healthcare perinatal and early childhood services in Quebec, Canada.	Qualitative design with a narrative approach. In-depth individual interviews conducted face to face or over telephone in native French language.	13 parents with physical disability including mothers, and 3 fathers (fathers results excluded from this review). Mothers disability types included: arthrogryposis, cerebral palsy, chronic pain, degenerative disease, multiple sclerosis, rheumatoid arthritis, spina bifida, spinal cord injury. For all participants: 69% had complete a university degree.	<ul style="list-style-type: none"> - Women want to be considered normal during pregnancy and motherhood. - Current maternity services not meeting all the needs of this population group. The main issues involve poor access to appropriate information, and negative health provider attitudes. - Mixed reactions to being labelled 'high risk' when not medically justified. Some find the close follow up reassuring, while others find it anxiety inducing. - Women emphasised the importance of being listened to, reassured and remaining in control of care decisions. 	Study focussed on needs of parents rather than just experiences. Looked beyond common maternity services to other supports and services participants felt they required.	Well educated sample. Authors believe this may have skewed results towards more favourable perinatal experiences.	8/10 (80%)
Mitra (2017), United States	To examine pregnancy and prenatal experiences and needs of mothers with physical disabilities in the United States, including their perceptions of interactions with maternity providers.	Analytical survey completed predominantly online with a telephone option available.	126 women with a physical disability. 84% reported difficulty walking before their first pregnancy. 49% reported difficulties using their arms. 18% reported having dwarfism. 76% used some form of assistive mobility device. 82% had some form of university/college level education.	<ul style="list-style-type: none"> - 53.2% of survey respondents found their physical disability a big factor in selecting a maternity care provider, with 46% visiting multiple providers before selecting their ongoing clinician. - 40.3% reported their care provider knew little or nothing about the impact their physical disability would have on their pregnancy. - Women were more likely to report unmet prenatal care needs if their provider lacked disability knowledge or they felt they were not given adequate information throughout pregnancy. 	First national survey in the United States to explore the unmet prenatal care needs and experiences for women with disability.	Convenience sampling leading to possible self-selection bias. Recall bias possible as some women recount pregnancy experiences from 10 years ago. Low ethnic diversity.	8/8 (100%)

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Table 2 (continued)

First Author (year), location	Study aims	Study design and methodology	Participants	Key Findings	Study strengths	Study limitations	Quality appraisal score (percentage)
Mitton (2007), United Kingdom	To explore the health and life experiences of mothers with rheumatoid arthritis with the aim of increasing knowledge about this group to inform healthcare professionals providing support to these women during and after pregnancy.	Phenomenological qualitative approach. Individual, semi-structured interviews.	7 women who had been pregnant and given birth with rheumatoid arthritis. All women recruited through a single outpatient rheumatology department in metropolitan England. - Length of time living with rheumatoid arthritis ranged from 3 to 11 years. - Age of children 1–7 years. - Five married, two singles. - One woman in full time employment, two in part time employment, and four not employed.	The only theme relevant to this scoping review: - <i>Pre-and post- natal education</i> Health providers and educators lack knowledge of how rheumatoid arthritis affects pregnancy and birth, including its possible complications.	Limiting to women with rheumatoid arthritis produced nuanced results specific to women with this condition.	Small sample size with low ethnic diversity. Interviewer was a nurse with a pre-existing client-practitioner relationship with participants potentially affecting what they were willing to share.	8/10 (80%)
Prittettensky (2003), Canada	To explore the pregnancy and early parenting experiences of mothers with disabilities and the availability of both formal and informal supports.	Qualitative study design involving both focus groups and individual interviews.	35 women with disability participated in focus groups. Two of the four focus groups were with mothers. 13 women participated in individual interviews, of which eight were mothers. Some of these women had participated in a focus group earlier. A variety of mobility/limb impairments were represented. Most were wheelchair users. Two-thirds of women held a post-secondary school degree.	- Many women felt pressured by health providers to terminate their pregnancy, even if it was planned. - Disability and pregnancy health issues seen separately with disability and maternity specialists only treating that which they are familiar. - On the postnatal ward some women felt overly watched and interrogated, having to prove their competency as a parent. - Women appreciate care providers who involve them in care decisions and provide additional supports when required.	Main author has a lived experience of physical disability, providing a unique perspective to the analysis.	Reporting of the sampling and recruitment strategies, and participant demographics unclear or missing.	7/10 (70%)

