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Review Article

Ethical Challenges Faced by Individuals with Disabilities in Accessing Healthcare: A Systematic Review of Barriers, Discrimination, and Autonomy in Decision-Making.

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Abstract

Background: Despite progressive legal frameworks such as the Rights of Persons with Disabilities (RPwD) Act, 2016, and India's ratification of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), persons with disabilities (PWD) continue to face ethical challenges in accessing equitable healthcare in India. The objective of the study is to systematically synthesize evidence on ethical issues related to healthcare access, specifically barriers, discrimination, and autonomy in decision-making affecting PWD in India.
Methodology: A systematic search of seven electronic databases and grey literature sources was conducted for studies published between January 2005 and March 2025. Peer-reviewed quantitative, qualitative, and mixed-methods studies, along with relevant policy and advocacy reports, were eligible. Study quality was appraised using STROBE and CASP checklists for peer-reviewed literature, while grey literature was assessed based on source credibility and methodological transparency. The review protocol was registered with PROSPERO (CRD420251028645).
Results: Thirty sources were included, comprising 22 peer-reviewed studies and 8 grey literature or policy documents. Most peer-reviewed studies were of moderate methodological quality. The synthesis revealed persistent physical, financial, informational, and communication barriers to healthcare access. Attitudinal and institutional discrimination by healthcare providers was commonly reported, and autonomy was frequently compromised through substituted decision-making and inaccessible consent processes, particularly among individuals with intellectual or psychosocial disabilities. Ethical challenges were more pronounced in rural, tribal, and socio-economically marginalized populations.
Conclusion: Despite legal protections, significant ethical inequities in healthcare access for PWD persist in India. Strengthening implementation of existing laws, promoting disability-inclusive healthcare training, operationalizing supported decision-making, and improving disability-disaggregated health data are critical to advancing ethical, equitable, and inclusive healthcare.

Keywords: Disability; healthcare access; discrimination; autonomy; India.

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Introduction

Disability is a major public health and human rights concern globally and in India. The World Health Organization estimates that approximately 15–16% of the world's population lives with some form of disability, reflecting substantial and diverse healthcare needs across the life course [1]. In India, the 2011 Census reported 26.8 million persons with disabilities, accounting for 2.21% of the population [2]. This figure is widely acknowledged to be an underestimate, as it relies on a narrow, impairment-based definition and excludes functional and psychosocial limitations captured in newer international frameworks.

India has made significant legal and policy commitments toward protecting the rights of persons with disabilities. As a signatory to the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), India recognizes the right of persons with disabilities to the "highest attainable standard of health" without discrimination (Article 25) [3]. Domestically, the Rights of Persons with Disabilities (RPwD) Act, 2016 mandates barrier-free access to healthcare facilities and explicitly prohibits discrimination on the basis of disability [4]. More recently, the Mental Healthcare Act, 2017, has introduced provisions aimed at safeguarding autonomy through supported decision-making mechanisms.

Despite these legal safeguards, substantial ethical challenges persist in the healthcare experiences of persons with disabilities in India. Evidence consistently indicates that healthcare access remains inequitable, fragmented, and inadequately responsive to disability-related needs. These challenges can be conceptualized across three interrelated ethical domains: (i) barriers to healthcare access, (ii) discrimination within healthcare systems, and (iii) compromised autonomy in healthcare decision-making. Together, these domains reflect systemic failures to uphold the ethical principles of justice, dignity, beneficence, and respect for persons.

Barriers to healthcare access are multifaceted, encompassing physical, financial, informational, and communication-related obstacles. Many healthcare facilities remain physically inaccessible due to inadequate infrastructure, lack of assistive equipment, and absence of trained communication support such as sign language interpreters. Financial barriers further compound exclusion, as persons with disabilities are disproportionately affected by poverty and higher out-of-pocket healthcare expenditures. National-level analyses have reported that more than half of persons with disabilities in India are unable to afford needed healthcare, compared with approximately one-third of the non-disabled population [5]. Such barriers not only delay or prevent care but also raise fundamental concerns about distributive justice and equity.

Beyond access, discrimination, both attitudinal and institutional, remains a pervasive ethical concern. Persons with disabilities frequently report stigma, marginalization, and devaluation by healthcare providers, often stemming from inadequate training and entrenched social biases [6]. These discriminatory practices may manifest as dismissive attitudes, diagnostic overshadowing, or denial of appropriate care. Women with disabilities experience particularly severe and intersectional forms of discrimination; qualitative studies from India have documented exclusion from sexual and reproductive health services, violations of reproductive autonomy, and heightened vulnerability to abuse and neglect [7].

