

# Promoting Inclusive Healthcare: Overcoming Barriers to Sexual and Reproductive Health for Women with Intellectual Disabilities

Mini Review

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## Abstract

This review highlights the barriers and facilitators affecting the sexual and reproductive rights of women with intellectual disabilities. Major obstacles include lack of resources, inadequate training, and systemic discrimination. Essential interventions include training healthcare providers on disability-specific needs and effective communication. Improving these areas can significantly enhance the reproductive health and autonomy of women with intellectual disabilities.

**Keywords:** Intellectual Disabilities; Sexual Rights; Reproductive Rights; Sexual Health; Reproductive Health; Healthcare Barriers; Sterilization; Contraception

## Abbreviations

SSR: Sexual and Reproductive Health; WHO: World Health Organization; CRPD: Convention on the Rights of Persons with Disabilities; SDGs: Sustainable Development Goals; UN: United Nations; PRISMA-P: Preferred Reporting Items for Systematic Reviews and Meta-Analyses

## Introduction

In the last decade, it has been recognized that people with disabilities have the same rights, needs, and desires as those without disabilities [1]. This is particularly relevant for sexual and reproductive rights, which have historically been ignored. Persistent stereotypes that depict them as asexual, hypersexual, incapable of reproduction, and unsuitable as sexual partners, along with negative perceptions of their parenting abilities, contribute to discrimination and exclusion [2].

This perception of the rights of people with disabilities has been reflected in international legislation, with the publication of the World Health Organization's (WHO) World Report on Disability in 1994 [3] and the approval of the United Nations (UN) Convention on the Rights of Persons with Disabilities (CRPD) in 2006 [4].

Access to sexual and reproductive health services and respect for the sexual rights of all individuals are key objectives of the United Nations' 2030 Agenda for Sustainable Development Goals (SDGs) [5], under the motto "leaving no one behind". However, women with intellectual disabilities face double discrimination, limiting their participation as equal members of society and their access to community health resources and sexual and reproductive health services.

Healthcare plays a crucial role in promoting and protecting these rights [6], but barriers to access and quality of services can undermine these efforts.

This manuscript focuses on a systematic review conducted by Pérez-Curiel et al. [7], which analyzes how healthcare acts as a barrier or facilitator of the sexual and reproductive rights of women with intellectual disabilities.

prevention and intervention work is being done by non-government organisations, which receive little or no funding from government. These key drivers include patriarchy that is still rife, cultural norms that protect perpetrators, religion that endorses subordination of women and children and, above all, the stigma associated with GBV, as mentioned earlier. The consequences of GBV for society at large have always been clear, but the persistence and increase in its occurrence clearly indicates that more needs to be done to facilitate successful collaboration among all stakeholders.

## Methods and Materials

This systematic review [7] encompasses a wide range of references from the existing scientific literature, highlighting how the healthcare of women with intellectual disabilities is interrelated with their sexual and reproductive rights. The review was conducted according to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA-P)[8]. Six parallel searches were conducted (see Figure 1), arising from the breakdown of Article 23 of the CRPD (UN, 2006) [4], which enshrines the right to form a family, and Article 25, which defends the right to health. After removing duplicates and applying



inclusion criteria first to titles and abstracts, then to full texts, 151 articles were selected.

Despite the extensive results of the review, this manuscript will focus on the theme of sexual and reproductive health, as it is directly related to the healthcare field. Additionally, being aware of the importance

of applying a gender perspective in our research, studies involving women (either exclusively or jointly with men) will be included.

As shown in Table 1, within the theme of sexual and reproductive health, four sub-themes were identified: barriers and facilitators, menstrual health, contraception, and sterilization.