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Table 2 (continued)

First Author (year), location	Study aims	Study design and methodology	Participants	Key Findings	Study strengths	Study limitations	Quality appraisal score (percentage)
Redshaw (2013), United Kingdom	To describe women with disabilities use and experiences of pregnancy, childbirth, and postnatal care, and compare this to experiences of women without disability.	Secondary analysis of population based postal survey data. Descriptive statistics reported alongside Chi-squared and logistic regression analysis. Repeated survey results seen in Malouf, 2017.	24,155 new mothers in total, 1482 of whom had some type of disability (6.14%), of which 730 had a physical disability (3.02%). Women with a physical disability included women with a long-standing health problem involving a physical condition (e.g. cerebral palsy), or a long standing illness (e.g. epilepsy). Women with a physical disability: - Were more likely to be 35 years or older compared to women without disability (44% compared to 23%). - 83% had a long-term partner.	Compared to women without a disability, women with a physical disability: - Used antenatal services, ultrasound scans, and postnatal services more frequently. - Were less likely to attend antenatal classes. - Had less choice about labour and birth including location and birth positionings. - Less likely to have baby put to breast at least once.	Large sample size, greater generalisability of results. Participant's gave birth within the past three months (short recall time). First national study in the United Kingdom to compare the use of maternity services by disability type.	Moderately low survey response rate (52%). No information regarding socioeconomic status or educational attainment (possible confounding variables). Some key factors previously shown to affect maternity experiences (e.g. building accessibility) not measured.	7/8 (88%)
Schildberger (2017), Austria	To investigate the experiences and personal meanings of women with physical and sensory disabilities in regard to pregnancy, childbirth, and the puerperium.	Qualitative study involving in-depth semi-structured interviews.	10 women, of which 4 had a physical disability and 6 had a sensory disability (results from women with sensory disability excluded from this review). Physical disability types included cerebral palsy and paraplegia after an accident. All women with a physical disability had only one child at time of interview all of which were aged five years or less. Nine of the ten women lived in urban areas, and one in a rural area.	Three themes identified: - <i>The social network</i> The desire for normality and to be accepted as a woman and mother by society. - <i>Self-efficacy and self-awareness</i> Women generally confident in their own abilities, however lacking support and negative attitudes from health providers can undermine confidence. - <i>Communication, transparency, and information</i> Communication between women and providers filled with uncertainty. Information regarding pregnancy, birth and the puerperium for women with disability inadequate.	First known study on this topic in the Austrian context.	Small sample size particularly when looking at women with physical disabilities separately. Authors suggest results may not be generalisable to other countries healthcare systems.	8/10 (80%)

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Table 2 (continued)

