

## Section 6. COVID-19 Lessons Learned and Moving Forward

### A. *Disproportionate Effect Upon Persons with Disabilities*

As this position statement is being written, we are in the midst of the COVID–19 pandemic, with over 25 million confirmed cases and over 450,000 deaths attributed to the virus in the United States alone. Persons with disabilities have been disproportionately affected by the COVID–19 virus, particularly persons with intellectual or developmental disabilities (IDD) and persons with disabilities with underlying health conditions (*e.g.*, chronic lung disease, diabetes, chronic kidney disease, a serious heart condition, or a weakened immune system), that place them at risk for contracting the virus, higher risk for hospitalization once the virus is contracted, and with a greater risk of dying from the virus. Complications from, and death rates due to, COVID-19 for people with IDD are disproportionately higher when compared to people without IDD. Mortality rates have been cited to be up to 15% in individuals with IDD.<sup>1</sup> Concerning individuals with Down syndrome specifically, there is an estimated four-fold increase in risk for COVID related hospitalization and ten-fold increase in COVID-19 related death.<sup>2</sup> In addition, the Center for Disease Control and Prevention (CDC) has identified persons who have limited mobility who cannot avoid coming into contact with persons who may be infected, such as direct support providers and family members, as being at an increased risk of becoming infected or having

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<sup>1</sup> Landes SD, *et al.*, COVID-19 outcomes among people with intellectual and developmental disability in California: The importance of type of residence and skilled nursing care needs. *Disability and Health Journal*, 2020,1-5. *See also*, Turk MA, *et al.*, Intellectual and developmental disability and COVID-19 case-fatality trends: TriNetX analysis. *Disability and Health Journal*, 2020, 100942. *See also*, Landes SD, *et al.*, COVID-19 outcomes among people with intellectual and developmental disability living in residential group homes in New York State. *Disability and Health Journal*, 2020, 100969.

<sup>2</sup> Clift AC, *et al.*, COVID-19 mortality risk in Down syndrome: Results from a cohort study of 8 million adults. *Annals of Internal Medicine*, 2020, 21 October 2020: Letters.

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unrecognized illness.

In April 2019, the American Association on Health & Disability conducted a survey on COVID-19 & Disability to assess the impact of the coronavirus pandemic on access to healthcare on adults with a range of disabilities.<sup>3</sup> Over 2,400 persons responded to the survey. 47% of the respondents reported having a direct care worker (*e.g.*, home health aide, personal care aide or unpaid family caregiver) in their homes and 77% of those reporting having direct care workers continue to receive those services at home, but over half, 54% of those respondents, reported they were unable to maintain safe distances from their direct care worker.<sup>4</sup> Respondents were also asked if there were able to get regular healthcare treatment (such as physical therapy, dialysis, bloodwork, etc.) during the COVID – 19 outbreak. 36% of the respondents did not receive regular healthcare. Among those who did, 56% reported access has been disrupted.<sup>5</sup> Among the study's findings, television and the Internet were the main sources of information for respondents regarding the coronavirus, with healthcare providers and healthcare systems play in a less significant informational role.<sup>6</sup>

As we are still learning about the virus, we know that being older and having multiple comorbidities, like hypertension, diabetes, cardiovascular disease, chronic lung disease and obesity, are leading indicators of poor outcomes from the infection.<sup>7</sup> In gauging the risk and severity of illness for COVID patients with disabilities, the Center for Disease Control and

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<sup>3</sup> Drum, C.E., Oberg, A., Cooper, K., & Carlin, R. (2020). COVID-19 & Adults with Disabilities: Health and Health Care Access Online Survey Summary Report. Rockville, MD: American Association on Health and Disability. Available At: [COVID-19 & ADULTS WITH DISABILITIES: HEALTH AND HEALTH CARE ACCESS \(aahd.us\)](https://aahd.us/COVID-19-ADULTS-DISABILITIES-HEALTH-AND-HEALTH-CARE-ACCESS)

<sup>4</sup> *Id.*

<sup>5</sup> *Id.*

<sup>6</sup> *Id.*

<sup>7</sup> Jordan RE, Adab P, Cheng KK. *Covid-19: Risk Factors for Severe Disease and Death*. *BMJ*. 2020; 368:m1198. Available at: <https://www.bmj.com/content/368/bmj.m1198/rr-2>

