

Persons with disabilities during the COVID-19 pandemic: guaranteeing fundamental rights and equity in care

Pessoas com deficiência na pandemia da COVID-19: garantia de direitos fundamentais e equidade no cuidado

Personas con discapacidad en la pandemia de COVID-19: garantía de derechos fundamentales y equidad en el cuidado

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Abstract

This is a scoping review of the PubMed, Scopus, BIREME, SciELO, and Web of Science databases, including publications from December 2019 to May 2020 with the objective of identifying and systematizing the literature on the status of persons with disabilities in the initial months of the COVID-19 pandemic. The review aimed to search for original peer-reviewed articles published in indexed journals, in addition to the specialized gray literature. We reviewed 386 texts and included 33 articles and documents in the study. The review's results pointed to three thematic categories that reflect the main discussions on the theme in the literature: vulnerabilities of persons with disabilities during the pandemic; rights of persons with disabilities in this context; and protective measures and access to information on COVID-19 for persons with disabilities. In the context of the public health emergency, historically marginalized communities such as persons with disabilities run the risk of feeling more vulnerable, suffering deprivations, discrimination in screening plans for care, and prejudices and stigmas that influence decision-making in healthcare and exacerbate preexisting inequalities, making this group more susceptible to illness and lack of social protection. Although persons with disabilities have been acknowledged as a risk group for COVID-19, governments have been slow to develop plans to fight COVID-19 for this population. Few studies have attempted to understand the effects of the COVID-19 pandemic on persons with disabilities, especially in the sense of implementing measures in prevention, control, and protection that guarantee equity in care.

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Introduction

The COVID-19 pandemic has exacerbated challenges related to healthcare and social protection for persons with disabilities. According to estimates, persons with disabilities represent about one billion persons (15% of the world population) ¹, who already experienced invisibility and confinement, in addition to a routine of healthcare needs. Their social vulnerability has increased during the pandemic. The World Health Organization (WHO) thus acknowledged persons with disabilities as a risk group for COVID-19, making recommendations on specific measures in prevention, control, assistance, and social protection by governments, healthcare workers, communities, and families ².

Having a disability increases the probability of higher cost of living and unemployment, lower schooling, and difficulty in access to health, so that persons with disabilities experience more situations of poverty ³. Even so, the guarantee of persons with disabilities' rights is part of a recent past, beginning in the world in the 1960s, the result of robust social movements in the defense of human rights, dignity, autonomy, and equal opportunities ⁴. In that same decade, from the social sciences perspective and based on the so-called social model, a sociopolitical approach to disability gained force as the product of development of contemporary societies, resulting from socioenvironmental factors such as urban violence, population aging, and work accidents, among others ⁵.

Since then, the social model has predominated in the field of studies on disability, while not overlooking biomedical progress and the needs of persons with physical impairments. The model proposes that disability should be understood as a broad and relational concept, like any form of disadvantage in the body's relationship to lesions and society ⁶. Thus, in a diverse social and environmental context such as that of a pandemic, persons with disabilities, not only experience an increase in morbidity and mortality due to the presence of comorbidities but also tend to have their access to public policies compromised, including essential rights such as health, education, transportation, and social assistance, besides the physical and social consequences of increased social isolation. The context of the pandemic exacerbates social and health inequities, especially in low and medium-income countries with less capacity to respond to the pandemic, and where 80% of the world's persons with disabilities live ⁷.

Brazil is one of these lower-income countries, where nearly 46 million inhabitants, or some 24% of the population (Brazilian Institute of Geography and Statistics. <https://sidra.ibge.gov.br/home/pnadcm>, accessed on 18/Aug/2020), report having some type of disability and tend to experience the pandemic disproportionately. When updating the data from the 2010 *Population Census*, which aimed to standardize the Brazilian data with the international data, based on the recommendations by the Washington Group, nearly 13 million Brazilians, or some 6.7% of the country's population, presented some type of disability ⁸. Although the circulation of SARS-CoV-2 has occurred since December 2019 and the pandemic was declared by the WHO on March 11, 2020 ⁹, little is known about the effects on persons with disabilities in Brazil or in the world in general. Few institutional documents have been published at the international level, such as the guidelines by the WHO ², or at the national level in Brazil, such as the recommendations in booklet format by the Ministry of Women, Family, and Human Rights ¹⁰, thus revealing a gap in publications on the issue. The current study, therefore, aims to identify and systematize the literature on the status of persons with disabilities in the early months of the COVID-19 pandemic.

Method

This is a scoping review ^{11,12,13} on the status of persons with disabilities in the early months of the COVID-19 pandemic, including the health and living conditions of persons with disabilities and government and institutional responses to guarantee their rights and healthcare.

Search strategy and data sources

A systematic search was performed in the PubMed, Scopus, BIREME, SciELO, and Web of Science databases in April and May 2020. The search string used in all the databases was “coronavirus infections” OR “COVID-19” OR “SARS-CoV-2” AND “disability” OR “handicapped” OR “disabled persons”. A manual search and crossed reference lists from the main articles were also added.

The review was oriented to identify original peer-reviewed articles published in indexed journals, in addition to the specialized gray literature (manuals and resolutions by official national agencies; opinion and orientation texts by national or international organizations of persons with disabilities) published from December 2019 to May 2020.

Inclusion and exclusion criteria

The selection criteria for this review were studies and documents that addressed the situation of persons with disabilities in the context of the COVID-19 pandemic, published from December 2019 to May 2020, with a central focus on persons with disabilities, and in the English, Portuguese, and Spanish languages. The selection excluded literature reviews and clinical studies, as well as studies in which handicap and/or disability was only addressed as an outcome of COVID-19.

Selection and inclusion of articles and documents

After excluding duplicate articles, each article was analyzed by a pair of researchers who separately applied the inclusion and exclusion criteria based on reading the titles and abstracts. The articles were selected by consensus between the reviewers, and in case of disagreement a third reviewer was included to opine on the study’s inclusion or exclusion. Texts from the gray literature were selected by manual search and submitted to an independent assessment by two researchers to decide on inclusion.

Analysis of the included studies

General and methodological information was extracted from the texts included for the review and is described in Boxes 1 and 2. Given the type of material found in the review, the included studies and documents were summarized based on the thematic synthesis method proposed by Thomas & Harden¹⁴. Free search codes were organized in “descriptive” themes and later interpreted to produce the analytical categories presented in this study.

Results

The database search yielded 370 articles, and the gray literature search yielded 34 texts potentially eligible for the review. Figure 1 summarizes the process of identification, selection, eligibility, and inclusion of articles and documents for a synthesis of the literature. After retrieving all the potentially relevant texts in the databases and manual search, we removed the duplicates and then proceeded to the selection phases with a reading of the titles and abstracts based on the inclusion and exclusion criteria. After the initial selection, all the eligible full texts were read for analysis and selection by the researchers. Thirty-three articles and documents were included in this review.