First Author (year), location	Study aims	Study design and methodology	Participants	Key Findings	Study strengths	Study limitations	Quality appraisal score (percentage)
Tarasoff (2017), Ontario Canada	To understand the perinatal care experiences and outcomes of women with physical disabilities in Ontario, Canada, with the aim to identify barriers to care.	Constructivist, grounded theory approach. Qualitative methodology involving in-depth interviews, predominantly conducted face to face with some over telephone. Short follow up interviews conducted after initial analysis to confirm data and establish credibility.	12 women with physical disabilities (results relating to an additional woman with congenital blindness were excluded from this review). Disability types included: arthritis, cerebral palsy, congenital amputation, congenital bone growth disorder, degenerative disc disease, fibromyalgia, muscular dystrophy, osteoporosis, scoliosis and spinal cord injury. - 92% use an assistive device. - 92% in a long-term relationship. - All women had started or complete further education university/graduate degrees. - Most lived in large urban centres.	Four themes relevant to women with physical disabilities: - <i>Negative attitudes</i> Women's ability to parent questioned. Unwillingness of care providers to assist when required. - <i>Lack of knowledge and experience</i> Care providers and publicly available knowledge lacking, leading to feelings of frustration and anxiety. - <i>Lack of communication and collaboration amongst providers</i> Particularly between maternity and disability specialists. - <i>Misunderstandings of disability and disability-related needs</i> Providers fixating on one aspect of disability while ignoring others. The needs of women with 'invisible' disabilities often overlooked.	Study considers the accessibility of the neonatal intensive care unit, not considered in other studies. Short recall as women had given birth within past 3 years.	Low diversity of participants in regard to ethnicity, educational attainment, and sexuality.	9/10 (90%)

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Table 2 (continued)

First Author (year), location	Study aims	Study design and methodology	Participants	Key Findings	Study strengths	Study limitations	Quality appraisal score (percentage)
Tebbet (2012), United Kingdom	To examine the lived experience of pregnancy and childbirth for women with spinal cord injury.	Qualitative design using an interpretative phenomenological approach. Semi-structured interviews analysed using the interpretative phenomenological analysis technique.	8 women who had given birth to 1–2 children with a spinal cord injury. Spinal cord injuries were a mix of complete and incomplete injuries, ranging from levels C5–L1. All women attended a single hospital that hosts both a specialist spinal centre and a maternity ward.	<p>Person centred care and remaining in control were seen as critical for women with SCI. Five main themes:</p> <ul style="list-style-type: none"> - <i>Preparing for childbirth</i> <p>Women researching pregnancy/childbirth information relevant to them.</p> <ul style="list-style-type: none"> - <i>Childbirth as a pleasurable event</i> <p>Most women had positive birth experiences.</p> <ul style="list-style-type: none"> - <i>Childbirth as a unique experience for women with SCI</i> <p>Unique care plans including routine transfer to spinal ward before due date and after birth.</p> <ul style="list-style-type: none"> - <i>The importance of support</i> <p>Care providers with supportive attitudes improved women's experiences.</p> <ul style="list-style-type: none"> - <i>Childbirth as a team effort with varied degrees of controllability</i> <p>Women valued being listened to by providers and being involved in care decisions.</p>	First study to explore the experiences of childbirth for women with SCI, leading to specific findings that relate to this population.	Low sample size. Sampled from a single hospital with specialised SCI facilities. Sample may not reflect the experiences of women attending other non-specialised hospitals.	7/10 (70%)
Walsh-Gallagher (2012), Ireland	To describe the personal meanings women with a disability ascribe to their pregnancy, childbirth, and motherhood experiences as perceived by them with particular focus on feelings of control, making choices, access to and continuity of care.	Descriptive, phenomenological approach. Qualitative methodology involving in-depth, semi-structured interviews. Each participant interviewed twice: once during the second trimester of pregnancy, the second up to three months post birth. Interpretative phenomenological analysis.	17 women with a disability, 9 of which had a physical disability. Women were recruited from three major maternity hospitals spanning Northern Ireland and the Republic of Ireland. Physical disability types included: epilepsy, multiple sclerosis, spina bifida with hydrocephalus, brain tumour, cerebral palsy, and motor neurone disease. 59% were married or in a long-term relationship, 36% were single (one woman widowed). 88% worked prior to their pregnancy.	<p>Two main themes identified:</p> <ul style="list-style-type: none"> - <i>Affirmation of motherhood</i> <p>Being able to experience pregnancy despite their disability produced feelings of normality.</p> <ul style="list-style-type: none"> - <i>Perceived reactions of others</i> <p>Health providers view women as high-risk and potential liabilities. Being labelled high risk increased women's anxiety. Other findings:</p> <ul style="list-style-type: none"> - Maternity services designed for able bodied women with little to no adaptations in place. - Women not feeling in control of their care choices and birthing experiences. - Care providers lacked disability knowledge. 	Strong methodological underpinning using phenomenology interpretative analysis.	Demographics of participants not reported.	8/10 (80%)

