

The Impact of COVID-19 Pandemic on People with Intellectual Disabilities: A Literature Review

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Abstract

The ongoing coronavirus disease 2019 (COVID-19) pandemic has affected the global population, especially the vulnerable groups such as children, the elderly, indigenous people, and people with disabilities. Restriction and limited access to education, health, and public services due to measures taken to cope with the pandemic have made life even more difficult for people with disabilities, particularly those with intellectual ones. People with intellectual disabilities were not counted as a high-risk population, thus being excluded in most public health measurements that are done to encounter the pandemic. Several investigations have been conducted to explore the impacts of the COVID-19 pandemic on children, women, and the elderly, yet very few discussed how pandemics affected people with intellectual disabilities. This article is a review of existing literature using Medical Subject Headings (MeSH) keywords like “COVID-19” and “intellectual disabilities” which was conducted in Pubmed, Web of Science, Mendeley, Google Scholar and ResearchGate to find related studies. Here we reviewed studies on the impacts of the COVID-19

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pandemic on people with intellectual disabilities, including access to education, healthcare, public services, and other related concerns. We also discussed the inclusivity of COVID-19 prevention and control measures taken so far and how it should be designed to accommodate people with intellectual disabilities. This review is expected to provide an insight for the stakeholders and policymakers to employ better and more inclusive approach in the management of pandemic to ensure the wellbeing and rights of people with disabilities in general and people with intellectual ones in particular.

Key Words

COVID-19, people with intellectual disabilities, inclusive society

Introduction

The pandemic of coronavirus disease 2019 (COVID-19), which started at large at the beginning of 2020, has caused major negative impacts on not only the health sector but also almost every single aspect of life. By mid of July 2021, the new emerging disease already infected 186.255.516 people and caused the death of 4.021.947 people around the world (Johns Hopkins University & Medicine 2021). In Indonesia, the pandemic has infected 2.491.006 people and caused 65.457 of them to die (Satuan Tugas Penanganan COVID-19 2021).¹ Physical distancing as a measure to stop the spread of COVID-19 has shut down businesses, restricted travelling, closed offices and schools, and limited access to healthcare (Kaufman *et al.* 2021). Developed nations such as the UK and the US provide aid funds, online education, healthcare services, treatment and vaccination to support their people during the lockdown (GOV.UK 2021; USAGov 2021). However, developing nations like Indonesia are struggling with economic inflation, the increasing rate of unemployment, neglected non-infection patients and students as the internet and technology are luxuries for most of its citizens (Safitri *et al.* 2021; Satria 2021).

According to the World Health Organization (WHO), intellectual disability (ID) or impaired intelligence is a significant inability of a person in getting complex or new information and acquire or apply new skills. It usually occurs before adulthood and affects development (World Health Organization 2021). A study shows that 10.37 out of 1000 people worldwide were identified to have ID from 1980 to 2009, with a higher

¹ This figure was at the time of writing this article in June 2021. In December 2021, around 4.2 million people are infected and 144.000 people died of COVID-19 in Indonesia (<https://covid19.go.id>).

prevalence in male adults and children or adolescents than in females (Maulik *et al.* 2011). In Indonesia, 1.389.614 people were identified to have ID in 2013 (Warista, Dewi and Damanik 2018). People with ID are in struggle in doing daily activities due to limited verbal ability, delayed language and motor skills, difficulties in learning and controlling impulses (Parekh 2017). Moreover, they have limited access to health care services, education, job, and public services, especially in low and middle-income countries like Indonesia (Cameron and Suarez 2017).

The pandemic of COVID-19 has limited access to all, including people with ID. Due to government regulation to prevent vulnerable people from getting infected by Covid-19, a lot of social services have been shut down including schools and health care facilities for people with ID (Courtenay and Perera 2020). Not only did it limit access to people with ID, but also caused new challenges for the caregiver and family of people with ID in taking care of them (Menon *et al.* 2020). Taking care of people with ID is stressful and exhausting, and the stress due to its prolonged tenure has escalated the pressure (Alexander *et al.* 2020). Pandemic also has resulted in limited work availability, downsizing of businesses, and even the closing down of factories, leading to even more limited work options, hours, and salary, for people with ID. Some of them were even laid off or dismissed instead of being given chances to work from home like other people (Schall *et al.* 2021). Moreover, people with ID are more vulnerable than the general population. They struggle with low self-esteem, poor critical thinking abilities, and emotional instability, which lead to the inability to protect themselves from coronavirus infection. General protection such as hand hygiene, mask-wearing, and social distancing are difficult to be enforced on them (Buono *et al.* 2021). In regards to comorbidities, people with ID usually have several underlying diseases such as metabolic, respiratory, and cardiovascular disease, which put them at higher risk of severe COVID-19 infection (Turk *et al.* 2020).

To date, there have been several investigations on the impact of the COVID-19 pandemic on vulnerable populations such as children, pregnant women, and the elderly. However, very few studies discuss how the pandemic affected people with ID. Thus, we would like to fill in the gap by reviewing existing literature on the impact of the COVID-19 pandemic on people with ID. We hope this review could serve as an insight for the stakeholders to use a better and more inclusive approach in the management of pandemics, to ensure the wellbeing and rights of people with disabilities in general and people with intellectual disabilities in particular.

