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People with Disabilities in COVID-19: Fixing Our Priorities

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While the COVID-19 pandemic has wreaked disproportionate havoc in marginalized racial/ethnic communities, little attention has been given to people with disabilities in the press, public health surveillance, and research. A few articles, including this Special Issue, consider the discriminatory nature of categorical exclusion from and guidelines for the rationing of medical equipment and services. While important, this focus captures only one—late-stage—injustice towards people with disabilities in the pandemic, and leaves untouched other important periods. We focus on these understudied periods. First, we describe the most relevant and unique disadvantages that people with disabilities experience in healthcare and community living that place them at greater risk for disparate COVID-19 outcomes. Then we highlight the need to ensure accurate data collection in order to better understand COVID-19 disparities and improve prevention and treatment of, and preparedness for, current and future infectious disease pandemics among people with disabilities. People with disabilities comprise the largest health disparities population in the U.S. (Krahn, Walker and Correa-De-Araujo 2015). However, the disporportionate burden they are bearing during this pandemic suggests our society's moral stature is lacking as we fail to take care of our most vulnerable members.

Disability, health disparities and COVID-19

The absence of attention to people with disabilities in the COVID-19 pandemic is peculiar, yet not surprising. People with disabilities comprise 26% of adults and 20% of children in the U.S., and cut across all geographies, age, sex, racial, and ethnic subgroups of society. Notwithstanding federal laws requiring equal treatment and prohibiting discrimination, people with disabilities often remain an afterthought, living as invisible citizens. People with disabilities are equally marginalized in healthcare. As compared to their non-disabled peers,

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they are less likely to have private or employer-funded health insurance and access to preventative services, and more likely to report unmet healthcare needs, have lower social determinants of health (from poverty to unemployment to social isolation) and, as a result, have poorer health outcomes (Yee et al. 2018). Many of these health outcomes, including obesity, diabetes, acute and chronic respiratory diseases, and cardiovascular disease, are preventable and are risk factors for more severe COVID-19 outcomes (Krahn, Walker and Correa-De-Araujo 2015). Significantly, the prevalence of disability and associated poorer health outcomes are higher among Blacks/African Americans, Latinx and American Indians/ Alaska Natives (Yee et al. 2018), communities with disproportionately high rates of COVID-19 infection and mortality.

The COVID-19 pandemic has highlighted another systemic vulnerability for people with disabilities: inaccessible health information. Contrary to best practices that require the provision of reliable preventative and treatment advice, accessible information about COVID-19 (e.g., Braille, plain language, American Sign Language) has been neither immediately nor consistently available. Whether medical clinics and hospitals have adopted policies to assure accessibility of services and reasonable accommodations is unknown, but doubtful: many healthcare facilities fail to provide such measures during regular times, due in part to clinicians' lack of knowledge and insufficient training in the needs and rights of people with disabilities (Agaronnik et al. 2019; Sabatello 2019). These systemic deficiencies are further compounded for persons with disability who reside in congregate care settings.

Disability, community living, and COVID-19

Despite federal law and Supreme Court rulings, many people with disabilities are denied their right to choose to live independently in the community. Instead, they are more likely—and often structurally compelled—to live in long-term, congregate care settings, including nursing homes (where many younger people with disabilities reside alongside older adults with functional limitations), psychiatric institutions, residential group homes, and private institutions. The reasons for this outcome are systemic, including: inadequate federal and state funding for home-and community-based services; a lack of accessible, affordable housing stock; the privatization of congregate care living options; and Medicaid's—the major financer of long-term supports and services—bias toward institution-based care (McDonald et al. 2020).

