

# COVID-19 in people with developmental disabilities: a scoping review

COVID-19 em pessoas com deficiências do desenvolvimento: uma revisão de escopo

COVID-19 en personas con trastornos en el desarrollo: una revisión de alcance

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## Descritores

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## Abstract

**Objective:** To examine the emerging evidence on developmental disability type and frequency in the population affected by COVID-19, identifying more frequent forms of categorization, incidence/prevalence and comorbidities.

**Methods:** For this scoping review, we searched for observational studies in the MEDLINE (PubMed), Scopus (Elsevier), ISI Web of Science (Clarivate), LILACS (VHL) and grey literature databases. As eligibility criteria, studies should present results of developmental disability (DD) occurrence in people with COVID-19, allowing comparison with the general population, or between groups of disabilities. Two independent reviewers mapped the information using a previously elaborated data extraction instrument. Two other researchers verified the data and assisted in table elaboration to present the results.

**Results:** There was a diversity of terminologies used to categorize DD. People with DD and comorbidities that represent a higher risk for COVID-19 required hospitalization more frequently than the general population. Out of a total of 4930 studies, 14 were selected for assessment. Of these, 5 articles were longitudinal studies.

**Conclusion:** In people with DD, COVID-19 had higher morbidity, lethality and mortality rates in younger age groups, in the poorest population, in the institutionalized population, requiring life support technologies and specialized care. The vulnerability of people with DD to COVID-19 depends on disease type and severity and the presence of comorbidities, highlighting the need for attention in diagnosis and preventive measures, such as vaccination.

## Resumo

**Objetivo:** Examinar a evidência emergente sobre os tipos e a frequência de deficiências do desenvolvimento na população afetada pela COVID-19, identificando formas de categorização, incidência/prevalência e comorbidades mais frequentes.

**Métodos:** Para esta revisão de escopo realizou-se busca por estudos observacionais nas bases de dados Medline (PubMed), Scopus (Elsevier), ISI Web of Science (Clarivate), Lilacs (BVS) e 'literatura cinzenta'. Como critérios de elegibilidade, os estudos deveriam apresentar resultados de ocorrência de deficiências de desenvolvimento em pessoas com COVID-19, permitindo comparação com a população em geral, ou entre os grupos de deficiências. Dois revisores independentes fizeram o mapeamento das informações utilizando um instrumento de extração de dados previamente elaborado. Outros dois pesquisadores verificaram os dados e auxiliaram na elaboração dos quadros de apresentação dos resultados.

**Resultados:** Observou-se diversidade de terminologias empregadas para categorizar as DD. As pessoas com DD e com comorbidades que representam maior risco para a COVID-19 necessitaram de internação

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hospitalar com maior frequência do que a população em geral. De um total de 4930 estudos, 14 foram selecionados para avaliação. Destes, 5 artigos foram estudos longitudinais.

**Conclusão:** Em pessoas com DD, a COVID-19 apresentou taxas de morbidade, letalidade e mortalidade mais altas em faixas etárias mais jovens, na população mais pobre, na população institucionalizada e que requer tecnologias de suporte de vida e cuidados especializados. A vulnerabilidade das pessoas com DD à COVID-19 depende do tipo e da gravidade da deficiência e da presença de comorbidades, evidenciando a necessidade de atenção no diagnóstico e nas medidas preventivas, como a vacinação.

## Resumen

**Objetivo:** Examinar la evidencia emergente sobre los tipos y la frecuencia de trastornos en el desarrollo (TD) en la población afectada por COVID-19 e identificar formas de categorización, incidencia/prevalencia y comorbilidades más frecuentes.

**Métodos:** Para esta revisión de alcance se realizó una búsqueda de estudios observacionales en las bases de datos Medline (PubMed), Scopus (Elsevier), ISI Web of Science (Clarivate), Lilacs (BVS) y 'literatura gris'. Como criterio de elegibilidad, los estudios debían presentar resultados de casos de TD en personas con COVID-19 y permitir la comparación con la población general, o entre los grupos de trastornos. Dos revisores independientes realizaron el mapeo de la información con la utilización de un instrumento de extracción de datos previamente elaborado. Otros dos investigadores verificaron los datos y ayudaron a elaborar los cuadros de presentación de resultados.

**Resultados:** Se observó diversidad en la terminología empleada para categorizar los TD. Las personas con TD y con comorbilidades que representan mayor riesgo de COVID-19 necesitaron internación hospitalaria con mayor frecuencia que la población general. De un total de 4930 estudios, 14 fueron seleccionados para el análisis, de los cuales 5 artículos fueron estudios longitudinales.

**Conclusión:** En personas con TD, el COVID-19 presentó índices de morbilidad, letalidad y mortalidad más altos en rangos de edad más jóvenes, en la población más pobre, en la población institucionalizada y que requiere tecnologías de soporte vital y cuidados especializados. La vulnerabilidad de las personas con TD depende del tipo y gravedad del trastorno y de la presencia de comorbilidades, lo que deja en evidencia la necesidad de atención en el diagnóstico y en las medidas preventivas, como la vacunación.

