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## Commentary

## The public health response to the COVID-19 pandemic for people with disabilities



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## ABSTRACT

With the rapidly changing landscape of the COVID-19 outbreak, how to best address the needs and continue to protect the health and well-being of people with disabilities (PwDs) is a global public health priority. In this commentary we identify three public health areas of ongoing need and offer possible strategies to address each. These areas include: the types of data that would help clarify risks for PwDs and help assure their safety long term; the prevention, treatment and mitigation measures for PwDs that are needed through the duration of the outbreak; and the issues of equity in access to and quality of medical care for PwDs. Because of the rapid nature of the public health response, it is critical to reassess and readjust our approach to best address the needs of PwDs in the months and years to come and to incorporate these new practices into future emergency preparedness responses.

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## Background

People with disabilities (PwDs) represent a large and diverse group, with about 1 in 4 adult Americans reporting some type of disability.<sup>1</sup> While disability is not inherently linked to increased risk of getting COVID-19 infection or in experiencing more severe disease, factors or circumstances associated with disabilities may increase these risks. Specifically, PwDs are more likely to have an underlying health problem<sup>2,3</sup> and are more likely to live in congregate care settings than those without disabilities.<sup>4</sup> Both of these factors have been shown to increased risk for COVID-19 infections.<sup>5,6</sup> Additionally, because of the nature of some disabilities, individuals may have difficulty practicing routine preventive measures. For example, people who rely on assistance with personal care will be unable to maintain physical distancing, while others may have difficulty communicating symptoms of illness, resulting in delays in diagnosis and additional virus spread.

There is little doubt now that the COVID-19 pandemic is unprecedented in our lifetime. We will continue to learn how to contain and control the spread of the virus in the months and even

years to come. With this rapidly changing landscape, assuring PwDs are not disproportionately impacted is a global public health priority.<sup>7</sup> In this commentary we identify three areas of pressing scientific need and offer possible strategies for each: (a) what are the types of data that would help clarify risks for PwDs and assure the right types of health protection efforts (prevention, treatment, and mitigation) are in place?; (b) what can be done to improve the health protection measures for PwDs through the duration of the outbreak?; and (c) how can we address the evolving issues of equity in access to and quality of medical care for PwDs? These three areas of need for PwDs are not new or unique to the COVID-19 pandemic. They have been identified from prior emergencies and are integrated into the framework we discuss below for COVID-19.<sup>7,8</sup>

## What are the types of data needed to identify and mitigate risks for PwDs?

With every emergency, addressing the needs of high-risk populations requires scientific data: to highlight who is at greatest risk so we can target intervention strategies and, subsequently, to monitor the effectiveness of interventions. The critical nature of data on who becomes infected with the SARS-CoV-2 virus and who is more likely to die has been highlighted by the CDC, showing that

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older adults, racial and ethnic minority groups, and those with underlying chronic health conditions are more likely to be severely impacted.<sup>9,10</sup> Unfortunately, there is little information that allow public health experts to break out the impact on PwDs. Instead, we mostly rely upon circumstantial information, such as reports of COVID-19 outbreaks among PwDs living in residential care facilities,<sup>11</sup> or inferences we can make about the risk of severe health outcomes in PwDs, given their higher rates of chronic health conditions.<sup>9</sup> It is uncertain whether children with disabilities are at higher risk of serious complications from COVID-19 infection <https://emergency.cdc.gov/han/2020/han00432.asp>. We do know that children with underlying neurologic conditions are more likely to die from seasonal influenza, also a respiratory-based illness.<sup>12</sup> A focus on children with disabilities as a vulnerable group must be a priority in future data collection efforts.

Incorporating disability identifiers into new or revised surveillance or other data collection systems for monitoring the COVID-19 outbreak is essential. Disability is a critical demographic identifier, similar to age, race/ethnicity, and gender with a standardized set of survey questions.<sup>13</sup> Using this standard set provides information about disability type (e.g., mobility, vision, hearing, cognition, self-care, or independent living), helping us pinpoint groups of PwDs who are at higher risk, leading to more effective mitigation measures. CDC recently updated the COVID-19 case report form to include a disability identifier (<https://www.cdc.gov/coronavirus/2019-ncov/php/reporting-pui.html>). The challenge will be to convey the importance of reporting these vulnerability factors to the health care and public health workers on the front lines who are completing these forms.

Although most people with disabilities will be identified using the standard disability screening tool, this approach is likely to overlook people with intellectual disabilities. Intellectual disability represents a small proportion of people with disabilities, yet one at high risk for severe health outcomes from COVID-19 infections. A recent analysis of national mortality data for deaths attributed to pneumonia prior to the COVID-19 outbreak indicated a 2 to 6 times higher death rate due to pneumonia in people with intellectual and developmental disabilities compared to without these disabilities.<sup>14</sup> These findings suggest that this population might be particularly vulnerable to dying from COVID-19 infections given that the virus can cause lung complications including pneumonia.

In addition to new surveillance or data collection systems, national, state, and local mortality data may be used to examine people with different types of disability, even while acknowledging challenges in accuracy of death certificate data in capturing and coding information on specific type of disability.<sup>15</sup> Linking service system data with mortality data, that is now available in more real-time,<sup>16</sup> at the state and local level, may provide a more accurate picture of the consequence of the pandemic on segments of the disability population and help target prevention efforts. Beyond mortality information, using existing secondary data sources, such as state Medicaid data or health system specific electronic health records, may allow for selective snapshots that can have important healthcare and policy implications.<sup>17,18</sup>

### **What can be done to improve the health protection measures for PwDs?**

The spread of the virus and the public health response to contain it has evolved quickly over recent months. The response strategy moving forward will involve a combination of routine virus testing with a focus on high risk settings and populations, isolating and caring for those with newly identified infection, and tracing and following up on anyone who has come into close contact with newly diagnosed cases—with the goal of stopping virus

spread.<sup>19</sup> Incorporating the needs of PwDs as they relate to these basic public health functions is important to making this strategy a success and protecting this high risk group. With each of these strategies, access barriers for PwDs will need to be addressed, such as how someone who is blind will access a drive through testing center, especially when ride-sharing services are not recommended.

