

Vaccination plans must include disability community's needs

February 24 2021, by Bonnielin Swenor and Sabrina Epstein



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The Johns Hopkins Disability Health Research Center recently launched the [COVID-19 Vaccine Prioritization Dashboard](#) to decipher how state policies have—and have not—prioritized the needs of people with

disabilities in vaccination plans. The website, created with the Center for Dignity in Healthcare for People with Disabilities, interprets public information so that the disability community can understand the varying qualification rules and application processes.

Bonnielin Swenor, director of the Johns Hopkins Disability Health Research Center and Sabrina Epstein, student researcher and communications intern for the center discuss vaccination policy, disability, and the importance of the Prioritization Dashboard.

What barriers have people with disabilities encountered during the pandemic?

Bonnielin Swenor: Results from a qualitative study that is currently under review from the Disability Health Research Center show that the needs of people with [disabilities](#) have not factored into COVID-19 planning since the start of the pandemic.

Sabrina Epstein: For example, people who are blind or have low vision must use screen readers to navigate state websites to obtain information about vaccination eligibility and for making appointments. But most states are presenting that information in infographics that screen readers cannot read. Many vaccination and testing sites are drive-through only, and many people with disabilities can't drive for a variety of reasons. Several states require online registration for appointments, but not everyone is capable of navigating websites. People who are deaf or hard of hearing have had a difficult time at testing and vaccination sites where everyone is wearing masks but there are no interpreters or captioning tools to provide them service.

What data exist to document the lack of equity and inclusion of people with disabilities?

BS: There is limited disability data across many areas, a challenge that has existed long before the pandemic. This lack of data does not mean inequities do not exist. But these data gaps limit our ability to address inequities for the disability community. I launched the Disability Health Research Center at the end of 2019, in part to fill this gap in data. The Center is focused on providing evidence of the inequities facing the disability community in order to support policy and societal change. COVID only fast tracked that mission.

In general, has the disability community been included in equity and inclusion discussions related to public health policies?

BS: When most people discuss equity and inclusion—and I am grateful we are having these discussions more broadly—they think of race, ethnicity, gender identity, and age. But disabilities almost never enter the equation in public health policies and beyond. It is a paradigm shift for people to look at disability through the lens of equity and inclusion. That's been our uphill battle. Until recently, we have not been at the tables where equity is being discussed. The Disability Health Research Center is working to change that during the pandemic and beyond.

SE: There's been a lot of discussion during the pandemic that [young people](#) will be okay if they get COVID because only old and sick people are dying. As a young person who is also a sick person with a rare genetic condition, it is invalidating to hear that. And it's a wake-up call to say we need to change the way people are devaluing the lives of people with disabilities.

What was the genesis of the COVID-19 Vaccine Prioritization Dashboard?

SE: I was trying to register my grandfather, who lives in Texas, for his vaccine and I realized that I qualified for the vaccine in Texas. But I did not qualify for the vaccine where I live in Maryland, which was very strange and frustrating. That's when my public health brain began to wonder, "Where else is this going on?" As I examined each state's vaccine prioritization plans, it became clear that they were all very disjointed. Each one defines high-risk chronic conditions differently. That makes it difficult to figure out if you qualify and to advocate for a better plan when it's not clear what other states are doing. It definitely came out of my own disability experience and having a disability community to turn to in order to learn that my experience was part of a larger problem.

How do state vaccination rollout plans differ?

SE: What we noticed as we started going through all the state plans was that states were defining long-term settings in different ways. In some states, "long-term settings" referred specifically to nursing homes while other congregate care group homes were grouped into different priority phases. As of the most recent weekly dashboard update, 27 states placed "other types of congregate care settings" into a different phase than long-term care settings. States have also interpreted the CDC's definitions for chronic conditions in varying ways, which is why it is so important to not only show the phases but also define each condition for every state. Eight states, for example, are dividing chronic conditions across multiple phases. There is very little uniformity with how the states created a group called "other disability-related group phase."

How has the prioritization dashboard made information from the states more accessible for people with disabilities?

SE: The dashboard offers several different options. Options are key to accessibility because it's never one size fits all. The website itself is accessible by screen readers. But you can also download the data into a CSV, Excel spreadsheet, PDF, or print it out. There is also a Google sheet that is feeding the website all of the information, which then has additional accessibility.

What impact has the prioritization dashboard had so far?

BS: The National Council on Disability cited the dashboard a day after we launched it in a letter to the National Governors Association. The letter used our data to demonstrate that 29 states have de-prioritized people of all ages with disabilities from early vaccination phases even though the CDC and the National Academies of Sciences, Engineering, and Medicine have said their higher health risks should place them in the early rollouts.

I've never in my career seen something have such a fast impact. And it was an idea from Sabrina, a Johns Hopkins undergraduate. She is outstanding. To me, as someone who has a disability—I have a vision impairment—it illustrates the value of including people in research who are part of and understand the disability community.

I have hope for the future impact of this area of work, as we're beginning to see a shift at the federal level. The Biden-Harris administration appointed a disability advocate to the COVID-19 Health Equity Task Force and has included "disability" in an executive order establishing a group to explore how federal datasets can best disaggregate information according to race, ethnicity, gender, and disability.

Are there best practices that states could be following?

SE: We have not settled on any best practices so far because the prioritization process is just one piece of the bigger picture. Just because your group is prioritized doesn't necessarily mean you can get an appointment and get a vaccine in your arm. There are a lot of steps in between and a lot of barriers that people with disabilities face. Some states have de-prioritized people with disabilities and that is not a best practice.

BS: This data gives us some insight on which states are truly including the disability community in these decisions and which aren't. If we had to make one best practice: Don't make decisions about people with disabilities without including this community in the process and the discussions.

Provided by Johns Hopkins University

Citation: Vaccination plans must include disability community's needs (2021, February 24)
retrieved 25 April 2024 from

<https://medicalxpress.com/news/2021-02-vaccination-disability.html>

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