## Introduction

The world population is experiencing the devastating effects of an acute respiratory disease known as COVID-19, which was elevated to pandemic status by the World Health Organization in March 2020, whose infectious agent is a new coronavirus called SARS-CoV-2.<sup>(1)</sup> The clinical characteristics of COVID-19 can range from an asymptomatic state to severe respiratory failure and multiple organ dysfunction, and the virus appears to be more fatal in individuals with underlying comorbidities.<sup>(2)</sup>

Higher rates of comorbidities, associated with increased risk of exposure and lack of access to information and health care, contribute to making many people with disabilities vulnerable to COVID-19 infection or its consequences.<sup>(3)</sup> The needs of people with disabilities, especially those who rely on personal care, have not been considered in the elaboration of public health guidelines and in the recommendation of routine prevention measures (e.g., social distancing and hand washing).<sup>(4)</sup>

Among the different disability types, “developmental disability” (DD) is a term that overlaps with all developmental disorders.<sup>(5)</sup> Intellectual and developmental disabilities (IDD) involve limitations

of learning, behavior, language, and motor functions. In the United States, IDD includes intellectual disabilities, cerebral palsy, Down syndrome, and other rarer syndromes such as fragile X syndrome and Prader-Willis syndrome.<sup>(6)</sup> The term “medically complex patients” is a categorization that encompasses the group of people who have long-term dependence on supportive technology (including tracheostomy) associated with developmental delay and/or genetic abnormalities.<sup>(7)</sup> There is also the term “neurological disorders” that is categorized as epilepsy, cerebral palsy and other acquired encephalopathies, neurological development disorders, neurogenetic syndromes, brain malformation and others. Associated deficiencies are measured in relation to the cognitive, affect, motor, sensory, communication, activity and participation domains of the International Classification of Functioning, Disability and Health.<sup>(8)</sup>

Among the groups at greatest risk for serious complications due to the disease are individuals who live in long-term care institutions and receive more frequent and qualified nursing care.<sup>(9)</sup> So, people with DD should be included in the priority groups during the preparation and planning of immunization programs for COVID-19. In the

United Kingdom, people with disabilities are in priority group 6 for vaccination.<sup>(10)</sup> In that country, considering all disability types, it was found that 60% of COVID-19 deaths were in this population group.<sup>(11)</sup>

COVID-19 also poses a high risk for people with intellectual disabilities (including those with neurological disabilities here). This increased risk is not only related to the disability itself, but also to associated comorbidities.<sup>(12)</sup> Gleason et al. (2021) observed that these patients are more likely to be admitted to Intensive Care Units and then experience higher chances of mortality, even when compared to the general population with comorbidities such as congestive heart failure, renal failure and lung disease.<sup>(12)</sup>

Among neurological disorders, cerebral palsy deserves much attention. It is a syndrome clinically defined as a movement or posture disorder that occurs during the fetal/baby brain development and these patients fall into the group of people with IDD.<sup>(13)</sup> Motor problems in cerebral palsy are basically classified according to the affected limbs, such as hemiplegia, diplegia and quadriplegia, and also movement difficulty type, such as spasticity, dyskinesia and ataxia.<sup>(1)</sup>

Changes in diaphragmatic movement and in muscles involved in swallowing present in some individuals with cerebral palsy may result in aspiration of saliva or feeding resulting in recurrent pneumonia.<sup>(14,15)</sup> They are more frequent in those with dyskinesia and ataxia, continuing into adulthood. The more severe the symptoms of cerebral palsy, the greater the chances of difficulties in salivation and swallowing saliva and food, recurrent respiratory infections, hypoventilation during sleep and the need for tracheostomy.<sup>(1)</sup> In individuals with cerebral palsy, respiratory dysfunction is the major cause of morbidity and mortality.<sup>(1,15)</sup>

The diaphragm is the main muscle involved in breathing, sneezing and coughing that are fundamental reflexes for airway clearance.<sup>(1)</sup> Coordinating sneezing and coughing is of fundamental importance when people contract acute respiratory infections, especially in the case of the SARS-CoV-2 outbreak.<sup>(1)</sup>

In this context, the following question arises: What are the characteristics and frequency of DD in the population affected by COVID-19? More specifically, how have DD been categorized in epidemiological surveys of COVID-19? What are the incidence and/or prevalence rates of people with DD infected with this disease, and which comorbidities have been most observed in this population group?

Thus, this scoping review aimed to examine the emerging evidence on the types and frequency of DD in the population affected by COVID-19, especially people with cerebral palsy, identifying how DD have been categorized, and the incidence/prevalence and the most frequent comorbidities in this population group.

## Methods

This scoping review was structured based on the JBI Manual for Evidence Synthesis,<sup>(16)</sup> and described according to the Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR) recommendations.<sup>(17)</sup> Observational studies were selected to verify the occurrence of COVID-19 in people with DD, from January 2020 to April 2021, without language restriction.

The electronic search was carried out in the following databases: PubMed Central, Scopus (Elsevier), ISI Web of Science (Clarivate), LILACS (VHL) and grey literature. To define the search strategy, the JBI recommendation for scoping reviews was adopted, which is based on the mnemonic PCC – population, concept and context.<sup>(16)</sup> In this regard, terms related to the population affected by COVID-19 (as population), and to the different classifications of DD (as concept) were selected. As there was an intention to broadly search for emerging evidence, the context was kept open.

Terms from the Medical Subject Headings (MeSH) were adopted for the search, which were completed by manual search in the reference lists of selected articles. The following strategy was employed: (“COVID-19” OR “SARS-CoV-2”) AND

(“Intellectual disability” OR “developmental disability” OR “cerebral palsy” OR “medically complex patients” OR “neurological disorders” OR “neurological conditions”), without the use of filters.

The eligibility criteria were: (1) presenting results of occurrence of DD in people with COVID-19, allowing comparison with the general population, or (2) presenting results of occurrence of DD in people with COVID-19, allowing comparison between groups of disabilities, regardless of the type of classification adopted.

