

Women with disabilities and their motherhood: scoping review

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Abstract *This review aims to disclose the gaps and needs for acknowledging the rights to experience motherhood of women with disabilities. To do so, we map how much is known about these women's experience with motherhood, shedding light on their sexual and reproductive rights. The present work followed the scoping review by the Joanna Briggs Institute (JBI). This research is structured by elaborating the question, identifying the relevant studies, selecting the studies, extracting the data, sorting, summarizing, and creating reports based on the results. Results: we found 1050 articles, of which 53 were selected for the analysis. considering the different themes, we generated three axes: (1) infantilization, dehumanization, and discredit in the experience of motherhood; (2) obstetric ableism – an expression of violence in obstetrics; (3) reproductive justice – politicize motherhood and care. The study showed the urgent need to regard women with disabilities as people having the right to make sexual and reproductive health choices. Health professionals need permanent education to acknowledge and guarantee such a need as interweaving relationships to reach decision-making and autonomy.*

Key words *People with disabilities, Women's health, Reproductive rights*

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Introduction

The objective of this scoping review¹ is to show how important awareness becomes of motherhood experience for women with deficiency^{2,3}, and determine presences and absences.

Maternity is here defined as the desire, planning, pregnancy, delivery, and birth of a child, called the perinatal period. Although the existence of women with deficiency is not limited to experiencing maternity, it is often during pregnancy that many will have first contact with the health system, where they experience ableism and sexism by having reproductive rights violated.

Women with a deficiency should be recognized for needing personal assistance, support, and monitoring⁴, and diversity of race, ethnicity, territory, class, and social orientation. A deficiency becomes an experience of social oppression when society cares little or nothing about human diversity^{5,6}. Consequently, during pregnancy, health necessities and care of women with a disability may be prevented by barriers such as attitudes, architecture, and communications supported by social discrimination⁷. It is imperative to determine gaps in knowledge production and health care of motherhood of women with a disability regarding their functional expressions. Such an effort aims to subsidize research and promote public policies that foster sexual and reproductive rights currently provided by law in the scope of formal equality^{8,9}. Ableism is an oppression system that sees human skills as a natural and hierarchical estate, placing people with disabilities at the top of the abjection pyramid, referring to the lack, correction of the body, impossibility, and defect^{10,11}. This set is based on compulsory ability¹¹.

We perceive the right to motherhood of women with a disability as a right to care, social practice, and policies¹². Historically, care is interpreted as a matter of women, in the domestic and private range¹³, or fixed as “health” at the most. Such a perception is forged by cultural models that cover the relational and material dimension of care, oppression reproduction, and social inequalities¹³⁻¹⁶. Processes of surveillance, control, and expectations create ideal models of motherhood, providing behavior and labels on how to deliver, breastfeed, or post-delivery behavior: a field of care genderized by oppressions and hybridizations. That naturalizes a given image of a caring woman, where women with a disability need to be justified. This supposed “natural-

ization” to care for women in general excludes women with a disability, marked as presumably disabled^{17,18}.

In other words, the same social space-time delimits reproduction and child care as women’s primary functions deny and discourage a woman with disability from becoming pregnant or a mother as an expression of care¹⁷. Concepts and norms operate before the body and motherhood, so-called expected or typical that “regards women with a disability or chronic diseases as unfit to care, unstable, and asexual”¹⁷ (p. 8). This exclusion of sexuality and expressions about the life reproduction of Women with a disability regards Sexual and Reproductive Rights as human rights.

Referring to rights, the World Report on Disability¹⁹ resumes the Convention on the Rights of People with Disabilities (CRPD)²⁰ to emphasize that People with Disabilities hold legal capacity on equal terms with other people, among which the right to marry, constitute family, and maintain their fertility, as well as having ensured their access to sexual and reproductive. The bias that people with disabilities are asexual or should have their sexuality and fertility control is widespread, creating barriers to recognizing their sexual and reproductive rights. Therefore, specific actions in sexual and reproductive health care should be encouraged to guarantee a positive experience concerning the exercise of sexuality, the building of affective relationships, and their expression, if they so wish, in the experience of motherhood¹⁹.

