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U.S.

Covid-19 Is Deadlier for People With Autism, Down Syndrome. Now Families Are Pushing Hard for Vaccines.

People with intellectual development disorders are more than twice as likely to die once infected by Covid-19, a WSJ study finds

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A higher Covid-19 death rate among people with autism, Down syndrome and other intellectual development disorders has sparked a lobbying effort by family members and caregivers to persuade states to give priority to the group in vaccine rollouts.

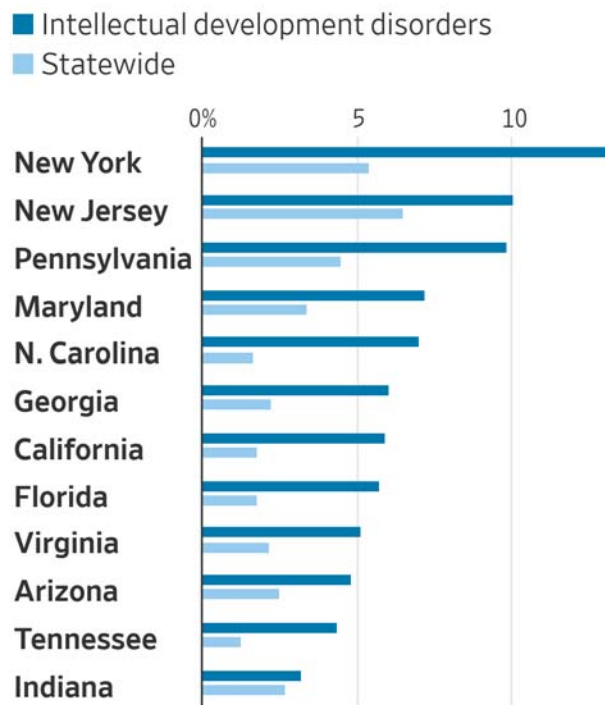
People with such disorders, who account for one in 50 Americans, are on average more than twice as likely to die from Covid-19 as the wider U.S. population, according to a Wall Street Journal analysis of data from 12 states. The analysis mirrors similar, recent studies. One study, conducted by nonprofit organization FAIR Health, found the group's death rate is higher than many others already widely recognized as particularly vulnerable to the disease.

The higher rate is because many people with these disorders suffer from conditions such as respiratory and heart disease, which are known to contribute to lower rates of survival

from Covid-19, medical experts say.

Family members and caregivers are concerned that the vulnerable won't be prioritized for vaccines despite the high death rates. They say people with these conditions have been consistently ignored by officials throughout the pandemic and the disorders are little understood even by medical professionals, making diagnoses and treatments more difficult.

Percentage of Covid-19 cases resulting in death for people with intellectual disabilities compared with the general statewide population



Note: Statewide mortality rates are cumulative through mid-October. Cases reflect a positive Covid-19 test result.

Source: the states

“They have been an afterthought,” said Margaret Puddington, whose 40-year-old son has Cornelia de Lange syndrome, a rare disorder, and who earlier this month appeared before a panel of the New York City Council Committee on Health to argue for people with intellectual development disorders to be among the first to receive a vaccine.

“My fear is that the people who get it tend to get very sick and pass away at alarming rates,” said Ms. Puddington, who is 72.

New York state is currently providing vaccines just to high-risk hospital workers, nursing-home residents and staff, followed by those in congregate care, or 24-hour care. Other states have prioritized nursing homes ahead of other care facilities.

Some congregate care facilities accommodate people with intellectual development disorders, but the large majority of people with such disorders live in more informal facilities or family homes, said Kristyn Roth, an executive at the Autism Society of America, a nonprofit that has been lobbying the Centers for Disease Control and Prevention and others for priority for vaccines.

So far, states are mainly following guidelines from the CDC, which has prioritized medical professionals and people in long-term care facilities for vaccinations. If vaccine supplies run short, the CDC recommends making some facilities for people with intellectual development disorders a secondary priority. The CDC declined to comment.

Tennessee has been an outlier, specifically making its entire intellectual development disorder population a priority, citing its own studies that the death rate for this group is 3½ times higher, according to a state official.

Grahame Morgan, a caregiver in a home for people with intellectual development disorders run by nonprofit YAI in Medford, N.Y., said five out of eight residents at the facility died in the early months of the pandemic.