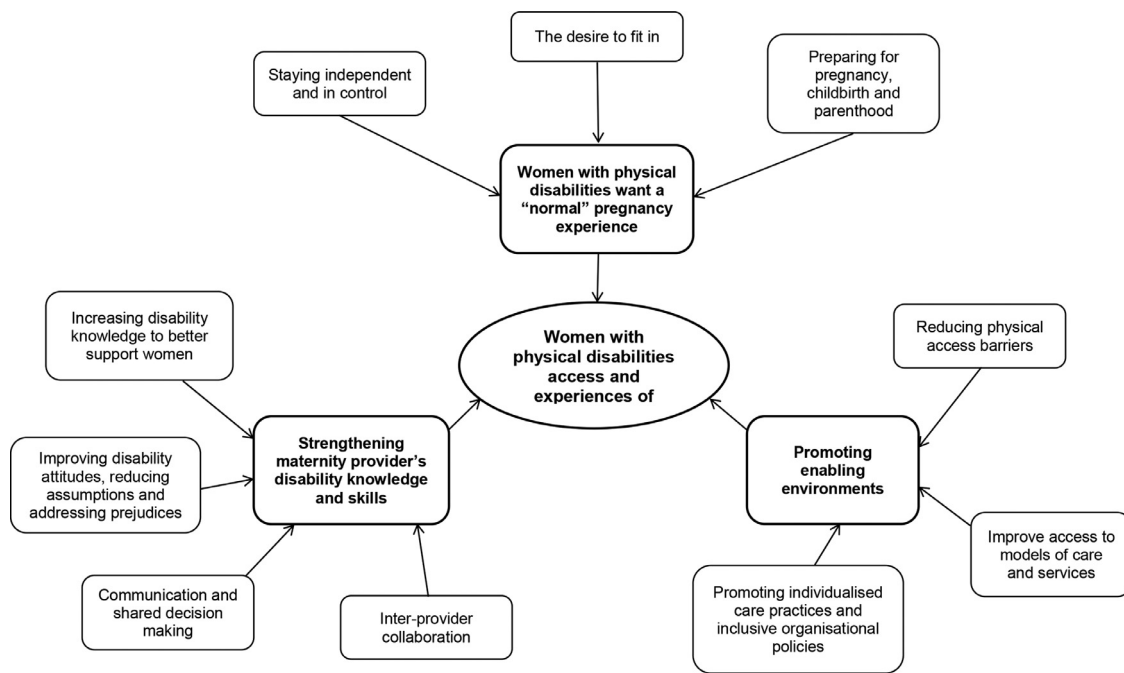


Fig. 2. Thematic synthesis overview.

"I say yes [I was treated differently] in a positive way as everything was done to make my pregnancy and delivery go as smoothly as possible." (Hall et al., 2018)

Despite these varied attitudes, women agreed they wanted to be treated with respect and did not want to be made to feel like a "spectacle" while receiving care (Tarasoff, 2017).

Staying independent and in control was emphasised by women in these studies. During pregnancy, many women experienced a decline in mobility and exacerbations of their physical disability which decreased their independence and increased their reliance on partners, family members, and maternity providers (Bertschy et al., 2015; Iezzoni et al., 2015b). Women stressed the importance of being strong self-advocates to remain in control of care decisions. Finding a maternity provider who was respectful of their knowledge and right to make decisions was essential as articulated here:

"find a good doctor that's willing to work with you. If he's not, you find another." (Mitra et al., 2016)

