Discrimination and Access to Healthcare for People with Disabilities: An Integrative Literature Review*

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Theme: Health promotion, well-being, and quality of life

Contributions to the discipline: This study contributes to obtaining and investigating new scientific evidence that will help with research into the discrimination faced by people with disabilities in health services. It is of the utmost importance that professionals can identify the main barriers and challenges faced by this public and implement health promotion strategies, to improve well-being and equal access to services, directly impacting the quality of life of this population.

Abstract

Introduction: People with disabilities face many challenges on a daily basis. Despite legislative advances and inclusion policies, discrimination against people with disabilities persists in various areas of life, including access to health services. Aim: This study aims to conduct an integrative literature review to investigate the factors associated with discrimination faced by people with disabilities in health services. Materials and Methods: The search was conducted in February 2024 in the IBECS, Lilacs, BDEnf, Medline (PubMed), Scopus, and Web of Science databases. The health descriptors (DeCS) "people with disabilities," "social discrimination," and "health services" were used. Original articles available in full, from the last five years, and in any language were included. The exclusion criteria were duplicate articles and those that did not answer the guiding question. Results: A total of 162 records were identified, from which 17 studies were selected, resulting in a final sample of 10 articles. The main factors associated with the discriminatory experiences faced by people with disabilities when accessing and using the health system were "stigmatization," "negligence," "prejudice," and "access difficulties." Conclusions: Significant drivers of discrimination were identified, including financial barriers, lack of training for health professionals, and other gaps that generate prejudice, stigmatization, and neglect. It is essential to implement public policies to ensure service accessibility, provide financial assistance for people with disabilities, establish training programs for health professionals, and conduct more research on this subject.

Keywords (Source: DeCS)

Disabled persons; health services accessibility; disability discrimination; health vulnerability; health of the disabled.

Discriminación y acceso a la salud de personas con discapacidad: una revisión integradora de la literatura*

* El estudio se realizó con la dedicación de todos los autores y el apoyo del grupo de investigación y extensión de promoción de la salud en el ámbito de los países lusitanos: cuidado, comunicación y tecnologías a la persona con y sin vulnerabilidad, registrado en el directorio del Conselho Nacional de Desenvolvimento Científico e Tecnológico (CNPq) de Brasil, y en actividades en la Universidade da Integração Internacional da Lusofonia Afro-Brasileira (Unilab).

Resumen

Introducción: las personas con discapacidad se enfrentan a numerosos retos cotidianos. A pesar de los avances legislativos y las políticas de inclusión, la discriminación de las personas con discapacidad persiste en diversos ámbitos de la vida, incluido el acceso a los servicios de salud. Objetivo: realizar una revisión integradora de la literatura para investigar los factores asociados a la discriminación que sufren las personas con discapacidad en los servicios de salud. Materiales y método: la búsqueda se realizó en febrero de 2024, en las bases de datos IBECS, Lilacs, BDEnf, Medine (Pub-Med), Scopus y Web of Science; se utilizaron los descriptores de salud (DeCS) "personas con discapacidad", "discriminación social" y "servicios de salud". Se incluyeron artículos originales, disponibles en su totalidad, de los últimos cinco años y en cualquier idioma. En cuanto a los criterios de exclusión, se optó por excluir los artículos duplicados y los que no respondían a la pregunta orientadora. Resultados: se identificaron 162 registros, de los cuales se seleccionaron 17 estudios y, al final, la muestra totalizó 10 hallazgos. De estos hallazgos, los principales factores asociados a la experiencia discriminatoria a la que se enfrentan las personas con discapacidad a la hora de acceder y utilizar el sistema de salud fueron la "estigmatización", la "negligencia", los "prejuicios" y las "dificultades de acceso". Conclusiones: se encontraron algunos factores de discriminación significativos, como las barreras financieras, la falta de formación de los profesionales de la salud y otras brechas que generan prejuicios, estigmatización y negligencia. Por lo tanto, es fundamental contar con políticas públicas que garanticen la accesibilidad de los servicios, ayudas económicas para los pacientes con discapacidad, programas de formación para los profesionales de la salud y más investigación sobre este tema.

Palabras clave (DeCS)

Personas con discapacidad; accesibilidad a los servicios de salud; capacitismo; vulnerabilidad en salud; salud de las personas con discapacidad.