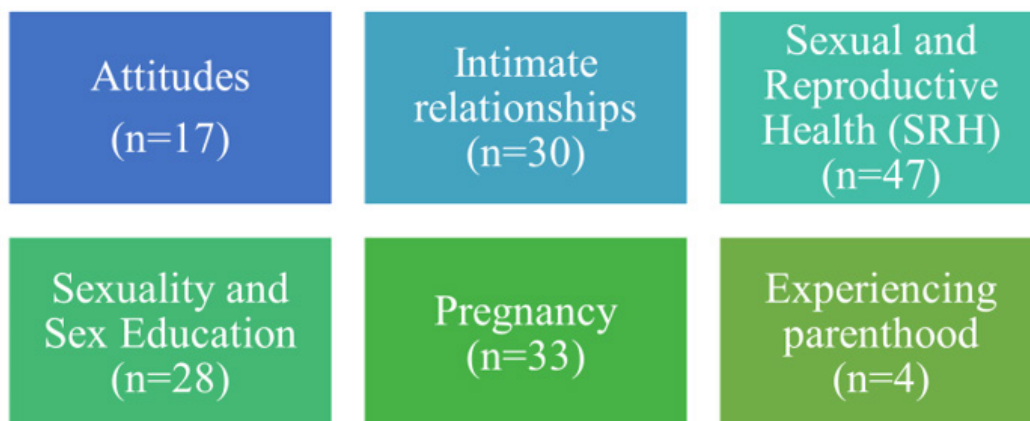


Figure 1: Organization of results by themes.

Note: The total number of articles does not add up to 151 as the same article can be classified under more than one theme.

Table 1: Summary of themes in sexual and reproductive health and their references.

SUBTEMÁTICA	REFERENCIAS
Barriers and facilitators (n=13)	59.09% of the references include women with intellectual disabilities. [9-21]
Menstrual Health Management (MHM) (n=8)	El 100% of the references include women with intellectual disabilities. [22-29]
Contraceptive Choices (n=9)	69.23% of the references include women with intellectual disabilities. [10,11, 19, 30-35]

## Results

To better understand the results, they have been summarized in a table (see Table 2) that presents each identified theme along with its main findings and implications for clinical practice.

The aim of this table is to serve as a tool for healthcare professionals and, ideally, policymakers, highlighting critical areas needing urgent review and suggesting potential strategies or recommendations to improve healthcare for women with intellectual disabilities, thereby promoting and defending their sexual and reproductive rights.

Table 2: Sexual and reproductive health.

Sub-Theme	Main Findings	Implications
Barriers	Negative and judgmental attitudes towards sexual activity, stigmatization, and unprofessional behavior by healthcare providers.	Clinical practice: Larger gaps in medical care, more difficulties in dealing with patients, higher health risks as people with disabilities avoid medical visits.
Facilitators	Educational opportunities, community participation in awareness activities, training for family members and service providers on sexual and reproductive health rights.	Clinical practice: Improved training for healthcare professionals and community awareness.
Menstrual Health Management (MHM)	Parents/guardians lack adequate information on menstrual care.	Clinical practice: Improve education and support for women with intellectual disabilities and their caregivers, addressing communication barriers and practical skills.
Contraceptive Choices	Lack of autonomy in contraceptive decisions, mainly made by others (doctors, service staff, parents).	Ethical considerations: Promote autonomy and provide accessible information on contraception, enabling women to participate actively in reproductive health decisions.
Sterilization	Common practice of non-therapeutic hysterectomy, strong opinions of obstetricians and gynecologists in favor of sterilization.	Legal and ethical considerations: Address ethical and legal dilemmas, ensuring informed decisions and protection of reproductive rights for women with intellectual disabilities.



## Discussion

The reviewed studies indicate that the quality of healthcare directly impacts the sexual and reproductive rights of women. The main identified barriers include lack of resources, inadequate training of healthcare personnel, systemic discrimination, and experiences of ableism by healthcare staff [41], negatively affecting health outcomes and limiting access to essential services. Improving these areas is essential to ensuring the rights enshrined in the CRPD [4].