Autonomy in healthcare decision-making represents a third, closely linked ethical domain. Historically, paternalistic models of care have dominated, especially for individuals with intellectual or psychosocial disabilities, where decisions are often made by families or clinicians without meaningful patient involvement. Reports of coerced sterilization and non-consensual medical interventions highlight ongoing violations of bodily integrity and informed consent [8]. Although recent legislation promotes supported decision-making, implementation in routine clinical practice remains inconsistent and poorly evaluated.

While numerous studies, reports, and policy documents have addressed individual aspects of these challenges, the existing literature is fragmented across disciplines such as public health, law, ethics, and disability studies. To date, there has been no comprehensive systematic review synthesizing the ethical dimensions of healthcare access for persons with disabilities in India, particularly through the integrated lens of barriers, discrimination, and autonomy.

Accordingly, this systematic review aims to synthesize evidence published between 2005 and 2025 on the ethical challenges faced by persons with disabilities in accessing healthcare in India. Using a PRISMA-aligned methodology, the review integrates findings from peer-reviewed studies, grey literature, and policy documents to: (i) map key ethical concerns across the three domains, (ii) assess the quality and scope of available evidence, and (iii) identify gaps with implications for policy, practice, and future research. By consolidating this evidence, the review seeks to contribute to a more ethically grounded and disability-inclusive approach to healthcare in the Indian context.

Methodology

This systematic review was conducted and reported in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) 2020 guidelines. The methodology was defined a priori in a registered review protocol, which specified eligibility criteria, search strategy, screening procedures, data extraction, quality appraisal, and synthesis methods. The protocol was registered with the International Prospective Register of Systematic Reviews (PROSPERO) under the registration number CRD420251028645. No protocol deviations occurred during the conduct of the review.

Eligibility Criteria

Inclusion Criteria

We included English-language sources published between January 2005 and March 2025 that:

- Focused on individuals with physical, sensory, intellectual, or psychosocial disabilities in India.
- Examined ethical issues related to healthcare access, discrimination, or autonomy in decision-making.
- Included peer-reviewed quantitative, qualitative, or mixed-methods studies, reviews, case studies, and grey literature (e.g., government or NGO reports, legal documents, policy briefs).
- Were relevant to disciplines such as public health, ethics, law, disability studies, or health policy.

Exclusion Criteria

We excluded studies that:

- Were not conducted in the Indian context.
- Did not address healthcare access or ethical dimensions.
- Were published before 2005.
- Were unavailable in full text or not in English.
- Focused solely on clinical outcomes, rehabilitation efficacy, or biomedical interventions without ethical or access-related analysis.
- Conference abstracts, editorials, and dissertations were excluded unless complete reports were publicly accessible.

Search Strategy

A comprehensive literature search was conducted across the following electronic databases: PubMed, Embase, Web of Science, Scopus, CINAHL, Global Health, and IndMed. Searches were limited to English-language publications from January 2005 to March 2025. The final search was completed on 31 March 2025.

A sample PubMed search strategy was as follows: *(“persons with disabilities” OR disabled) AND (“healthcare” OR “health services”) AND (access OR barrier OR discrimination OR autonomy) AND India.*

Grey literature was identified through targeted searches of websites and repositories of the World Health Organization (WHO), Ministry of Health and Family Welfare (MoHFW), Government of India, National Human Rights Commission (NHRC), Rehabilitation Council of India (RCI), National Centre for Promotion of Employment for Disabled People (NCPEDP), Human Rights Law Network (HRLN), and the UNCRPD database, as well as through Google Scholar searches using predefined keywords. Reference lists of included studies were hand-searched to identify additional relevant sources. Key legislative and policy documents, including the Rights of Persons with Disabilities Act, 2016, were also included.

Study Selection

All records retrieved from the database and grey-literature searches were studied by the reviewers, and duplicate records were removed. Title and abstract screening were conducted independently by two reviewers, followed by full-text assessment of potentially eligible sources. Discrepancies were resolved through discussion and consensus.

The study selection process is illustrated in the PRISMA 2020 flow diagram (Figure 1). A total of 1,520 records were identified (1,500 from databases and 20 from other sources). After the removal of 200 duplicates, 1,320 records were screened. Of these, 1,200 records were excluded at the title and abstract stage. Full texts of 120 articles and reports were assessed for eligibility, resulting in the exclusion of 90 sources for reasons such as non-Indian context, lack of ethical or access-related focus, or insufficient relevant data. Ultimately, 30 sources were included in the qualitative synthesis, comprising 22 peer-reviewed studies and 8 grey literature or policy documents.