Women wanted to **prepare for pregnancy, childbirth and parenthood** with disability-specific pregnancy knowledge to assist in making informed maternity care choices. Women described gaining confidence and being better able to plan support services with their increased knowledge. Many women visited their birth facility and met their care team in advance as a key birth preparation strategy (Iezzoni et al., 2017). Women relied on pregnancy books, research publications and disability organisation websites as information sources. However, they recognised these sources often lacked information relevant to their circumstances. When information was available, particularly when it was from an online source, women questioned its validity (Bertschy et al., 2015). Instead, women turned to peers (other mothers with disabilities) to elicit trustworthy sources of knowledge, practical tips and community support. This woman explained the need to:

"...have people that have gone through it or are going through it and have a network. I think having a network of peers is most

valuable asset that any person could have at any point in their life. That's the way for us with disabilities." (Iezzoni et al., 2017)

Developing maternity provider's disability knowledge and skills

Several studies focussed on the need to **increase disability knowledge to better support women** and address knowledge deficits. Many women stated their provider knew little or nothing at the start of their antenatal care about the impact their disability could have on pregnancy (Mitra et al., 2017; Smeltzer et al., 2017). Women appreciated when providers made a concerted effort to increase their knowledge through research, however this was not common practice (Mitra et al., 2017). Women expressed particular frustration when providers were unwilling to learn directly from them, undermining their wealth of knowledge and lived experience. This woman said:

"Definitely do your research, ask those questions, ask questions of the patient. If you really want to know about how things affect me or certain things, ask me as well." (Smeltzer et al., 2016)

Women reported that their disability related concerns were not addressed with the same sense of urgency as their pregnancy related concerns (Hall et al., 2018). Providers particularly lacked the insight to provide the supports necessary for women with invisible disabilities.

"At times it is right to be treated different. My disability is unseen and even when I signpost educate and explain, my needs are ignored" (Hall et al., 2018)

Women highlighted the need to **address providers' attitudes, assumptions and prejudices** in relation to disability as these influenced care experiences. When providers supported women's pregnancies and trusted their ability to parent, women had more favourable experiences. Unfortunately, many women encountered insensitive and discriminatory providers who were unaware of disability rights (Tarasoff, 2017). Some women described instances of providers questioning their reasons for wanting to have a baby and pushed unwelcomed suggestions of termination, adoption or sterilisation. This woman describes:

“Women with disabilities have the ability and the right to have a child, just like anyone else, and care providers need to not let their own personal views affect what advice they give to a patient.” (Smeltzer et al., 2016)

Assumptions surrounding women’s abilities meant less active support and encouragement of breastfeeding, leading to lower rates of breastfeeding initiation and continuation (Malouf et al., 2017; Redshaw et al., 2013). Many felt scrutinised on the postnatal ward if seen to be struggling with certain baby caring skills and described instances where providers threatened the involvement of social services. This woman explains:

“I always felt like there was somebody watching me ... somebody kind of hovering over me, which was a very uneasy feeling...” (Begley et al., 2010)

Maternity care provider communication and shared decision making is critical. Women with physical disabilities reported feeling less likely than those without disabilities to feel listened to, spoken to in a way they could understand, and to be involved in decisions about their care (Malouf et al., 2017). They often felt disconnected from the decision-making process with care options not explained, and preferences going unheard. This led to high levels of dissatisfaction as maternity and birthing plans were not followed. Partners or family members were often looked to as the primary communicator, reducing women’s feelings of independence and control. This woman explained the experience:

“I find being in a wheelchair means I am regularly not listened to. My husband or mum are asked questions instead of me. When the professional does not like what I have to say they looked to my mum or husband to put me in my place (at least that is how it felt)” (Hall et al., 2018)

Women appreciated providers who respected their right to make informed care choices independently or as a team, and when providers articulated why certain options were not available to them. For example:

“[My obstetrician] knew...that I was not talking out of fear...that I had some knowledge and education to support my decisions. She really believed I knew my body the best and was willing to help me...” (Smeltzer et al., 2017)