Search for relevant literature was done in Pubmed, Web of Science, and ResearchGate, Mendeley, and Google Scholar using the Medical Subject Headings (MeSH) terms like “COVID-19”, “Intellectual Disability”, “pandemic”, “outbreak”, “coronavirus”, and “people with disability”. Articles written in English and published before May 2021 were considered eligible, and were evaluated for their relevancy and reviewed for its eligibility. In addition to scientific reports and research (e.g., cohort, cross-sectional, qualitative studies), legal documents (e.g., government regulation, report, and law) were also searched and reviewed.

Limited Access to Work, Education, and Healthcare for People with Intellectual Disabilities

The ongoing COVID-19 pandemic is a serious health threat to millions of people around the world. In tackling this pandemic, governments around the world conducted public health measures to protect their citizens from COVID-19 such as closing public places such as schools, offices, restaurants, and museums, and enforce people to stay at home (World Health Organization 2020). These policies have had a considerable impact on people with ID (Courtenay 2020). Due to lack of activities in their lives, the loss of work or daily activities may have a very significant impact on people with ID (Lysaght, Ouellette-Kuntz and Morrison 2009; Embregts, Tournier and Frielink 2020). The stay-at-home measure during the COVID-19 pandemic has given new challenges for families of children and adults with intellectual and developmental disabilities, in the form of the absence of education and health services (Eshraghi *et al.* 2020). Most people with ID need special education services which integrate behavioural support and interventions such as speech therapy and occupational therapy that are difficult to do outside schools (Liptak, Stuart and Auinger 2006; Boulet, Boyle and Schieve 2009). Moreover, people with ID often have some underlying medical conditions such as epilepsy, psychiatric disorders, sleep disorders, and gastrointestinal problems that require intensive and rapid supervision from healthcare professionals (Centers for Disease Control and Prevention 2020). The impact of the limited access to education and medical support due to pandemics is enormous, adding a substantial burden to caregivers and also jeopardizing the overall health and wellbeing of people with ID (Jeste *et al.* 2020).

A survey on families of children with ID shows that children with ID lost their access to medical and educational support during the pandemic leading to overburdening on caregivers and eventually disrupting the

wellbeing of both caregivers and the children (Aman and Pearson 2020). Most families of children with ID at the very least were unable to get one of the behavioural or educational services, some of them even lost them all, with only a few families still having direct service. Although some families were supported by face-to-face education services, other families were likely relying on tele-education services as they were afraid to send their children to school (Jeste *et al.* 2020). However, the distant educational structure could not meet the need of children with ID because direct instruction is best for them to understand the lesson. Thus, the National Academic of Science, Engineering, and Medicine urged the reopening of schools for children with special needs (Dibner, Schweingruber, and Christakis 2020).

Regarding healthcare, adults with ID are more likely to have limited access to quality health care and health promotion programs because they are usually undetected (Centers for Disease Control and Prevention 2009). Most healthcare services in developed countries like the US were delivered through telemedicine during the pandemic. A recent survey shows that both patients and caregivers had high satisfaction in the use of telemedicine offered by pediatric clinics in the US (Rametta *et al.* 2020). Telemedicine also benefited people with rare disorders including ID during the pandemic as it could still provide necessary healthcare (Jeste *et al.* 2020). Extension for Community Healthcare Outcomes (ECHO) in New Mexico proposed telemonitoring consultation to diagnose and treat autism and certain syndrome that appeared due to ID by providing video conference between consultations provider and the patients (Arora *et al.* 2011; Mazurek *et al.* 2016). However, telemedicine is not available in low and middle-income countries, leaving people with ID in these countries with very limited access to healthcare during the COVID-19 pandemic.

Limited Access to Information about COVID-19 for People with Intellectual Disabilities

Providing information about COVID-19 and its preventive measures for people with ID is important because they rely solely on others in receiving information (Courtenay and Perera 2020). People with ID have difficulties in accessing medical services resulting in an increased risk of infection. Nevertheless, they also face challenges to get information about COVID-19 prevention measures (Gulati *et al.* 2020). Access to information for persons with disabilities in remote or rural areas was very minimal, especially at the early phase of the pandemic, leading to misinformation such as using

hand sanitiser instead of soap to wash hands (“Informasi Covid-19 untuk Penyandang Disabilitas di Wilayah Terpencil Minim”). The lack of an internet network, the absence of reliable radio and television transmission has made people who live in low and middle-income countries, including those with ID, lose access to proper information about COVID-19.

Persons with disabilities have different characteristics and abilities to access information. Therefore, the government has to ensure that the information about pandemics is delivered through specific approaches. Groups of people with hearing impairment, for example, communicate through sign languages. But, the government did not provide sign language interpreters to convey information regarding COVID-19 since the beginning of the pandemic (Firmanda 2021). The same thing was also experienced by people with visual impairments, where information about guidelines for COVID-19 prevention and control was written in inaccessible format (Nilawaty 2021). People with ID need information that is simple, easy to understand, and repeatedly delivered. However, most of the information regarding COVID-19 was not delivered in a particular approach targeting this vulnerable group, including people with ID.