Discriminação e acesso à saúde de pessoas com deficiência: uma revisão integrativa da literatura

* Este estudo foi realizado com a dedicação de todos os presentes autores e com o apoio do grupo de pesquisa e extensão de promoção da saúde no cenário dos países lusófonos: assistência, comunicação e tecnologias à pessoa com/sem vulnerabilidade, cadastrado no diretório do Conselho Nacional de Desenvolvimento Científico e Tecnológico (CNPq) do Brasil, e em atividade na Universidade da Integração Internacional da Lusofonia Afro-Brasileira (Unilab).

Resumo

Introdução: as pessoas com deficiência enfrentam vários desafios diários. Apesar dos avanços legislativos e das políticas de inclusão, a discriminação contra pessoas com deficiência persiste em diversas áreas da vida, incluindo o acesso aos serviços de saúde. Objetivo: realizar uma revisão integrativa da literatura para investigar quais os fatores associados à discriminação sofrida por pessoas com deficiência nos serviços de saúde. Materiais e método: a busca ocorreu em fevereiro de 2024, nas bases de dados IBECS, Lilacs, BDEnf, Medine (PubMed), Scopus e Web of Science; foram usados os descritores em saúde (DeCS) "pessoas com deficiência", "discriminação social" e "serviços de saúde". Foram incluídos artigos originais, disponíveis na íntegra, dos últimos cinco anos e em qualquer idioma. Quanto aos critérios de exclusão, optou-se por excluir artigos duplicados e que não respondiam à questão norteadora. Resultados: foram identificados 162 registros, dos quais foram selecionados 17 estudos e, ao final, a amostra totalizou em 10 achados. Desses achados, os principais fatores associados à experiência discriminatória enfrentada por pessoas com deficiência ao acessar e utilizar o sistema de saúde foram "estigmatização", "negligência", "preconceito" e "dificuldades de acesso". Conclusões: alguns impulsionadores significativos da discriminação foram encontrados como barreiras financeiras, falta de treinamento dos profissionais de saúde e demais lacunas geradoras de preconceito, estigmatização e negligência. Portanto, é fundamental que se tenham políticas públicas para garantir a acessibilidade dos serviços, assistência financeira aos pacientes com deficiência, programas de capacitação para profissionais de saúde e mais pesquisas nessa temática.

Palavras-chave (Fonte DeCS)

Pessoas com deficiência; acessibilidade aos serviços de saúde; capacitismo; vulnerabilidade em saúde; saúde da pessoa com deficiência.

Introduction

People with disabilities (PwDs) represent a significant portion of the world's population and face several daily challenges, many related to accessibility, inclusion, and discrimination (1). Disability can take many forms—physical, sensory, intellectual, and mental—affecting the lives and social participation of these individuals (2). Historically, PwDs have been marginalized and excluded from many spheres of society, facing physical, social, and institutional barriers that limit their full development and participation (3, 4).

Demographic data reveal the extent of the disabled population worldwide, highlighting the importance of understanding their specific needs and combating the challenges they face (5). According to a report by the World Health Organization, it is estimated that more than one billion people, or approximately 15% of the global population, live with some form of disability. This number is growing as the world's population ages and chronic conditions become more prevalent (6).

Despite legislative advances and inclusion policies, discrimination against PwDs persists in various areas of life, including access to health services (7, 8). Discrimination can manifest in various ways, from enabling practices by health professionals to the failure to adapt services and facilities to meet the specific needs of these patients (9).

Access to health services is crucial to ensuring the well-being and quality of life of PwDs, yet many face obstacles when trying to obtain adequate medical care (8). Physical barriers, such as non-adapted facilities and inaccessible transportation, along with social barriers, such as discriminatory attitudes and a lack of cultural sensitivity among health professionals, as well as communication barriers when interacting with health professionals, can limit these individuals' access to quality health care (8, 10).

It is worth highlighting that health care for the disabled population still needs to be improved (11). Furthermore, there is an undeniable need for changes to improve care and communication with people with disabilities. Reducing barriers to access for this population is essential to reducing failures and damage to the health system (12).

Given this scenario, studies investigating the discrimination faced by PwDs in health services are justified to identify the main barriers and challenges and to propose strategies to promote inclusion and equal access (9). Gaining a better understanding of the experiences of these individuals in health services is essential for developing policies and practices that promote equity and ensure that everyone has access to health care (13).

In this context, the aim of this study is to conduct an integrative literature review to investigate the factors associated with discrimination suffered by PwDs in health services, analyzing the main issues, knowledge gaps, and recommendations to promote more inclusive and accessible care.

