

Immediate and Long-Term Implications of the COVID-19 Pandemic for People With Disabilities

Some people with disabilities may have greater risk of contracting COVID-19 or experiencing worse outcomes if infected. Although COVID-19 is a genuine threat for people with disabilities, they also fear decisions that might limit life-saving treatment should they contract the virus.

During a pandemic, health systems must manage excess demand for treatment, and governments must enact heavy restrictions on their citizens to prevent transmission. Both actions can have a negative impact on people with disabilities.

Ironically, the sociotechnical advances prompted by this pandemic could also revolutionize quality of life and participation for people with disabilities. Preparation for future disasters requires careful consideration. (*Am J Public Health*. Published online ahead of print October 15, 2020: e1–e6. <https://doi.org/10.2105/AJPH.2020.305890>)

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At the beginning of the COVID-19 pandemic, *The Lancet* published a letter noting the increased risk of severe complications of this infection for people with disabilities.¹ Fear of infection is extremely salient for people with disabilities, but they have expressed even more profound fears pertaining to potential discrimination and violations of their right to equitable treatment. Public commentary about disability in the context of COVID-19 treatment has only recently begun to emerge, largely in response to calls for guidelines about how to ration and prioritize limited and overstretched health resources. This situation has triggered strenuous advocacy by disabled groups and opinion leaders with disability around the world, highlighting issues of equitable worth,² the disposability of people with disabilities,³ and the stereotypical assumption that all people with disabilities are vulnerable.⁴ These fears of exclusion and discrimination are always present for people with disabilities but have been exacerbated by the pandemic.

In this article, we examine the challenges experienced by people with disabilities in response to large-scale disasters and the decisions made by those in authority as they seek to manage the impacts for the whole community. We first describe what is known about the impact of

disasters and pandemics on people with disabilities. We then examine the impact of medical decision-making and rationing of health care for people with disabilities, but also the potential benefit to be gained from the sociotechnological developments triggered by COVID-19. Finally, we examine the need for improved preparation to prevent disadvantage in future pandemics that will undoubtedly occur.

DISABILITY DURING DISASTERS AND PANDEMICS

Disasters disproportionately affect people with disabilities; this is undisputed and has been repeatedly demonstrated across a range of large-scale events. For instance, during Japan's 2011 earthquake and tsunami, the mortality rate for those with disabilities was 2.06% as opposed to 1.03% in the general population.⁵ When Hurricane Katrina devastated New Orleans, Louisiana, in 2005, 38% of those not evacuated were people with disabilities,⁶ who were then

exposed to preventable health complications, inadequate care, and further harm.

It is now well known that COVID-19 has also disproportionately affected people with underlying chronic health conditions. The latest statistics from the United Kingdom show that death rates for people with disabilities are double those of people without disabilities, even after controlling for residential location and for sociodemographic and household factors (2.4 and 1.9 times higher for women and men, respectively).⁷ However, this disparity may not be directly associated with any inherent vulnerability, but may be related to broader social inequities and potential treatment discrimination, triggering calls for official inquiries in several countries.⁸ In pandemic conditions, people with disabilities are typically more exposed to the risk of infection than the general population as a result of their need for daily care and support from external service providers. The need for personal care, support services, therapy, and rehabilitation does not stop

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during a pandemic.⁹ In fact, the demand for services may increase. Several other pressures impinge on the capacity of people with disabilities to receive essential supports or services, placing them at risk for health complications and possibly preventable deaths. For instance, it is likely that people with disabilities will be discharged from hospitals earlier, other nonpandemic treatments will be delayed,¹⁰ equipment and medications will be depleted, workforce will be redirected to more pressing demands, and the sustainability of organized community volunteering will be threatened or prohibited. If the pandemic also leads to an absolute scarcity of medical resources, those with existing health conditions will experience disproportionate impact because access to regular health care is likely to be jeopardized. This risk is magnified for people living in residential institutions, such as prisons or care homes, who are totally dependent on the largely untested crisis management skills of the responsible organizations.