Boxes 1 and 2 summarize the scientific texts. Most of the 15 scientific publications were editorials^{7,15,16,17,18} and opinion articles^{19,20,21,22,23,24}, and the rest were observational^{25,26} current issues²⁷, or an essay²⁸. The countries or regions responsible for these publications feature the United States and United Kingdom (Box 1). Most of the selected documents from the gray literature were institutional documents^{2,3,29,30,31,32,33,34,35} and opinion articles^{36,37,38}, while the rest were interviews/news stories^{3,39}, editorials⁴⁰, and protocols or other technical documents^{10,41,42,43}. Most of these were published by international agencies such as the United Nations (Box 2). The results were systematized in three thematic categories that group the principal findings to be developed in the discus-

Box 1

Description of selected articles and synthesis of results.

Study (year)	Country	Type	Objective	Main findings
Safta-Zecheria ¹⁷ (2020)	Romania	Editorial	Discuss the potential health risk for persons with disability in residential care institutions during the COVID-19 outbreak.	High risk of contagion requires public policies and government actions to guarantee measures for protection and care for persons with disabilities: financing, support for family/caregivers, and maintenance of care.
Pan-American Health Organization ¹⁵ (2020)	United States	Editorial	Identify additional measures for persons with disabilities to mitigate the impacts of COVID-19 on this population.	Specific government actions for protection such as maintenance of care, support for families, caregivers, and the community based on prevention and control of the infection.
Jalali et al. ²³ (2020)	Iran	Opinion article	Present the challenges that persons with disability face during the COVID emergency in Iran.	Interruption of specialized care, difficulties with subsistence, precarious access to health services and information, and strict isolation measures are challenges imposed on persons with disabilities.
Courtenay ¹⁸ (2020)	United Kingdom	Editorial	Present the challenges for persons with intellectual disability in the United Kingdom during the COVID-19 pandemic.	Maintenance of care requires adaptations and collaboration between service providers and the family to reduce the risk of infection and impacts from structural changes on services.
Bettger et al. ²⁴ (2020)	United States	Opinion article	Describe adjustments for continuity of rehabilitation services in the context of national responses to COVID-19.	Actions to guarantee workers' safety, implementation of services for maintenance of care such as telerehabilitation, training of teams to orient patients and families in homecare, and measures for monitoring patients in recovery from COVID-19.
Vieira et al. ²² (2020)	Switzerland	Opinion article	Explore the impact of COVID-19 and preventive measures on the well-being of vulnerable populations.	Barriers to accessing health services require preventive measures that include information in simple and accessible format. The supply of mental health services via telehealth should be encouraged.
Pineda & Corbuan ²⁰ (2020)	United States	Opinion article	Debate the impacts of the current pandemic for persons with disabilities, based on the principles of urban equity and the social theory of disability.	Equitable cities can modify the state of vulnerability based on actions planned with participation by persons with disabilities that guarantee accessible information and communication, financial support, and maintenance of care.
Mukherjee ¹⁹ (2020)	United States	Opinion article	Reflect on markers of vulnerability in contexts of the pandemic related to disability, race, and ethnicity.	Refusal to provide treatment has been common, and prejudice can influence discrimination in screening plans and healthcare decisions. Judicialization has been frequent. Oversight and guarantee of rights for persons with disabilities are necessary.

(continues)

Box 1 (continued)

Study (year)	Country	Type	Objective	Main findings
Qi & Hu ²⁷ (2020)	United Kingdom	Current issues	Analyze the Law on Prevention and Treatment of Infectious Diseases (LPTID) during the COVID-19 pandemic.	The LPTID does not address the specific needs of persons with disabilities, creating difficulties and barriers to protective measures required by the COVID-19 pandemic. The disability perspective should be included in the development of laws, policies, and practices.
Shew ²¹ (2020)	United States	Opinion article	Present the contributions by persons with disabilities for confronting the COVID-19 pandemic.	Technologies, adaptation of spaces and worktime, and infrastructure solutions created by persons with disabilities have been used as the basis for adjustments to the functioning of various services during the COVID-19 pandemic.
Yarımkaya & Esentürk ²⁸ (2020)	Turkey	Essay	Describe the benefits of physical activity for children with autism spectrum(ASD) disorder and present strategies during the COVID-19 pandemic.	High-intensity exercise for at least 20 minutes or moderate-intensity exercise 30 minutes every day with ample space and participation by the family has positive effects on health and quality of life for children with ASD and their families in lockdown.
Armitage & Nellums ⁷ (2020)	United Kingdom	Editorial	Discuss the impact of COVID-19 on healthcare provision for persons with disabilities.	Improving the provision of healthcare for this group based on awareness-raising on the rights and needs of persons with disabilities, guaranteed continuity of care with safety for workers and families, access to employment and education. Persons with disabilities should be included in the elaboration of strategies and actions.
Schiariti ¹⁶ (2020)	Canada	Editorial	Present the challenges faced by persons with disability in the COVID-19 pandemic.	During the pandemic, an inclusive approach should be adopted, based on rights and guaranteed participation by persons with disabilities in designing and implementing emergency plans.
Negrini et al. ²⁵ (2020)	Italy	Observational, cross-sectional	Furnish preliminary data on the impact of COVID-19 on rehabilitation services during the initial stages of spread of the pandemic in Europe.	The interruption of admissions for rehabilitation, early discharge, and reduction of activities involved 194,800 hospitalized patients in 10 countries. Outpatient activities were suspended in 87%. Seven countries reported experiences in rehabilitation for acute COVID-19 patients.
Lakhani ²⁶ (2020)	Australia	Ecological study with spatial analysis	Identify areas with the highest concentration of elderly with disability and the barriers to accessing primary healthcare services in the city of Melbourne.	Of the 8,910 areas that were identified, 2,085 present a significantly high level of difficulty in accessing primary healthcare services and 807 present a significantly high percentage of elderly with disability. This method can be used to define regions for priority measures in public health emergencies such as COVID-19.

Box 2

Description of selected documents from the gray literature and synthesis of results.

