



INFOCUS

by Brooke Ellison



COVID-19 AND THE EROSION OF DISABILITY RIGHTS

Introduction

The historical lore that will be crafted around the COVID-19 pandemic will be a tale of social inequalities. However, while the existence of social inequalities is well documented and have characterized societies for centuries, the COVID-19 pandemic, like many other societal catastrophes before, has made visible, tangible, and measurable how these social inequalities have real and consequential impacts on the lives of marginalized people. There is perhaps no demographic group that has felt the slings and arrows of societal injustice more

acutely than people with disabilities throughout the pandemic. At every phase of the COVID-19 pandemic, people with disabilities have disproportionately experienced its cruelty. And, yet, like all seminal moments in history, our slow but collective reemergence from the pandemic provides a pristine opportunity to learn. The pandemic brought some of our most gaping societal fault-lines into stark relief, and we need to use this time of increased clarity to better understand the multitudinal ways that people with disabilities are denied many of the



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basic freedoms that others enjoy and how these denials have immeasurable – even fatal – impacts on their lives.

Disproportionate disease Burden

The COVID-19 pandemic has taken a nearly unfathomable human toll. However, the enormity of the death toll associated with COVID-19 among the general population, drastically underestimates the death toll among people with disabilities. As the U.S. Centers for

Disease Control And Prevention (CDC) has studied extensively and articulated, people with underlying medical conditions were at a much higher risk of experiencing severe outcomes from Covid 19. Severe outcomes are characterized by hospitalizations, admissions to intensive care units (ICU), intubation or mechanical ventilation, or death. According to one study, the underlying medical conditions known to put people at greater risk include history of

myocardial infarction, cerebrovascular disease, congestive heart failure, dementia, diabetes, chronic pulmonary disease, and hyperlipidemia (1). Many people who live with a physical disability, are predisposed to many of the comorbidities that also increase the likelihood of severe outcome if infected with COVID-19. (2). While this is known, quantifiably, to be the case, a true “health disparity” implies the presence of an unnecessary inequality among

different populations with respect to the burden and risk of experiencing health-care challenges. We should ask ourselves “Why is it that people with disabilities suffer higher rates of the conditions that put one at greater risk to die from COVID-19?” The answer to this question gets to the very heart of the human rights abuses and historical disadvantages that people with disabilities have, likewise, encountered.

Sociocultural factors

Article 25 of the UN Convention on the Rights of Persons with Disabilities (CRPD) was drafted to ensure the rights of people with disabilities to receive the highest standard of healthcare, without discrimination (3). Article 25 states, “Persons with disabilities have the right to the enjoyment of

the highest attainable standard of health without discrimination on the basis of disability.” While 164 countries have signed the convention, and 182 countries have ratified the CRPD (4), the actual care and services that people with disabilities receive are far from adequate. While this fact, in itself, is a social injustice in need of remedy, as Dickinson and Kavanagh have argued, health inequalities only worsen during epidemics and pandemics. The fact is that marginalized communities have fewer resources available to them and struggle to access the basic supplies and services needed for survival. This confluence of predisposition to underlying conditions, inadequate access to primary healthcare, and marginalization from needed social supports and services has put people with disabili-

ties in a dangerous, yet avoidable situation.

It is not only comorbidities that have affected the disproportionality with which people with disabilities have acquired COVID-19, but so, too, have the logistical needs that their lives demand. Successful combat of the SARS-CoV-2 virus is contingent upon strategic decisions and planning. Yet, as it has become clear very early on, many of the planned measures designed to respond to and control the pandemic failed to include people with disabilities. For instance, COVID-19 exposed the existing lack of health information accessible for people with disabilities. In an article published by Dror and colleagues, the authors explored the accessibility of web-based health information provided by countries



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around the world (5). The researchers found that, upon investigating websites from the health authorities of 189 countries, only 4.7% had fully implemented the Web Accessibility Initiative access guidelines. This, as the authors argue, prevents millions of disabled people from acquiring the information they need to stay safe during the pandemic.