Specific interventions such as training healthcare personnel on disability-specific needs, effective communication methods (e.g., more accessible language, less medical jargon [42,43]), and infrastructure investment can mitigate these barriers and improve the reproductive health of women [44,45]. These attitudinal barriers, as highlighted by various authors, also affect the social and emotional lives of people with disabilities [46,47].

Research shows that most women with intellectual disabilities often feel excluded from medical decisions, and in instances such as choosing contraceptive methods [48], they are neither informed

about the options nor asked for their preference [30, 31, 34, 35]. This ethical challenge is also reflected in practices like non-therapeutic hysterectomy, still common and recommended by some older doctors as a safe procedure that improves quality of life and can prevent sexual abuse.

The healthcare sector has a significant platform to take a step forward in eliminating stereotypes and developing programs that promote personal autonomy and self-determination, especially in affective, sexual, and reproductive aspects.

## Conclusion

This review aims to synthesize the latest scientific evidence regarding Articles 23 and 25 of the CRPD [4], highlighting the need to address barriers in healthcare to improve the sexual and reproductive health of women.

Proposing a mini-review on this topic is not only important but necessary if it invites reflection (see Figure 2). During the reading of this article, approximately 400 women with intellectual disabilities are suffering from this silent (and even normalized) violence [49].

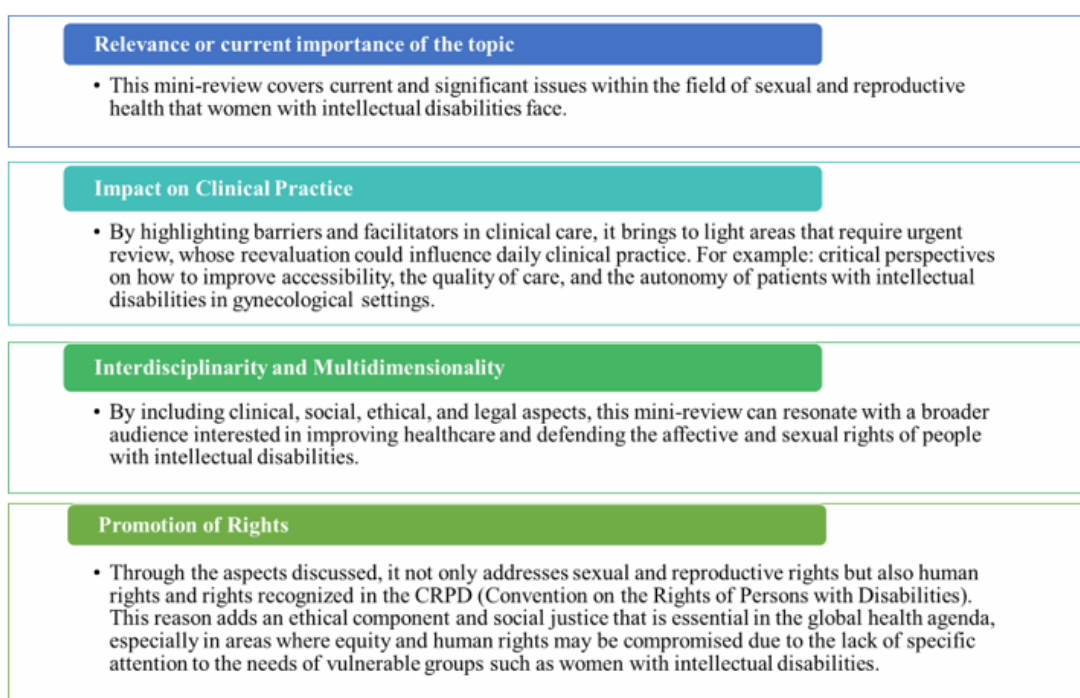


Figure 2: What does this mini-review provide me?

