

COVID-19 Vaccination Challenges for People with Disabilities

1. How individuals with disabilities fit within priority populations.



My name is Thomas Mangrum, Jr. I live in Washington, DC in a senior citizens building. I have a disability and other serious medical conditions. I use a motorized wheelchair for mobility. Before the COVID-19 crises, I received personal support services from a direct service provider (DSP) five days a week from 8am – 4pm, but haven't received services lately, except for 4-6 hours once every 2 weeks. I do still receive periodic visits from a nurse to monitor my medical conditions. I've been told that the DSPs won't come to my home because I live in senior housing and they're afraid of being infected with COVID-19. I feel very isolated.

People with disabilities will be within priority groups based both on the setting where they live and/or a medical condition that puts them at high risk. In both groups they are also at risk for being overlooked for vaccinations:

- In congregate care settings, residents with disabilities may be overlooked if they do not fit within vaccine allocation priority age range (typically given as adults >65 years-old). The reality is that thousands of adults with disabilities ages 18-64 continue to reside in and receive services in congregate care settings.
 - *The problem:*
 - When a COVID-19 vaccine is made available, individuals with disabilities living in congregate care settings and below the age of 65 may be left out of vaccine allocation plans. Leaving these individuals out of vaccination plans would endanger their health and lives.
 - *Action steps:*
 - Include *all* residents in congregate care settings in priority group allocations, i.e. remove language specifying age minimum.
 - Define scope of “congregate care setting” to include not only nursing homes, but all settings that provide long-term, residential care.
 - *Sources:*
 - [COVID-19 Has claimed the lives of 100,000 long-term care residents and staff](#)
 - [Graphic: Percent of Working-Age People with Disabilities Still Living in Nursing Homes, 7/2020](#)
- In communities, many individuals with disabilities are at a higher risk of infection, severe illness, and even death from COVID-19 because of underlying medical conditions. According to the CDC, adults with disabilities are three times more likely than adults without disabilities to have chronic conditions such as heart disease, stroke, and diabetes, as well as more likely to have higher risk of a weakened immune system.
 - *The problem:*

- Often these underlying medical conditions are related to their primary disability, but if the disability is not listed as a priority risk factor for vaccine allocation, then people may struggle to understand that they are eligible for a priority group; navigate avenues to prove eligibility for priority groups; and/or navigate limited mobility, understanding of health guidelines, or ability to communicate symptoms.
- *Action steps:*
 - Clearly communicate all vaccine allocation and distribution plans to healthcare providers, public health personnel, and direct service providers at the federal, state, and local levels.
 - Collaborate with state and local stakeholders in the disability community to reach individuals with disabilities living in home- and community-based settings (HCBS).
- *Sources:*
 - [CDC: People with Disabilities and COVID-19](#)
 - [The impact of COVID-19 on individuals with intellectual and developmental disabilities](#)

2. New data about risk related to disability is not guiding systems.



My name is Rachel Mueller and I am a person with a disability. I am from Sterling Heights, MI. I just lost my Grandpa to the COVID-19 virus. The COVID-19 emergency has stopped me from going to school and community-based instruction, workplace and community activities. Also, my direct support professional cannot come to my house. I also cannot schedule my hearing aid appointment. I am worried about going out into the community and staying safe. I am worried about being able to find a job.

A recent analysis of private health insurance claims data by the Johns Hopkins University School of Medicine found that individuals with intellectual and/or developmental disabilities are three times as likely to die if they contract COVID-19 as people without such disabilities. Another study published in the *Annals of Internal Medicine* found that individuals with disabilities have four times the risk for COVID-19-related hospitalization and ten times the risk for COVID-19-related death, as compared to persons without Down syndrome.

- *The problem:*
 - Data about results in nonelderly congregate care settings is incomplete and does not capture the full extent to which individuals with disabilities have been impacted by COVID-19. The data that does exist has not been reflected in federal and state vaccine allocation plans.
- *Action steps:*
 - Collect and report data on how COVID-19 has impacted individuals with disabilities across the lifespan and across all forms of disability.
 - Utilize collected data to inform COVID-19 vaccine allocation and distribution plans, i.e. when deciding priority populations, at the federal, state, and local levels.
- *Sources:*

- [Risk Factors for COVID-19 Mortality among Privately Insured Patients from Johns Hopkins University School of Medicine](#)
- [COVID-19 mortality risk in Down syndrome](#)
- [‘This is Really Life or Death.’ For People with Disabilities, Coronavirus is Making it Harder Than Ever to Receive Care.](#)

3. Access to vaccine distribution.



My name is Sandra Bauman and I am a person with intellectual disability and significant somatic complaints. I am from Baltimore, Maryland. I live in my own home with some support services. My needs are difficult. Finding an aide has been difficult. I need information about COVID-19 to be in plain language as it's hard for me to understand and feel safe during these hard times if information is not accessible.