The disproportionate burden that people with disabilities have experienced during the pandemic can be seen, most visibly, in the sheer numbers: the unimaginable numbers of people with disabilities who perished from the virus. While one in 15 people live with a disability, according to the UK's Office of National Statistics, six out of ten COVID-19 related deaths were among people with disabilities (6). These data were accumulated

in a developed nation-state, but it is arguable that they are much more exaggerated in developing nations, where an estimated 80% of people with disabilities live and where there are far fewer resources available (7). From this standpoint, people with disabilities have been multiplicatively disadvantaged throughout this pandemic, dying at far higher rates than the general population. They are, being denied access to pandemic planning protocols and information, and disproportionately live in the countries least-able to provide resources to people who require additional social supports.

Long-Term-Care confinement

While COVID-19 strained the entire global healthcare system, the residents in long-term care facilities (LTCs) were the ones who experienced the most devastating impacts of the pandemic. According to data compiled by the Kaiser Family Foundation (KFF), within the United States alone, 1.3 million individuals with disabilities live in nursing homes, 800,000 live in assisted living facilities, and 75,000 live in intermediate care facilities. As the data collected by KFF very early in the pandemic showed, by April 2020 more than 10,000 deaths due to COVID-19 in long term care facilities, representing 27% of the deaths due to the pan-

demic in the US. By November 2020, that number had jumped to 100,000 deaths among LTC residents and staff. Likewise, the data collected by KFF demonstrated that, within six U.S. states, over 50% of all COVID-19 deaths were among long-term care residents with disabilities (8). These data were true, even though people with disabilities living in long-term care facilities account for less than 1% of the US population.

Given the findings of much research, it has been clear that the COVID-19 pandemic took a disproportionate toll on residents of long-term care facilities, with this population accounted for some 38% of COVID deaths. While residents of long-term care facilities are undeniably among the sickest members of the collective population, it is not solely for this reason that they were the most vulnerable. The structure and operation of LTCs are less akin to those of healthcare settings like hospitals than they are to other institutionalized organizations like prisons. The latter are characterized by high person-density - higher density is incentivized - and little opportunity for physical distancing; while autonomous decision-making is essentially nonexistent. As physician and researcher Cynthia Holzer argued (9), the routines embedded within American long-term care facilities, in particular, are organized "for



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the efficient operation of the facility, rather than the needs of the residents” (p. 205). The business model implemented in many long-term care facilities has fostered a particularly high turnover rate among long-term care staff, which can be as high as between 70% and 100% turnover per year. In a time like a pandemic that, as mentioned, has been spread through staff-spread infection, this high turnover rate is especially consequential.

Not only were people with disabilities living in nursing homes more at risk of becoming infected with COVID-19 due to the structure of these facilities, and dying from the

virus because of their propensity to have underlying health conditions, but they also suffered from isolation. Soon into the pandemic, healthcare facilities of all kinds discontinued visitation rights for family members. Loved ones, who would otherwise visit their friends and family members in nursing homes, were denied access to do so due to the risk of bringing in infection. Disabled residents of these institutions were denied all access to the very people who had historically provided love, protection, comfort, and meaning for their lives. The ongoing consequences of this situation are still felt to this day.



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A report issued in March 2021 by Human Rights Watch assessed the ongoing effects of the nursing home visitation restrictions on their residents' physical and mental health (10). Based on data obtained from interviews and reports from stakeholders in the field, the report revealed instances of "extreme weight loss, dehydration, untreated bedsores, inadequate hygiene, mental and physical decline, and inappropriate use of psychotropic medications among nursing home residents." (10). Failures to ensure sufficient nursing homes staff, and to adequately regulate these facilities, reduced the ability to provide sufficient and consistent support to nursing home residents when they most needed it. Not only was support and care inadequate when other residents were dying at an incalculable rate, but also there were no loved

one to provide the care, support, and love they so desperately needed. In addition, as the Human Rights Watch report stated, family members and independent monitors, who were unable to visit facilities throughout the pandemic, would often help ensure the adequacy of care and transparency, both of which faltered during the pandemic. Thus, the sense of longing, the feelings of isolation, and the measurable erosion of quality care experienced by people with disabilities living in long-term care facilities have had a disastrous effect.