Materials and Methods

This is an integrative literature review that seeks to contribute to improving and updating existing scientific databases (14). To construct this integrative review, seven stages were stipulated: i) Construction of the guiding question; ii) Definition of the inclusion and exclusion criteria; iii) Application of the search strategy; iv) Selection of articles by title and abstract; v) Selection of articles by full text; vi) Assessment of the quality of the articles, and vii) Synthesis of the final sample (15).

The research question was constructed following the PICo strategy, an acronym for "P" for population; "I" for interest; "Co" for context (16), in which population referred to PwD; interest, to social discrimination; and context, to health services. Thus, the question was "What factors are associated with the discriminatory experience faced by PwD when accessing and using the health system?"

The inclusion criteria were original articles available online in the last five years, in any language, and produced in any country. Exclusion criteria were duplicate articles and articles that did not answer the research question.

The searches were performed in February 2024 in the following databases via the VHL (virtual health library): Índice Bibliográfico Español en Ciencias de la Salud (IBECS); Latin American and Caribbean Health Sciences Literature (Lilacs); Nursing Database (BDEnf), and in the international databases: Medical Literature Analysis and Retrieval System online (Medline) via PubMed; Scopus; and Web of Science, accessed in person in the city of Redenção in Ceará, through the Federated Academic Community, from the Portal of Journals of the Coordination for the Improvement of Higher Education Personnel (known as "Capes"). Regarding the search strategy, the guiding question was used to select the health sciences descriptors (DeCS) and the Medical Subject Headings (MeSH), combined by the Boolean operator "AND" in the advanced search of the databases. The search strategy and its controlled and uncontrolled descriptors are presented in Table 1.

Table 1. Search strategies used in the databases. Redenção, Ceará, Brazil, 2024

Strategy in Portuguese					
Person	"pessoas com deficiência" OR "deficiência física" OR "deficiências físicas" OR "deficiente físico" OR "limitação física" OR "pessoa com deficiência física" OR "pessoa com desvantagem" OR "pessoa com incapacidade" OR "pessoa com incapacidade física" OR "pessoa com limitação física" OR "pessoa com necessidade especial" OR "pessoas com deficiência física" OR "pessoas com deficiências" OR "pessoas com deficiências físicas" OR "pessoas com desvantagens" OR "pessoas com incapacidade física" OR "pessoas com incapacidade física" OR "pessoas com incapacidades" OR "pessoas com limitação física" OR "pessoas com limitações físicas" OR "pessoas com necessidade especial" OR "pessoas com necessidades especiais"				

AND				
Interest	"discriminação social" OR "ableísmo" OR "capacitismo" OR "discriminação"			
AND				
Context	"serviços de saúde" OR "consumo de serviços de saúde" OR "rede prestadora de serviços de saúde" OR "serviço de saúde" OR "serviços de atenção ao paciente" OR "uso de serviços de saúde"			
Strategy in English				
Person	"disabled persons" OR "disabled person" OR "person, disabled" OR "persons, disabled" OR "handicapped" OR "people with disabilities" OR "disabilities, people with" OR "people with disability" OR "persons with disabilities" OR "disabilities, persons with" OR "disability, persons with" OR "persons with disability"			
AND				
Interest	"social discrimination" OR "discrimination, social" OR "discriminatory practices" OR "discriminatory practice" OR "practice, discriminatory" OR "exposure to discrimination" OR "exposure to discriminations" OR "discrimination exposure" OR "discrimination exposures" OR "exposure, discrimination"			
AND				
Context	"health services" OR "health service" OR "services, health"			

Source: Prepared by the authors.

The articles obtained from applying the search strategy were exported to the Rayyan software (17), where duplicate articles were identified and excluded, and then moved on to stage 4, in which the articles were preliminarily selected based on their title and abstract, and later based on their full text. The Preferred Reporting Items for Systematic Reviews and Meta-Analyses – Prisma (18) checklist was used in these stages. The articles were independently selected by two authors, with a third author designated to resolve possible conflicts.