A scoping review allows us to determine the value of performing a complete and systematic review, identifying gaps as part of reviewing continuous process¹. Breckenridge *et al.*²¹, when researching the access of women with disabilities who are victims of domestic violence, highlighted the need for additional research to explore the consequences of this type of violence, with women with disabilities playing a leading role.

Both the anti-ableist discussion on disability and the right of women with disabilities to exercise their sexuality, as well as guidance on their maternity plans, have little place in the training of health professionals. Thus, there is an urgent need to identify gaps in knowledge when applying a scoping review. Understanding the extent and nature of the literature on a given subject allows us to consider the value of future systematic reviews or gaps in the literature²².

As authors, we declare our commitment to the rights of women with disabilities and users of the Sistema Único de Saúde (Unified Health System). We believe that a scoping review map-

ping, understanding, and systematizing knowledge about their motherhood experiences may support care, training, guarantee of rights, and research.

Methodology

We followed the method of the *Joanna Briggs Institute* (JBI): formulate questions, identify relevant studies, select studies, collect data, sort, summarize, and report results²³. The related protocol²⁴ has been published, allowing the disclosure to reviewers^{23,25,26}, registered with the OSF (Research and Data Management Software for Open Science)²⁷.

To formulate the question, we applied the *population, concept, and context* – PCC model²³, where “P” is women with a disability, “C” is motherhood situation, and “C” refers to sexual and reproductive rights.

The scoping review question is related to sub-questions of *population, concept, and context* attributes²³. Our core question is: how the sexual and reproductive rights of women with a disability are recognized in research considering their motherhood experiences? Sub questions are: which aspects qualitative researchers highlight in the motherhood experience of women with a disability?

The Search strategy focuses on articles published and guided by librarians to define the search term from the descriptions available in the health area (DeCS). Our terms were “disabled persons” AND “pregnancy”, with a pilot search in August 2021, in the databases: PUBMED (National Library of Medicine, which includes Medline), and Lilacs (Latin-American and the Caribbean Literature on Health Sciences), assessing the thematic reach and identifying indexation terms and key words (Chart 1).

We were surprised by the number of articles found from the descriptors since we started the search using descriptors for people with a disability – “Disabled person” (equivalent to P, population), and Pregnancy – “pregnancy”, given that there is no equivalent for motherhood (equivalent to C, concept). Many articles refer to not being human or several persons with a disability or caregivers of persons with a disability, and we chose to make a test by adding the word Woman – “Woman”. When adding the descriptor for reproductive rights – “reproductive rights” (equiv-

alent to C, context) – fewer articles were likely to be implicit in the other pieces.

From this pilot search, we found other keywords and descriptors used in relevant articles to elaborate a complete search strategy. We noticed that the more descriptors we added, the more identified articles varied. We accept the librarian's suggestions and, inspired by other scoping reviews²⁸⁻³¹, and in the search strategy, we assumed several descriptors connections depending on the database and periodicals consulted.

The descriptors used were “disabled persons”, “disabled person”, “pregnancy”, “pregnant women”, and “reproductive right”, associated with the Booleans operators AND. We used the operator OR to broaden our searches with the words “motherhood” and “women with a disability” which are not descriptors registered in the DeCS, but terms used in usual language. Being synonyms, it assisted the strategy to broaden the number of references. The Search strategy using keywords and identifying indexed words (search key) was adapted to each source of information, according to Chart 2.

We selected PubMed as a reference for international articles, SciELO, because it covers many Brazilian articles offering access to the full text, and Lilacs as a reference for Latin-American pieces. We included the periodical *Disability & Society* since it is recognized for publishing *Disability Studies*.

When verifying the references in the identified articles, we included eight other articles, including English, Portuguese, and Spanish, from 2007 to 2021.

The selected articles were listed, and their full texts were transferred and stored in Zotero, eliminating duplicates, and later analyzed by reviewers. Articles not complying with the inclusion criteria and not responding to the purpose of this study were excluded from registering justification. The stages above are summarized according to the flowchart suggested on the JBI webpage, PRISMA-ScR²⁶, (Flowchart 1). The eligible articles were distributed to reviewers, followed by a form with the guiding question, “how sexual and reproductive rights of women with a disability are recognized in research considering their motherhood experience?”. The form was applied to the selected articles and generated in Supplementary Chart, available at: <https://doi.org/10.48331/scielodata.OZOBW6>.