Sociocultural factors

The disproportionate toll that the COVID-19 pandemic took on people living with disabilities in terms of cases and deaths is an injustice, but it has been well-established in the media. Likewise, the risk of people with disabilities living in long-term care facilities during the pandemic has been the focus of much social criticism. However, in addition to these direct disparities, people with disabilities suffered disproportionately in sociocultural ways throughout the pandemic, as they have through a somewhat perverse twist of fate in disasters of many kinds. (11). In these instances, it would be unfair and inadequate to presume that the disproportionate impact that disasters of any kind, pandemics included,

have on people with disabilities is solely related to a degree of physical vulnerability. Rather, there are structural biases and sociodemographic inequalities experienced by people with disabilities that exacerbate the impact that a disaster brings about, affecting a broad variety of human rights issues that have historically challenged the lives of people with disabilities. Some of the rights concerned relate to access to adequate health-care, access to housing, opportunities for employment, involvement in education, access to transportation and infrastructure, and their subjection to poverty. Until these matters are addressed, people with disabilities will chronically bear a disproportionate burden in times of disaster.

As we have seen during the COVID-19 pandemic, access to needed services can be difficult to acquire. Many people with disabilities require daily care and support services from external service providers in order to live their lives, and none of these needs stops during the time of a disaster like COVID-19, as Kendall has written. While measures like physical distancing were required to slow the spread of COVID-19, many people with disabilities were either unable to physically distance from service providers who could carry the virus or, conversely, did not have access



to the services they required because the services had to be discontinued. Both of these extremes put their lives at risk. Equipment and medical supplies, including respiratory care supplies like oxygen and ventilator tubing, remain essential for the lives of people with disabilities who require them yet, as was documented many times throughout the pandemic, access to these supplies was regularly inadequate, and much of the supply in existence was routed to clinical healthcare settings. In addition, during a pandemic like COVID-19, healthcare workers, who many people with disabilities rely on for care, can be redeployed to seemingly more immediate locations, like hospitals. The need for healthcare resources is a constant in the lives of many people with disabilities. Yet, during the COV-

ID pandemic, these resources were stretched thin - nearly to the point of depletion - leaving people with disabilities without access to supplies and services on which their lives depend. While some people with disabilities went without needed supplies while others, who had the financial means to do so, spent thousands of dollars to veritably stockpile medical supplies so as to avoid an inability to receive them.

Triaging of care

The centrality of the human rights challenges experienced by people with disabilities throughout the COVID-19 pandemic lies in the old-fashioned yet persistent notion that the lives of people with disabilities are less valuable than the lives of people without disabilities. That erroneous belief has sat at

the cornerstone of many disproportionate burdens that people with disabilities have borne during various types of disasters: the Fukushima nuclear power plant disaster - in which people with disabilities had a mortality rate twice that of those without - and the Hurricane Katrina, in which 38% of those who were not evacuated from the floods were people with disabilities (12). The perceived relative worth of people with disabilities has played no small role in the overall impact of the COVID-19 pandemic on the lives of this population, and this has been made manifest in many of the most gut-wrenching circumstances that the pandemic has created.