All titles/abstracts of references retrieved during the search were independently read by two reviewers (PSP and TPT), and those that did not meet the election criteria were excluded. When an abstract was not available or did not provide sufficient information for a decision, the study was selected to read its full text. Then, full texts were read and the same election criteria were used. Articles that met these criteria were included. In cases of disagreement in any stage, the decision was made with the participation of a third reviewer (LSC).

An instrument for data extraction was developed, and information mapping was carried out by two independent researchers. We recorded the

following information for each article included: authors and year of publication, place of study, objective and study design, control group, sample characteristics such as size, age, IDD types (if available). Moreover, main results include, when available, prevalence and incidence data, proportions and confidence intervals. After mapping, two other reviewers verified the information and the team prepared data presentation in the form of descriptive tables.

## Results

Of a total of 4930 scientific articles detected in the search, 13 were selected. The references of these 13 articles were investigated in order to certify the existence of some other article not found through the original search. Another technical report that met the inclusion criteria was found.<sup>(5)</sup> Figure 1 shows the selection of 14 studies. Charts 1 and 2 show the results of information extraction from included studies.

The study by Clift et al. (2020) encompasses research with more than 6 million people in the deri-

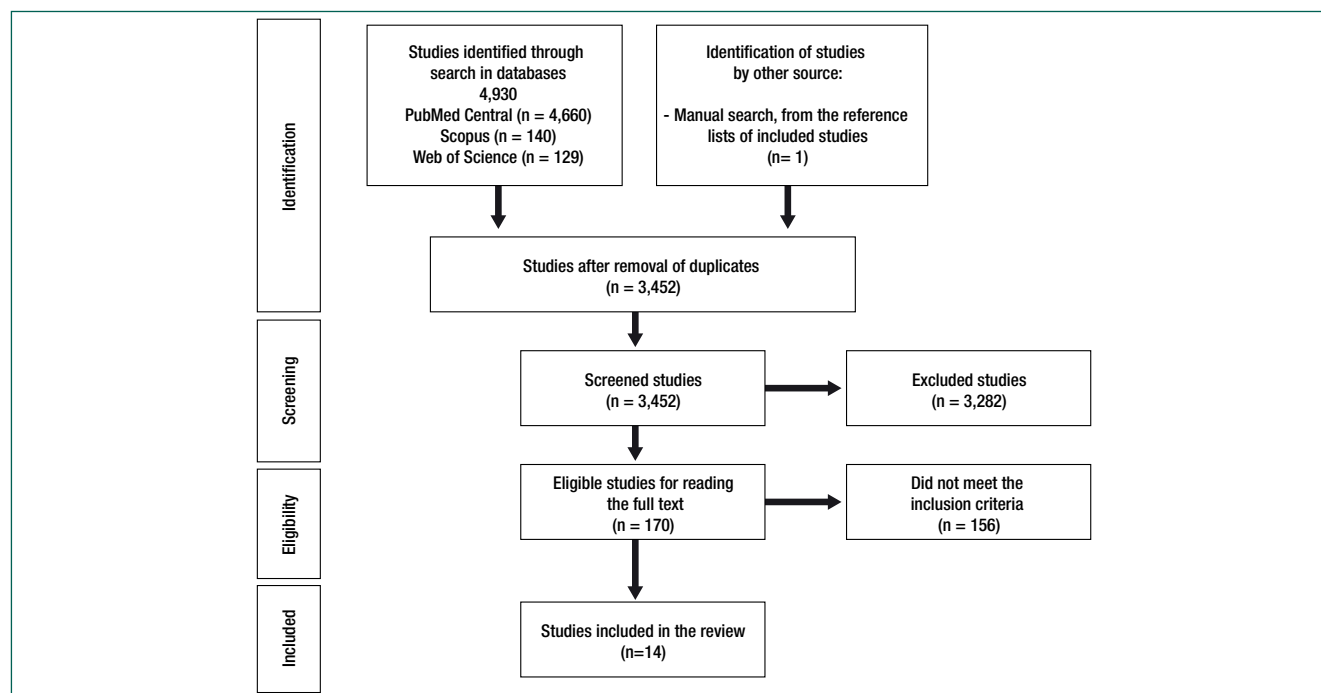


Figure 1. Process of identification and selection of included studies

**Chart 1.** Characteristics of participants included in the studies

Authors/date/country	Groups and sample size	Age*	Categorization/disability types
Chakraborty (2020) <sup>(6)</sup> / United States	- People with COVID-19: 4.483.338 - People with disabilities (based on non-institutionalized population): mean of 15.95% per county	Not reported	Serious difficulties in self-care, hearing, vision, independent living, walking and/or cognitive.
Fair Health (2020) <sup>(6)</sup> / United States	- People with COVID-19: 467.773	Not reported	- DD: speech and language, school skills, and central auditory processing disorders. - Intellectual disabilities and related conditions: Down syndrome and other chromosomal abnormalities, intellectual disabilities and congenital malformations.
Landes et al. (2020) <sup>(6)</sup> / United States	- People with DD who live in long-term care institutions: 20.431 - General population of the state of New York: 19.453.291	Not reported	Not reported
Fernandes et al. (2021) <sup>(7)</sup> / United States	People hospitalized for COVID-19: 281, of whom 59 were considered clinically complex patients.	M: 10 years IQR: 1-17 years	Not reported