Chart 1. Initial research in August 2021.

Database	Descriptors/key word	Achados
PUBMED	"DISABLED PERSONS" AND "PREGNANCY"	1;161
	"DISABLED PERSON" AND "WOMAN" AND "PREGNANCY"	774
	"DISABLED PERSON" AND "PREGNANCY" AND "REPRODUCTIVE RIGHTS"	11
LILACS	"DISABLED PERSON" AND "PREGNANCY"	59
	"DISABLED PERSON" AND "WOMAN" AND "PREGNANCY"	8
	"DISABLED PERSON" AND "PREGNANCY" AND "REPRODUCTIVE RIGHTS"	0

Source: Authors.

Chart 2. Search strategy.

Database/ periodical	Search strategy	Articles found
SciELO	((disabled person) OR (disabled persons) OR (women with a disability)) AND ((pregnancy) OR (pregnant women) OR (Motherhood))	36
Lilacs	((women with a disability) AND (pregnancy OR pregnant women OR motherhood))	670
PubMed	("women with a disability" OR "disabled person" OR "disabled persons") AND ("pregnancy" OR "pregnant women" OR "motherhood")	304
Disability and society	Motherhood or pregnant women or pregnancy	Open access 32

Source: Authors.

Results and discussions

Of the 1,050 articles identified, we gathered 1005 to read the titles and abstracts without duplicates. Afterward, we excluded 907, leaving 98 for full reading, of which 54 were selected for this analysis. We established 2007 as the start of the search, the year of the United Nations International Convention on the Rights of Persons with Disabilities, a milestone for human rights and the dignity of people with disabilities. In the searches, the first articles date back from 2010 to 2012 - there were five. After that, production increased, converging with recognition of the sexual and reproductive rights of people with disabilities in the World Report on Disabilities in 2012. From 2013-2017, we gathered 24 articles and 24 articles from 2018 to August 2021.

We gathered articles from 21 countries, mainly from the USA with 13, Brazil with 10, Canada with 4, and Ireland with 3. From South Africa, Spain, Chile, Ghana, Austria and Israel. One publication: Ethiopia, Scotland, Australia, United Kingdom, Cameroon, Poland, Uganda, Nepal, Portugal, Mexico, and Iceland, two articles each.

As for the method and techniques, 37 articles applied individual or focus-group interviews with women with disabilities, and 1 article used blog reports by women with disabilities. Almost 70% of the articles include the accounts of the women themselves. Although some aimed not to investigate the motherhood experience itself^{35,42-45} the interviewees overvalued it when mentioning their sexuality stories. For this reason, they are also included here. Another seven articles are in the theoretical-analytical or review category (one is a scoping review, and two integrative reviews), three are case studies, and four investigated health professionals.

Following the scoping review method, our analysis was subject to a theoretical discussion on sexual and reproductive rights, supported by the female ethics of care, intersectionality, interdependence, and reproductive justice⁸⁴⁻⁸⁷.

A critical and reflective reading of the collection generated three axes: infantilization, dehumanization, and discredit in motherhood experience; obstetric ableism: expression of obstetric violence; Reproductive Justice: politicized motherhood and care.