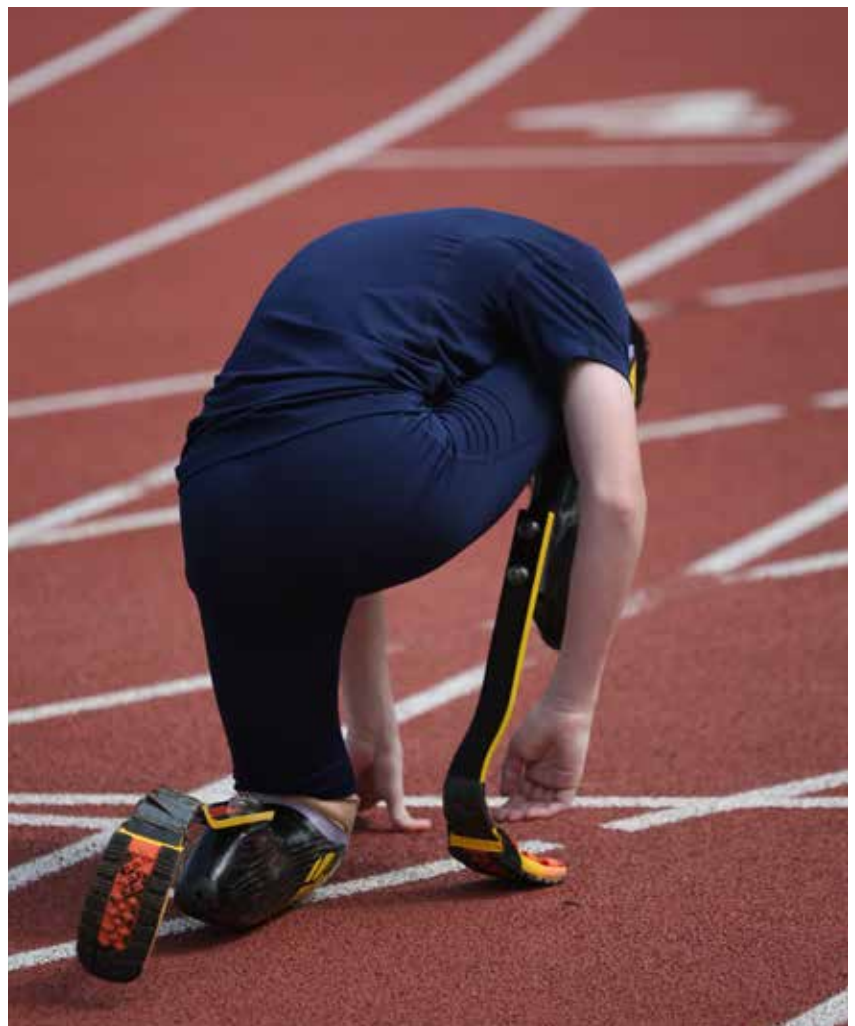
The coronavirus pandemic has exposed many vulnerabilities within our healthcare

system, and central among these is the lack of access to resources needed to provide adequate and safe medical care. We have seen these distributive injustices represented across many resources, including access to Personal Protective Equipment (PPE), hospital beds, medication and even healthcare personnel, and the provision of lifesaving and life-sustaining technology. Throughout the months of this pandemic, and even in years preceding it, ethicists, policymakers and philosophi-

cal thinkers have given attention to how the radical shifts in the demand for healthcare, like that brought about by the COVID-19 pandemic, would influence the metrics by which scarce healthcare resources are allocated and how care is triaged. This conundrum has consistently put people with disabilities in crosshairs.

Among the many concerns that people with disabilities have had to navigate during the pandemic has been what is called the U.S. “critical care

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crisis triage protocols.” These protocols provide guidance to hospitals and healthcare providers on how to distribute care when the number of people in need of support exceeds the capacities to meet their needs. The crisis care protocols in place throughout the pandemic were used as a framework for allocating healthcare resources. In other words, the system that determines who receives care over others – was based on a series of relatively subjective criteria, including a patient’s anticipated or demonstrated resource-intensity needs, the relative survival possibilities of patients deemed likely to benefit from medical treatment, and assessments of pre-or post-treatment quality-of-life. (12) The concepts of “anticipated or demonstrated resource-intensity needs” and “perceived quality-of-life” have consistently put people with disabilities in an unsafe situation concerning the prioritization of their lives. The nature of many people with disabilities lives is such that they are complex and require resources. In other words, they are resource-intense, through no fault of their own. Yet, they are valuable; they are far more valuable than the undervalued way they have been represented in history, in media, by philosophical thinkers, and even by people like physicians and ethicists who have notoriously undervalued the quality of life for people with