Bova et al. (2020) <sup>(8)</sup> / Italy	Children with chronic neurological disorders with or without associated disabilities: 514	M: 8.8 years SD: 4.6 years	- Epilepsy (61.7%) - Neurogenetic syndromes (23.7%) - Cerebral palsy and other acquired encephalopathies (13%) - Neurodevelopmental disorders (10.3%) - Brain malformations (8.4%) - Metabolic and degenerative brain disorders (8%) - Inflammatory and post-infectious diseases (3.3%) - Other (3.3%)
Landes et al. (2021) <sup>(9)</sup> / United States	- Persons receiving qualified nursing services: 354.640 - People who do not receive qualified nursing services: 39.157.583	Not reported	Not reported
Gleason et al. (2021) <sup>(12)</sup> / United States	- People with IDD: 128.074 - People without IDD: 64.730.386	Not reported	Not reported
Clift et al. (2020) <sup>(18)</sup> / England	Primary care patients: - 6,080,000 people in the derivation cohort - 2,170,000,000 in the validation cohort	- Derivation cohort: M: 48.2 years SD: 18.6 years	Frequencies in the derivation cohort: Learning disability (1.76%) Epilepsy (1.32%) Rare neurological conditions including motor neuron disease, multiple sclerosis, myasthenia, Huntington's disease (0.31%). Cerebral palsy (0.11%) Down syndrome (0.05%)
Göttinger et al. (2020) <sup>(19)</sup> / Europe	Children and adolescents with COVID-19: 582	M: 5 years IQR: 0.5-12 years	Neurological disorders (4.47%) - Epilepsy (1.55%) - Cerebral palsy (1.37%) Chromosomal abnormalities (1.72%) - Down syndrome (1.37%)
Shekdermian et al. (2020) <sup>(20)</sup> / Canada and United States	Children with COVID-19 positive results admitted to Pediatric Intensive Care Units: 48	M: 13 years IQR: 4.2-16.6 years	- No comorbidity (17%) - Clinically complex (40%), including developmental delays and/or genetic abnormalities. - With other comorbidities (33%)
Zachariah et al. (2021) <sup>(21)</sup> / United States	Children hospitalized with confirmed COVID-19: 50 - Non-severe form: 41 - Severe form: 9	- Non-severe form: M: 9 years Min: 6 days Max: 21 years - Severe form: M: 14 years Min: 8 years Max: 19 years	Neurological conditions (14%) - Convulsive disorder - Neurodegenerative disorders - Cerebral palsy
Garces et al. (2020) <sup>(22)</sup> / Brazil	People with flu-like symptoms: 19,967, of which 69 had neurological diseases.	M: 40.8 years SD: 20.2	- Neurological diseases (0.35%) - Down syndrome (0.03%)
Turk et al. (2020) <sup>(23)</sup> / United States	- People with IDD: 474 - People without IDD: 29.808	- People with IDD: M: 45.7 years - People without IDD: M: 45.6 years	- Invasive and specific developmental disorder (56%) - Intellectual disability (33%) - Chromosomal abnormality (21%) - Cerebral palsy (18%)
Perera et al. (2020) <sup>(24)</sup> / England and Ireland	People with IDD who died due to COVID-19: 66	M: 64 years Min: 31 years Max: 88 years	- Mild intellectual disabilities (34%) - Moderate to profound intellectual disabilities (66%) - Down syndrome (30%)

\* The central tendency measures available for the total sample or for the assessed groups were collected; M – mean; SD – standard deviation; Med – median; IQR – interquartile range; Min – minimum; Max – maximum