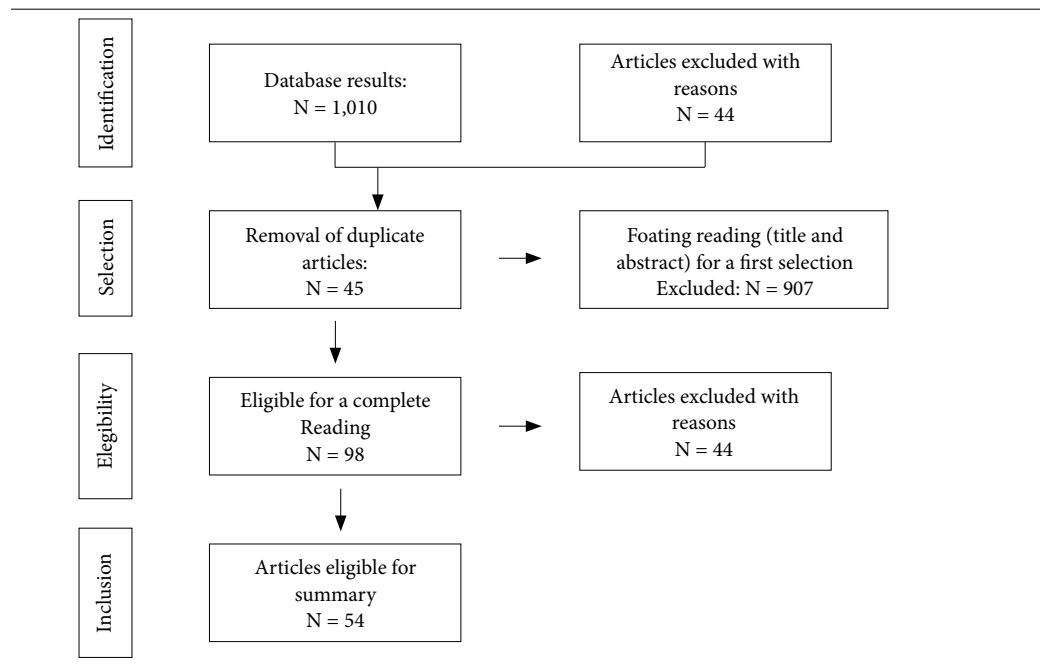


Figure 1. Flow of articles to be included.

Source: Authors.

Infantilization, dehumanization, and discredit in motherhood experience

For women with disabilities, prejudice and discrimination related to the exercise of motherhood emerge in family and close relationships^{18,32-35,37-39,41,42,44,50-53,56,57,60-62,64-68,70,76,77,79}. The “overprotection” category leads to processes of infantilization of women with disabilities. This process, discussed in the light of Goffman⁸⁸ in the tension between virtual and real identity, leads to an understanding that people living with a stigma can perceive themselves as discredited or potentially discreditable due to what is expected of their performance. Such social interaction processes are closely related to symbolic mediations between the real needs of people with disabilities and the stereotypes attributed to them based on ideals of body normativity feed into ableist structures¹¹. The stigmatized people are not passive before those diminishing structures; on the contrary, they realize and sometimes denounce them. However, such an oppression system may be so powerful that disregard any denouncing. For that reason, some stigmatized people, depending on the environment, use the mark of their stigma as a strategy to assume an identity¹⁰. People who live with stigmas branding them as

unique – distinctive marks or characteristics - are not passive in the face of these structures¹⁰.

Infantilization is a social construction that removes subjects from their place of authority over their feelings, thoughts, and desires. By being regarded by Family members as eternal children, as mentioned in some articles, women with a disability are often discredited and perceived as unfit to affirm motherhood and sexuality. Interpreting the disabled body as inappropriate, which fundamentals discrimination, should not be confused with the need to be recognized and required for care. We point out that the so-called body impairments, which may broadly vary within the different groups of disabilities, are interpreted as symbols of the risk of bearing a child with a disability. Two of the articles studied mention this as a fear of ancestors or a family curse^{34,52}. Such attitudes from close people – parents, caregivers, friends, or neighbors – have caused frustrated Dreams, sterilization, and forced abortions imposed by the legal guardians^{35,58,71}, a prejudice directly exercised by the spouse who often results in distancing and abandonment^{37,39}, and an immeasurable mark of pain and suffering for women. Compulsory sterilization regards biopolitics ruling women’s bodies, particularly violent on those interpreted as being at risk, over whom the

state is present by its representatives, imposing restrictions on rights^{89,90}.

Other analyses summarize the role expected of women with a disability when experiencing pregnancy^{17,18,32,34,41,43,44,57,59,62,64,68}. Discrimination joins the stereotypes that disqualify those women for possibly performing such a role or their capacity to do so. Given this process, a need for a new ethic of care arises - interdependence in the negotiation of care, including the children themselves as peers^{17,32,33,62,64,73}. We emphasize the importance of establishing parenting arrangements where diversity recognizes negotiated needs without resorting to mechanisms of infantilization, whether of women or children⁹¹.