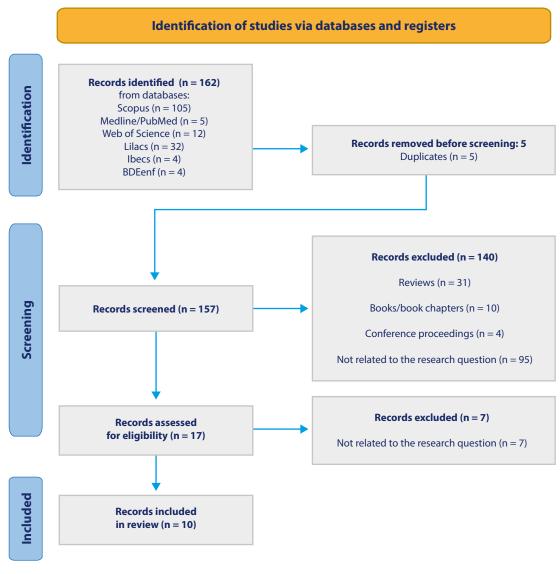
To define the quality of the studies, the classification proposed by Melnyk and Fineout-Overholt (19) of six levels was used: Level 1 - meta-analysis of multiple controlled studies; Level 2 - individual study with an experimental design; Level 3 - study with a quasi-experimental design, such as a study without randomization with a single pre- and post-test group, time series, or case-control; Level 4 - study with a non-experimental design, such as descriptive correlational and qualitative research or case studies; Level 5 - case report or data obtained systematically, of verifiable quality or program evaluation data, and Level 6 - opinion of reputable authorities based on clinical competence or opinion of expert committees, including interpretations of information not based on research.

In the process of collecting and analyzing the data from the final sample, Microsoft Excel spreadsheets were used to gather and organize the data and for the authors to create tables. This allowed the data to be visualized easily and clearly, making it easier to understand and interpret the results.

Results

After applying the search strategy in the advanced query of the selected databases, the total sample was 162 articles, of which 5 were excluded because they were duplicates. After screening the records by title and abstract, a further 45 were excluded for not being original articles, and another 95 papers were excluded for not answering the research question. Seventeen findings remained to be read in full, and a further seven were excluded. In the end, 10 articles were included in the final review sample. The selection process and other information can be better visualized in the Prisma flowchart in Figure 1.

Figure 1. PRISMA Study Selection Process Flowchart



Source: Adapted from Prisma flowchart, 2020.

Of the 10 articles included in the final sample of this review, 100% (n = 10) were in journals indexed in the Scopus database; 90% (n = 9) were published in English and only 10% (n = 1) were in Portuguese. As for the country of origin, there was a greater incidence of the United States of America, with 20% (n = 2); other countries

such as New Zealand, Ghana, Hong Kong, the United Kingdom, Iran, Brazil, Germany, and Liberia also appear as countries of origin of the studies, all with 10% (n = 1) each.

As for the level of evidence of the studies, 60% (n = 6) of the papers received level IV, as they were descriptive studies; 30% (n = 3) of the articles received level V, as they used secondary data in their research, and 10% (n = 1) received level II, as it was an experimental study. The bibliographic results can be seen in Table 2.

Table 2. Data Relating to the Studies Included in the Sample Characterization. Redenção, Ceará, Brazil, 2024

C *	Year/Country	Title	Journal/Database/ Language	Type of Study/ NE@
A1	2019/ United States of America	A cross-sectional study to investigate the effects of perceived discrimination in the health care setting on pain and depressive symptoms in wheelchair users with spinal cord injury (20)	Archives of Physical Medicine and Rehabilitation/Scopus/ English	Secondary data study/V
A2	2022/New Zealand	Ableism, human rights, and the COVID-19 pandemic: Healthcare-related barriers experienced by deaf people in Aotearoa New Zealand (21)	Int. J. Environ. Res. Public Health/Scopus/ English	Qualitative descriptive exploratory/IV
A3	2022/Ghana	Experiencing motherhood as a blind mother in the Greater Accra Region of Ghana: A qualitative study (22)	BMC Pregnancy and Childbirth/Scopus/ English	Qualitative descriptive exploratory/IV
A4	2022/Hong Kong	Navigating stigma and discrimination: Experiences of migrant children with special needs and their families in accessing education and healthcare in Hong Kong (23)	Int. J. Environ. Res. Public Health/Scopus/ English	Qualitative descriptive exploratory/IV
A ₅	2021/United Kingdom	Overt acts of perceived discrimination reported by British working-age adults with and without disability (24)	Journal of Public Health/Scopus/English	Secondary data study/V
A6	2023/ United States of America	Perceived disability-based discrimination in health care for children with medical complexity (9)	Pediatrics/Scopus/ English	Qualitative descriptive exploratory/IV
A ₇	2023/Iran	Prevalence of subjective unmet mental healthcare needs, barriers, and socioeconomic inequality among adult individuals with physical, visual, hearing, and speech disabilities in West of Iran (25)	Health & Social Care in the Community/ Scopus/English	Quantitative cross-sectional analysis/IV
A8	2023/Brazil	Social discrimination against adults with hearing loss in Brazilian health services: results of the National Health Survey (26)	Ciência & Saúde Coletiva/Scopus/ portuguese	Secondary data study/V
A9	2019/ Germany	Stigma experiences and perceived stigma in patients with first-episode schizophrenia in the course of 1 year after their first in-patient treatment (27)	European Archives of Psychiatry and Clinical Neuroscience/Scopus/ English	Randomized clinical trial/II
A10	2021/Liberia	The Ebola crisis and people with disabilities' access to healthcare and government services in Liberia (28)	International Journal for Equity in Health/ Scopus/English	Secondary data study/V