**Chart 2.** Objectives and results presented by included studies

Authors (YEAR)/country	Objectives/study design	Synthesis of results
Chakraborty (2020) <sup>(4)</sup> /United States	Determine whether COVID-19 incidence is significantly higher in American counties that have high percentages of people with disabilities based on criteria such as race, poverty, sex, and age/ Cross-sectional study	COVID-19 incidence is higher in people with disabilities in physical and social vulnerability. High incidence rates were significantly associated with: (1) high percentages of people with disabilities who are women, black, Asian, Hispanic, Native American, poor and under the age of 18, and (2) lower percentages of people with disabilities who are men, non-Hispanic white, above the poverty limit, 65 years of age or older.
Fair Health (2020) <sup>(6)</sup> /United States	Examine the relationships between the mortality rate (dependent variable) and the independent variables: age, sex, and pre-existing comorbidities/ Cohort study	Patients with intellectual disabilities and related conditions have the third highest risk of death from COVID-19 in all age groups (OR: 2.75, 95% CI: 1.66-4.56), and also among patients under 70 years (OR: 3.61, 95% CI: 1.88-6.93).
Landes et al. (2020) <sup>(6)</sup> /United States	Describe COVID-19 outcomes among people with IDD living in long-term care facilities in New York State and the general population of the same state/ Cross-sectional study	People with IDD who live in long-term care institutions have a higher risk of presenting more serious results for COVID-19. Higher rates of positive diagnosis, mortality and lethality were observed in relation to the general population.
Fernandes et al. (2021) <sup>(7)</sup> / United States	Demographically and clinically characterize pediatric patients with COVID-19 and identify hospital admission variables predictive of disease severity in the states of New York, New Jersey and Connecticut/ Cohort study	Seven children died, 4 of whom were clinically complex patients, 2 had asthma as the only previous medical problem, and 1 had no comorbidity.
Bova et al. (2020) <sup>(8)</sup> /Italy	Investigate the effects of lockdown on the health of children with neurological disorders and their access to care during lockdown / Cohort study	The prevalence of COVID-19-related symptoms was significantly lower during the lockdown period than in the previous 2-month period. Children who left their homes during the lockdown period presented higher risks of presenting the symptoms associated with COVID-19 (OR: 3.63; 95% CI: 1.52-8.67).
Landes et al. (2021) <sup>(9)</sup> /United States	Determine the impact of the residential environment and level of qualified nursing care for COVID-19 for people with IDD who receive and do not receive such care/ Cross-sectional study	People who receive nursing services have a 60% lower contamination rate than those who do not receive this care. The mortality rate is 2.8 times higher among those who receive the services. Higher rates of diagnosis are in long-term care institutions that have more individuals. Higher lethality and mortality rates are concentrated in institutions with 24-hour nursing care.
Gleason et al. (2021) <sup>(12)</sup> / United States	Describe the relative impact of COVID-19 on individuals with intellectual disabilities in relation to the general population/ Cross-sectional study	Intellectual disability was the strongest independent risk factor for the diagnosis of COVID-19 (OR: 2.58, 95% CI: 2.5-2.67) and the second strongest independent risk factor after age for mortality from the disease (OR: 5.9, 95% CI: 5.28-6.62).
Clift et al. (2020) <sup>(16)</sup> /England	Derive and validate a risk prediction algorithm to estimate hospital admission and COVID-19 mortality outcomes in adults/ Cohort study	4,384 deaths from COVID-19 occurred in the shunt cohort, 1,722 in the first validation period cohort, and 621 in the second validation period cohort. Cerebral palsy and neuromotor disease were comorbidities associated with hospital admission in all adjustment scenarios, although they are not part of the 20 comorbidities most associated with hospitalization for the disease.
Göttinger et al. (2020) <sup>(19)</sup> / Europe	Investigate data on COVID-19 in children and adolescents across Europe/ Cohort study	Among patients with neurological disorders (n=26), 5 were admitted to ICUs (OR: 2.8; 95% CI: 1.0-7.9).
Shekarderian et al. (2020) <sup>(20)</sup> /Canada and United States	Describe and characterize COVID-19 infection in North American pediatric ICUs/ Cross-sectional study	The most important comorbidity was detected among "clinically complex" patients, a term that involves patients who are dependent on long-term technological support for survival such as tracheostomy and developmental delay and/or genetic abnormalities.
Zachariah et al. (2021) <sup>(21)</sup> / United States	Describe the epidemiological, clinical, and laboratory characteristics of patients with COVID-19 hospitalized at a children's hospital and compare these parameters between hospitalized patients with and without the disease/ Cross-sectional study	Of the children without any comorbidity, 25 developed the mild form and 8 developed the severe form of the disease. Of the children with neurological problems, 6 developed the mild form and 1 developed the severe form. Children who had neurological problems were at no greater risk of developing severe forms of the disease.
Garces et al. (2020) <sup>(22)</sup> / Brazil	Estimate the prevalence and risk factors associated with COVID-19/ Cross-sectional study	The prevalence of COVID-19 was higher among older people, men, and in people with cardiovascular disease, neurological disease, obesity, lung diseases and kidney diseases. However, after regression analysis, neurological diseases, history of asthma and Down syndrome were not factors associated with COVID-19.
Turk et al. (2020) <sup>(23)</sup> /United States	Compare the trend of COVID-19 among people with and without IDD with stratification by age group/ Cross-sectional study	People with IDD have a higher prevalence of specific comorbidities associated with unfavorable COVID-19 outcomes. In both groups, disease incidence is higher in the age group of 18-74 years. However, people with IDD had higher lethality of the disease among the youngest, while in the population over 75 years the disease behaved similarly to the rest of the population.
Perera et al. (2020) <sup>(24)</sup> / England and Ireland	Investigate whether risk factors and comorbidities for the general population synchronously apply to the intellectual level of the population with disabilities, and whether there are additional risk issues of known and common comorbid disorders and, if so, what their cumulative burden is/ Cross-sectional study	In the population with intellectual disabilities, mortality is concentrated in younger age groups than in the general population. Epilepsy associated with moderate intellectual disability seems to be a factor associated with mortality from the disease in this group. Dysphagia was a factor associated with mortality in the group with more severe disabilities. Down syndrome was the most frequent diagnosis among deaths. Most of people who died lived in long-term care institutions.

OR – Odds Ratio; CI – Confidence Interval; IDD – intellectual developmental disability; Intensive Care Unit.

vation data set and more than 2 million validation data.<sup>(18)</sup> Derivation and the first period of the validation cohort was from January 24, 2020 to April 30, 2020. The second temporal validation cohort covered the period from May 1, 2020 to June 30,

2020. In Europe, a multicenter study analyzed a cohort that started from the date of onset of symptoms until the date of diagnosis when SARS-CoV-2 was first detected.<sup>(19)</sup> In an Italian study, data were collected from the records of the same patients before

and after the lockdown decree in that country.<sup>(8)</sup> The study by Fernandes et al. (2021) is a retrospective and prospective cohort study with data from pediatric patients hospitalized in the states of New Jersey and Connecticut.<sup>(7)</sup> The study conducted by Fair Health (2021) is also a longitudinal study.<sup>(5)</sup> All other studies (66.6%) are characterized by being cross-sectional studies.<sup>(4,6,9,12,20-24)</sup>

## Discussion

The studies included in this review did not allow to define the real risk of COVID-19 infection according to disability type. The diversity of terminologies used to categorize patients with IDD was observed in this survey. Terms with medically complex people and neurological disorders were also found.<sup>(7,8,20)</sup> The term “neurological conditions” encompasses the frames of seizure disorders, neurodegenerative disorders, and cerebral palsy.<sup>(21)</sup> IDD also encompasses the categories involved in the first three terms described. Finally, “neurological diseases” is a term used by Garces et al. (2020) that does not present a delimitation of what are the diseases contained in the term.<sup>(22)</sup> This diversification of terminologies makes it difficult to analyze, and this study highlights the need to seek uniformity of nomenclature, as it would facilitate studies and research on the subject, communication between professionals and increase access to information.