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disabilities. They have failed to appreciate their value despite the intensity of resources that people with disabilities might need to lead meaningful lives. According to a study done at the University of Georgia, throughout the COVID-19 pandemic, unconscious biases within the healthcare system influenced how individuals with intellectual disabilities were prioritized in emergency triage protocols, such that able-bodied patients were frequently provided resources over people with intellectual disabilities. The argument was made that these individuals were poor candidates for life support, an unfounded claim. In other circumstances, equally devastating, adults with disabilities have been prevented from having visitors or advocates accompany them to the hospital throughout the pandemic. In some cases, these individuals are

unable to communicate their needs, and this puts them at high risk for abuse or denial of treatment. (13)

The bioethical concept of managing how scarce resources should be allocated is known as “distributive justice”, which argues for a fair process. However, fairness and justice are not identical concepts, in the same way, that treating people equally does not imply equal outcomes when people begin at different starting points, and the disproportionality with which pandemics victimizes people with disabilities. Making “fairness” far less relevant than justice. Particularly in the event of this COVID-19 pandemic, which preys upon those with weakened bodies, people with disabilities are already at increased peril. This disease is discriminatory against people who experience physical problems. For people with disabilities, their bodies have already failed them, and we, as a society, cannot fail them as well.

Access to vaccines

The disadvantages experienced by people with disabilities throughout the pandemic have continued since the development and distribution of vaccines. Despite the fact that many allocation structures for the distribution of vaccines prioritized people with underlying healthcare conditions,



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many of whom were people with disabilities, the ability for this population to, in actuality, receive that vaccine has been muddled and complex. According to disability activists and advocacy organizations around the world, throughout the pandemic and continuing into the vaccination phase, people with disabilities have been left behind, as activists in Canada had argued (14). A similar argument was made by health department officials in Australia, who stated that two months into the vaccination efforts, only 6.5% of people with disabilities had been vaccinated, despite the fact that this population was prioritized in the vaccine roll-out.(15) The sentiment felt by many people with disabilities is not unfounded, as not only

have the vaccination protocols been challenging for this population but so, too, have the attempts to navigate the existing structural barriers that people with disabilities face when navigating daily life.

Particularly during the early phases of the vaccination rollout, securing an appointment for a vaccine was extremely difficult. It required access to online web portals or repeated phone calls to Departments of Health. For many people with disabilities, these platforms are inaccessible. This level of inaccessibility prevented members of this population from securing vaccine appointments, despite their eligibility for them. In addition, as vaccination sites were created with the general population in mind, not all

vaccination sites have been accessible for wheelchair users or people with disabilities. Until the very recent integration of mobile vaccination units and advocacy efforts to ensure that vaccination sites are fully accessible, people with disabilities have been without options. And, these logistical challenges accompany the existing structural barriers that people with disabilities encounter in their daily lives, such as a lack of accessible transportation or support persons to assist when attending the vaccine appointment. Finally, for many people with disabilities, leaving their homes or even their beds is either a challenge or an impossibility, veritably removing this entire population from access to the vaccine.

In addition to the logistical barriers that people with disabilities have faced within the terms of getting vaccinated, there have been many concerns regarding how their unique bodies might be affected by that vaccine. As is the case with many marginalized groups, people with disabilities have been largely excluded from the clinical trials that demonstrate the safety and efficacy of medical interventions, including the COVID-19 vaccines. As has been well documented, there has been skepticism and hesitance among the general population about the safety of the COVID-19 vaccine. Preliminary data collected among people with disabilities on this same issue, though, have demonstrated levels of skepticism or concern at or above those found in the general population. For instance, according to a survey conducted with people living with spinal cord injury, 72% of respondents who had already received the COVID-19 vaccine had concerns about it. (16) Similarly the same study, also shows that only about 60% of respondents said they had enough information about the safety of the vaccine for people with spinal cord injury. Many were concerned about the lack of resources, outreach efforts, and information dissemination provided to people living with this condition. The existing trauma

and strain on their bodies might put them at higher risk for complications from the vaccine. While it is quite possible that these concerns do not reflect the accuracy of available scientific and clinical data regarding vaccines and their effect on people with disabilities like spinal cord injury, what is quite clear is that people with disabilities are not receiving the information and reassurance they need to feel comfortable receiving the vaccine.