Source: Prepared by the authors.

Note: C* - article code; NE® - level of evidence.

The results relating to the factors associated with the discriminatory experience faced by PwDs when accessing and using the health system were listed in two separate tables. The first (Table 3) highlights the contextual factors, organized into four categories of discrimination: Stigmatization, Negligence, Prejudice, and Access difficulties.

Table 3. Contextual Factors Associated with the Discriminatory Experience Faced by PwD When Accessing and Using the Health System. Redenção, Ceará, 2024

Type of Discrimination	Perceived Discrimination	
Stigmatization	Lack of awareness of the needs and rights of people with disabilities	A2; A3; A4; A6 (n = 4 - 40 %)
0.18	Paternalistic attitudes of professionals	A3; A4; A9 (n = 3 - 30%)
Negligence	Negligence Lack of training and qualification of health professionals in dealing with PwDs	
Dunitudina	Attitudes/aggressions based on disability	A2; A3; A4; A6; A10 (n = 5 - 50 %)
Prejudice	Disbelief in the abilities of PwDs, such as attitudes of pity or overprotection	A2; A3 (n = 2 - 20 %)
Difficulty of	Poor service/poor accessibility	A6; A10 (n = 2 - 20 %)
access	Financial barriers/health insurance	A7; A3; A5 (n = 3 - 30 %)

Source: Prepared by the authors.

Table 4 highlights the results referring to the individual factors, allowing for better visualizing and a clearer understanding of the trends and patterns identified.

Table 4. Individual Factors Associated with the Discriminatory Experience Faced by PwD When Accessing and Using the Health System. Redenção, Ceará, 2024

Individual Factors	Article (n - %)	
Low income/disadvantaged social class	A1; A3; A5; A7; A9 (n = 5 - 50 %)	
Low schooling	A1; A8 (n = 2 - 20 %)	
Low autonomy/limited activities	A8; A9 (n = 2 - 20 %)	
Older age	A8; A9 (n = 2 - 20 %)	
Black race	A1; A8 (n = 2 - 20 %)	

Source: Prepared byt the authors.

Discussion

The results of this review highlight the scarcity of studies on the discrimination faced by PwDs in health services, which represents a substantial limitation for research in this area. This lack of studies can compromise a comprehensive understanding of the phenomenon and hinder the development of effective policies and interventions. Furthermore, the absence of studies centered on the perspective of PwDs themselves can result in an incomplete analysis of discrimination, potentially underestimating or ignoring essential aspects of their experience.

The care provided to PwDs or people with reduced mobility is often ineffective, which undermines their needs and rights. It is therefore necessary to raise awareness of the specific needs and rights of PwDs to implement strategies for providing qualified and effective care (29). Additionally, the effectiveness of various health promotion, prevention, and recovery actions—intended to cover everyone—is still hindered by physical, spatial, and attitudinal barriers, which consequently prevent PwDs from fully benefiting from health services (30).

One of the obstacles to healthcare access for this population is the persistence of "paternalistic attitudes," which limit their autonomy. Moreover, it is common for decision-making to be done by health professionals rather than the patients themselves, often leading to care that does not adequately consider their preferences, values, or independence (31).