Based on the analytical summary of this first axis, we stress care as a human-interdependent relationship without the “overprotection” pitfalls, which removes the disabled woman from the center of the relationship. The transmutation of care into overprotection, shaping “enchanted circles of secrecy”⁸⁸ and restricting the sociability processes, is mediated by the symbols of stigma⁸⁸. The need is paramount to break with these discriminatory, enabling, dehumanizing, and objectifying mechanisms of women with disabilities, who have become objects of desire for others.

We should not equate prejudice and discrimination and conceptualize stigma as a mark or set of marks of distinction. It may impact dehumanizing, depersonalizing, and objectifying women with disabilities.

Obstetric ableism: expression of obstetric violence

Ableism is as powerful as the racist, sexist, and classist structures fed by patriarchal logic dehumanizing black, peripheral, poor, and disabled women. This objectification fosters expressions of violence, which in childbirth scenes are translated as obstetric violence⁹². Obstetric violence is an expression of gender violence, shedding light on the experiences of a woman when dealing with the institutions providing prenatal, childbirth, and postpartum care. Obstetric violence is based on power asymmetries and hierarchies of gender, class, race, and corporeality, bringing attitudes, practices, and procedures based on the dehumanization and objectification of women. This violence can be magnified if we intertwine gender, class, race, and disability.

Here, we use obstetric ableism as a double of obstetric violence against women with disabilities. It acquires political value in the same way

as obstetric racism - the obstetric violence faced by black women in perinatal care⁹³. Obstetric violence of an enabling nature is not an individual phenomenon but a long-term structure based on models of the body, norms of its presentation, and function. It is expressed in the carelessness that words, gestures, and glances reveal when ignoring or not welcoming the presence of women with disabilities in the care spaces for pregnant women^{33,35-39,42,44,47-50,53-55,58,61,62,64-67,69,75,77,79,81-83}, including recommending abortion or sterilization when these women express interest or want information about their sexual and reproductive health^{35,45,58}. Obstetric ableism is reflected in the environmental barriers found in health services^{36,53,62,63,66,74,76,78-81,83}, in the denial of sexuality and, alongside this, the right to reproductive decisions tailored to the needs demanded by the diversity of expressions of disability^{45,46,48,56,79,83}. It often prevails a hegemonic view that the pregnancy of a woman with a disability characterizes an obstetric risk or is the result of sexual violence. In most cases, this view is not based on clinical evidence or rights, compromising humanized care, not assuring a companion at birth³⁷, disrespecting the birth plan, and affecting cesarean rates^{49,69}.

Disability is seen as a flaw, a lack, or a defect that decharacterizes and undermines bodily impairment as a legitimate expression of a body that reorganizes itself in interactions with the world. As such, cultural representations of a disabled, pregnant woman denote a generation of disabled children, prospecting risky heredity and fear-provoking^{42,52}. Empowering structures are intertwined with dangerous emotions, which evoke displeasure, fear and subjectivity based on suffering. They attribute women with disabilities to the inability to care for their children and exercise motherhood^{43,51}. On this axis, it is worth mentioning the fear of threats of losing child custody by social workers acting as agents of biopolitical control of the State^{46,48,52,54,56}.

Reproductive justice: politicizing motherhood and care

One of the articles states that motherhood is a political act³². Politicizing motherhood means denouncing the patriarchal structure that limits women to a private space, without rights and responsible only for looking after the home and children. In the articles, we found interesting accounts of the desire to become pregnant as an expression of claiming femininity, strength, a

personal dream, ability, or even social confrontation to broaden the gaze of those close to her about her sexuality and condition as a being of desire^{32,38,39,48,51,56-58,61,64,73,75,76}.

At this point, we evoke the concept of Reproductive Justice⁹⁴ understood as a formulation – based on intersectional feminism of black American and Afro-Latin American women – where guaranteeing sexual and reproductive rights necessarily entails taking into account the inequality relations triggering oppression and denial of social and economic rights, making decisions and survival impossible for women, mainly black and poor women⁹⁵.