Opportunity to rebuild

As the global population ages and as we see the ongoing effects of the COVID-19 pandemic on physical and mental health, the number of people worldwide with a disability will see a significant increase. This is not a tragedy. It is an opportunity. People with disabilities are human beings, fully deserving of the full spectrum of human rights. Disability rights are human rights. And, yet, for far too long, people with disabilities have historically been viewed as less worthy, less valuable, and less deserving of our concern than are those without disabilities. This has been seen repeatedly, in the level of disregard they are afforded during times of disaster, in the ways that nations and economies have been built and developed. This either objectify their bodies, quantify their relative lack of productivity or marginalizes



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their existence so that their social participation is either discouraged or denied. Concepts like the quality adjusted life year (QALY) or the disability adjusted life year (DALY), that calculate a country's Global Burden of Disease through the estimate of the number of years of healthy life lost due to living with a disability, have been used by international organizations like the World Bank in international development initiatives for the creation of public policy creation. Central to these concepts is the notion that a life lived with a disability is some inferior or less desirable state: that which degrades or erodes some other, more optimal state of existence. Until that interpretation of disability changes, and until the world stops seeing disability as a detriment or net negative, people with disabilities will continually find themselves in a position of disadvantage or multiplicative discrimination whenever disasters arise or distribute different decisions must be made.

However, in the coming months and years, as the world begins to awaken from the oppression generated by the pandemic, and begin to rebuild itself, it will also have the opportunity to reconstruct society more equitably. It gives us the chance to reimagine the respect it affords to diverse ways of life and rebuild our communities and policies in a more just way. Policies that allow people with disabilities to live at home, in their communities, rather than in long-term care facilities, must be included, as should the reconstruction of our healthcare

system so that it is more accessible to people with diverse needs. This must include the reimagining of our infrastructure, our built environments, and our networks to be usable for everyone. Furthermore, policies that allow people with disabilities to emerge from conditions of poverty and become, to whatever degree they are able, contributing members of society, should also be included. And, most importantly, this must include deliberate and protracted efforts to reframe disability from a vision of vulnerability or societal detriment

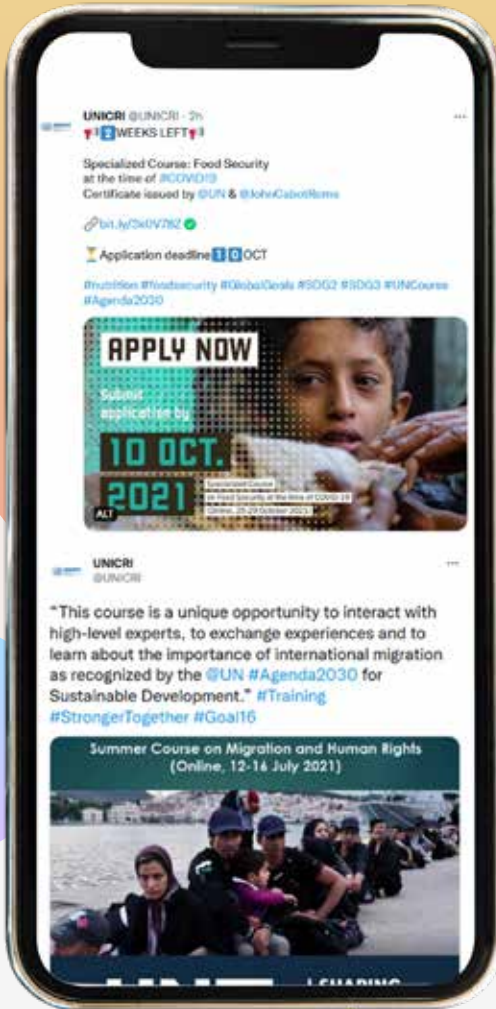
to one of empowerment and societal richness. People with disabilities must be provided with opportunities, not just to achieve the bare minimum but to thrive and excel and demonstrate their worth, no matter what their level of achievement might be. This is our opportunity. Emerging from the pandemic in the years ahead, this is our chance to set policies straight, to promote inclusion for everyone, and to approach the future – whatever challenges it may bring – in a safer, more secure, more sustainable, and more inclusive way.

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