Study (year)	Country	Type	Objective	Main findings
Humanity & Inclusion ³⁷ (2020)	Switzerland	Opinion article	Identify appropriate measures to reduce the impact of COVID-19 on persons with disabilities.	Recommends the adoption of an approach based on the guarantee of rights of persons with disabilities, which includes participation in the development of responses to the impacts of COVID-19, the availability of information in an accessible format, and support for health services and telerehabilitation.
International Labour Organization et al. ³³ (2020)	International agency	Institutional document	Present elements that can help take full advantage of the response to COVID-19 by social protection systems to support persons with disability.	Access to information should be guaranteed, including persons with disabilities and families in financial recovery, assessing needs, and expanding support and support networks.
World Health Organization ² (2020)	International agency	Institutional document	Present individual government measures for health professionals and service providers on ways to deal with and reduce the impact of the COVID-19 pandemic on persons with disabilities.	Access should be guaranteed to information and health services, encouraging remote activities to avoid crowding, including telerehabilitation. Government measures should be inclusive for persons with disabilities and service providers, besides guaranteeing support to deal with complex needs.
International Labour Organization ³⁰ (2020)	International agency	Institutional document	Highlight actions for the promotion of equal opportunities and decent work for persons with disabilities during the COVID-19 pandemic.	Emphasizes the need for social justice, effective inclusion, equal opportunities, and decent work. The document suggests ensuring home office work, accessible and inclusive communication such as access to public information, with persons with disabilities sharing in the creation. An adequate social protection system should also be provided.
United Nations ³ (2020)	International agency	Interview with Catalina Devandas (United Nations expert)	Present accommodation measures for the reduction of risks of infection to deal with COVID-19.	Incentives for home office work or paid leave, additional financial aid, and adequate support for persons with disabilities and their families.
Ofner et al. ³⁸ (2020)	Canada	Opinion article	Describe preventive measures for individuals and health services during the COVID-19 pandemic.	Individual actions involve receiving help for essential tasks and avoiding leaving home, besides seeking ways to protect, listen, support, adapt, and accommodate. Services should guarantee care for needs and the presence of the accompanying person, considering individual characteristics in COVID-19 screening services, which should be accessible and receptive.

(continues)

Box 2 (continued)

Study (year)	Country	Type	Objective	Main findings
Office of the High Commission of the Human Rights, United Nations ³¹ (2020)	International agency	Institutional document	Reflect on difficulties encountered by persons with disabilities in the context of the COVID-19 pandemic, based on social determinants of health.	Discrimination, dependency, exclusion from schooling, lower income, and other factors are involved in the increased risk of infection for persons with disabilities. Social distancing should be adopted, but offering information in accessible formats, guaranteeing financial resources and quality healthcare.
Office of the High Commission of the Human Rights, United Nations ⁴⁰ (2020)	International agency	Editorial	Reflect on government involvement to deal with the COVID-19 pandemic and emphasize the application of principles of nondiscrimination.	Government is responsible for life-saving interventions. The principles of nondiscrimination, participation, empowerment, and responsibility need to be applied to all policies. States should adopt additional measures for social protection for its support to reach those at greatest risk of being disproportionately affected by the crisis.
Pan-African Network of Persons with Disability ³⁴ (2020)	International agency	Institutional document	Present measures for protection of persons with psychosocial disability by local and national governments during the COVID-19 pandemic.	Emphasizes the guarantee of access to information and services, as well as their continuity for harm reduction. Suggests avoiding measures of coercion/medication that compromise health. Community and psychosocial support should be established, with channels for support and care in cases of domestic violence. Inclusion of persons with disabilities in decisions.
United Nations Children's Fund ³² (2020)	International agency	Institutional document	Present the impacts of the COVID-19 pandemic for persons with disabilities and measures to prevent and overcome them.	Difficulties in access to remote education, interruption of support services, discrimination in the supply of care, and barriers to access information increase the risks of morbidity and mortality from COVID-19. Accessibility and continuity should be guaranteed in education and health services and actions for prevention of domestic violence.
United Nations ²⁹ (2020)	International agency	Institutional document	Present the impact of COVID-19 on persons with disabilities with a view towards inter-sector collaboration and recommendations for dealing with the pandemic.	Preexisting inequalities, specific health needs and conditions, interruption of essential services, social distancing, and lack of access to information contribute to the increased vulnerability of persons with disabilities. Continuity should be guaranteed in access to health services, education, social security and protection, access to information, preventive measures, and representativeness in planning strategies.

(continues)

Box 2 (continued)

Study (year)	Country	Type	Objective	Main findings
United Nations ³⁶ (2020)	International agency	Opinion article	Present the impact of COVID-19 pandemic on persons with disabilities.	The pandemic is intensifying preexisting inequalities for persons with disabilities. Measures adopted by governments face numerous barriers, creating exclusion and increasing this population's vulnerability. Persons with disabilities should be part of the process of developing measures in the pandemic that include their needs, based on the rights of persons with disabilities and investing in a more inclusive and accessible society.
Chilean National Service for Persons with Disability ³⁵ (2020)	Chile	Institutional document	Furnish guidelines for communication and care for persons with disabilities during the COVID-19 pandemic.	Professionals should adhere to inclusive practice, guaranteeing the individual's participation in the process of care, access to medicines, treatments, and essential equipment for life. Such practice should respect and prioritize the autonomy of persons with disabilities, whenever possible addressing questions and comments to the individual rather than to the accompanying person. Accessibility in the environment, information, and different forms of communication should be guaranteed.
Chilean National Service on Disability ⁴³ (2020)	Chile	Protocol	Present guidelines and actions for residences of adults with disability during the COVID-19 pandemic.	Recommends the presence of a coordinating professional in the strategies for prevention, in collaboration with primary care, altering the functioning to guarantee the protective measures recommended by health organizations, maintaining residents informed about such measures and isolating a worker or resident in case of symptoms.
Brazilian National Secretariat for the Rights of Persons with Disability, Brazilian Ministry for Women, Family, and Human Rights ¹⁰ (2020)	Brazil	Booklet	Announce recommendations on COVID-19 for professionals that provide care to persons with disability and rare diseases.	Recommends investigating problems related to disability that are potential risk factors, working with prevention, maintenance of remote care or homecare, orienting accompanying persons and caregivers on protective measures, and prioritizing the guarantee of human rights based on scientific knowledge in all the actions.
Brazilian Office of the Public Prosecutor for Labor Affairs ⁴²	Brazil	Technical note	Present guidelines for protection in labor relations for workers with disability.	Work flexibilization measures should guarantee the right to perform work activities remotely, and when possible, dispense with obligations for guaranteed pay or workday flexibilization, covering the cost of private transportation, ensuring that such measures do not mean a cut in pay. Adopt measures for prevention and protection. Individuals should be placed on sick leave in case of a COVID-19 diagnosis.