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Prevention has stated:

“[D]isability alone may not be related to a higher risk for getting COVID–19 or having severe illness. Most people with disabilities are not inherently at higher risk for becoming infected with or having severe illness from COVID–19. However, some people with disabilities might be a higher risk of infection or severe illness because of their underlying medical conditions.”<sup>8</sup>

However, persons with disabilities are vulnerable to contracting COVID – 19 as they are most likely to live in nursing homes, group homes and other congregate living situations; may be less able to take protective measures like cleaning their hands frequently, physical distancing on account of the need of support personnel, including personal care attendants or family caregivers; and may not have access to personal protective equipment. Moreover, persons with disabilities are also vulnerable to discrimination in their ability to receive care and treatment for COVID-19 as many states enacted medical scarce resource allocation policies, and visitation policies that discriminated against persons with disabilities. Policies included categorical exclusions or disqualification from receiving critical care because of disability; de-prioritization due to disability; removal and reallocation of personal ventilators from certain adult patients with disabilities; and generalized assessment of quality of life or life expectancy after the provision critical care.

### ***B. Medical Scarce Resource Rationing Policies***

As the number of cases mounted and hospitals were overwhelmed, many states and healthcare systems implemented previously developed medical scarce resource allocation or rationing policies, commonly known as “Crisis Standards of Care.” Those policies set forth triage

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<sup>8</sup> CDC People with Disabilities- Coronavirus Disease 2019; <https://www.cdc.gov/coronavirus/2019-ncov/need-extra-precautions/people-with-disabilities.html>

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criteria for healthcare providers to assess who would and who would not receive care or to determine priority of care. More often than not, those policies discriminated against persons with disabilities solely based on the existence of a disability.

In March and April 2020, disability rights advocacy groups and persons with disabilities filed complaints with the Department of Health and Human Services Office of Civil Rights (HHS OCR) alleging that guidelines put forth by Alabama, Kansas, New York, Pennsylvania, Tennessee, Utah, and Washington illegally discriminated against persons with disabilities. The crux of complaints by disability rights advocates were that policies that base triage decisions on quality-of-life judgments or exclude patients with specific conditions are discriminatory. For instance, Alabama's now-rescinded guidelines, called for hospitals to withhold ventilators from patients with "severe or profound mental retardation" and "moderate to severe dementia."<sup>9</sup> Kansas' guidelines similarly provided for removing ventilators from people using them for a chronic condition who were judged lower priority in order to give them to other individuals.<sup>10</sup> In Pennsylvania, the Department of Health issued guidelines that used criteria to automatically de-prioritize persons with disabilities based on "pre-existing conditions that are disabilities."<sup>11</sup> Utah's guidelines recommend excluding patients with advanced neuromuscular diseases "requiring

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<sup>9</sup> Alabama Disability Advocacy Program and the Arc of the United States, complaint to Mr. Roger Severino, Dir., Office of Civil Rights, U.S. Department of Health & Human Services, dated March 24, 2020. Available at: [https://adap.ua.edu/uploads/5/7/8/9/57892141/al-ocr-complaint\\_3.24.20.pdf](https://adap.ua.edu/uploads/5/7/8/9/57892141/al-ocr-complaint_3.24.20.pdf)

<sup>10</sup> Disability Rights Center of Kansas complaint to Mr. Roger Severino, Dir., Office of Civil Rights, U.S. Department of Health & Human Services, dated March 27, 2020. Available at: <https://www.centerforpublicrep.org/wp-content/uploads/2020/03/Kansas-OCR-complaint-3.27.20-final.pdf>

<sup>11</sup> Disability Rights Pennsylvania complaint to Mr. Roger Severino, Dir., Office of Civil Rights, U.S. Department of Health & Human Services, dated March 24, 2020. Available at: <https://www.disabilityrightspa.org/wp-content/uploads/2020/04/DRP-9.pdf>

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assistance with activities of daily living.”<sup>12</sup> As reported by the Center for Public Integrity in April, 25 states have policies that also have similar provisions.<sup>13</sup>