Clift et al. (2020) were the only authors to establish risk estimates for each disability type.<sup>(18)</sup> This study greatly helped the present analysis by listing the comorbidities that most predispose individuals to have more severe forms of the disease. As 66% of the studies included in this review were cross-sectional studies, there was great difficulty in establishing causality, considering a population that has so many confounding factors.

Furthermore, COVID-19 incidence in the population of people IDD is influenced by socioeconomic issues such as sex, economic deprivation, age and housing type.<sup>(4,6,23)</sup> Finally, comorbidities and degree of dependence on life support technologies and specialized care are also important ele-

ments in the analysis of mortality and mortality, mainly.<sup>(7,9,20,23)</sup>

In the analysis performed in hospitalizations at the New York pediatric hospital, from March 1 to April 15, 2020, neurological conditions were not associated with disease severity requiring mechanical ventilation.<sup>(21)</sup> However, clinically complex patients from April to May 2020 were responsible for most hospital admissions in the United States. For the authors, the study with children and their comorbidities leads to a difficulty in drawing a parallel with the adult population, considering that, in the latter, comorbidities are mostly the result of a person’s lifestyle. Among children, most carry comorbidities resulting from congenital anomalies.<sup>(7)</sup> This result with this population group was also reported by Shekerdemian et al. (2020).<sup>(20)</sup> We should point out that current vaccination campaigns are focused only on the adult population, with priorities for higher risk groups. However, the results and difficulties reported in these studies demonstrate the importance of attention and focus on clinically complex patients, either due to particularity, age group or comorbidities.

In a multicenter study conducted in 82 health institutions located in 25 European countries, with 582 patients who presented acute respiratory syndrome with a mean age of five years. Neurological disorders had a marginal statistical significance: OR 2.8 (95% CI: 1.0–7.9).<sup>(19)</sup>

In another cohort study conducted in the United Kingdom between May 1, 2020 and June 30, 2020, aiming at validating a risk prediction algorithm to estimate hospital admission and mortality results for COVID-19 among adults, it was observed that having Down syndrome, cerebral palsy, Parkinson’s, epilepsy, motor diseases, multiple sclerosis, Huntington’s disease, severe myasthenia or intellectual disabilities were risk factors for hospitalization. Of these, Down syndrome was the most at risk.<sup>(18)</sup>

In a study conducted in England and Ireland between June 8 and June 19, 2020, it was observed that, in the population with intellectual disabilities, mortality is concentrated in younger age groups than the general population (mean of 64 years). Epilepsy associated with moderate intellectual dis-

ability seems to be a factor associated with mortality from the disease in this group. Dysphagia was a factor associated with mortality in the group with more severe disabilities. Down syndrome was the most frequent diagnosis among deaths. Most people who died lived in long-term care institutions.<sup>(24)</sup>

In a study by Turk et al. (2020) in the United States, people with IDD who were diagnosed with COVID-19 had a higher rate of comorbidities associated with severity and mortality from the disease (including respiratory problems) in all age groups.<sup>(23)</sup> The authors used Tri Next, a data platform that receives data from 42 health care organizations in the United States. Data were relative until May 14, 2020. These individuals had higher mortality rates in the age group from 0 to 74 years, and the highest prevalence occurred between 18 and 74 years. The authors point to differences that need to be further investigated when comparing groups with IDD and groups without these disabilities in relation to the presence of comorbidities. In addition, they also point to the need to analyze a possible heterogeneity of the frailty effect, resulting in a disproportionate percentage of individuals with IDD dying from the disease at younger ages when compared with or without such disabilities at ages over 75 years.

In the state of New York, in the United States, until May 28, 2020, people with IDD who live in long-term care institutions are at higher risk of developing COVID-19 in its most severe forms when compared to the general state population.<sup>(6)</sup> In the state of California, from early May to October 2, 2020, higher mortality and lethality rates were detected among patients with IDD who lived in environments that provided more intensive skilled nursing care.<sup>(9)</sup>

A study was carried out with 514 individuals with neurological disabilities (epilepsy, cerebral palsy and other encephalopathies) in Italy between 7 and 22 May 2020, investigating the two months before the first lockdown in this country and May 2020. About 50% of individuals investigated had at least one symptom of COVID-19, but without major complications. Children who left their homes during the lockdown and those who lived with their families were at greater risk of showing symptoms

of COVID-19. In the specific case of cerebral palsy, there was no statistically significant difference in the pre-lockdown period from the post-lockdown period. Similarly, there was no significant difference regarding the presence of chronic respiratory diseases and at least one symptom of COVID-19 before and after lockdown.<sup>(8)</sup>

In Brazil, in the state of Ceará, a survey was carried out with data from Integra-SUS with 19,967 patients who had flu-like symptoms, from January 8 to April 14, 2020, with a mean age of 40.8 years. Of these, 2070 tested positive for the disease. Neither neurological diseases, Down syndrome nor history of asthma showed significant results in the regression model.<sup>(22)</sup>

An epidemiological survey of private health insurance users was conducted from FAIR Health, which is the largest service of this modality in the United States. People with intellectual disabilities and conditions related to this condition such as Down syndrome and other chromosomal abnormalities, mild, moderate and severe intellectual disabilities, congenital malformations had the third highest risk of death from COVID-19 until the age of 70 years. In total, data from 467,773 patients diagnosed with COVID-19 from April 2020 to August 31, 2020 were examined.<sup>(5)</sup> The findings presented by these studies reinforce the need for specific education and instruction for these groups, with their own approaches to understanding patients and/or families about disease prevention.