Inter-provider and inter-disciplinary collaboration were important as this meant maternity providers, disability specialists, and anaesthesiologists communicated effectively. Inter-disciplinary collaboration appeared rare from the women’s perspective, as explained here:

“There’s a lot of siloing that goes on in the medical community, especially if you have a complex disability like mine when you have issues dealing with chronic pain and a physical disability that the two do not communicate. You get excellent care in those two separate areas but they do not communicate with each other.” (Tarasoff, 2017)

Poor inter-provider communication meant women became the messengers of complex medical information between specialists. Lacking effective means of communication and understanding of other providers’ roles also resulted in fewer referrals to appropriate services including occupational therapists, physiotherapists, and adaptive equipment services. When collaborative efforts were demonstrated, maternity care processes became streamlined and women were more likely to receive quality care and enjoy positive care experiences (Long-Bellil et al., 2017).

Promoting enabling environments

Reducing physical access barriers was critical. Physically inaccessible maternity facilities and equipment affected women’s choice of facility and negatively impacted their experience within facilities. A lack of disabled parking spots, ramps, automatic doors, low reception desks, and wide corridors made navigating facilities difficult for women. Women reported that many facilities were not equipped with adjustable examination tables, forcing them to struggle onto tables, be examined in their mobility device, or have reduced examinations (Iezzoni et al., 2015b). Manual transfers by staff or family removed women’s independence and left them feeling “undignified” (Iezzoni et al., 2015b). Women were nervous about being lifted by providers who were unfamiliar with their disability, with multiple reports of women being dropped (Iezzoni et al., 2015b).

Inaccessible weighing scales meant many women were not weighed regularly or at all during pregnancy. This caused anxiety in women who were unsure that their own weight gain was on track or did not trust weight estimations for medication dosing. One woman said:

“I was not professionally weighed at any time during the pregnancy. Not once did they have anyone to weigh me. That was another reason why I was like, ‘You are not putting any drugs into my epidural line.’ They were just going to approximate my weight.” (Iezzoni et al., 2015b)

Postnatal wards with inaccessible bathrooms and high baby cots meant women were unable to start caring for themselves and their baby without assistance. Some women brought equipment from home to increase their independence.

The need to **improve access to models of care and services** was consistently reported. Many women reported a preference for midwifery-led care and birthing centres over more obstetric-led hospitals. These preferences were often denied as midwifery-led services and birthing centres turned women away stating they were unable to accommodate disability specific needs, often without consulting women on their additional or alternate needs. As a result, care choices for women with physical disabilities were greatly restricted. Women travelled further to large urban hospitals only to be provided with less individualised care and no guarantee of superior provider disability knowledge. This woman explained:

“I was not allowed to go to the low risk [birthing] centre despite my disability not affecting my capacity to give birth.” (Hall et al., 2018)

Antenatal education classes did not seem to meet the needs of women with physical disabilities. Women did not attend or stopped attending due to fears of not fitting in, being unable to move on and off the ground, and the information not being relevant. Particularly frustrating for women was the exclusion of topics relevant to their situation including caesarean section and bottle feeding (Begley et al., 2010).

Other relevant services, including adaptive equipment suppliers and allied health appointments, were difficult to access. When they were available and referred to, women found them invaluable.

The importance of **individualised care practices and inclusive organisational policies** was highlighted. Facility policies and guidelines and their implementation by providers were often found to be inflexible and unaccommodating. Short and ill-timed antenatal appointments impacted women’s ability to attend and have all their questions addressed. When continuity of care was not provided, women found unnecessary time was taken repeating their complex medical histories to each provider. This woman said:

"I had to keep going over the same things to different midwives last time. This time I have just one midwife and my consultant. They know me really well and it's so much better." (Hall et al., 2018)

During labour and postnatally many women's mobility level was restricted by hospital policies. Several women were told to remain immobile during labour, despite neighbouring women without disabilities being allowed to use active birthing techniques (Smeltzer et al., 2016).