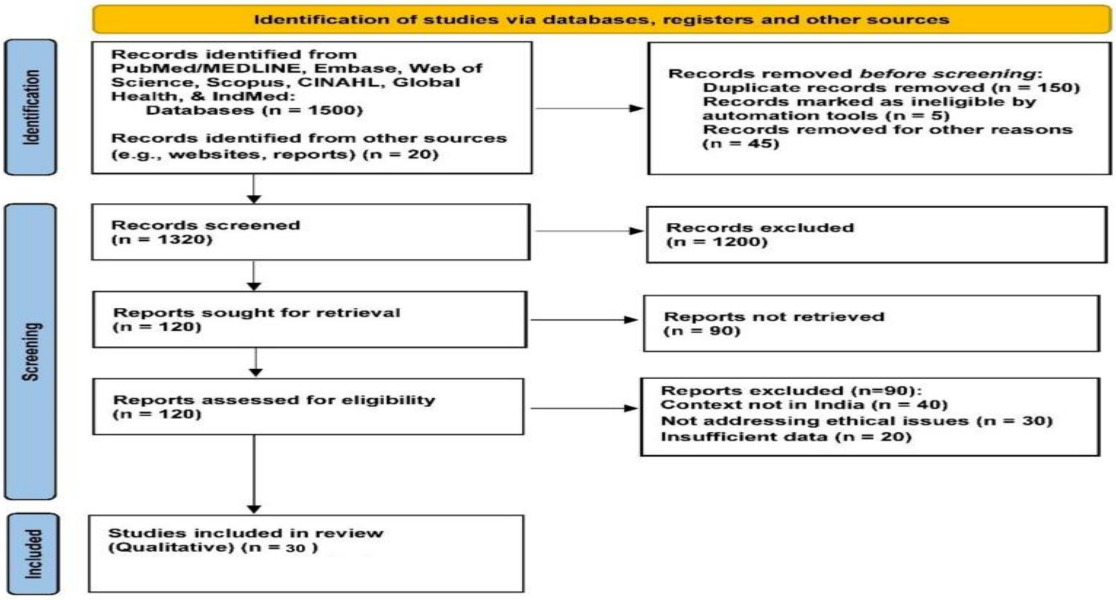


Figure 1: PRISMA 2020 Flow Diagram- Systematic Review on Ethical Challenges in Healthcare Access for Individuals with Disabilities.

Data Extraction and Synthesis

Data were extracted using a standardized data extraction form capturing: author and year, study design, population and setting, type of disability, ethical domain addressed (barriers, discrimination, and autonomy), key findings, and recommendations. Given the heterogeneity of study designs and outcomes, a narrative synthesis approach was employed.

Findings were organized thematically across the three predefined ethical domains: barriers to healthcare access, discrimination within healthcare systems, and autonomy in decision-making. Sub-themes were identified within each domain (e.g., physical versus financial barriers; attitudinal versus institutional discrimination; informed consent and supported decision-making). Where available, quantitative indicators (such as proportions, prevalence estimates, or odds ratios) were reported descriptively to illustrate the magnitude of ethical challenges. Meta-analysis was not undertaken due to methodological and outcome heterogeneity.

Quality Assessment

The methodological quality and risk of bias of included studies were assessed using tools appropriate to the study design. Quantitative observational studies were appraised using the STROBE checklist, supplemented by selected items from the NIH Quality Assessment Tool, focusing on sampling methods, measurement validity, and confounding. Qualitative studies were evaluated using the Critical Appraisal Skills Programme (CASP) qualitative checklist, assessing credibility, methodological rigor, and analytical transparency.

Each peer-reviewed study was categorized as high, moderate, or low quality. Overall, most peer-reviewed studies were of moderate methodological quality, with common limitations including non-representative samples and reliance on self-reported data. Grey literature and policy documents were not scored using STROBE or CASP; instead, their credibility was assessed based on the reputation of the issuing organization, transparency of methods, and consistency with other evidence. A summarized overview of quality appraisal findings is provided in Table 1, and a visual representation of STROBE adherence is shown in Figure 2. Study quality was not used as an exclusion criterion but was considered in the interpretation of findings.

Table 1: Quality appraisal of qualitative studies using the Critical Appraisal Skills Programme (CASP) checklist (10 items)