(continues)

Box 2 (continued)

Study (year)	Country	Type	Objective	Main findings
U.S. Department of Health and Human Services ⁴¹ (2020)	United States	Bulletin	Orient service providers on actions guided by compliance with the civil rights of different segments of the population.	Emergency planning should meet the needs of persons with disabilities with diverse conditions, guaranteeing accessible information through all the available tools for effective communication, stocking items that can help persons maintain independence and respecting requests for treatment adjustments based on religion, as well as faith-based practices.
United Nations ³⁹ (2020)	International agency	News story	Inform on the emergency response plan for COVID-19 by the Australian Health Protection Principal Committee and the impact for persons with disabilities.	Vulnerability of persons with disabilities during the pandemic is the result of interaction between biological factors and attitudinal, environmental, and institutional barriers. The original emergency plan did not include the needs of persons with disabilities and disability support workers. This triggered a significant defense of the community, leading the Australian government to create an advisory group for PWDs to provide their input and develop a specific plan for the COVID-19 context. It is essential for countries to adopt a human rights approach to build equitable societies.

sion: vulnerabilities of persons with disabilities in the pandemic; rights of persons with disabilities in this context; and measures for protection and access to information on COVID-19 targeted to persons with disabilities.

Discussion

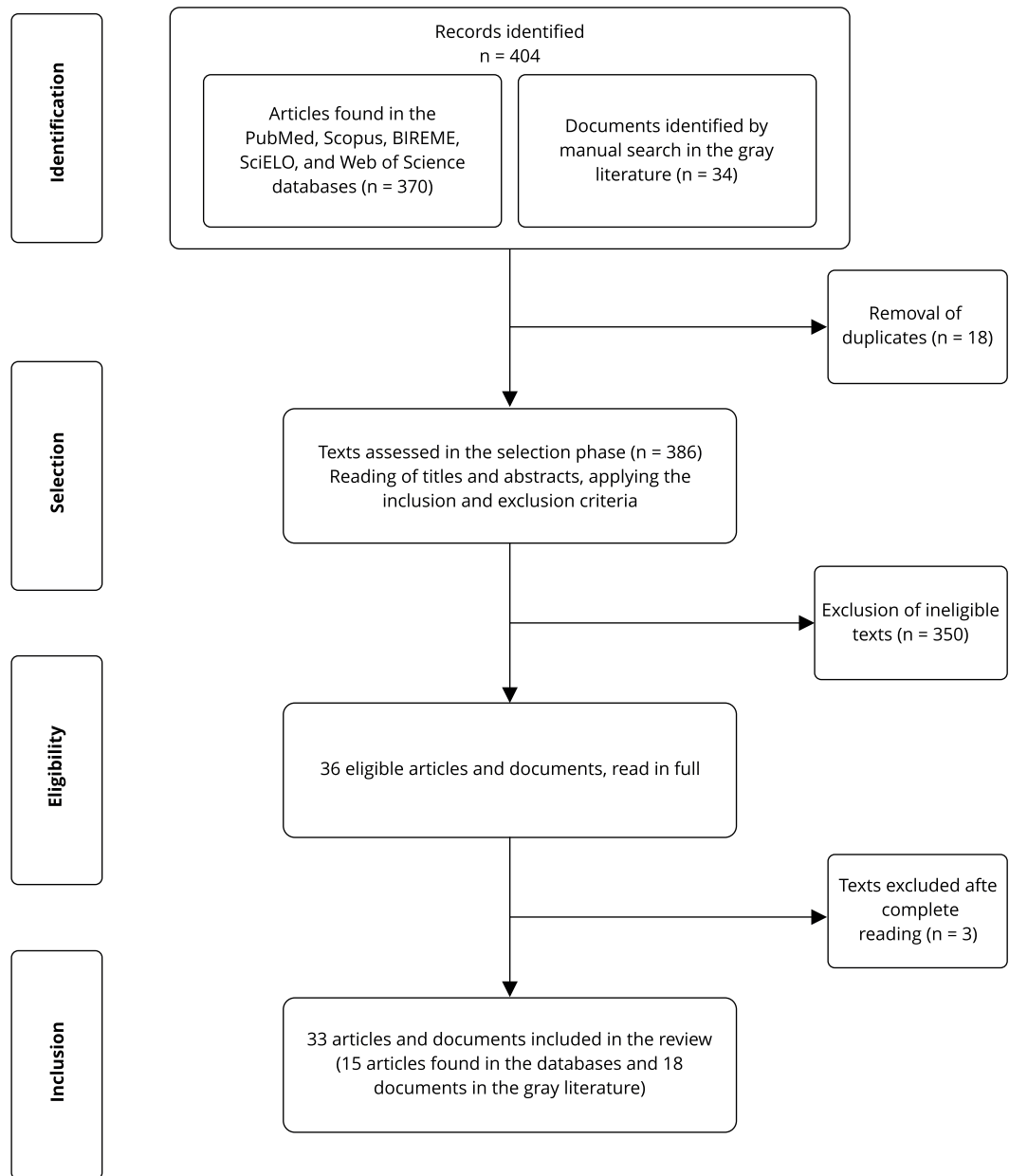
The emergence of the COVID-19 pandemic, high hospitalization rates, and the crisis of health systems around the world raised the discussion on the prioritization of the supply of health services and equipment, besides the need for measures in prevention and protection, including social distancing. The reviewed literature indicates that in a context of public health emergency, historically marginalized communities like persons with disabilities may be more vulnerable, suffer more deprivations, discrimination in screening plans for patient care, and prejudices and stigmas that influence decision-making in healthcare and intensify preexisting inequalities, making these groups more susceptible to illness and lack of social protection ^{19,29,36,39}.

Vulnerabilities of persons with disabilities during the COVID-19 pandemic

Persons with disabilities are not inherently vulnerable. Attitudinal, environmental, and institutional barriers result in higher levels of vulnerability, such that this group, which presents underlying health conditions, is at greater risk of acquiring COVID-19 and/or of having more serious forms of the disease ³⁹. The perspective here is that of non-deterministic or natural social and health vulnerability, associated with individual and collective situations and contexts. The condition of vulnerability can thus be transformed by support from society, institutions, and governments ⁴⁴.

Figure 1

Detailed flowchart of the identification, selection, eligibility, and inclusion of the reviewed texts.



The social model of disability, the explanatory theoretical model of disability that seeks to supplant the biomedical model, expands the understanding of vulnerability of persons with disability, shifting the view of inequalities related to the body to the social structures. This model is based on a new understanding of the impairments experienced by persons with disabilities, not limited to diagnoses of abnormality or pathology and the domestic spaces. That is, the issue of disability should be discussed as part of public life, a question of justice, related directly to social issues ⁴⁵.

One of the social and health effects of the pandemic that puts persons with disabilities in a situation of vulnerability is the exacerbation of economic losses and the absence of mechanisms of social protection, which can mean that persons with disabilities have up to four times higher odds of falling ill in the context of the pandemic ^{20,37}. Even countries that ratified the United Nations Convention on the Rights of Persons with Disabilities have experienced difficulties in incorporating this group's needs in the midst of a public health emergency, revealing the fragility of implementing the convention's countries ^{27,39}.