Preventing spread and reducing the risk of infection are critical strategies during a pandemic, and usually entail physical distancing, isolation, and protective equipment. Ironically, many of these responses are impossible for people with disabilities or raise new disadvantages. For example, the reliance on personal caregivers not only places people with disabilities at greater risk for exposure but also renders physical distancing impossible. People with disabilities can be left in particularly tenuous positions if workers in these organizations are reluctant to observe preventative strategies themselves or are unable to continue delivering services through fear or illness. Important messaging about COVID-19

prevention does not always reach people with disabilities, either because it is not delivered in an accessible form or because dissemination often depends on resource-poor community organizations.¹¹

RATIONING OF HEALTH CARE

Of even greater concern to people with disabilities is fear about rationing of health care in times of excess demand created by this pandemic. Increased demand for treatment is putting extraordinary pressure on global health systems, stretching our human and medical resources beyond sustainable limits. As more people require intensive care, ethical dilemmas will become inevitable. Physicians, nurses, and hospital administrators will be required to make life-and-death decisions that will test the boundaries of ethics and morality beyond anything they have experienced before. There is already evidence of rationing in countries that have experienced high rates of COVID-19 infection and hospitalization.¹² Indeed, the US Office for Civil Rights has already fielded multiple complaints about rationing measures adversely affecting those with disabilities.¹³ Some health services have published specific disabilities that would result in deprioritization of patients should ventilator care be needed,¹⁴ and there have been reports of cases in which the decision of whether or not to provide medical care to disabled people has been influenced by the perceived value of their lives.¹⁵ So how will ethical decisions concerning people with disabilities be made in such a fast-moving environment? There

are legitimate fears that these “heat of the moment” decisions will be based on stereotypical biases and unfounded assumptions, and will only serve to exacerbate the vulnerable and potentially “dispensable” position of people with disabilities.

According to some researchers, sensible allocation of medical resources is not just a discretionary decision, but a necessary response to the overwhelming effects of a pandemic.¹⁶ A key principle of medical ethics is to do no harm, but when health systems become overwhelmed in a crisis, there is no avoiding harm.¹⁷ Health professionals can only try to mitigate harm, accepting that not everyone can be saved. Unsurprisingly, there have been many recent calls for guidelines to support the decision-making process, but guidelines require solid clinical evidence and robust ethical debate, both of which are time-consuming.

Most current guidelines agree that resource allocation should be driven by coherent ethical principles, agreed upon in advance and communicated transparently, but recognizing that decisions may need to be rapidly revised in changing circumstances. After the 2001 World Trade Center attacks, the United States was compelled to develop principles that could accommodate rapid increases in health care demand.¹⁸ However, during crises, it was recognized that health care providers could not always meet the standards of care set by regulatory authorities, exposing them to liability. Thus, allowing for altering standards of care during crises afforded them some protection. This contentious proposal has been debated consistently over the last few decades with no clear resolution,¹⁹ but it paves the way for

justification of differential access to treatment.

In normal circumstances, all patients would be treated as though there were no restrictions to resources. Causing harm to a patient in this context would be negligent. The fundamental principles that drive ethical decision-making²⁰ include the following:

1. maximizing the universal benefit produced by scarce resources, which equates to the principle of efficiency;
2. promoting and rewarding the greatest instrumental benefit, which equates to the principle of utility or utilitarianism;
3. treating people equally irrespective of characteristics, which equates to the principle of fairness or egalitarianism;
4. giving priority to the worst off or most in need, which has been labeled prioritarianism or egalitarianism; and
5. imposing the least amount of burden or harm by balancing one's actions, which could be likened to a principle of liberty.

These values sound ideal and, if applied, should result in outcomes that benefit the whole of society. However, in extraordinary circumstances, the subjective nature of these values means they can be interpreted in multiple ways, leading to diverse responses. Important nuances can be overlooked. For instance, treating people equally can mean that some people are still disadvantaged because they are less able to benefit. Judgments about what constitutes disadvantage can differ considerably and will naturally be biased by the stereotypes and beliefs held by individual decision-makers.