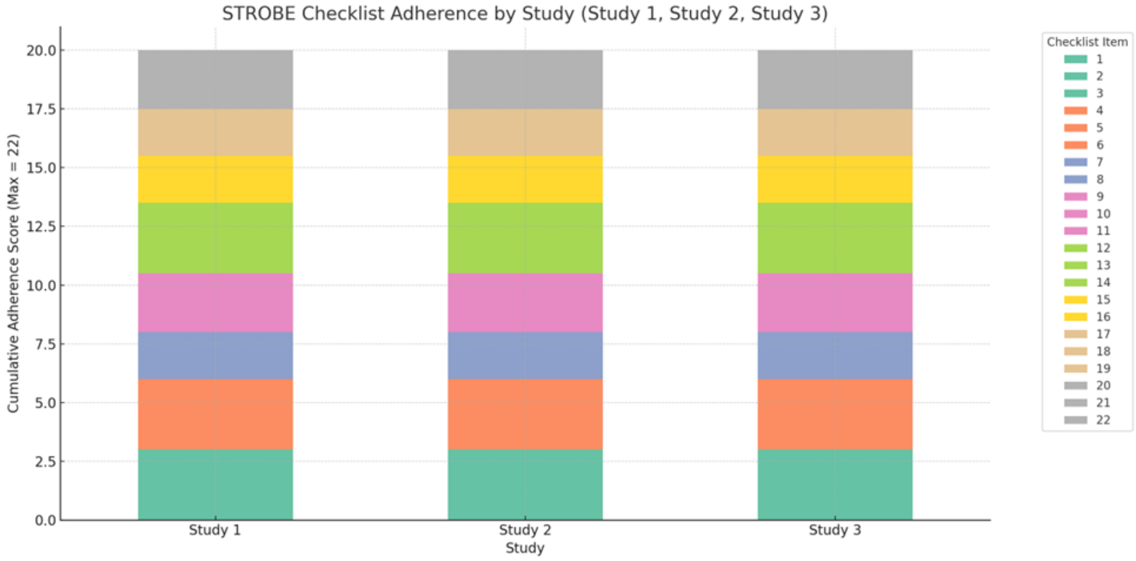
CASP DOMAIN	APPRAISAL QUESTION	Dean et al., 2017	Wullink et al., 2009
1. Study aims	Was there a clear statement of the research aims?	Yes	Yes
2. Methodology	Is a qualitative methodology appropriate for the research question?	Yes	Yes
3. Research design	Was the research design appropriate to address the aims?	Yes	Yes
4. Recruitment	Was the recruitment strategy appropriate and clearly described?	Yes	Yes
5. Data collection	Were data collected in a way that adequately addressed the research issue?	Yes	Yes

6. Reflexivity	Has the relationship between researchers and participants been adequately considered?	Unclear	Unclear
7. Ethics	Have ethical issues been taken into consideration (approval, consent, confidentiality)?	Yes	Yes
8. Data analysis	Was the data analysis sufficiently rigorous and systematic?	Yes	Yes
9. Findings	Is there a clear statement of findings supported by data (e.g., quotations)?	Yes	Yes
10. Value	Does the study contribute valuable insights to policy, practice, or research?	Yes	Yes
Overall quality	Number of CASP criteria met (out of 10)	9 / 10	9 / 10

Table 1 Scoring System: Yes = criterion clearly met; Unclear = partially reported or insufficient detail; No = not addressed.

Overall, the included qualitative studies demonstrated **moderate to high methodological quality**. All studies clearly articulated their aims, employed appropriate qualitative methodologies, and provided rigorous data analysis with well-supported findings. Ethical considerations were consistently addressed. However, **limited reporting on researcher reflexivity** was noted across studies, which is a common limitation in qualitative health research. No study was excluded on the basis of quality; appraisal findings were considered during the interpretation of results.

Figure 2: STROBE Checklist Adherence across included quantitative observational studies.
*This report presents a visualization of STROBE adherence across three observational studies labeled Study 1 (*Kumar et al., 2020*), Study 2 (*Gudlavalleti et al., 2014*), and Study 3 (*Mitra & Sambamoorthi, 2014*). The stacked bar chart below illustrates the contribution of each STROBE checklist item to the cumulative adherence score for each study.*



Reporting quality ranged from moderate to high. Large population-based studies demonstrated stronger adherence to STROBE criteria compared with smaller cross-sectional studies. No study was excluded on the basis of quality appraisal.

Assessment of Publication Bias

Formal assessment of publication bias was feasible only for the subset of quantitative studies reporting comparable healthcare access outcomes. To mitigate potential publication bias, grey literature was intentionally included. A funnel plot was constructed to explore small-study effects among quantitative studies comparing healthcare access between persons with disabilities and non-disabled populations. The funnel plot is presented as Figure 3 and demonstrates approximate symmetry around the pooled effect estimate; however, interpretation is cautious due to the small number of studies and outcome heterogeneity. Potential biases and evidence gaps are further discussed in the Discussion section.