## Future Directions

It is proposed that as a result of reflection, effective policies and practices are developed to promote a greater understanding of the specific needs in the socio-health care of people, particularly women with intellectual disabilities. Policies and continuous and complementary training plans for healthcare professionals that protect the sexual and reproductive rights of people with intellectual disabilities are also important. Additionally, analyzing the interventions proposed in this line to address the challenges identified in this article and developing new longitudinal research to evaluate the impact of the best proposals on the healthcare of women with intellectual disabilities on their sexual and reproductive health is crucial.

## Study Limitations

Systematic reviews have some limitations, such as the heterogeneity of included studies, which can affect the comparability of results. Additionally, there may be selection biases due to data availability and the variable quality of original studies.

## Conflict of Interest

The authors declare no conflicts of interest in relation to this manuscript.

## References

1. Hunt X, Carew MT, Braathen SH, Swartz L, Chiwaula M, et al. (2017) The sexual and reproductive rights and benefit derived from sexual and reproductive health services of people with physical disabilities in South Africa: beliefs of non-disabled people. *Reproductive Health Matters* 25(50): 66-79.
2. Muswera T, Kasiram M (2019) Understanding the sexuality of persons with intellectual disability in residential facilities: perceptions of service providers and people with disabilities. *Social Work* 55(2).
3. Agaronnik N, Pendo E, Lagu T, DeJong C, Perez Caraballo A, et al. (2020) Ensuring the reproductive rights of women with intellectual disability. *Journal of Intellectual & Developmental Disability* 45(4): 365-376.
4. Nations UN (2007) Convention on the Rights of Persons with Disabilities. *European journal of health law* 14(3): 281-298.