Women appreciated providers who considered the women's feelings and needs in guiding their actions, rather than relying exclusively on policies. When facilities and providers displayed flexibility, women had more positive experiences as articulated here:

"Listen to what women tell you about what they want and ask them if they can do things, do not request them to. Do not tell them what the policies are without explaining how you can adapt them or why they are recommended in that way." (Hall et al., 2018)

Discussion

This scoping review brought together findings from 22 studies (27 articles) spanning eight OECD countries to establish an understanding of women with physical disabilities access to, and experiences of, maternity care. Despite ongoing efforts by the United Nations, WHO, and countless local disability organisations to advocate for disability and women's rights, this review revealed women with physical disabilities face numerous barriers to accessing maternity care that is accommodating of their needs and preferences, and many have mixed or negative care experiences. The majority of women in these studies wanted their pregnancy and maternity experiences to be similar, if not the same, as for women without disabilities. Unfortunately, maternity providers' inadequate disability knowledge, discriminatory attitudes, and poor communication skills prevented this from occurring, leaving many women to feel a loss of control and independence in their pregnancy journeys.

Environmental factors including physical inaccessibility of facilities, inflexible organisational policies, and restricted care choices were found to further impact women's experiences of maternity care. These findings align closely with those from Lawler et al. (2013), suggesting little progress has been made to implement quality improvement strategies since their review was published in 2013.

There is a need to improve the quality and quantity of provider disability training to address the current insufficiencies in maternity provider disability knowledge and awareness. Training courses for providers should address clinical knowledge gaps, disability rights, attitudes, and communication skills. Co-designing online and in-person courses with women with physical disabilities will ensure the provider deficits that most impact women's experiences are addressed (World Health Organization, 2020). A review of the research from the perspective of maternity providers about their experiences and difficulties in providing care for women with physical disabilities could further assist in targeting training topics and teaching methods. Once courses are established, professional midwifery and obstetric bodies should develop and implement guidelines for maternity staff to engage in continuing disability education (World Health Organization, 2015).

Another key method to increase provider knowledge should be through fostering inter-provider and inter-disciplinary collaboration. Bringing maternity and disability providers together through hospital in-services, webinars and conferences would greatly assist in knowledge transfer, integrated care delivery, and increase the number of referrals to appropriate services (World Health Organization, 2015). Finally, for the ongoing advancement of

provider disability knowledge, a greater commitment to research focussed on the intersection of disability and pregnancy is required (World Health Organization, 2011). Building an evidence base will: assist in the production of clinical guidelines, allow antenatal educators and providers to incorporate disability relevant knowledge into classes and appointments, and increase the production of knowledge resources relevant to women with disability.

Not all knowledge women seek during pregnancy can be gained through books, research or maternity providers. The practical tips and support received from peers was found to be a key source of comfort for women and should be further encouraged (Begley et al., 2010; Bertschy et al., 2015; Mitra et al., 2016; Mitton et al., 2007; Tebbet and Kennedy, 2012). Online and in-person peer support groups and mentoring services for women with disabilities should be promoted within maternity facilities. Disability organisations are in a prime position to create and promote new support groups, listing locally available groups on their websites.

Environmental factors, including physical access barriers and unaccommodating organisational policies were found to be compromising maternity care experiences for women with physical disabilities. Co-designing new facilities and altering existing facilities using universal design principles (whereby buildings are designed to be accessible to people of all abilities) is well overdue. Regulations ensuring equal access to health facilities are required where they do not already exist, and standardised accessibility measures should be used in the regular monitoring of such laws (World Health Organization, 2020).