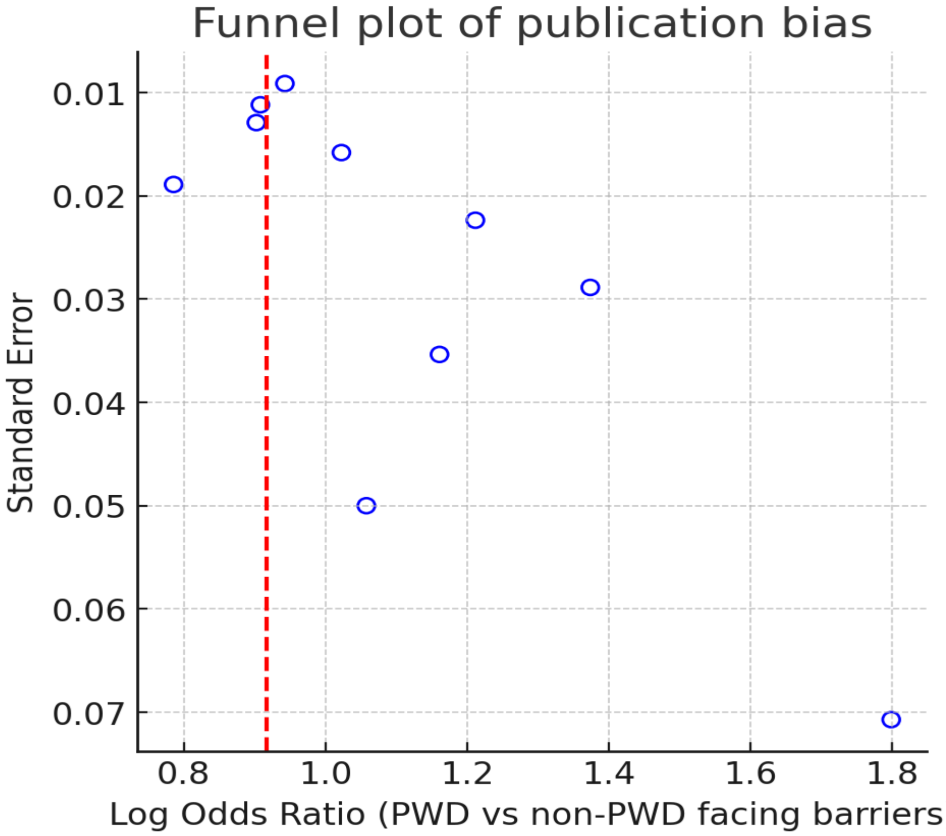


***Figure 3**: Funnel plot assessing publication bias for quantitative studies (each point represents a study's effect size (log odds ratio of poorer access for PWD vs non-PWD) versus its standard error). The red dashed line indicates the average effect. Approximate symmetry suggests no strong publication bias, but interpretation is cautious given the small number of studies and heterogeneity of outcomes.*

Results

Study Characteristics

A total of 30 sources met the inclusion criteria, comprising 22 peer-reviewed journal articles and 8 grey literature or policy documents. The characteristics of included sources are summarized in Table 2.

Table 2: Characteristics and key findings of included studies/reports (2005–2025) on healthcare access challenges for people with disabilities in India.

SOURCE (Author, Year)	POPULATION & SETTING	STUDY DESIGN	KEY FINDINGS (Relevance to Barriers, Discrimination, Autonomy)
Gudlavalleti et al. 2014 (South India Disability Evidence "SIDE" study)	839 adults with disabilities vs 1,153 without; rural districts in Andhra Pradesh & Karnataka	Cross-sectional survey (community-based; matched comparison)	PWD had significantly higher healthcare needs: 18.4% needed hospital care in the past year vs. 8.8% of non-disabled. Greater burden of chronic conditions (4.6× risk of diabetes, 5.8× risk of depression). PWD faced more barriers to accessing services than others – common barriers included a lack of information about services, high cost of services, and transportation difficulties. Highlights both physical/financial **barriers** and resulting health disparities.
Kothari, 2014 ("Right to Health of Persons with Disabilities in India" report)	Persons with various disabilities across India: policy and legal scope	Policy analysis & qualitative inquiry (consultations in 4 zones of India)	Found that the healthcare system often fails to accommodate PWD. The 1995 Disabilities Act lacked specific health rights. Documented cases of denial of treatment and discrimination in government hospitals. Emphasized non-discrimination as a legal mandate and noted that many PWD rely on caregivers for decisions, indicating compromised autonomy. Recommended inclusion of health rights in law (precursor to RPwD Act 2016).
Senjam & Singh, 2020 (Indian J Public Health Commentary)	Not applicable (commentary drawing on national data and WHO reports)	Commentary (summary of evidence and policy)	Estimated ~2.2% of Indians have disabilities (acknowledged as a likely underestimate). Identified major barriers: physical inaccessibility of facilities (e.g. ~ only 3.6% of public buses were wheelchair-accessible in 2018), cost (53% of PWD couldn't afford care vs 32% non-PWD), and provider knowledge gaps. Noted discrimination by healthcare staff and societal stigma towards disabled patients. Urged inter-ministerial coordination and disability inclusion in health programs.