A key component to continuing to protect PwDs is to have accurate and accessible health information on the virus and ways to continue to protect oneself. There are many audiences for this type of information in addition to the PwDs. They include health care providers, service providers who assist PwDs, and family members and other caregivers. Because the information on the virus and the public health response is changing rapidly, it is important that we update the materials often and continue to look for creative ways to get the information out to individuals and communities. Communication materials need to be accessible (e.g. Braille, sign language) and easily understood by all audiences. Advocacy organizations with a direct line to PwDs should be engaged throughout the process of developing, disseminating, and evaluating the impact of the communication materials.

We already know from recent epidemiologic investigations of virus spread and containment strategies with other high-risk populations or settings, specifically residents of nursing homes and homeless shelters, that improved infection control guidelines have relevance to PwDs who live in congregate care settings.<sup>6,20</sup> The recommendations resulting from these investigations mirror the broader response strategy referenced above of testing, isolating and tracing, but also include some specifics, such as limiting family/visitor access, screening staff before entry for temperature and symptom checks, reinforcing adherence to standard infection control strategies and ensuring that facilities have adequate supplies of masks, gloves and other personal protective equipment.

An emerging issue that will undoubtedly impact our public health protection response for PwDs for the longer term, is addressing the social and emotional needs of those living under isolated conditions. Following Hurricane Katrina, it was found that PwDs already had meaningful support networks in place that allowed them to be more resilient through the disaster compared to many without disabilities.<sup>21</sup> Enhancing that resiliency through targeted strategies may be beneficial given that the need to self-isolate may go on for some time. These strategies may include easing of restrictions on visits by family members in residential or group home settings by offering routine virus and symptom testing, working with advocacy groups to create virtual and setting-specific ways to engage with those socially isolated (virtual gatherings, social chat rooms, online exercise and movie or game nights), and working with local businesses to provide easier ways to address essential needs and services (specialized grocery delivery services including extending curbside pickups, ride share services that target PwDs, and exclusive hours of service for health care or hygiene services – dental, hair appointments.)<sup>7</sup>

### **How can we address health care equity for PwDs?**

Some PwDs worry that they may not get the best healthcare because of their disability. This fear was intensified early on in the global COVID-19 outbreak discussions of the need to ration life-saving medical equipment. PwDs are disadvantaged because of the pervasive negative biases and inaccurate assumptions about their quality of life. When quality of life, quality-adjusted life years, or disability-adjusted life years are considered in medical rationing decisions, PwDs are unfairly disadvantaged, not because they have lower quality of life, but because they are wrongly assumed to have lower quality of life.<sup>22</sup> In fact, several states adopted crisis standards

of care guidelines that categorically excluded people with intellectual disability from accessing scarce medical resources.<sup>23</sup>

While the shortage of critical care and medical equipment is lessening, a recent New Yorker article featured several adults who are deaf and blind who expressed concerns about the inherent biases they may face in receiving equitable treatment.<sup>24</sup> To communicate with doctors or other health care providers, a person who is deaf and blind needs an interpreter. Because of infection control requirements, the lack of this essential help in the ICU or other hospital settings leaves a person with communication needs especially vulnerable. The no visitor policies adopted by hospitals to protect patients, hospital personnel, and visitors is particularly problematic for patients with disabilities who rely on assistance with activities of daily living. Exceptions to the no visitor policy are needed to ensure that known and acknowledged support persons (such as designated family member, direct support professionals, or other designated caregivers) are permitted to be with the patient starting with admission and through to the care/treatment process. Such an exception would likely be considered a “reasonable accommodation” under the Americans with Disabilities Act and would improve communication between the hospital staff and PwDs and allow for informed and shared decision making.<sup>25</sup> Hospitals may consider adopting protocols for providing infection control briefings and providing appropriate PPEs to support persons.

As we move further along in the pandemic’s trajectory, we can anticipate the need for prioritizing new treatments. On the horizon are potential antivirals or other pharmaceuticals for the early treatment of infections and ultimately, a vaccine for prevention. Initial supplies may be limited, particularly for a vaccine. PwDs should be included among those prioritized for receiving these potential life-saving treatments given the risk for contracting the disease they experience.

Lastly, many PwDs have complex medical issues that required ongoing care.<sup>26</sup> As we move into the next phases of virus containment, we need to think through how to safely address routine health care issues and assure that PwDs receive needed care.

## Moving forward

PwDs represent a diverse group with varying needs in responding to COVID-19 pandemic. Data on who is at greatest risk of infection will help us better anticipate and meet the needs of PwDs. From what we know about other respiratory infections, people with intellectual disabilities and children with neurologic disabilities may be at higher risk of severe outcomes from COVID-19 disease, and we can act now to ensure they have information and supports to mitigate this potential risk. We can also anticipate that many PwDs will shelter-in-place for long periods of time to reduce their risk of infection. We can plan services and supports to meet the need for meaningful social interactions to maintain mental health and well-being while self-isolating. Because of the rapid nature of the public health response, it is critical to periodically reassess and readjust our approach to best address the needs of PwDs in the months and years to come and to incorporate these new practices into future emergency preparedness responses.

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