Here, we elucidate the need for other practices and the production of knowledge in which women with disabilities and their struggles for rights become part of women's care approaches. Therefore, it requires literacy on rights based on *Disability Justice*⁹⁶, shifting disability from a discriminatory view of a woman's tragedy (as mentioned in the articles: the blind woman, the "wheelchair user", the woman with intellectual disabilities, etc.) to an inclusive view of active, dialogical listening. In her blog, Mia Mingus reminds us that disability evokes neediness and sadness. As such, it is rejected as undesirable and depicted as a tragic event. This structure of thought nourishes discriminatory practices, which ground arguments based on a eugenic vision justifying the right to abort fetuses with disabilities. The author's first-person writing defends accessibility as a tangible resistance to the isolation of people with disabilities. Accessibility as a right to interdependence. Her perspective aligns with the Ethics of Care as a critique of the neoliberal logic of the independence of bodies¹². She proceeds to formulate the concept of accessibility as justice, requiring to cover class, language, childcare, and toilets not separated by gender. Mia Mingus underlines that accessibility should not be limited to logistics for people with disabilities but should move towards understanding and practicing accessibility as justice, not just inclusion or diversity.

Under *Disability Justice*, accessibility distances from the "we're just like you" model of equality to a model of disability that embraces difference, confronts privilege, and challenges the allegedly "normal" on all fronts. The author does not defend swelling the ranks of the privileged but advocates dismantling the systems that anchor them. Therefore, the discussion set accessibility as a value without which justice cannot be reached, while it questions a society of inaccessi-

bility, producing invisibility and consequent oppression of disabled people.

Confronting such oppressions in the care of women with disabilities urges building decisions on health, sexuality, and reproductive planning, unbuilding the practices of social integration – fueled by a view that discriminates between lines of care for women A or B, fostering exclusion. The logic of inclusion regards interaction, making disability a characteristic that needs to be made ordinary, not exceptional. The basis lies in looking at women's needs as rights-based, accessible, and inclusive, where sexuality, reproductive planning, and justice are socially legitimized.

We found a gap in the articles regarding recognizing sexual and reproductive rights as human rights for women with disabilities. This absence may indicate an open agenda for new research to promote inclusive policies and practices. To do so, it would be favorable to apply the references of *Disability Justice* embedded in the framework of *Reproductive Justice*. Some articles refer to sexual and reproductive rights^{18,35,40,41,43-45,47,53,55,57,67}. Although professionals are concerned about providing adequate care^{63,72,74,78}, they emphasize that they lack "training" for the delivery of a woman with a disability. It becomes relevant to build inclusive practices that assure accessibility and tackle physical, communicative, and informational barriers accessible to the needs of women with disabilities, unbuilding the ableism that feeds attitudinal barriers. The issue is not providing "training" on new practices but addressing the dehumanizing logic of women with disabilities. Other means of communication become necessary for informed decisions and acceptance. Many women regretted having their home births or births with midwives rejected because they fell into the high-risk group^{49,58,69}. However, the bodily impairments did not imply any obstetric risk for these women.

The phrase "occupational injustice" is associated with financial difficulties in arranging and planning family care⁴¹ for women with intellectual disabilities and is not exclusive^{51,57}.

Final considerations

This review has also allowed us to recognize that the maternity of women with disabilities demands political strategies to be acknowledged in terms of rights. To that end, we highlight: (1) the family and close relationships do not necessarily guarantee security and acceptance for women

with disabilities in their sexual and reproductive lives. This is the first locus of infantilization as a process to be unbuilt by health services from adolescence onwards; (2) beyond opposing obstetric violence as an expression against black women, we need to confront what we call obstetric ableism aimed at women with disabilities; (3)

In theory, to challenge of addressing stereotypes against the maternity of women with disabilities and their sexual and reproductive rights lies in tackling ableist vocabulary and practices, deepening the principles of *Reproductive Justice* with a disability *Justice*.

Collaborations

FRC Morais worked on the conception, search, selection of articles, interpretation of data and final writing. MCN Moreira worked on the conception, selection of articles, critical review, analysis and final writing. LML Costa worked on the critical review, analysis and final writing.

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