There is no doubt that during times of excess demand, the goal

of the health care system must shift from saving individuals to saving as many lives as possible. However, the standard of care to which individual physicians have ascribed is unlikely to change. This clash between crisis care protocols and altered standards of care places physicians and triage nurses in untenable positions. The only possible ethical response is for governments, policymakers, employers, and society to do all they can to prevent resource scarcity and its potentially detrimental impact on people with disabilities. There is also an onus on authorities to protect those who are at higher risk for severe consequences or may be more disadvantaged by resource restrictions. We must rigorously investigate cases where life-saving treatment has been withheld from people with disabilities—not to seek prosecution, but to raise awareness of the implicit discrimination that can underlie decisions made in times of uncertainty.

THE ONGOING IMPACTS OF COVID-19

The ongoing impact of COVID-19 is as yet unknown, but early evidence suggests that recovery may be a long and slow process, with potentially lasting health, cognitive, and emotional consequences.²¹ This is not surprising given that researchers found significant pulmonary impairment in one third of people who had contracted SARS²² in the previous year. Another study²³ found poor physical and emotional functioning, general ill health, and a lack of vitality 1 year following a MERS infection. After the H7N9 virus in China in 2013, patients showed lung fibrosis and

dysfunction, reduced physical and emotional functioning, and poor quality of life up to 2 years following infection.²⁴ In an Australian study of 506 children hospitalized for influenza A H1N1 in 2009,²⁵ 11.3% showed neurological complications, including seizures, encephalopathy, cognitive impairment, loss of consciousness, and paralysis. Poor health and socioeconomic outcomes were found among adults who were in utero during the 1918 Spanish influenza pandemic, suggesting a possible impact on fetal development.²⁶ Similarly, researchers²⁷ found that intelligence scores of men born 6 to 9 months after the Hong Kong flu epidemic of 1969 were lower than those for the men born in the same months a few years before or after. These findings suggest that we may see a sharp increase in disability following this pandemic, putting additional strain on the service systems and creating even more uncertainty for people who rely on services.

The pandemic may also create a new population of vulnerable people who would not ordinarily be considered vulnerable—people who are used to having a voice but have now lost their sources of income or support. With yet another global financial crisis seeming inevitable, people with disabilities will be likely to experience serious financial, social, and health hardship. Many researchers have documented the harmful effects of economic recession on marginalized populations across a range of countries and eras. For instance, a recent systematic review²⁸ confirmed that people with disabilities are more likely to experience more than just financial insecurity during times of austerity, including loss of independence and choice in their daily lives,

diminished social participation, reduced amount and quality of care, and increased need for family members to take on caregiving roles. Many people with disabilities have begun contemplating how governments will continue to deliver hard-earned disability rights and supports in the face of such unprecedented debt and universal disadvantage.

Malli et al.²⁹ warned that universal financial hardship can also lead to hardening of attitudes toward minority groups, less public commitment to charity, reduced willingness to volunteer, and, perhaps, greater use of stereotypes to manage complex environments. It is also not uncommon for contagious diseases to be stigmatized in society, resulting in discriminatory treatment and social exclusion of infected people.³⁰

SOCIAL AND TECHNOLOGICAL ADVANCES

Although government attempts to manage the spread of the virus (e.g., closure of businesses, travel restrictions) are generating frustration, not all impacts have been negative. For some people with disabilities, this pandemic has magnified their disadvantage, but for others, it has allowed their voice to be heard simply because everyone has been relegated to the same medium of isolation and communication.

Technologies are generally slow to be translated into practice, but this pandemic has shifted the balance by creating conditions of necessity. The last few months have demonstrated how quickly and efficiently we can harness technology and develop

new techniques. The pandemic has set the scene for a future where artificial intelligence and robotics can be deployed to keep humans safe from infection, with examples such as cleaning robots in hospitals, robotic customer service delivery, and automated standard care procedures.³¹ These technologies are yet to be applied systematically to the lives of people with disabilities, but they have the potential to alter the nature of disability in society in the future.