In response, on March 28, 2020, HHS OCR issued a bulletin reminding healthcare providers of the application of federal disability rights laws during the pandemic.<sup>14</sup> The bulletin reaffirmed that the nondiscrimination mandates in Section 504 and Section 1557, the nondiscrimination laws for which HHS OCR has jurisdictional responsibility for, in addition to other civil rights laws, remain in effect during the pandemic. In addition, the bulletin stated:

“ . . . [P]ersons with disabilities should not be denied medical care on the basis of stereotypes, assessments of quality of life, or judgments about a person’s relative “worth” based on the presence or absence of disabilities or age. Decisions by covered entities concerning whether an individual is a candidate for treatment should be based on an individualized assessment of the patient based on the best available objective medical evidence.”

Following suit, the very next day after HHS OCR issued its bulletin, the Department of Justice, Civil Rights Division, issued its own statement about the applicability during the pandemic of the civil rights legislation that it has jurisdictional authority over – the Americans with Disabilities Act, the Civil Rights Act of 1964, the Fair Housing Act, the Education Amendments of 1972 – among others.<sup>15</sup> Subsequently, HHS OCR entered into settlement agreements with:

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<sup>12</sup> Disability Law Center, *et al.*, complaint to Mr. Roger Severino, Dir., Office of Civil Rights, U.S. Department of Health & Human Services, dated April 6, 2020. Available at: [thearc.org/wp-content/uploads/2020/04/Utah-HHS-OCR-Complaint.pdf](https://thearc.org/wp-content/uploads/2020/04/Utah-HHS-OCR-Complaint.pdf)

<sup>13</sup> Center for Public Integrity, Coronavirus and Inequality, State Policies May Send People with Disabilities Back of the Line for Ventilators. April 8, 2020. Available at: <https://publicintegrity.org/health/coronavirus-and-inequality/state-policies-may-send-people-with-disabilities-to-the-back-of-the-line-for-ventilators/>

<sup>14</sup> US Department of Health and Human Services Office of Civil Rights BULLETIN: Civil Rights, HIPAA, and the Corona Virus Disease 2019 (COVID – 19). Available at: <https://www.hhs.gov/about/news/2020/03/28/ocr-issues-bulletin-on-civil-rights-laws-and-hipaa-flexibilities-that-apply-during-the-covid-19-emergency.html>

<sup>15</sup> Statement by Assistant Attorney General for Civil Rights Eric S. Dreiband Protecting Civil Rights While Responding to the Coronavirus Disease 2019 (COVID-19) [https://www.ada.gov/aag\\_covid\\_statement.pdf](https://www.ada.gov/aag_covid_statement.pdf)

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- Alabama, to remove the existence of profound mental retardation and moderate severe dementia as disqualifying criteria to receive ventilator services;<sup>16</sup>
- Pennsylvania, to discontinue using the mere existence of specific impairments or disabilities as de-prioritization criteria to access critical care and ventilators;<sup>17</sup>
- Tennessee, to discontinue disqualifying individuals with advanced neuromuscular disease, metastatic cancer, traumatic brain injury, dementia, and other disabilities from use of a ventilator in times of scarcity; utilizing long-term life expectancy as a determining factor in the allocation of scarce medical resources; and to discontinue removing personal ventilators from persons with disabilities who brought them to an acute hospital so that hospitals can give them to others they deemed more worthy;<sup>18</sup> and
- Utah, to discontinue disqualifying persons with advanced neuromuscular disease, dementia, cystic fibrosis and other disabilities requiring assistance with daily living from receiving lifesaving care during the pandemic, including removal of language permitting a patient’s long-term life expectancy as a factor in the allocation and reallocation of scarce medical resources.<sup>19</sup>

### ***C. Hospital Visitor Policies***

At the same time that states adopted discriminatory crisis standards of care, in attempts to minimize exposure of persons to the COVID–19 virus and as a form of rationing personal protective equipment, healthcare systems and hospitals also adopted “no visitor” policies. Those

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<sup>16</sup> HHS OCR Press Release, April 8, 2020, OCR Reaches Early Case Resolution with Alabama After It Removes Discriminatory Ventilator Triage Guidelines. Available at: <https://www.hhs.gov/about/news/2020/04/08/ocr-reaches-early-case-resolution-alabama-after-it-removes-discriminatory-ventilator-triaging.html>