Listening to the voices and needs of people with disabilities during outbreak response planning and emergency response is very important to maintain physical and mental health and reduce the risk of being infected with COVID-19 (Susanto 2020). Considering the right of access to information, there should be no discrimination experienced by people with disabilities. The government must cooperate with all elements of the society, including organizations or communities of people with disabilities in the regions, so that information about the COVID-19 pandemic can be conveyed based on their respective conditions. In addition, working with organisations that provide volunteers can be a good alternative solution to overcome the problem of limited access to information, especially in remote areas.

Regarding the COVID-19 information which is new, abundant, and a little bit complex, WHO has urged governments in each country to provide sign language for all recorded events and live broadcasts such as press conferences, news, and social media; converse public material into an “easy to read” format so that it is accessible to people with ID or cognitive impairments; develop accessible written information with structured titles, large print, contrasting colours, and braille versions for people with hearing and vision impairments; use more inclusive images and do not stigmatize people with disabilities, and lastly collaborate with disability organizations to disseminate public health information (Kimumwe 2020).

The International Disability Alliance (IDA) has issued recommendations for a disability-inclusive COVID-19 response, which include general information about COVID-19, tips for preventing/mitigating infection including public space restriction policies, the use of accessible technology in COVID-19 related services, information regarding supported services such as rehabilitation services and sign language interpreters, information on the available call centre special for people with disabilities, counselling/psychological assistance for people with disabilities, social assistance and education services for people with disabilities (International Disability Alliance 2021).

The Impact of the Ongoing Pandemic on Mental Health of People with Intellectual Disabilities

Individuals with intellectual disabilities (ID) are at greater risk of experiencing a decline in health during COVID-19 pandemic, due to various factors, including difficulties in accessing services, restrictions caused by physical distancing, lockdown, and staying at home policy as well as the fear and anxiety caused by mass media coverage on the pandemic (Holmes *et al.* 2020; Ho, Chee and Ho 2020). The pandemic of COVID-19 had also brought a formidable challenge for people with ID, especially people with autism who rely on strict daily activity routines to maintain a sense of control over their environment, emotional stability and minimize the occurrence of challenging behaviours (Murphy *et al.* 2005). Moreover, the pandemic impacted the level of social support for people with ID such as day care and break arrangements, resulting in the increasing stress among caregivers of people with ID (Tsai and Wang 2009). During the pandemic, some non-pharmacological strategies to support people with ID like community support were not available or limited, leading to an increasing risk of reliance on medication to support mental health and manage challenging behaviour (Tromans *et al.* 2020).

Studies show that adults with autism spectrum disorder (ASD) experienced a higher level of depression and anxiety during the pandemic of COVID-19 (*e.g.* Lake *et al.* 2021). Meanwhile, children with ASD demonstrated poor mental well-being during the pandemic, leading to increased aggressive, anxious, and sedentary behaviour (Theis *et al.* 2021). Families and caregivers of children with ID also had stressful experiences during the pandemic due to the change in daily activities, were over worried about the risk of infection to their children, and had a higher risk of breakdown. All these resulted in higher depression and anxiety during the pandemic (Willner *et al.* 2020). A survey by Theis *et al.*

(2021) shows that the majority (96.4%) of parents of children with ID said that the physical activity and the mental health of children with ID during lockdown were worse compared to that before the pandemic. Furthermore, a study in Zambia and Sierra Leon about the effect of Covid-19 on children and young people with disability shows that participants who were female, had two or more disabilities, and aged between 12-14 had worse mental health well-being. Some factors associated with this condition were the type of disability, knowledge about COVID-19, types of isolation, and worry about the long-term impact of the pandemic (Sharpe *et al.* 2021).

A study by Wos *et al.* (2021) shows that the caregiver of people with ID, especially parents, whom 73% of the survey respondent identified as a support source, felt overwhelmed by managing time between their professional, domestic, and responsibility of taking care people with ID and faced significant difficulty due to the lack of access to special equipment for the necessary rehabilitation exercises for people with ID. The parents felt enormous pressure from the support quality they could give to their children, especially adult ones, compared to the professionals. The study also shows that the caregivers had poor ability in using technology, making it difficult for them to utilize online healthcare or school platforms. All these resulted in stress and anxiety on the caregivers.

Conclusion

This article has shown that the existing literature found that the COVID-19 pandemic has negatively impacted people with Intellectual Disabilities. Not only were their rights restricted, but also the un-inclusive measures taken to cope with the pandemic have left people with Intellectual Disabilities in the dark. As the pandemic does not seem to end soon, we hope this review could serve as an insight for the stakeholders and policymakers to employ better and more inclusive approach in the management of pandemic to ensure the well-being and rights of people with disabilities in general and people with Intellectual Disabilities in particular.

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