To reduce the risk of contracting COVID-19, it is necessary to be vigilant, welcome and support families of people with cerebral palsy. We need to encourage social distancing, good hand hygiene, minimize going to places such as stores and restaurants and ensure that any equipment used outside the home such as walkers and wheelchairs is properly cleaned.<sup>(1)</sup> Increased risk of illness can be explained by the need for supportive home care, shared transport, living in long-term care institutions and a sensory intolerance to the use of masks.<sup>(12)</sup>

It is still too early to say whether what predisposes individuals to the severity of COVID-19 is their neurological and intellectual condition or whether it is the comorbidities associated with their



condition. In the case of cerebral palsy, the problems associated with breathing and swallowing are factors clearly involved in the most severe evolution of the disease. However, when respecting the principles of social isolation, the condition itself does not determine whether a person is more susceptible to contracting the disease. New studies should be conducted investigating COVID-19 in these patients so that health actions are specifically directed to them.

As a limitation of this review, importantly, all included studies presented data from the so-called “first wave” of the COVID-19 pandemic and that the emergence of new strains of SARS-CoV-2 (in particular the alpha, beta, gamma and delta variants) may have changed the epidemiological picture of COVID-19 among people with DD. Although this population group has been included as a priority for vaccination, the results presented here show the importance of constant and careful epidemiological observation to support health policies.

The results of this study reinforce the need to prioritize people with DD in vaccination programs for COVID-19. In Brazil, until July 2022, vaccination of this group was performed according to age group and associated comorbidities, not according to the severity of their condition.

## Conclusion

The diversity of terminologies and categorizations of DD makes it difficult to analyze the risk of disability for COVID-19. The degree of vulnerability of people with DD to COVID-19 depends on disability type and severity and presence of comorbidities, emphasizing the need for attention in diagnosis and preventive measures such as vaccination.

## References

1. Brandenburg JE, Fogarty MJ, Sieck GC. Why individuals with cerebral palsy are at higher risk for respiratory complications from COVID-19. *J Pediatr Rehabil Med*. 2020;13(3):317–27.
2. Hozhabri H, Picci Sparascio F, Sohrabi H, Mousavifar L, Roy R, Scribano D, et al. The global emergency of novel coronavirus (SARS-CoV-2): an update of the current status and forecasting. *Int J Environ Res Public Health*. 2020;17(16):5648.
3. Kamalakannan S, Bhattacharjya S, Bogdanova Y, Papadimitriou C, Arango-Lasprilla JC, Bentley J, Jesus TS; Refugee Empowerment Task Force International Networking Group of The American Congress of Rehabilitation Medicine. Health risks and consequences of a COVID-19 infection for people with disabilities: scoping review and descriptive thematic analysis. *Int J Environ Res Public Health*. 2021;18(8):4348. Review.
4. Chakraborty J. Social inequities in the distribution of COVID-19: an intra-categorical analysis of people with disabilities in the U.S. *Disabil Health J*. 2021;14(1):101007.
5. Fair Health. Risk factors for COVID-19 mortality among privately insured patients: a claims data analysis. New York: FAIR Health Inc., 2020 [cited 2022 June 9]. Available from: <https://s3.amazonaws.com/media2.fairhealth.org/whitepaper/asset/Risk%20Factors%20for%20COVID-19%20Mortality%20among%20Privately%20Insured%20Patients%20-%20A%20Claims%20Data%20Analysis%20-%20A%20FAIR%20Health%20White%20Paper.pdf>
6. Landes SD, Turk MA, Formica MK, McDonald KE, Stevens JD. COVID-19 outcomes among people with intellectual and developmental disability living in residential group homes in New York State. *Disabil Health J*. 2020;13(4):100969.
7. Fernandes DM, Oliveira CR, Guerguis S, Eisenberg R, Choi J, Kim M, Abdelhemid A, Agha R, Agarwal S, Aschner JL, Avner JR, Ballance C, Bock J, Bhavsar SM, Campbell M, Clouser KN, Gesner M, Goldman DL, Hammerschlag MR, Hymes S, Howard A, Jung HJ, Kohlhoff S, Kojaoghlani T, Lewis R, Nachman S, Naganathan S, Paintsil E, Pall H, Sy S, Wadowski S, Zirinsky E, Cabana MD, Herold BC; Tri-State Pediatric COVID-19 Research Consortium. Severe Acute Respiratory Syndrome Coronavirus 2 Clinical Syndromes and Predictors of Disease Severity in Hospitalized Children and Youth. *J Pediatr*. 2021;230:23-31.e10.
8. Bova SM, Basso M, Bianchi MF, Savaré L, Ferrara G, Mura E, Redaelli MG, Olivieri I, Veggiotti P; Milan COVID-19 and Child Neurology Study Group. Impact of COVID-19 lockdown in children with neurological disorders in Italy. *Disabil Health J*. 2021;14(2):101053.
9. Landes SD, Turk MA, Wong AW. COVID-19 outcomes among people with intellectual and developmental disability in California: the importance of type of residence and skilled nursing care needs. *Disabil Health J*. 2021;14(2):101051.
10. Mahase E. COVID-19: all adults on learning disability register should be prioritised for vaccination, says advisory committee. *BMJ*. 2021;(24):372:n547.
11. Office for National Statistics (ONS). Updated estimates of coronavirus (COVID-19) related deaths by disability status, England: 24 January to 20 November 2020. United Kingdom: ONS; 2020 [cited 2022 June 9]. Available from: <https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/articles/coronaviruscovid19relateddeathsbydisabilitystatusenglandandwales/24januaryto20november2020>
12. Gleason J, Ross W, Fossi A, Blonski H, Tobias J, Stephens M. The devastating impact of COVID-19 on individuals with intellectual disabilities in the United States. *NEJM Catal*. 2021;2(2):1-12.
13. Rosenbaum P, Paneth N, Leviton A, Goldstein M, Bax M, Damiano D, et al. A report: the definition and classification of cerebral palsy April 2006. *Dev Med Child Neurol Suppl*. 2007;109:8–14.
14. Castilho LS, Rampi CM, Cruz AJ, Lages FS, Leão DM, Abreu MH. Gastroesophageal reflux disease in patients with developmental disabilities. *Rev Eletr Extensão*. 2020;17(36):22–32.