In many parts of the world, telehealth blossomed in just a few short weeks³² despite years of unsuccessful promotion of this tool for people with disabilities. Instead of being an alternative form of communication to be used in exceptional circumstances, telehealth has become the only option to deliver health care. Barriers have been pushed, or temporarily circumvented, to accelerate the adoption of existing technologies. It has created long-awaited opportunities for people with disabilities to receive evidence-based health care comfortably in their own homes.

To accommodate this change, patients and clinicians have had to learn how to use new tools, managers have had to change workflows, providers have had to develop or expand platforms, and insurers have had to manage reimbursements. Such coordinated multilevel change is rare, but clearly possible. Although quality of care must not be compromised, this pandemic has offered us the largest natural trial of technological tools. We need to take the opportunity to gather evidence to optimize this kind of health care beyond COVID-19.

Jadad³³ recently laid down a challenge to society to use rapid advances in digital technology triggered by the disease pandemic as a way of promoting a “health

pandemic.” He concluded that by building on the unprecedented level of interconnectivity, digital technologies must now become a vehicle for ensuring good health for most citizens. If harnessed, these new technologies and social practices could build the capacity of people with disabilities to withstand the next pandemic. However, these sociotechnological developments must be equitably distributed and accessible.

PREPARATION FOR THE FUTURE

Preparation for future pandemics is an area where we should now expect to see positive change for people with disabilities. Epidemiologists agree that a pandemic of this kind will happen again in the future. In 2007, Markel predicted that the “next pandemic we face in our world will be the first in human history where we will have had some semblance of advance warning—and hence, the opportunity to prepare.”^{34(p57)} Given the advances in surveillance, rapid communications, modeling, and testing, he believed that we would be able to mobilize successful containment and prevention through ethically and socially appropriate strategies. Despite these positive predictions, our lack of preparedness for this pandemic has been obvious, and even more pronounced in relation to disability.

In 2007, researchers also warned that if we do not incorporate the needs and rights of people with disabilities into our pandemic planning, the effects of future pandemics may not only be catastrophic, but also catastrophically unjust.³⁵ By raising awareness about the perspectives

of people with disabilities, we can make recommendations about how to overcome this inequality and future-proof our society for the next pandemic. The World Health Organization recently released a comprehensive guidance brief containing recommendations for people with disabilities, families, organizations, health systems, and governments about how to prepare and prevent disadvantage. This type of guidance and leadership is essential if we are to harness the potential silver lining in this devastating event. Research must examine the experiences of people with disabilities during and following the pandemic to inform policymakers and public health officials about mechanisms to include for prevention of similar situations in the future.

RECOMMENDATIONS

Although the long-term impact of this pandemic is still unpredictable, it will increase pressure on disability services and health systems and bring hardship for society, which will disproportionately affect those with disabilities. We will need to be vigilant in coming years to assess and respond to these impacts and minimize the long-term negative impact of important public health measures. We need to monitor and ameliorate the subsequent wave of illness and distress that is likely to occur in the coming months and years for people with disabilities as the full impact of COVID-19 becomes apparent.

More than ever before, the digital divide must be bridged. Current technologies are not suitable for all circumstances and all people, but this pandemic will allow us to highlight pressure points and practices in need of innovation. Practitioners have

started to describe how different interfaces are preferred by people with different conditions, or at different stages of the interaction. Physical rehabilitation and allied health therapies still lack reliable tools for virtual delivery, which must be investigated further. The translation of technology into practice is often slow and steeped in apprehension, but people with disabilities themselves must capitalize on this time of upheaval to demand innovations that suit them and meet their needs.

Some people with disabilities may be at greater risk for infection during pandemics because of their heightened vulnerability to severe consequences of infection, increased likelihood of exposure, and inability to adhere to physical distancing without jeopardizing their own care and safety. They are also more vulnerable to shortages in medical supplies and delays in treatment. This situation raises considerable concern for people with disabilities and requires specific attention in future policy.