Federal, state and local plans lack details related to how priority groups will be identified and/or self-identify to receive a COVID-19 vaccine. The lack of detail creates barriers to navigation for individuals with disabilities who will need to navigate additional barriers to access vaccine.

- *The problem:*
 - Current federal and state plans for vaccine allocation and distribution lack clarity about exactly who is included in priority groups. Additionally, inconsistent definitions of priority groups (e.g. healthcare personnel, congregate care settings) across federal and state plans adds to confusion and could decrease rates of priority group identification/self-identification in the disability community.
- *Action steps:*
 - The CDC must adopt and encourage the use of consistent definitions of priority groups in COVID-19 vaccine allocation and distribution guidance that is inclusive of the disability community.
 - Public messaging providing identification of priority groups and how, when, and where to receive a COVID-19 vaccine must be consistent, accessible (i.e. close-captioned, in ASL, etc.), and clearly stated.
 - Federal, state, and local public health personnel must tailor messaging and plans for dosage-tracking on 2-dose COVID-19 vaccines for the disability community to ensure follow-up dose compliance.
- *Sources:*
 - [ACIP COVID-19 Vaccines Work Group: Phased Allocation of COVID-19 Vaccines.](#)
 - [State Vaccination Plans from The Council of State Governments](#)
 - [Vaccine Cards And Second-Dose Reminders Are Part of Warp Speed's Immunization Plans.](#)

4. Direct Care Professionals (DSPs) and others providing support.



My name is Gary Heckert. I live in Newark, Delaware, I am the parent of an adult with autism, intellectual disabilities, and behavior challenges who lives in an apartment in our town with round-the-clock staff. My greatest concern in this COVID-19 world is what will happen to him if his staff are unable to report for work. His emotional stability and well-being are highly dependent on maintenance of routine, including familiar staff who understand his spoken and unspoken communication. Our state developmental disabilities system does not have sufficient PPE to ensure the health and safety of clients and staff alike. It is important that adequate supplies of PPE are available to both clients and providers to keep all safe and well.

Many individuals providing persons with disabilities the support they need for activities of daily living are outside of the facility-based medical system, limiting their access to vaccine priority. Additionally, they do not fit within the standard definition of health care workers because they are outside of the health care setting.

- Individuals with disabilities rely on a wide array of both paid and unpaid direct support professionals (DSPs). DSPs provide a wide variety of home- and community-based, health-related services that support individuals with disabilities, including for personal care, activities of daily living, access to health services, and more. The work of DSPs is crucial to the physical health, livelihoods, and quality of life for thousands of individuals with disabilities.
 - *The problem:*
 - The often close and intimate nature of the support provided by DSPs places both individuals with disabilities and DSPs at higher risk for spreading and contracting the novel coronavirus. However, DSPs have thus far been left out of emergency funding for pay, training, and personal protective equipment granted to other healthcare workers. The result is an increasingly unstable workforce, as evidenced by results of a survey of over 9,000 DSPs conducted in early May, showing that 42% of respondent knew someone in the DSP workforce who left their job due to the pandemic.
 - *Action steps:*
 - It is critical to both DSPs and the individuals they serve that DSPs be classified as essential healthcare workers and included in priority groups of COVID-19 vaccine allocation plans.
 - Provide additional, emergency funding to DSPs working in congregate care settings, as well as home- and community-based settings, to ensure they have the PPE necessary to keep themselves and the individuals they support safe.
 - *Sources:*
 - [Results of The Direct Support Workforce and COVID-19 National Survey 2020](#)
 - [CDC guidance for direct service providers during COVID-19](#)
 - [A detailed profile of America's direct care workforce from PHI National](#)

To read more stories about how the COVID-19 pandemic has affected the lives of individuals with disabilities and their families, visit [here](#).

AUCD COVID-19 vaccine work, as of 12/8/2020:

- [Frequently Asked Questions: COVID-19 Vaccine Distribution Considerations for the Disability Community](#)
- [Comments to the National Academies Committee on Equitable Allocation of Vaccine for the Novel Coronavirus](#)
- [Comments to the Advisory Committee on Immunization Practices, Re: CDC2020-0117](#)