Persons with disabilities may present an increased risk of acquiring COVID-19 due to such factors as barriers to the implementation of some basic hygiene measures, difficulty in access to basic rights such as running water, housing, food, and health services, more difficulty in maintaining social distancing due to the additional support they need or because they are institutionalized ^{2,15,29,37}. Lack of income is a disproportional difficulty for persons with disabilities and their households, which normally bear extra costs and expenses related to the disability. persons with disabilities have less access to employment, and when they are employed, they are more prone to be working in the informal sector, with greater instability and less access to social security. They are also less likely to finish their education and have higher odds of being excluded from schooling ¹⁵.

Factors such as age, chronic underlying conditions, the nature of some disabilities, and obstacles to accessing health services exacerbate this population's existing health problems, such as restriction of the respiratory or immune system function, cardiac diseases, or diabetes, potentially placing this group at greater risk, in the case of COVID-19, of progressing to more serious infection and with higher mortality ^{2,32,33,38}.

Persons with disabilities are overrepresented in the incarcerated, institutionalized, and homeless populations and have a greater risk of infection due to the precarious conditions in these settings. The pandemic has seen an increase in the number of persons with disabilities living in emergency shelters and informal settlements ^{29,31}. In addition, when these groups are institutionalized, their dependency increases on community-living persons and the need for contact with persons living outside these institutions. Mortality in persons with disabilities has been higher than in persons without disability in rehabilitation facilities and state institutions, including prisons, group housing, and rest homes ²¹. This group's interaction with various providers of care and support and friends produces a greater risk of acquiring COVID-19 due to the increase in exposure, while restrictions on visitors and support persons in institutions can deteriorate the conditions of care and produce mental distress ³⁸.

Persons with psychosocial disabilities, generally confined to psychiatric facilities and prisons, may have a greater risk of acquiring COVID-19 due to difficulty in maintaining social distancing, besides the fact that these settings tend to be unhealthy and to lack ideal health support ³⁴. Children with autism spectrum disorder and persons with intellectual disabilities may face more difficulty with social distancing and lockdown, generating a source of stress and other mental health problems. The effects of sedentary life caused by isolation and inequalities in access to online learning spaces may be part of the concerns for avoiding greater impact from the pandemic on the lives of persons with disabilities ^{28,31}.

The health measures adopted by some governments to confront the pandemic may create numerous barriers that intensify this population's exclusion and increase its vulnerability, for example, severe measures of protection and prevention such as social distancing, suspension of transportation, commerce, logistic circulation, and services, health rationing decisions based on discriminatory criteria, or lack of accessibility in the contents produced to inform the population on the pandemic. If these measures fail to take the needs of persons with disabilities into account, unwanted outcomes such as the deaths of persons with disabilities reported in China may happen due to government policies ^{27,36}.

Measures to prevent the spread of the novel coronavirus may not allow the most vulnerable and marginalized or those at greatest risk to protect themselves efficiently. The response to other health needs, non-communicable diseases, and underlying health conditions, which are so essential for some persons with disabilities, may become impossible during the pandemic due to restrictions on access to healthcare and decreased social support, generating negative feelings, fear, and symptoms of anxiety and depression ^{2,22,33,37,38}.

According to data from an observational study, ten European countries reported the interruption of admissions for rehabilitation, early discharge, and reduction of healthcare activities, reaching interruption of 87% of outpatient activities in Italy, Belgium, and the United Kingdom, with an estimate of millions of persons with disabilities affected in Europe²⁵. This group may also experience difficulties in access to health services when they are disqualified from receiving priority care during the pandemic, further increasing the existing inequalities³⁷.

Expenses related to the disability may increase during the pandemic due to the impact of the crisis and causes harms to the support system, overburdening persons with disabilities and their families. It is thus necessary to provide adequate social protection to cover these costs and decrease the inequalities. Measures to decrease the spread of the novel coronavirus should be linked to an increase in the response to health needs and support for the supply chain, furnishing adequate inputs and health services and guaranteeing the maintenance of vital health services for persons with disabilities^{30,37}. The assessment of persons with disabilities' needs during the pandemic should consider the existence of more vulnerable groups (children, women, elderly, persons with high levels of dependency) to implement social benefits, income support, increased disability benefits, and income transfers to all persons with disabilities regardless of work status during the pandemic^{23,33}.

Rights of persons with disabilities in the context of the COVID-19 pandemic

Since the majority of the world's countries are signatories to the United Nations Convention on the Rights of Persons with Disabilities and this important document aims to promote, protect, and ensure the full and equitable exercise of human rights and fundamental freedoms by all persons with disabilities, promoting respect for their inherent dignity⁴⁶, the context of the COVID-19 pandemic has raised numerous challenges for the enforcement of this convention's objectives in the world.

One reason for more frequent ethical consultation during the pandemic is the informed refusal of treatment for persons with disabilities, which has led some governments to be sued due to criteria applied in the exclusion from care, considered discriminatory¹⁹. The following are essential in this context: action by groups in defense of the rights of persons with disabilities in the control and oversight of measures adopted by governments and the guarantee that these rights are served at the operational levels^{14,37}.

The guarantee of human rights, respect for the dignity and the rights of persons with disabilities, and mitigation of existing inequalities constitute a path to furnish impartial and inclusive access to health services and social protection. The idea that everyone has the right to lifesaving interventions, that vulnerable populations need specific equitable policies, and that these policies are the responsibility of governments needs to be strengthened in the pandemic's context^{28,37,40,47}. The shortage of funds or the use of public or private insurance plans should never be a justification for discriminating against vulnerable groups. Combined multilateral efforts and the principle of solidarity prove to be paths for overcoming inequalities and improving government and society's capacity during the pandemic^{40,47}.

Effective participation by persons with disabilities in developing effective responses to the COVID-19 pandemic

The struggle by persons with disabilities and their representative organizations write the history of defense and conquests of affirmative actions, changes in legislation, and the establishment of policies for the protection of this group⁴⁸. Thus, during the pandemic as well, it is essential to ensure that persons with disabilities and their representative organizations have effective participation and responsibilities in all stages of the elaboration of strategies to fight the pandemic, monitoring all phases of the response and recovery from the pandemic, to identify and guarantee an inclusive approach, based on rights, which includes the impacts suffered during health emergencies^{16,29,36,37,40}.

Inclusive systems of care guarantee that everyone benefits and generate positive impacts on the well-being of persons with disabilities and their families and communities. The experience by the Australian government, which initially drafted a plan for the response to the health emergency which did not take the needs of persons with disabilities into account, triggered a significant response by

the persons with disabilities community. The Australian government ultimately created an advisory group in April 2020, including persons with disabilities, to draft a specific plan to fight the COVID-19 pandemic together with this community, two months after launching the initial plan ^{16,29}. Importantly, persons with disabilities already had experience with the adaptation of spaces and worktime, and this can be used as a reference in the current context, using the solutions and infrastructures conquered by persons with disabilities that can be replicated during the pandemic ²¹.