Congregate care settings have long been associated with poorer outcomes, from decreased access to care to lack of control and self-determination to abuse and neglect (McDonald et al. 2020). But the COVID-19 pandemic again highlights how deadly congregate care is and should provoke urgency for systems reform. Emerging reports indicate that residents in institutions, group homes, nursing and other large, long-term residential care facilities are at far higher risk for infection and death. It is also emerging that guidelines about visitations and infection control procedures—key dimensions of disease control and access to supports—are limited and inconsistent across states (Chidambaram 2020). Since a large number of people with disabilities reside in congregate settings (comprehensive national data are not available; however, over 330,000 people with intellectual and developmental disabilities alone are estimated to live in congregate settings (Larson et al. 2018)), proper monitoring and transparent reporting of COVID-19 trends among people with disabilities is necessary to improve future preparedness for a second, or even multiple, cycle(s) of the pandemic.

Data recording

Reports about COVID-19 trends among people with disabilities are scarce. Although disability status should be considered important demographic information (given its prevalence and known risk factors for poorer outcomes), it is not systematically collected and has, to date, not been included in authoritative reports. Highlighting the problem with a lack of public health surveillance of people with intellectual/developmental disabilities (IDD), to our knowledge there are only two current reports of COVID-19 trends among this population in the US. An article in the *New York Times* (Hakim 2020) details that as of April 6, 2020, the COVID-19 death rate among adults with IDD receiving services in the state of New York was 9.5%, compared to a substantially lower overall death rate from COVID-19 in New York state of 4.0%. The second report is from a study that utilized real-time electronic medical record data to analyze case-fatality rates among individuals with a positive COVID-19 diagnosis in a majority US sample. This study reports higher rates of death among those with IDD at younger ages – ages 0–17, IDD 1.6%, without IDD <.01%; ages 18–74, IDD 4.5%, without IDD 2.7% – but similar rates of death at older ages – 75 and older, IDD 21.1%, without IDD, 20.7% (Turk et al. 2020). Whereas the generalizability of these findings to people with other types of disabilities is unknown, they provide warning that COVID-19 outcomes may be more severe for persons with IDD, likely due to a combination of risks associated with congregate living and health factors. Guidelines requiring systematic collection and reporting on COVID-19 trends among people with disabilities are urgently needed to assure an accurate understanding of the effect of this pandemic, and inform future work to reduce this disproportionate burden.

In addition, there is a need for addressing concerns about the way in which IDD is reported on death certificates. In prior years nearly half (48.5%) of the death certificates for adults with IDD inaccurately reported their disability as their cause of death (Landes et al. 2019). Beyond the illogic of identifying a disability, as opposed to an illness or disease, as a causal health event leading to death, this practice makes it difficult for public health researchers to understand mortality risks among, and thus be able to effectively address premature mortality, for this population. Since the inaccurate coding of IDD on death certificates was prominent in prior years for individuals who died from respiratory diseases, it is imperative during the time of this pandemic that those completing death certificates for people with IDD who die from COVID-19 report: 1) COVID-19 as the cause of death in Part I of the death certificate; and 2) the disability in Part II of the death certificate. Failure to accurately record IDD, or any other disability, on the death certificate prevents us from ever understanding the full effect of the pandemic on this population.

With people with disabilities entering the COVID-19 pandemic worse off than their non-disabled peers in terms of risk factors for more severe outcomes, a broken healthcare system with a history of medical biases against people with disabilities, and an absence of consolidated disability-friendly guidelines for emergency preparedness, it is likely that people with disabilities are discounted, and as result, fairing comparatively worse than their non-disabled peers in the pandemic.

Systemic and holistic changes are clearly needed to address the factors leading to poorer social determinants of health among people with disabilities. These include access to affordable and high quality care, disability competency training among healthcare providers (Sabatello 2019), and development of community-living opportunities that promote independence and social inclusion. Research to learn about individual-, familial- and community-level challenges experienced by people with disabilities in the current COVID-19 pandemic will be invaluable for developing disability inclusive emergency preparedness plans. For now, however, intermediary steps are already available and require immediate implementation. Assuring disability accessible COVID-19 information and accurate reporting of disability status in all aspects of COVID-19, including cumulative incidence and mortality rates and death certificates are first steps in fixing our priorities. They can mitigate infection risks and treatment, provide key data about the true impacts of this pandemic on the largest health disparities group in the U.S., and facilitate improvements in our response to current and future health crises.

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