Most importantly, we need detailed disability emergency plans developed at all levels of government and in communities, based on reliable population-level data, tracking, and surveillance systems. We need to identify and support families and citizens who have disabilities that might impact on emergency responses. We also need to develop an in-depth understanding of the experiences of people with disabilities during crisis situations. Our responses need to allow for the time, organization, and advance planning required by people with disabilities rather than expecting rapid unachievable responses.

We can use the pandemic as a trigger to build a whole-of-society planning approach based on respectful, dignified language,

rather than messaging that reinforces the vulnerability and potential expendability of people with disabilities. We must also develop accessible communication systems that ensure the flow of accurate information to all citizens. Training must be provided for health professionals and service providers to facilitate their ability to avoid stereotypical responses when under pressure. The way we make decisions today about who has access to scarce resources will shape our post-COVID society. Those decisions are complex, but they should never be made according to stereotypical assumptions about the value of individual citizens or groups of citizens. COVID-19 may ironically provide the impetus to promote attitude-shifting initiatives.

CONCLUSIONS

In pandemic conditions, people with disabilities are trapped between the challenge of living with long-term restrictions that have a devastating impact on their quality of life, and the knowledge that strict enforcement of these restrictions will keep them alive. Although isolation is already a fact of life for many people with disabilities, it has now become a life-saving imperative. However, mitigation attempts should not lead to increased segregation, stigma, or undignified treatment of people with disabilities. Yamin and Lockwood observed that the most shocking abuses have been committed in the name of a higher purpose. They concluded that “quarantine, shelter-in-place and isolation policies can certainly violate civil liberties and create discrimination and stigmatization if not carefully tailored.”^{36(p38)} Physical isolation

and restricted access to health care could dominate our society for some time to come, and economic, biological, and social human rights will be challenged for some subgroups of people long after the pandemic has ended.

An aggressive pandemic of this nature is a great equalizer simply because it has raised challenges for people who have not previously experienced threats to their quality of life or participation in society. The virus itself and our response has redefined the notion of vulnerability.³⁷ As O'Sullivan and Phillips³⁸ noted, vulnerability is a deficit term that conveys weakness, but during a pandemic we are all vulnerable in different ways. All citizens have tasted the exclusion and restriction that is a daily experience for people with disabilities or chronic health conditions. What will this increased awareness mean for people with disabilities in the post-COVID-19 era? Will we be further divided by inequities, stereotypes, and selfishness born from fear and desperation? Or will the future be characterized by social acceptance and inclusion for people with disabilities, born from shared hardship and empathy, facilitated by technological and social advances? What will happen to generous and vitally important disability schemes, such as the National Disability Insurance Scheme in Australia? Will more people become disabled in the long term, and what impact will this have on our distribution of resources? How will technological changes last and be positive for all people?

Fulton³⁹ argued that we may not know the answer to these questions yet, but that cities as we know them will be changed

forever. Some of the lasting changes he has predicted include an increased public health effort, greater emphasis on digital social networks and events, different types of jobs focused on preparation for disasters and virtual working environments, online shopping and contactless delivery, flexible transport systems and schedules, and new urban design. If they last, these changes will potentially create unprecedented opportunities for people with disabilities—opportunities for employment, connection, and inclusiveness. Fulton also described the possibility of a wave of renewed appreciation for suburban community activities, engagement with nature, and local ownership over spaces that are protected and inclusive. If he is right, we could be closer than ever to a level playing field for people with disabilities. **AJPH**

CONTRIBUTORS

All authors contributed to the conceptualization of this article. E. Kendall wrote the initial draft on the basis of discussions with all authors. All other authors contributed to writing and editing the article.

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CONFLICTS OF INTEREST

The authors have no conflicts of interest to report.

HUMAN PARTICIPANT PROTECTION

Human participant protection was not required because this study did not involve human participants.

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