15. Gibson N, Blackmore AM, Chang AB, Cooper MS, Jaffe A, Kong WR, et al. Prevention and management of respiratory disease in young people with cerebral palsy: consensus statement. *Dev Med Child Neurol.* 2021;63(2):172–82.
16. Munn Z, Moola S, Lisy K, Riitano D, Tufanaru C. Chapter 5: Systematic reviews of prevalence and incidence. In: Aromataris E, Munn Z, editors. *JBIManual for Evidence Synthesis.* Australia: JBI; 2020 [cited 2022 June 9]. Available from: <https://jbi-global-wiki.refined.site/space/MANUAL/4688607/Chapter+5%3A+Systematic+reviews+of+prevalence+and+incidence>
17. Tricco AC, Lillie E, Zarin W, O'Brien KK, Colquhoun H, Levac D, et al. PRISMA Extension for Scoping Reviews (PRISMA-ScR): checklist and Explanation. *Ann Intern Med.* 2018;169(7):467–73.
18. Clift AK, Coupland CA, Keogh RH, Diaz-Ordaz K, Williamson E, Harrison EM, et al. Living risk prediction algorithm (QCOVID) for risk of hospital admission and mortality from coronavirus 19 in adults: national derivation and validation cohort study. *BMJ.* 2020;371:m3731.
19. Götzinger F, Santiago-García B, Noguera-Julían A, Lanaspá M, Lancella L, Calò Carducci FI, Gabrovská N, Velizarova S, Prunk P, Osterman V, Krivec U, Lo Vecchio A, Shingadia D, Soriano-Arandes A, Melendo S, Lanari M, Pierantoni L, Wagner N, L'Huillier AG, Heining U, Ritz N, Bandi S, Krajčar N, Roglić S, Santos M, Christiaens C, Creuven M, Buonsenso D, Welch SB, Bogyi M, Brinkmann F, Tebrügge M; ptbnet COVID-19 Study Group. COVID-19 in children and adolescents in Europe: a multinational, multicentre cohort study. *Lancet Child Adolesc Health.* 2020;4(9):653-661. 20.
20. Shekerdemian LS, Mahmood NR, Wolfe KK, Riggs BJ, Ross CE, McKiernan CA, Heidemann SM, Kleinman LC, Sen AI, Hall MW, Priestley MA, McGuire JK, Boukas K, Sharron MP, Burns JP; International COVID-19 PICU Collaborative. Characteristics and outcomes of children with coronavirus disease 2019 (COVID-19) infection admitted to US and Canadian pediatric intensive care units. *JAMA Pediatr.* 2020;174(9):868-873.
21. Zachariah P, Johnson CL, Halabi KC, Ahn D, Sen AI, Fischer A, Banker SL, Giordano M, Manice CS, Diamond R, Sewell TB, Schweickert AJ, Babineau JR, Carter RC, Fenster DB, Orange JS, McCann TA, Kernie SG, Saiman L; Columbia Pediatric COVID-19 Management Group. Epidemiology, clinical features, and disease severity in patients with coronavirus disease 2019 (COVID-19) in a Children's Hospital in New York City, New York. *JAMA Pediatr.* 2020;174(10):e202430. Erratum in: *JAMA Pediatr.* 2021 Jun 21.
22. Garces TS, Sousa GJ, Florêncio RS, Cestari VR, Pereira ML, Moreira TM. COVID-19 in a state of Brazilian Northeast: prevalence and associated factors in people with flu-like syndrome. *J Clin Nurs.* 2020;29(21-22):4343–8.
23. Turk MA, Landes SD, Formica MK, Goss KD. Intellectual and developmental disability and COVID-19 case-fatality trends: TriNetX analysis. *Disabil Health J.* 2020;13(3):100942.
24. Perera B, Laugharne R, Henley W, Zabel A, Lamb K, Branford D, et al. COVID-19 deaths in people with intellectual disability in the UK and Ireland: descriptive study. *BJPsych Open.* 2020;6(6 e123):e123.