Dean et al., 2017 ("You're disabled, why did you have sex?" – Gujarat)	22 women with disabilities (age 18–49), Gujarat (urban & rural)	Qualitative (in-depth interviews; intersectional analysis)	Estimated ~2.2% of Indians have disabilities (acknowledged likely underestimate). Identified major barriers: physical inaccessibility of facilities (e.g. ~ only 3.6% of public buses wheelchair-accessible in 2018), cost (53% of PWD couldn't afford care vs 32% non-PWD), and provider knowledge gaps. Noted discrimination by healthcare staff and societal stigma towards disabled patients. Urged inter-ministerial coordination and disability inclusion in health programs.
Human Rights Watch, 2014 ("Treated Worse Than Animals")	Women and girls with psychosocial or intellectual disabilities in institutional care, across 6 Indian cities	Investigative report (qualitative interviews, facility visits)	Exposed severe violations of autonomy and rights: many women with mental disabilities were institutionalized without consent, subjected to neglect, abuse, and forced treatments (including electroconvulsive therapy without proper consent). Documented instances of forced sterilization or contraception in institutions as a means of menstrual management or to prevent pregnancies from sexual abuse. These practices were done with guardian or administrative consent, effectively stripping women of decision-making autonomy. The report also noted discriminatory attitudes among staff (treating patients as sub-human) and grossly inadequate services (barriers to basic healthcare like OBGYN care within institutions). Catalyzed calls for deinstitutionalization and stronger safeguards (some of which informed the Mental Healthcare Act 2017).
Thiagesan et al., 2023 (Ethical framework study, Tamil Nadu)	Not specific to one location – based on literature and stakeholder input (Public Health Ethics workshop in TN)	Thematic analysis (ethical analysis of barriers)	Articulated an ethical framework for addressing healthcare barriers for PWD, grounded in principles of justice, fairness, and trust. Reiterated that PWD have greater healthcare needs but face disproportionate access challenges – thus justice requires affirmative measures for easier access. Identified key barriers: lack of disability-friendly transport, inaccessible clinics and equipment (beds, examination tables), communication barriers (e.g. no sign language interpreters), and intersectional disadvantages (gender, age, caste intersecting with disability). Noted that

			despite RPwD Act 2016 requiring barrier-free healthcare and campaigns like Accessible India, implementation is lagging (e.g. audits showed only ~36% of government websites and half of airports were accessible by 2018). Stressed the ethical imperative to improve autonomy e.g. ensuring informed consent processes are accessible and respecting legal capacity.
Sharma & Sivakami, 2019 (BMC Public Health)	Persons with disabilities in rural Maharashtra (mixed ages; various disabilities)	Mixed-methods (survey + focus groups)	Focused on intersectionality: found that disabled women in rural areas and those from lower castes reported compounded difficulties in accessing health services. Common barriers were distance to health facilities and lack of transportation, exacerbated for those also facing gender/caste inequities. Qualitative findings highlighted discriminatory treatment by some providers, who prioritized other patients or were insensitive to communication needs. Illustrates how social factors intersect to deepen healthcare inequity for PWD.
Women with Disabilities India Network (WWDIN), 2019 (UNCRPD Alternate Report)	441 women with disabilities across 23 states (testimonies collected 2017–18)	Advocacy report (survey & interviews; submitted to UN Committee)	Reported systemic denial of sexual and reproductive health services to women with disabilities, especially those with intellectual disabilities. Contraception and abortion services were often inaccessible either refused outright or not made disability-friendly. In many cases, women (including minors) were coerced or forced into hysterectomies or sterilization by family or institutions "for convenience", violating their consent. Even when women were capable, their choices were overridden (guardians or doctors assumed they cannot decide). This underscores severe breaches of autonomy in decision-making and highlights gendered discrimination (violation of reproductive rights). The report urged stronger enforcement of laws prohibiting forced sterilization and called for supported decision-making frameworks.

Azizatunnisa et al., 2024 (Int. J. Equity Health)	People with disabilities in low- and middle-income countries (incl. India)	Systematic review (38 studies; quantitative)	Though not India-specific, included several Indian studies on health insurance. Found that health insurance coverage among PWD is generally low in LMICs. One included Indian study showed PWD are less likely to be enrolled in insurance schemes than others. Lack of insurance contributes to high out-of-pocket expenses. The review noted that when PWD do have insurance, it can increase utilization of health services. Highlights a financial barrier and an area of structural discrimination (historically, insurance schemes did not adequately target or accommodate disabled persons).
Duffy et al., 2018–2019 (multiple articles)	Mental healthcare policy and law in India	Legal/policy analysis (commentaries)	Analysed the Mental Healthcare Act 2017 vis-à-vis international standards. Noted that the Act enshrines rights to informed consent and participation for persons with mental illness, aiming to replace substitute decision-making with supported decision-making. However, Duffy et al. observed tensions in implementation: for example, involuntary admission is still permitted under certain conditions, raising debate on autonomy. They emphasized that any deprivation of liberty or treatment without consent should be an exceptional measure, aligning with UNCRPD's stance that disability per se should never justify loss of legal capacity. These papers underline progress in Indian law on respecting autonomy, while also cautioning about persistent paternalistic attitudes in practice.