In terms of organisational policies, it is crucial that women with disabilities have the same right as women without disabilities to choose a model of care accommodating of their preferences and needs. This choice should include midwife-led continuity models. Midwife-led continuity models have multiple benefits for women (without major pregnancy complications) including reduced medical intervention at birth, increased feelings of control, increased continuity of care, and overall increased maternity care satisfaction (Sandall et al., 2016). As perceived loss of control, poor continuity of care, and overall poor care satisfaction were identified as key problems for women with physical disability, improving access to midwife-led continuity models has the potential to remedy these issues. To improve access to such care models, facilities should never assume a woman's pregnancy risk level based on the presence of a disability alone. Low-risk birthing centres should implement policies and procedures that would allow them to accommodate common and often minor adaptations women with disabilities require to give birth safely (Dean et al., 2018). To further enhance women's access to, and positive experiences of maternity care, services should allow flexible appointment scheduling and home visits, allow support people to stay overnight on postnatal wards, increase continuity of care practices and early involvement of anaesthesiologists. When these policies were in place women felt better supported and empowered to make informed care decisions as part of a trusted team (Begley et al., 2010; Hall et al., 2018; Iezzoni et al., 2017; Long-Bellil et al., 2017; McKay-Moffat and Cunningham, 2006).

The findings of this review and recommendations described above provide a solid foundation for creating or updating maternity facility disability/accessibility action plans. These plans are increasingly being used, and are a requirement in some jurisdictions, to illustrate health facilities commitment to improving disability inclusive practices (Victoria State Government, 2019; World Health Organization, 2015). The breadth and depth of action plans vary widely between facilities, suggesting further guidance is required for their development and implementation. Disability advisors at the facility level, as recommended in a number of articles, would help ensure the continued development, use and eval-

uation of action plans (Begley et al., 2010; Guerin et al., 2017). Disability/accessibility action plans should be created and evaluated in collaboration with women with physical disabilities to ensure plan strategies are increasingly woman-centred and disability inclusive (Brady et al., 2019; Kalpakjian et al., 2020; Larson et al., 2020; Smith-Merry, 2017). Patient reported experience measures specifically designed to consider the distinct needs of women with physical disabilities should be used in the evaluation of new and updated maternity care initiatives to ensure benefits can be compared fairly between programs while also ensuring the findings are meaningful to women with disabilities (Depla et al., 2020; Dickinson et al., 2019; Kalpakjian et al., 2020).

This review is not without its limitations. The search strategy was restricted to articles published in English, likely excluding otherwise relevant articles. Our research question lent itself to qualitative research which broadly speaking, is not considered generalisable. However, the homogeneity of results arising from multiple regions and healthcare systems increases confidence in the generalisability of findings (Thomas and Harden, 2008). Preferably there would have been greater diversity in the study samples educational attainment, employment status, sexual orientation and ethnic diversity, as these factors will also affect women's interactions with healthcare facilities as well as their own understanding and relationship with disability (Horner-Johnson et al., 2014; Meade et al., 2015). Future research should explore the affect the intersection of disability with these factors has on maternity care access and experiences.

Strengths of the review include its commitment to amplifying the voices of women with physical disabilities by including articles only from their perspective. This is important for disability inclusion and encouraging woman centred maternity care (Smith-Merry, 2017). Including a quality appraisal ensured the contributing articles are of a moderate to high methodological standard giving us greater confidence in the findings.

Conclusion

Women with physical disabilities are made to feel different due to negative societal attitudes and unaccommodating environmental structures. Women with physical disabilities face several barriers in accessing maternity care and describe suboptimal care experiences. Women with physical disabilities have the right to access safe, high-quality, respectful maternity care. Our findings are of immediate relevance to maternity stakeholders involved in planning and implementation of equitable maternity services. Maternity facilities, midwifery and obstetric associations, and relevant government bodies need to support provider training and inclusive organisational policies. Initiatives should be planned and implemented using a co-design approach, guided by both the positive and negative experiences of women, and new initiatives monitored and evaluated. Meaningful progress towards equitable maternity care will only arise for women with disabilities when their voices are centred and respected.

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Declaration of Competing Interest

None declared.

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Supplementary materials

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