5. World Health Organisation. Sustainable Development Goals: Health Targets.
6. Gómez LE (2021) #Rights4MeToo: Training, assessment and intervention on the International Convention on the Rights of Persons with Disabilities. + *Calidad* 25: 9-26.
7. Pérez Curiel, Patricia, Eva Vicente, M Lucía Morán, Laura E Gómez (2023) The Right to Sexuality, Reproductive Health, and Found a Family for People with Intellectual Disability: A Systematic Review. *International Journal of Environmental Research and Public Health* 20(2): 1587.
8. Correction in the article «Declaración PRISMA 2020: una guía actualizada para la publicación de revisiones sistemáticas», *Rev Esp Cardiol.* 2021;74:790-799. *Revista Española de Cardiología (English Edition)* 75(2): 192.
9. Crabb C, Owen R, Heller T (2019) Female Medicaid Enrollees with Disabilities and Discussions with Health Care Providers About Contraception/Family Planning and Sexually Transmitted Infections. *Sexuality and Disability* 38(2): 299-312.
10. David HP, Smith JD, Friedman E (1976) Family planning services for persons handicapped by mental retardation. *American Journal of Public Health* 66(11):1053-1057.
11. Dotson LA, Stinson J, Christian L (2003) People Tell Me I Can't Have Sex. *Women & Therapy* 26(3-4): 195-209.
12. Jensen KM, Taylor LC, Davis MM (2012) Primary care for adults with Down syndrome: adherence to preventive healthcare recommendations. *Journal of Intellectual Disability Research* 57(5): 409-421.
13. Lin LP, Lin JD, Sung CL, Liu TW, Liu YL, et al. (2010) Papanicolaou smear screening of women with intellectual disabilities: A cross-sectional survey in Taiwan. *Research in Developmental Disabilities* 31(2): 403-409.
14. Mac Seing M, Zinszer K, Eryong B, Ajok E, Ferlatte O, et al. (2020) The intersectional jeopardy of disability, gender and sexual and reproductive health: experiences and recommendations of women and men with disabilities in Northern Uganda. *Sexual and Reproductive Health Matters* 28(2): 1772654.
15. Mesiäislehto V, Katsui H, Sambaiga R (2021) Disparities in Accessing Sexual and Reproductive Health Services at the Intersection of Disability and Female Adolescence in Tanzania. *International Journal of Environmental Research and Public Health* 18(4):1657.
16. Parish SL, Son E, Powell RM, Igdalsky L (2018) Reproductive Cancer Treatment Hospitalizations of U.S. Women with Intellectual and Developmental Disabilities. *Intellectual and Developmental Disabilities* 56(1): 1-12.
17. Shiwakoti R, Gurung YB, Poudel RC, Neupane S, Thapa RK, et al. (2021) Factors affecting utilization of sexual and reproductive health services among women with disabilities- a mixed-method cross-sectional study from Ilam district, Nepal. *BMC Health Services Research* 21(1).
18. Tanabe M, Nagujjah Y, Rimal N, Bukania F, Krause S (2015) Intersecting Sexual and Reproductive Health and Disability in Humanitarian Settings: Risks, Needs, and Capacities of Refugees with Disabilities in Kenya, Nepal, and Uganda. *Sexuality and Disability* 33(4): 411-427.
19. Wiseman P, Ferrie J (2020) Reproductive (In)Justice and Inequality in the Lives of Women with Intellectual Disabilities in Scotland. *Scandinavian Journal of Disability Research* 22(1):318-329.
20. Yates S, Carey G, Hargrave J, Malbon E, Green C (2021) Women's experiences of accessing individualized disability supports: gender inequality and Australia's National Disability Insurance Scheme. *International Journal for Equity in Health* 20(1).
21. Yen SM, Kung PT, Tsai WC (2014) The characteristics and relevant factors of Pap smear test use for women with intellectual disabilities in Taiwan. *BMC Health Services Research* 14(1).
22. Noroozi M, Goli S, Salehi M (2020) Parental experiences about the sexual and reproductive health of adolescent girls with intellectual disability: A qualitative study. *Iranian Journal of Nursing and Midwifery Research* 25(3): 254.
23. Griffin J, Carlson G, Taylor M, Wilson J (1994) Menstrual management and intellectual disability: New perspectives. *Occupational Therapy International* 1(3): 141-157.
24. Joshi GA, Joshi PG (2015) Study of menstrual patterns in adolescent girls with disabilities in a residential institution. *International Journal of Adolescent Medicine and Health* 27(1):65-68.
25. Arun S, Karthikayini S (2021) Challenges faced by primary caretakers of adolescent girls with intellectual disability during their menstrual cycle in Puducherry: A mixed method study. *Indian Journal of Community Medicine* 46(3): 416.
26. Nurkhairulnisa AI, Chew KT, Zainudin AA, Lim PS, Shafiee MN, et al. (2018) Management of Menstrual Disorder in Adolescent Girls with Intellectual Disabilities: A Blessing or a Curse? *Obstetrics and Gynecology International* 2018: 1-5.
27. Pikora TJ, Bourke J, Bathgate K, Foley KR, Lennox N, et al. (2014) Health Conditions and Their Impact among Adolescents and Young Adults with Down Syndrome. Yoshikawa T, editor. *PLoS ONE* 9(5): e96868.
28. Wilbur J, Kayastha S, Mahon T, Torondel B, Hameed S, et al. (2021) Qualitative study exploring the barriers to menstrual hygiene management faced by adolescents and young people with a disability, and their carers in the Kavrepalanchok district, Nepal. *BMC Public Health* 21(1).
29. Wilbur J, Mahon T, Torondel B, Hameed S, Kuper H (2019) Feasibility Study of a Menstrual Hygiene Management Intervention for People with Intellectual Impairments and Their Carers in Nepal. *International Journal of Environmental Research and Public Health* 16(19): 3750.
30. Ledger S, Earle S, Tilley E, Walmsley J (2016) Contraceptive decision-making and women with learning disabilities. *Sexualities* 19(5-6): 698-724.
31. McCarthy M (2009) I have the jab so I can't be blamed for getting pregnant': Contraception and women with learning disabilities. *Women's Studies International Forum* 32(3): 198-208.
32. McCarthy M (2011) Prescribing Contraception to Women with Intellectual Disabilities: General Practitioners' Attitudes and Practices. *Sexuality and Disability* 29(4): 339-349.
33. Schwartz BI, Alexander M, Breech LL (2020) Intrauterine Device Use in Adolescents with Disabilities. *Pediatrics* 146(2).
34. Walmsley J, Earle S, Tilley E, Ledger S, Chapman R, et al. (2016) The experiences of women with learning disabilities on contraception choice. *Primary Health Care* 26(9): 28-32.
35. Wu J, Zhang J, Mitra M, Parish SL, Minama Reddy GK (2018) Provision of Moderately and Highly Effective Reversible Contraception to Insured Women with Intellectual and Developmental Disabilities. *Obstetrics & Gynecology* 132(3): 565-574.
36. Björnsdóttir K, Stefánsdóttir Á, Stefánsdóttir GV (2017) People with Intellectual Disabilities Negotiate Autonomy, Gender and Sexuality. *Sexuality and Disability* 35(3): 295-311.
37. Christian L, Stinson J, Dotson LA (2001) Staff Values Regarding the Sexual Expression of Women with Developmental Disabilities. *Sexuality and Disability* 19(4): 283-291.
38. Li H, Mitra M, Wu JP, Parish SL, Valentine A, et al. (2018) Female Sterilization and Cognitive Disability in the United States, 2011-2015. *Obstetrics & Gynecology* 132(3): 559-564.
39. Márquez González H, Valdez Martínez E (2023) Legitimacy of hysterectomy to solve the "problem" of menstrual hygiene in adolescents with intellectual disability. *Gaceta Médica de México* 154(6).
40. Márquez González H, Valdez Martínez E, Bedolla M (2021) Clinical, Epidemiologic and Ethical Aspects of Hysterectomy in Young Females with Intellectual Disability: A Multi-Centre Study of Public Hospitals in Mexico City. *Frontiers in Public Health* 9.
41. Lindsay S, Fuentes K, Ragunathan S, Lamaj L, Dyson J (2022) Ableism within health care professions: a systematic review of the experiences and impact of discrimination against health care providers with disabilities. *Disability and Rehabilitation* 45(17): 2715-2731.