Abbreviations: (PWD = persons with disabilities; OR = odds ratio; OoPE = Out-of-Pocket expenditure)

Among the peer-reviewed studies, 10 were quantitative observational studies, 7 were qualitative studies, 3 employed mixed-methods designs, and 2 were systematic or scoping reviews. The grey literature included national policy reports, legal analyses, and advocacy documents [1,10,14,16]. Most studies were published between 2010 and 2024, with an increase following India's ratification of the UNCRPD [3].

Geographically, studies included national-level analyses as well as state-specific investigations, notably from Karnataka and Andhra Pradesh (community surveys) [9], Gujarat (qualitative studies on reproductive and sexual health) [7], and Tamil Nadu (ethical and policy analyses) [4]. Disability categories were often aggregated; however, women with disabilities, persons with psychosocial or intellectual disabilities, and institutionalized populations were specifically examined in multiple studies [7, 8, 12, 14].

Barriers to Healthcare Access

Physical and Environmental Barriers

Physical inaccessibility of healthcare facilities was reported in 21 of 30 sources (70%) [4,5,9,10]. Commonly documented barriers included absence of ramps or elevators, inaccessible toilets, lack of adjustable examination equipment, and absence of Braille or tactile signage [4,9]. Quantitative surveys reported a higher prevalence of infrastructural barriers among persons with disabilities compared with non-disabled populations, including building inaccessibility (12–13%) and non-adapted medical equipment (13%), versus approximately 2% among comparison groups [9]. Rural settings were consistently associated with longer travel distances and fewer accessible facilities [5,13].

Financial Barriers

Financial constraints were identified in 18 of 30 sources (60%) [5,9,11,13]. Quantitative studies reported that approximately half of persons with disabilities were unable to afford healthcare services, compared with roughly one-third of non-disabled individuals [5,9]. Limited insurance coverage, exclusion of disability-related needs from public schemes, and high out-of-pocket expenditure were commonly described [11,13]. Indirect costs such as transportation and caregiving were noted in several studies [5,9].

Informational and Communication Barriers

Informational or communication-related barriers were reported in 14 of 30 sources (47%) [5,9,12]. Quantitative data indicated that 10–15% of persons with disabilities lacked awareness of available services [9]. Qualitative studies described limited availability of sign-language interpreters, absence of easy-read or alternative communication formats, and healthcare providers' limited capacity to communicate with persons with intellectual or hearing impairments [12].

Service Availability and Human Resource Constraints

Inadequate availability of specialized services and trained personnel was reported in 16 of 30 sources (53%) [4,5,10]. Gaps were particularly noted in rehabilitation services, mental healthcare, and primary care settings, especially outside tertiary Centres [5,10]. Several studies documented limited provider training in disability-specific care [6].

Discrimination in Healthcare Settings

Attitudinal Discrimination

Attitudinal discrimination by healthcare providers was reported in 17 of 30 sources (57%) [5,6,7,12]. Qualitative studies described experiences of stigma, dismissive behaviour, and avoidance of direct communication with patients, particularly among individuals with intellectual or psychosocial disabilities [7,12].

Discrimination in Treatment and Quality of Care

Disparities in treatment quality, including delayed care, shortened consultations, and denial of services, were described in 12 sources (40%) [5,7,10]. Diagnostic overshadowing, where symptoms were attributed to disability rather than evaluated independently, was reported in several studies [12,17]. Preventive services, including reproductive and cancer screening, were inconsistently provided to women with disabilities [7,8].

Institutional and Structural Discrimination

Structural discrimination related to fragmented governance, poor inter-sectoral coordination, and limited integration of disability within health policy frameworks was identified in 10 sources (33%) [4,5,10,16]. Policy analyses highlighted gaps between legislative mandates and implementation at the facility level [4,10].

Autonomy and Healthcare Decision-Making

Substituted Decision-Making and Consent

Compromised autonomy in clinical decision-making was reported in 15 of 30 sources (50%) [7,8,12,16]. Substituted decision-making by family members or institutions, particularly for individuals with intellectual or psychosocial disabilities, was frequently documented [7,12]. Multiple reports described inaccessible consent procedures, including the absence of simplified language, alternative formats, or supported decision-making mechanisms [8,16].

Institutionalization and Autonomy

Restrictions on autonomy within institutional care settings were reported in 7 sources, particularly among persons with psychosocial or intellectual disabilities [8,14,16]. These included prolonged institutional stays and limited participation in treatment decisions.

Communication and Autonomy

Barriers to effective communication affecting decision-making were reported in 11 sources, including a lack of interpreters and assistive communication devices [12,17]. These limitations were associated with reduced patient participation in consent and treatment discussions [12].

