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Disabled people overlooked in push to end pandemic

ELISE YOUNG Bloomberg News

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Syringes with the Pfizer-BioNTech COVID-19 vaccine are placed on a tray as vaccinations are administered on the UNLV campus on Jan. 12 in Las Vegas.

ETHAN MILLER, GETTY IMAGES

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Millions of Americans with disabilities are being overlooked during the pandemic recovery, stuck at home without therapy or social programs, and struggling to book COVID-19 vaccinations.

In Connecticut, a switch March 1 to an age-based inoculation system angered advocates, who said the decision bumped special-needs residents. Disability-rights groups in Arizona are pushing for swifter access to shots, citing a higher COVID-19 death risk. Coast to coast, vaccination-booking websites that lack adaptive software are confounding people with vision problems.

“One year into the pandemic, we’re just getting around to wonder how to make vaccine sign-up universal and accessible,” Bryan Bashin, chief executive officer of San Francisco-based LightHouse for the Blind and Visually Impaired.

About 1 in 4 adult Americans, or 61 million people, have a disability that can affect mobility, cognitive function, hearing and sight, according to the U.S. Centers for Disease Control and Prevention. Thirty years after the Americans With Disabilities Act fundamentally changed how public and private entities must treat them, the pandemic is demonstrating once again how the disabled can be forgotten, advocates say.

In New Jersey, 29-year-old Evan Hookey of Princeton, who has autism, scored the first of two vaccine shots Feb. 21. His mother, Gina, said that after more than a year at home, he was so excited to be around people again that “you might have thought he was going to a birthday party.”

It’s not certain when Hookey will return to his job, stacking inventory at a Wawa convenience store, or his day program, where he exercises, socializes and does meal prep and art projects. Gov. Phil Murphy’s administration is allowing some of the state’s 400 such programs to reopen with 50% capacity and other restrictions on March 29.

In Wilbraham, Massachusetts, Brad Kane and his wife have gone more than a year without home therapy for four children with autism, ages 7 to 13. Each had been getting two to four hours of attention a day, five days a week. When the pandemic hit, the sessions ended with no sign of when they’ll restart. Some of the children have regressed.

“It’s harder to get them to do the things they need to do, like speech and emotional development,” said Kane, an editor. “Even getting everyone to sleep at the same time is an uphill battle.”

In February, Kaiser Health News and WebAIM, a nonprofit group that works on internet accessibility from Utah State University, identified almost 100 government vaccination websites lacking screen-reading technology for people with difficulty seeing. The count may be far higher because even some sites with the software can link to others without, according to the National Federation of the Blind, a Baltimore group that advocates for more than 7 million Americans with a visual disability.

“I should have the same options that anyone else has,” said Chris Danielson, federation spokesman. “Booking a shot is frustrating for everybody, with most people trying several times. We’re not asking for special treatment — we just want the same barriers, not more.”

In some places, advocates have gone to court in search of equal access.

The Idaho legislature on March 5 entered into a legal agreement to ensure that people with disabilities can testify before committees remotely. It resolved a federal lawsuit brought in January by five disability-rights groups that said in-person appearances put them at risk for the novel coronavirus.

A federal lawsuit by the Arc Maryland, claiming unequal access to COVID-19 vaccines, led several county governments in March to alter their websites to note that people with intellectual and development disabilities are eligible for the shots.

Edwin Singer, president of the Maryland Association of County Health Officers, said no one had set out to discriminate. “We had been taking names and putting people on the list and registering them since the state came out in January and said we could vaccinate people with disabilities,” said Singer, the health officer for Carroll County.

Elsewhere, local governments are making strides with their own outreach. Firefighters in Corpus Christi, Texas, administer as many as 100 shots a day going door to door to seniors and people with disabilities. Some New Jersey vaccination sites have streamlined check-in and designated areas to limit light, noise and crowds. Orange County, California, is channeling special-needs individuals to Anaheim for drive-up vaccinations in a Disneyland parking lot.

“It does take a little more staffing to take care of people in their cars, and it’s a little harder to make certain they’re not having a reaction,” Doug Chaffee, a county supervisor. But it’s more convenient for people with physical limitations and parents whose autistic children may object to masking or long waits, he said.

While some states, including Alabama and Washington, have recently expanded vaccine appointments to those with special needs, others don’t give them priority access. Disability Rights Connecticut on Feb. 24 filed a civil-rights complaint claiming discrimination after Governor Ned Lamont set vaccine eligibility by age. The CDC recommends a risk-based approach.

“It’s infuriating — people think that with the Americans With Disabilities Act, all disability-related issues have been magically fixed, but it’s not the case,” said Sey In, an attorney for the Arizona Center for Disability Law, which is trying to bump up appointments. He cited Thomas Jefferson University research showing that people with intellectual disabilities are almost six times more likely to die of COVID-19 than people without such a condition.