To guarantee accessibility, availability, and quality of services, governments should establish better strategies for planning and intervention that include healthcare professionals in direct care, in homecare and community-based formats, protective measures that prioritize persons with disabilities continuing to receive support, in safety, from caregivers and families. Plans to deal with health emergencies should seek to respond considering the entire population, but they cannot overlook the specificities of vulnerable populations. Policies targeted to persons with disabilities should consider the even more vulnerable segments within this group, such as institutionalized persons, women, and immigrants ^{7,17,24,29,39}.

Data disaggregated by gender, age, and disability, building evidence on the pandemic's impact, and preventive measures in different population groups allow a factual account of the pandemic's impact, allowing equitable responses that consider the intersectional nature of factors leading to exclusion ^{32,37}. Through the production of public, current, detailed, and non-discriminatory information, persons with disabilities can benefit from equity and justice in the allocation of funds and can be supported more effectively by national and international plans during crises such as the COVID-19 pandemic ^{23,33}.

Persons should quickly receive awareness-raising training on the rights and diverse needs of persons with disabilities to maintain this group's dignity and safeguard them from discrimination and prevent inequalities in the provision of care. To guarantee an inventory of items that will help persons with disabilities maintain independence, such as hearing aids, batteries, canes, and ancillary devices, reserved rooms for receiving persons with disabilities, considering this population's multiple needs, attention to all segments of the community, and decision-making in the sense of offering an equal opportunity to benefit from the efforts in confronting the pandemic are measures that can mitigate health inequalities that have been aggravated during the pandemic ^{28,38,41}.

Essential policies confront the pandemic with accommodations that include the diversity of persons with disabilities, decrease stigmatization, stimulate empathy and solidarity, and contribute to an effective response to the emergency. Connections between science and political actions need to be strengthened in the search for long-term solutions in confronting the pandemic and its consequences. Investment in the rights of persons with disabilities means investment in a more inclusive and accessible society, thus allowing to achieve the sustainable development goals ^{22,35,36,41}.

Measures for protection and access to information for persons with disabilities in the context of the pandemic

The COVID-19 pandemic involves the circulation of a highly transmissible virus and growing pressure on health systems and services ²⁷, besides measures to confront the pandemic, such as social distancing. All these have exacerbated the preexisting vulnerability of persons with disabilities ²⁰, resulting directly in an increasing lack of social protection and isolation of this population. Social protection measures are thus needed, including health, education, and access to information, targeted to this population in the governmental, institutional, and individual spheres (family and caregivers).

Governments

Access to health, including healthcare technologies ³², medicines, and health equipment ^{26,37}, the continuity of harm-reduction services and inclusion of persons with disabilities ³, as well as access to reliable and accessible information, need to be guaranteed in the discussions and decision-making on the measures for prevention of COVID-19 and care for persons with disabilities during the pandemic ^{2,22,27,34,37}. Screening centers for COVID-19 should be accessible and receptive, including physical accessibility and considering the individual characteristics of persons with disabilities ²⁷. The need

to produce responses to barriers to access and communication during the pandemic includes a call for change in the narrative, based on the inclusion of persons with disabilities as co-participants in responses to the pandemic, as advocates and users rather than victims ³⁰.

Rehabilitation services are essential, and governments thus need to include rehabilitation workers and other types of homecare or community-based care in the plans to guarantee personal protective equipment, training for the new reality, and capacity-building and instrumentalization for telerehabilitation ²⁴. In Brazil, the Unified National Health System (SUS) provides for the coexistence of points of care in the Network of Care for Persons with Disabilities ⁴⁹ at the different levels of care, which tends to support the maintenance of rehabilitation services, so long as protection for the health and training of workers is guaranteed. Although some initiatives specified by government recommendations ^{10,47} have happened, in addition to opportunities for training health professionals in the SUS for such care ⁵⁰, little is known about the health situation of persons with disabilities in the Brazilian context during the pandemic.

The production of information also includes analysis of the health situation of persons with disabilities through epidemiological studies ¹⁷. In this sense, one study describes the spatial method structure to identify priority areas for palliative care services in times of crisis, to organize the supply of services to support the health of more vulnerable persons ²⁶. Such a strategy could be used by government agencies for the decentralization and distribution of health or social protection services, based on equitable access. However, the reality has been a gap in observational studies on the health situation of persons with disabilities during the pandemic. When such studies are conducted, they should preserve the privacy and confidentiality of information pertaining to persons with disabilities, respecting the principles of research and healthcare ethics ³⁵.

Governments should also guarantee participation by regional agencies such as the Municipal Councils and organizations of persons with disabilities ²¹ and their families, in a coordinated action, monitoring action and budget guidelines that specifically address measures for the prevention of COVID-19, guaranteeing maximum dissemination of information and removing financial barriers to healthcare access ^{30,32}, including residential institutions ⁴⁷.

Information on COVID-19 should also be shared through accessible and timely formats, using accessible public communication technologies, avoiding stereotypes in images and messages and guaranteeing that protection is a central element in countries' strategic plans to respond to the pandemic ^{21,37}. Communication should incorporate the need for emergency measures in simple wording in the predominant languages in the affected areas, in various formats (audio, large print, and subtitles) ⁴¹.

As for work and income, with the need for social distancing and quarantine measures, orientation needs to be guaranteed on selfcare practices for the identification of potential signs and symptoms, forms of prevention with accessible communication, remote work with no pay cuts, and sick leave in case of symptoms for working persons with disabilities, as well as for family caregivers ^{21,42}. Strategies to guarantee social distancing and remote work should consider paid leaves, anticipation of individual vacations, collective vacations, or use and anticipation of holidays and banks of hours. The International Labour Organization (ILO) provides for the needs of individual assistance for persons with disabilities to perform their work activities ³⁰. For workers in the informal economy, there is a pressing need to guarantee labor benefits ³³. These recommendations in relation to flexibilization of work by persons with disabilities should be addressed to companies, public agencies, employers, physical persons, company unions, and workers from all economic sectors or nonprofit organizations ⁴².

Institutions and professionals in charge of health and social care

Social distancing has exacerbated the restrictions on access to health and social services for persons with disabilities, including COVID-19 diagnosis, especially for those living in institutions ^{31,39}. According to the United Nations, in the first two months of the pandemic, persons with disabilities had little or no accessible information on COVID-19 symptoms, prevention, or social distancing, especially on the need for maintaining contact with professional caregivers ³⁹ to maintain vital services like food, hygiene, and healthcare ³⁷.

