

How the pandemic makes life harder for people with disabilities

MAR 5, 2021

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The COVID-19 pandemic has been an anxious time for just about everyone. But, for people with disabilities—especially for those in school—the stress of everyday life has been compounded.

"I've had multiple spouts of anxiety and depression from thinking if I catch COVID, will my life be deemed important enough to a doctor to save me if there's ICU and ventilator shortages?" said Irma Gomez, assistant director of the learning commons and advocate for students with disabilities at Roosevelt University in Chicago.

Students with disabilities, whose education, support and therapy are tied to an in-person school environment, "have been in the limbo phase since last March," said Gomez, who has skeletal dysplasia and uses a wheelchair.

Gomez, who is also a student at the Harvard University Graduate School of Education, made those remarks during a recent episode of the AMA "Prioritizing Equity" video series that focuses on the unique way COVID-19 has affected people with disabilities and long-term improvement strategies for ensuring equity.

More action needed

The discussion was moderated by AMA Chief Health Equity Officer Aletha Maybank, MD, MPH, who noted that there has not been enough conversation or action regarding the challenges people with disabilities are facing during the pandemic.

These challenges may include the inability to wear a mask or use communication tools, and barriers to visiting health centers for COVID-19 testing or vaccinations.

Panelist Maurice G. Sholas, MD, PhD, agreed.

"Think about it, if you are a kid with cerebral palsy, and you require a device to communicate, and a device to express yourself, and another device to move yourself around in space, how does all that get cooked down to a Zoom call?" said Dr. Sholas, a pediatric physical rehabilitation physician in New Orleans.

Students who lack the needed equipment are missing out on learning, he said. But there are future concerns as well, as many of physical therapists and other skilled professionals who used to work in schools may have moved on to other jobs during the pandemic.

"When the pandemic is over, the very people that made our school systems accessible in-person are no longer working in our school systems because they had to provide for their family," Dr. Sholas explained.

"So, it's not really just a matter of open-shut, or in school, out of school," he added. "It's really a matter of making sure there's a space and place for kids with special needs to be able to learn and making a space and place for the people that support them to stay and endure."

Dr. Sholas made a similar point recently in a letter to *JAMA Pediatrics* that he co-wrote with other pediatric physical rehabilitation specialists.

"Nobody feels empowered ... when they're an afterthought," Dr. Scholas said. "There's nothing that proves you're an afterthought [like] when there's no room for you, there's no voice for you, there's no protocol for you and it's clear that nobody even thought that you mattered."

Protecting caregivers

Some people with disabilities rely on caregivers or assistants for daily needs, noted panelist Monica Schoch-Spana, PhD, a medical anthropologist and senior scholar with the Johns Hopkins Center for Health Security. She agreed with Dr. Scholas' point regarding workforce issues.

Schoch-Spana said that nearly 5 million U.S. workers who fill these roles—many of whom receive low wages—do not have health benefits and, particularly early on in the pandemic, faced shortages of personal protective equipment. Protecting the economic security and personal health of this essential workforce is an equity issue and critical to the overall well-being of some people with disabilities, she said.



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