According to the literature, a 2021 study highlighted how paternalistic attitudes have led to a devaluation of the abilities of PwDs, reinforcing a discriminatory view that undermines their autonomy and rights (32). For this reason, patient participation in their own care is associated with positive health outcomes, and any attitude that discourages this participation can lead to unfavorable results (31). The lack of training and qualification of health professionals is a worrying issue that affects the quality of care. Therefore, the adoption of inclusive practices in health services is essential to guarantee access to quality care while respecting each person's individual needs (33). Furthermore, health policies for this population must be clear and effective, promoting and funding the training of healthcare providers in inclusive practices. Without adequate training, healthcare professionals may be limited in their ability to provide equitable care (34).

Discrimination against PwDs through attitudes or aggression remains noticeable, both among adult patients and children. A UK study showed that adults with and without disabilities were three times more likely to be exposed to discriminatory attitudes (24). Other literature indicates that, in pediatrics, discrimination has impacted children's health, leading to limited access to healthcare, inadequate pain management, and non-holistic care (9).

A survey conducted in Ghana revealed the perceptions of health-care professionals regarding the care of PwDs and highlighted the impact of poor accessibility in health facilities, which poses a daily challenge in the pursuit of quality services (22). A study conducted in Brazil also revealed difficult accessibility conditions, including issues with public transportation and healthcare facility structures that lack ramps, tactile flooring, and other essential elements for PwDs (10).

Other authors indicate that ineffective communication is a recurring issue, particularly for those who are hearing impaired, due to the lack of training for professionals in sign language (22, 35). The results of this review also suggest that attitudes of pity or overprotection are common when it comes to the discrimination faced by PwDs in accessing and using health services. These attitudes can result in the infantilization of PwDs, undermining their ability to develop self-determination skills and independence (32).

According to a systematic review conducted in 2022, financial barriers are a common limitation in the access to and use of health services by children with neurological disabilities. Additionally, low-income or disadvantaged social class can be a significant factor in discrimination (36). This result can be explained by the fact that low-income individuals face obstacles such as being unable to afford the extra costs associated with their health condition, as well as medication and specialized equipment (37).

Financial difficulties are often exacerbated for PwDs, who frequently face high or additional costs for specific treatments, accessibility, and personal assistance (38). In line with this, a lack of resources can limit access to information about rights and available services, making PwDs more vulnerable to segregation and marginalization by health professionals or institutions that are not properly prepared to meet their needs.

Low educational attainment can limit the development of self-advocacy skills, as it directly affects the autonomy of PwDs, making them more vulnerable (39). The combination of the aforementioned factors with lower socioeconomic status directly contributes to the increased fragility and marginalization of PwDs, exacerbating their experiences of discrimination within the health system (40).

Older age among PwDs can be explained by the fact that aging is often related to increased limitations and growing demand for care, making them more exposed in healthcare settings (41). In addition, some studies have indicated that age is a factor that leads to discrimination in health services, as youth is often associated with productivity, leading to the perception that older individuals are unproductive or unhelpful. Furthermore, the chronic conditions often associated with aging can increase the complexity of care, reinforcing age as a significant factor in discrimination (42, 43).

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Ethnicity is another element that can influence intolerance toward this population (44). Studies show that people belonging to ethnic minorities, such as Black individuals, face significant inequalities in access to and quality of healthcare (45). In view of this, it is clear that PwDs face daily challenges in accessing services; if they are also from a racial minority, these challenges tend to be exacerbated (46).

Many adversities have hindered the use of health services by PwDs (47), including issues related to the communication and attitudes of professionals, transportation, and infrastructure (48, 49). According to the International Convention on the Rights of Persons with Disabilities, it is the responsibility of states and health services to ensure adequate access to services for PwDs by removing architectural, communication, and environmental barriers. The convention also emphasizes the responsibility of states to prevent discriminatory denial of healthcare services to PwDs (50).

Therefore, states, managers, and healthcare professionals have a significant responsibility to adopt changes that promote health and quality of life, as well as ensure equal access for all (51).

Conclusions

The findings of this review reveal a complex intersection of contextual and individual factors associated with the discriminatory experiences faced by PwDs in health services. Financial barriers, lack of training for health professionals, and other gaps that generate prejudice, stigmatization, and neglect are identified as significant drivers of discrimination. The scarcity of studies centered on the perspectives of PwDs themselves stands out as a crucial knowledge gap, while the lack of effective interventions underscores the need for concrete action.

Therefore, public policies are recommended to guarantee the accessibility of services, provide financial assistance for PwDs, implement training programs for health professionals, and conduct more research to inform interventions that promote more inclusive and accessible care for all.

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