<sup>17</sup> OCR Resolves Civil Rights Complaint Against Pennsylvania After it Revises its Pandemic Health Care Triage Policies to Protect Against Disability Discrimination. April 16, 2020 Available at: <https://www.hhs.gov/about/news/2020/04/16/ocr-resolves-civil-rights-complaint-against-pennsylvania-after-it-revises-its-pandemic-health-care.html>

<sup>18</sup> OCR Resolves Complaint with Tennessee After it Revises its Triage Plans to Protect Against Disability Discrimination, June 26, 2020. Available at: <https://www.hhs.gov/about/news/2020/06/26/ocr-resolves-complaint-tennessee-after-it-revises-its-triage-plans-protect-against-disability.html>

<sup>19</sup>OCR Resolves Complaint with Utah After it Revised Crisis Standards of Care to Protect Against Age and Disability Discrimination, August 20, 2020. Available at: <https://www.hhs.gov/about/news/2020/08/20/ocr-resolves-complaint-with-utah-after-revised-crisis-standards-of-care-to-protect-against-age-disability-discrimination.html>

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policies strictly prohibited patients from being accompanied by family members or any other third party. Immediately, those policies had a material detrimental effect upon persons who are deaf and hard of hearing and rely upon sign language interpreters to communicate critical information during a healthcare encounter, as well as persons with intellectual and developmental disabilities who are not able to communicate or who lack the capacity to provide informed consent. Persons with paralysis and mobility disabilities were also materially detrimentally affected by these policies as it meant they could not be accompanied by personal care attendants, family or other persons to provide support during hospitalizations. Quite often, persons with paralysis mobility disabilities require the assistance of family members, significant others or personal care attendants to assist with feeding, to assist with turning and positioning in bed, to facilitate or oversee safe transfers in and out of the person's wheelchair and advocating for them with physicians and nursing staff. While nurses and patient care technicians are required to provide that assistance, in an overwhelming number of instances they do not or do not do so correctly. Given that, persons with paralysis mobility disabilities have learned to bring someone with them during hospitalizations.

In May 2020, HHS OCR received complaints from Disability Rights Connecticut, CommunicationFIRST, the Arc of Connecticut, Independence Northwest: Center for Independent Living of Northwest CT, Center for Public Representation, and The Arc of the United States alleging that Connecticut's guidance regarding hospital visitation for people with disabilities violates the ADA, Section 504 and Section 1557, all of which are enforced by HHS OCR.<sup>20</sup> The

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<sup>20</sup> OCR Resolves Complaints after State of Connecticut and Private Hospital Safeguard the Rights of Persons with Disabilities to Have Reasonable Access to Support Persons in Hospital Settings During COVID-19. June 9, 2020.

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complainants alleged that Connecticut’s guidance concerning hospital “no visitor” policies during the COVID-19 pandemic allowed only narrow exceptions for support persons for individuals with disabilities receiving certain services from the state Department of Developmental Services (DDS), leaving large groups of persons with disabilities unable to avail themselves of the exception. The complainants alleged that without support persons, specific patients with disabilities in Connecticut facilities were being denied equal access to medical treatment, effective communication, the ability to make informed decisions and provide consent, and that they were being unnecessarily subjected to physical and pharmacological restraints.

In June 2020, HHS OCR resolved a complaint after Connecticut issued an executive order regarding non-visitation policies for short-term hospitals, outpatient clinics, and outpatient surgical facilities to ensure that people with disabilities are not denied reasonable access to needed support persons. As part of the resolution, on June 9, 2020, Connecticut issued an executive order<sup>21</sup> to ensure that people with disabilities have reasonable access to support personnel in hospital settings in a manner that is consistent with disability rights laws and the health and safety of patients, health care providers, and support persons. The order includes establishing a statewide policy requiring hospitals and other acute care settings to permit the entrance of a designated support person for a patient with a disability and permitting family members, service-providers or other individuals knowledgeable about the needs of the person with a disability to serve as a designated support person. Where patients with a disability are in

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Available at: <https://www.hhs.gov/about/news/2020/06/09/ocr-resolves-complaints-after-state-connecticut-private-hospital-safeguard-rights-persons.html>

<sup>21</sup> Connecticut’s executive order is available at <https://portal.ct.gov/-/media/Coronavirus/20200609-DPH-Order-regarding-patients-with-disabilities-in-health-care-facilities.pdf> - PDF.