As for educational institutions, measures were necessary to remote learning, even considering that they may not favor persons with disabilities due to the lack of support and access to software²⁹. The interruption of services such as schools, community centers, and treatments tends to negatively impact the health and well-being of persons with disabilities, potentially leading to setbacks in development³⁸. The challenge is to guarantee access to these services, maintaining the positive development of persons with disabilities in such diverse social contexts, overcoming environmental and social barriers.

In health institutions, the guarantee of access, continuity, and inclusion in care services should also consider the attributions of healthcare workers and should include possibilities for telecare^{2,15} and telerehabilitation¹⁷. It is necessary to guarantee that all procedures, even those already known to most of the population, are explained in multiple formats guaranteeing that persons with disabilities understand and enjoy autonomy in the choices³⁵. It is also necessary to reinforce orientation for family members concerning preventive measures⁴⁷. Emergency and hospitalization services need to be adapted, resolving environmental barriers and expanding access, considering all types of disability³⁵. Services also need to guarantee the right to have an accompanying person, and the information needs to be furnished in a functional, multilingual, and culturally appropriate way³⁸.

Rehabilitation services are essential, and telerehabilitation is a strategy to guarantee the continuity of healthcare, but requires training healthcare professionals and collaboration among them, guaranteeing resources and infrastructure, in addition to training for users and families. The suspension of these services can result in an increase in disabilities for those who require continuing care²⁴.

Barriers to accessing services and information, as well as noncompliance with preventive measures in the spaces responsible for care for persons with disabilities, discrimination, and various circumstances involving abuse and violence, can disproportionately affect women, elderly individuals, and other social minorities. Personalized approaches with orientation on management of risks and consequences of COVID-19, can be strategic in care for more vulnerable persons with disabilities, such as the elderly, avoiding unnecessary travel to health services²⁶. Information needs to be shared in an accessible format, adapted to different needs of persons with disabilities, incorporating strategies to assess the level of understanding³⁵.

This is also why measures against discrimination and violence involve the guarantee of access to information and quality services³⁴ as well as services to assist victims, inclusive and accessible via volunteer counseling networks and remote support²⁹. In this context, one of the documents refers to the need for community and psychosocial support via online tools that consider safe and concise measures in flexibilization of the quarantine for those with greater difficulties in maintaining lockdown, besides the supply of channels for support and care in cases of domestic violence³⁴.

Residential institutions for persons with disabilities should also invest in measures to reinforce hygiene, use of individual and collective personal protective equipment, social distancing, testing of workers and residents^{17,39,43}, and isolation of symptomatic individuals⁴³. Telerehabilitation can also be strategic in these institutions, decreasing the circulation of persons¹⁷, but so long as it considers differences in people's access to technologies and Internet²⁴. Another important aspect is the increased risk of mental distress due to the challenges imposed by the pandemic, demanding behavioral strategies and adaptative measures in the support services and professionals engaged in the continuity of care for persons with disabilities^{18,38}. According to a United Nations report, the lack of accessible information in some countries, such as failing to include sign language, has generated fear, anxiety, and confusion³⁹, requiring mental health services to use telemedicine in accessible language, taking into account guaranteed access to the Internet and other communications media for vulnerable populations²².

Family and caregivers of persons with disabilities in the context of the COVID-19 pandemic

The accompaniment of persons with disabilities by a support person, whether a family member, friend, or professional caregiver, must be a right, based some persons' need for additional support for essential tasks^{2,15,35,38}. However, persons with disabilities that depend on support may be in a difficult situation, since they or their caregivers may become sick or be exposed to risk of infection³⁰. It is thus essential to include the families and caregivers of persons with disabilities in public policies.

Health professionals should be alert to the families and caregivers of persons with disabilities, who are important for maintaining care and reducing the risk of infection and the impacts of environmental changes¹⁸. They should prepare the families and caregivers for the possibility of the persons with disabilities acquiring COVID-19 and care for their mental and physical health², besides orienting them on preventive measures¹⁸.

For children with autism, it is recommended to encourage physical activities, which can keep children physically active and calm at home, besides helping other family members reap psychological gains²⁸.

Where access to healthcare is difficult or health systems are overburdened by the pandemic, telehealth programs are essential to support family caregivers' skills²⁶. In Iran, educational materials were furnished to persons with specific disabilities and their families/caregivers, and a system was established with information on the medical and rehabilitation needs of persons with disabilities so that in case the principal caregiver is sick, the substitute caregiver can step in²³.

Caregivers and families should be alert to signs and symptoms before any interaction with persons with disabilities, since their illness may result in a break in home support. In case of COVID-19 infection in the caregiver or persons with disabilities, other contacts (family members, caregivers, friends) must be informed immediately. Caregivers also have the role of protecting, listening, supporting, adapting, and offering adequate accommodations for persons with disabilities^{15,18,38}.

The United Nations points to the need for families and caregivers to have adequate accommodations to provide support to persons with disabilities during this period. Designing reasonable measures for accommodation can reduce the risk of infection in persons with disabilities³⁹. Another key issue is guaranteed transportation or safe commuting for these persons, since inadequacies in public transportation can hamper or even prevent support for these persons from friends and family members, as in experiences with lockdown²⁷.

Final remarks

Persons with disabilities were acknowledged as a risk group for COVID-19 by international and national health organizations, besides persons with disabilities rights advocacy organizations. Importantly, however, this group is not inherently vulnerable. Attitudinal, environmental, and institutional barriers result in higher levels of vulnerability, so that persons with disabilities are historically marginalized, suffer more deprivations, difficulties in access and discrimination in the services' screening, and prejudices and stigmas that influence healthcare decisions, thereby intensifying preexisting inequalities.

Vulnerable populations such as persons with disabilities need specific policies that guarantee access to rights and equity in access to social protection policies, including in the context of the COVID-19 pandemic. The formulation and implementation of these policies are the responsibility of governments and should guarantee participation by persons with disabilities and their representative organizations, from the drafting of proposals to the monitoring of the pandemic's response and recovery plans. Besides governments, the rights and protection of life of persons with disabilities should also be guaranteed by civil society institutions through measures to strengthen community and family ties, access to caregivers, and guarantee of adequate information for greater autonomy of persons with disabilities in selfcare.

Evidence points to widespread delay by governments in establishing plans for COVID-19 that consider the needs of persons with disabilities, besides low participation by persons with disabilities in drafting these plans. These findings are consistent with the Brazilian reality, where the Federal Government presented a plan to deal with the pandemic for persons with disabilities nearly four months after the pandemic began⁵¹. The social adaptations proposed during the pandemic were already part of the demands by persons with disabilities about how to make society function to assimilate human diversities. The guarantee of home office work, workplace adaptations, supply of home services, expansion of social policies, inclusive forms of communication, and upgrading of information and services provision in societies' post-pandemic routine promote the full and equitable

exercise of all human rights and fundamental freedoms of persons with disabilities and other vulnerable populations.