42. Höglund B, Larsson M (2019) Midwives' work and attitudes towards contraceptive counselling and contraception among women with intellectual disability: focus group interviews in Sweden. *The European Journal of Contraception & Reproductive Health Care* 24(1): 39-44.
43. Wickström M, Larsson M, Höglund B (2020) How can sexual and reproductive health and rights be enhanced for young people with intellectual disability? - focus group interviews with staff in Sweden. *Reproductive Health* 17(1).
44. Lee K, Devine A, Marco MaJ, Zayas J, Gill Atkinson L, et al. (2015) Sexual and reproductive health services for women with disability: a qualitative study with service providers in the Philippines. *BMC Women's Health* 15(1).
45. Czeisler MÉ, Board A, Thierry JM, Czeisler CA, Rajaratnam SMW, et al. (2021) Mental Health and Substance Use Among Adults with Disabilities During the COVID-19 Pandemic-United States, February–March 2021. *MMWR Morbidity and Mortality Weekly Report* 70(34):1142-1149.
46. Gordon J (2020) *Addressing Disparities: Advancing Mental Health Care for All Americans*. National Institute of Mental Health.
47. Hamilton M, Fisher K, Hill T (2018) Evaluation of the NDIS final report. *International Journal of Care and Caring* 2(4): 595-597.
48. World Health Organisation (2024) *Violence against women*.
49. Bates C, McCarthy M, Milne Skillman K, Elson N, Hunt S, et al. (2021) She misses the subtleties and I have to help-help to make the invisible visible': parents' role in supporting adults with intellectual and developmental disabilities with intimate relationships. *International Journal of Care and Caring* 5(3): 489-507.