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such a setting for longer than one day, they may designate two support persons, provided only one is present at a time.

### ***D. Telemedicine as an Alternative to In-Person Visits***

As a result of COVID-19's high transmissibility, recommendations were made to limit in-person clinic visits and to find alternatives to face-to-face encounters, including using telemedicine for visits. Telemedicine is the provision of clinical services remotely, through telecommunications-based networks, usually to individuals who might otherwise be restricted from accessing healthcare due to environmental constraints.<sup>22</sup> The use of telemedicine for routine encounters has steadily increased and a review of telemedicine research studies suggests efficacy for treatment and follow-up among individuals with spinal cord injuries.

As telemedicine enables healthcare visits when in-person visits would be otherwise inconvenient or impossible, its relevance for disaster preparedness and mitigation is clear, however, there are significant barriers affecting persons with disabilities' ability to utilize telemedicine. The most significant obstacle is access to the Internet. The Internet is inaccessible in many rural and low-income communities due to the absence of infrastructure and the lack of investment in these communities.<sup>23</sup> In addition, for persons with paralysis and mobility disabilities that do not have manual dexterity may be limited in their ability to interact with virtual interface or bioperipheral devices, such as virtual stethoscopes, wireless weight scales and thermometers, which may need to be customized for their use.

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<sup>22</sup> Pasipanodya, E., *et al.*, Provision of care through telemedicine during a natural disaster: a case study, *Spinal Cord Series and Cases*. 2020; 6:60, <https://doi.org/10.1038/s41394-020-0309-2>

<sup>23</sup> Annaswamy, T., *et al.*, *Telemedicine barriers and challenges for persons with disabilities: COVID – 19 and beyond*, *Disability and Health Journal* 13 (2020) 100973.

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### *E. COVID–19 Screening Guidelines*

There remains little guidance to assist healthcare providers in screening for the presence of the COVID–19 virus in persons with paralysis and mobility disabilities. In March 2020, the Center for Disease Control and Prevention issued guidance on priority levels for testing patients with suspected COVID–19 and information on when to seek medical attention. That guidance, since revised multiple times, which includes a COVID–19 phone script for healthcare providers to use during telephonic triage for children ages two through 17 and adults, omitted guidance for persons with spinal cord injuries who may not present the typical symptoms of COVID–19 as a result of their spinal cord injury.<sup>24</sup>

A perspective published in the International Spinal Cord Society *Spinal Cord Series and Cases* journal identifies temperature dysregulation, impaired cough and abnormal sensations at or below the neurological level of injury as conditions present in persons with spinal cord injuries that may mask the presence of COVID-19 and calls upon the CDC to issue specific guidance to healthcare providers to enhance her ability to triage potential infected patients with spinal cord injuries.<sup>25</sup> CDC testing guidelines for COVID–19 do not account for the altered physiology in a person with a spinal cord injury and therefore the risk of missing a COVID–19 diagnosis in a person with a spinal cord injury may be elevated.

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<sup>24</sup> Center for Disease Control and Prevention, Healthcare Workers, Coronavirus Disease 2019 Phone Advice Line Tool. Available at: [Telephone Response Guide for Clinics | CDC](#) . Last accessed on November 29, 2020.

<sup>25</sup> Korupolu R. *et al.*, *COVID-19: Screening and triage challenges in people with disability due to Spinal Court Injury*. *Spinal Cord Series and Cases*. 2020 May 11; 6(1): 35.