Despite the large volume of documents systematized in this review, little is known about the reality of persons with disabilities during the pandemic. Studies are thus needed on the pandemic's effects on persons with disabilities for policies, programs, and services to be sized and to orient measures for prevention, control, and protection according to this population's health needs and demands. The scarcity of primary studies on the health situation of persons with disabilities during the COVID-19 pandemic and on the effects of government policies may compromise more effective responses to guarantee rights and equitable care.

Other reviews in 2020 aimed to understand the impact of the COVID-19 pandemic on different groups of persons with disabilities. A recent review describes impacts on activities of daily living, such as decreased access to healthcare, changes in social habits and lifestyle, mood changes, and decreased levels of physical activity⁵². Trauma and stress in the persons with disabilities community, including concerns about rationing and incapacity in healthcare, isolation, and deaths and illnesses in loved ones and members of the community were described as related to the pandemic⁵³, in addition to exacerbation of existing problems and barriers faced by persons with disabilities that suffer interpersonal violence. These issues include dependency on the aggressor for care and assistance, barriers to denouncing the abuse and to seeking help, fear of retaliation, and other negative consequences⁵⁴.

The emergency plans developed with a focus on the fighting spread of the virus and expanding emergency services often fail to consider specific issues of persons with disabilities and all areas of care. Rehabilitation strategies should include patients affected by COVID-19 and those with other potentially disabling conditions⁵⁵. Children with disability are disproportionately impacted by COVID-19 and by lockdown. Caregivers thus seek to adapt to growing stressors such as lack of access to necessary therapies, medical supplies, and nursing care. These families were already marginalized before the pandemic, and this only got worse in the current context⁵⁶. Our study is consistent with these reviews to the extent that it reveals the increasing barriers for persons with disabilities during the COVID-19 pandemic. Our option to conduct a comprehensive search without dividing into subgroups allowed a synthesis of findings that approaches the pandemic's impacts and the need for policies to guarantee equity in care for persons with disabilities.

Given the volume and pace of publications on COVID-19 in the second half of 2020, our study has the limitation of summarizing texts from the initial phase of the pandemic, while the responses may have changed as new studies were published. New studies are needed, seeking to accompany the trend in the health status of persons with disabilities during the pandemic and government and institutional responses for this specific population.

Considering the social and economic vulnerability of persons with disabilities and the increased risk of infection and death from COVID-19, an increase in scientific research on the health and living conditions of persons with disabilities is essential to produce effective responses in fighting the impacts of this pandemic and future health emergencies.

Contributors

J. H. S. Saldanha e M. M. C. Almeida participated in the study's conception, data analysis and interpretation, writing of the article, critical revision of the intellectual content and approval of the final version for publication. A. P. M. Pereira collaborated in the study's conception, data analysis and interpretation, writing of the article, critical revision of the intellectual content and approval of the final version for publication. A. O. C. Santos, B. S. Miranda, H. K. S. Carvalho, L. C. Nascimento, M. S. Amaral, M. S. Macedo e M. Catrini participated in the data analysis and interpretation, writing of the article and approval of the final version for publication.

Additional informations

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Resumo

Este trabalho é uma revisão de escopo realizada nas bases de dados PubMed, Scopus, BIREME, SciELO e Web of Science, que incluiu publicações de dezembro de 2019 a maio de 2020, com o objetivo de identificar e sistematizar a literatura sobre a situação das pessoas com deficiência nos primeiros meses da pandemia da COVID-19. A revisão foi orientada para a busca de artigos originais, publicados em revistas indexadas e revisados por pares, além de literatura cinzenta especializada. Foram revisados 386 textos e incluídos no estudo 33 artigos e documentos. O resultado da revisão apontou três categorias temáticas que refletem as principais discussões apresentadas na literatura sobre o tema: vulnerabilidades das pessoas com deficiência diante da pandemia; direitos das pessoas com deficiência nesse contexto; e medidas de proteção e acesso à informação sobre COVID-19 voltadas para pessoas com deficiência. No contexto de emergência em saúde pública, comunidades historicamente marginalizadas, como as pessoas com deficiência, correm o risco de se sentirem mais vulneráveis, bem como sofrerem privações e discriminação nos planos de triagem de atendimento, além de preconceitos e estigmas que influenciam nas tomadas de decisão na assistência em saúde e intensificam desigualdades preexistentes, tornando esse grupo mais suscetível ao adoecimento e à desproteção social. Embora as pessoas com deficiência tenham sido reconhecidas como grupo de risco para COVID-19, houve um atraso, por parte dos governos, na construção de planos de enfrentamento à doença para essa população. São escassos estudos para a compreensão dos efeitos da pandemia da COVID-19 nas pessoas com deficiência, especialmente no sentido da efetivação de medidas de prevenção, controle e proteção que garantam a equidade no cuidado.

Pessoas com Deficiência; Infecções por Coronavírus; COVID-19

Resumen

Se trata de una revisión de alcance, realizada en las bases de datos PubMed, Scopus, BIREME, SciELO y Web of Science, incluyendo publicaciones de diciembre de 2019 a mayo de 2020, con el objetivo de identificar y sistematizar la literatura sobre la situación de las personas con discapacidad durante los primeros meses de la pandemia de la COVID-19. La revisión se orientó hacia la búsqueda de artículos originales, publicados en revistas indexadas y revisados por pares, además de literatura gris especializada. Se revisaron 386 textos y se incluyeron en el estudio 33 artículos y documentos. El resultado de la revisión apuntó tres categorías temáticas que reflejan las principales discusiones presentadas en la literatura sobre el tema: vulnerabilidades de las personas con discapacidad ante la pandemia; derechos de las personas con discapacidad en ese contexto; y medidas de protección y acceso a la información sobre COVID-19, dirigidas a las personas con discapacidad. En el contexto de emergencia en salud pública, comunidades históricamente marginalizadas, como las personas con discapacidad, corren el riesgo de que se sientan más vulnerables, sufran privaciones, discriminación en los ámbitos de clasificación de atención, además de que padezcan prejuicios y estigmas que influyen en las tomas de decisión en la asistencia en salud e intensifican desigualdades preexistentes, haciendo este grupo más susceptible a la enfermedad y a la desprotección social. Pese a que las personas con discapacidad hayan sido reconocidas como grupo de riesgo para la COVID-19, hubo un atraso, por parte de los gobiernos, en la construcción de planes de lucha contra la COVID-19 para esta población. Son escasos los estudios para la comprensión de los efectos de la pandemia de la COVID-19 en las personas con discapacidad, especialmente en el sentido de la efectivización de medidas de prevención, control y protección que garanticen la equidad en el cuidado.

Personas con Discapacidad; Infecciones por Coronavírus; COVID-19

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