Discussion

This systematic review synthesizes two decades of evidence on the ethical challenges faced by persons with disabilities (PWD) in accessing healthcare in India. Despite progressive legislative frameworks such as the RPwD Act, 2016, and India's obligations under the UNCRPD, the findings demonstrate persistent ethical inequities across three interrelated domains: barriers to healthcare access, discrimination within healthcare systems, and compromised autonomy in decision-making [3,4].

Integration with Global Evidence

The ethical challenges identified in this review align closely with findings from other low- and middle-income countries (LMICs). Global syntheses and WHO reports consistently document poorer access to healthcare, higher unmet health needs, and lower quality of care among persons with disabilities compared with non-disabled populations [1,17]. Similar patterns have been reported in sub-Saharan Africa and Southeast Asia, where barriers extend beyond physical inaccessibility to include financial hardship, informational deficits, and systemic neglect [17]. India's scale, diversity, and mixed public–private healthcare system further complicates these challenges, particularly in rural and underserved regions [5,9].

High-income countries have reported comparable ethical concerns, particularly related to diagnostic overshadowing and consent capacity, but have implemented mitigating strategies such as disability health passports, liaison nurses, and structured supported decision-making models [17]. While these models may not be directly transferable, India's extensive community health workforce offers opportunities for contextually appropriate adaptation [5].

Policy and Practice Implications

The persistence of access barriers highlights the need for stronger implementation and monitoring of existing legal mandates, particularly the RPwD Act, 2016 [4]. Physical accessibility standards must be translated into enforceable facility-level requirements, supported by routine audits and accountability mechanisms [4,10]. Financial protection remains a critical ethical concern; public insurance schemes must explicitly incorporate disability-related needs, including assistive devices, rehabilitation, and long-term care [11,13].

Discrimination within healthcare settings underscores the limitations of legal reform in the absence of cultural and educational change. Integrating disability ethics and communication training into undergraduate and postgraduate health curricula has demonstrated improvements in provider attitudes and competence [6]. Standardized protocols ensuring respectful communication and accessible grievance redress mechanisms are essential [5,12].

Respect for autonomy requires moving from policy intent to practical implementation. Although Indian mental health legislation endorses supported decision-making, clinical practice continues to rely heavily on substituted decision-making [16]. Operationalizing autonomy through accessible consent processes, easy-read materials, interpreters, and assistive communication technologies is essential [8,12].

Strengths and Limitations of Included Studies

The included studies provide valuable insights across diverse settings and populations. Strengths include rich qualitative accounts of lived experience [7,12] and policy-level analyses that contextualize empirical findings [4,10,16]. However, most quantitative studies were cross-sectional, limiting causal inference [5,9,13]. Intellectual and psychosocial disabilities were comparatively under-represented, and many studies relied on self-reported data or were geographically concentrated in urban or southern regions of India [5,9].

Strengths and Limitations of the Review

A key strength of this review lies in its comprehensive scope, integrating peer-reviewed literature with grey literature and policy documents to provide a multidimensional ethical analysis [1,10,14]. Use of PRISMA-aligned methods and structured quality appraisal enhances transparency. Nevertheless, non-indexed regional studies may have been missed, and publication bias may favour studies highlighting barriers and discrimination over positive practices [17].

Research Gaps and Future Directions

The review highlights the need for longitudinal and intervention-based studies evaluating accessibility reforms, training programs, and supported decision-making initiatives. Nationally representative datasets with disability-disaggregated health indicators are essential for monitoring equity and informing policy [1,13]. Under-researched populations, particularly persons with psychosocial disabilities, institutionalized individuals, and those in rural, tribal, and northeastern regions, require focused investigation [8,14].

Ethical Implications

Ethical approval was not required as this was a review of published and publicly available data. However, as per the standard operating procedures followed in Tripura Medical College & Dr. BRAM Teaching Hospital, the Institutional Ethics Committee permission has been obtained. The findings reinforce core bioethical principles. Justice demands proactive accommodation and affirmative measures under the UNCRPD [3]. Autonomy requires dismantling paternalistic practices and enabling supported decision-making [16]. Beneficence and non-maleficence obligate health systems to prevent harm arising from inaccessible or discriminatory care [1,5]. Upholding dignity must remain central to all healthcare interactions involving persons with disabilities.

Conclusion

Over the past two decades, growing awareness has emerged about the ethical challenges faced by persons with disabilities in accessing healthcare in India. This review highlights three core issues: access barriers (physical, financial, informational), pervasive discrimination (attitudinal and systemic), and compromised autonomy through substituted decision-making and lack of consent. While India's policy landscape through the RPwD Act and Mental Healthcare Act has shifted toward a rights-based framework, implementation gaps persist. Addressing these issues is essential for achieving universal health coverage and ethical healthcare. This review offers evidence to guide reforms that ensure dignity, equity, and autonomy for persons with disabilities.

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