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The authors of that perspective advised healthcare providers that for persons with spinal cord injuries at or above the thoracic level VI (T6), noxious stimulation including infection below the level of injury may result in autonomic dysreflexia, a medical emergency with symptoms including elevated blood pressure, low heart rate, chest tightness, facial flushing, profuse sweating, vision changes, and pounding headache.<sup>26</sup> In addition, persons with spinal cord injury may develop “nonspecific symptoms” during infection including new or worsening spasticity, neuropathic pain, autonomic dysreflexia and or fatigue, all of which are not consistent with the current CDC guidelines for COVID-19. The perspective further reveals the results of an international survey of 783 healthcare professionals who care for individuals with a spinal cord injury who reported that 10.3% of their patients with COVID–19 had increased spasticity, 6.9% reported their patients had rigors, and 6.9% reported their patients had been asymptomatic, all of which calls for the need of special consideration during triage for persons with spinal cord injuries suspected of having the COVID–19 virus.

### ***F. De-prioritization in Vaccination***

As vaccines for the pandemic became available in limited supplies, the Center for Disease Control and Prevention and the National Academies of Science Engineering and Medicine established guidance for states to use in determining the priority of persons to receive the vaccines. The first priority group, designated as Phase 1a, included healthcare workers and residents and staff of nursing homes. The second priority group, designated as Phase 1b, included elderly people 75-plus and frontline essential workers, including police,

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<sup>26</sup> *Id.*

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firefighters, teachers, grocery store staff and the US Postal Service employees.<sup>27</sup> The guidance was issued to assist states in formulating their own priority categorizations.

The guidance also proposed persons *of all ages* with comorbid and underlying conditions, which would include high-risk persons with paralysis and mobility disabilities, that put them at significantly higher risk be included in priority phases to receive the vaccine after frontline healthcare workers Phase 1b or Phase 1c. As of February 10, 2021, 29 states – Alabama, Alaska, California, Connecticut, Florida, Georgia, Hawaii, Idaho, Illinois, Indiana, Kansas, Kentucky, Maine, Massachusetts, Michigan, Minnesota, Nevada, New Mexico, North Dakota, Oklahoma, Rhode Island, South Carolina, South Dakota, Texas, Utah, Vermont, Virginia, Washington, West Virginia – and Washington DC, have all de-prioritized persons with disabilities that fall into that category, including those with developmental disabilities.<sup>28</sup> Moreover, some states, like Illinois, prioritized direct service providers including family caregivers, but not the persons with disabilities for whom they care.

In addition, while persons with disabilities living in nursing homes were prioritized in the majority of states, Colorado, Georgia, Hawaii, Indiana, Maine, Minnesota, Mississippi, Texas and Vermont, have excluded in their prioritization of the vaccination high-risk individuals with disabilities who live in other congregate settings, such as acute psychiatric facilities and group homes for individuals with disabilities, including serious mental illness, developmental and intellectual disabilities, physical disabilities or substance use disorders.<sup>29</sup>

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<sup>27</sup> [CDC's COVID-19 Vaccine Rollout Recommendations | CDC](#)

<sup>28</sup> Data obtained from the Jon Hopkins Disability Health Research Center and the Center for Dignity and Healthcare for People with Disabilities COVID – 19 Vaccine Prioritization Dashboard. Last Accessed: February 9, 2021. Available at: [COVID-19 Vaccine Prioritization Dashboard – The Johns Hopkins Disability Health Research Center \(jhu.edu\)](#)

<sup>29</sup> *Id.*

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National disability advocacy organizations have appealed to the Biden Administration and the National Governors Association to have states prioritize high risk persons with disabilities given their high mortality risk if contracted with the virus and to establish more equitable frameworks for determining prioritization of receiving vaccinations.<sup>30</sup>

Finally, persons with disabilities have largely been ignored since the commencement of the pandemic in data surveillance, specifically rates of infection, hospitalizations, outcomes, and deaths. Data is critical to informing the public health response and can also assist in identifying which segments of the population with disabilities within a state to specifically target and prioritize for purposes of administration of the vaccine. States must capture the number of their respective constituents receiving home and community-based services and/or developmental disability services because persons receiving those services are likely to have one or more comorbidities that enhance their risk for contracting the virus and enhances their risk for poorer outcomes. From that data, local and national public health officials can generate evidence to support community-level advocacy and intervention efforts.

Lessons continue to be learned as the world continues to deal with this historic and unprecedented global pandemic.

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<sup>30</sup> See, e.g., National Council on Disability, February 10, 2021, [NCD makes recommendations to National Governors Association on COVID-19 vaccination equity | NCD.gov](#)