Grahame Morgan, a coordinator at YAI, said the pandemic had a devastating effect on the residents of the Medford facility.

PHOTO: GABRIELA BHASKAR FOR THE WALL STREET JOURNAL

“It just was shocking that it just got in so quickly, and got through the house so quickly and with such devastation,” Mr. Morgan said.

A YAI spokesman said the company quickly implemented aggressive safety protocols, stockpiled protective equipment and pulse oximeters, and doubled-down on education for staff once it recognized the outsize vulnerability of its clients.

Family members, caregivers and doctors say the devastating effects of the virus on people with intellectual development disorders aren't well understood.

In July, a group of doctors and researchers put together guidelines to help medical staff better assist people with these disabilities in the pandemic, after becoming alarmed by the high death rates and the lack of guidelines.

“There are a lot of suspicions about what is creating the higher death toll, but not a lot of numbers,” said Emily Johnson, a doctor who helped lead that group at the American Academy of Developmental Medicine & Dentistry, an organization for professionals who specialize in working with people with intellectual development disorders. “This absolutely needs to be studied.”

Across the 12 states for which the Journal analyzed comparable data, the mean death rate of people with these disabilities infected with the virus was 7.02% as of mid-October, compared with a mean death rate of 3.18% for the general population in the 12 states.

Of the 50 states, plus Washington, D.C., and Puerto Rico, that the Journal approached, 29 don't collect such data or declined to comment. The Journal left out states with too small a sample to be statistically relevant, as well as those that included dementia or severe brain trauma in their numbers or just had data on people with these disabilities in residential-care homes.

In North Carolina, a person with one of these disabilities is more than four times more likely to die from Covid-19 than somebody from the state's wider population. The death rate for these people was 7%, compared with 1.65% among the general population. In New York, 13% of people with an intellectual development disorder infected with Covid-19 died, the highest rate among the 12 states whose data was analyzed by the Journal, compared with 5.4% in the states' wider population of infected people.

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Should people with intellectual development disorders be prioritized to receive the vaccine? Join the conversation below.

Across states, people with such disabilities are likely dying at a greater rate than the wider population because they suffer higher incidences of obesity, immune disorders, respiratory illnesses and other conditions that have led to higher death rates during the pandemic, health experts say. Even without the virus, this community's death rate is typically higher than the general population in any year, due to these and other health issues, as well as high suicide rates for people with autism.

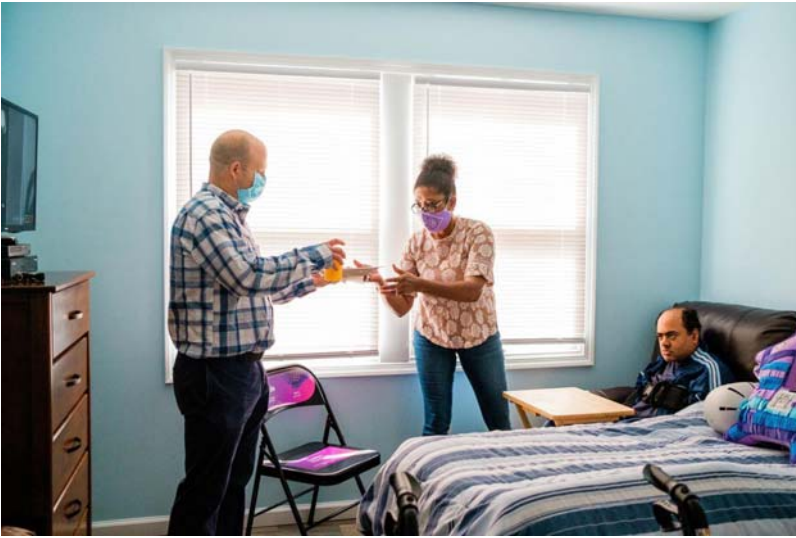
But Covid-19 has added another layer of fatalities.

According to an analysis of claims data for privately insured patients conducted by FAIR Health, people with intellectual development disorders died at a higher rate than those with conditions well known to contribute to higher Covid-19 death rates, such as leukemia, Alzheimer's disease and heart disease.

A separate October study of data from eight U.S. states by researchers at Syracuse University, Temple University and elsewhere found that 12.3% of adults with these disabilities died from Covid-19 infection, compared with 6.7% of the general public in these states.

Scott D. Landes, who has studied the effects of Covid-19 on people with disabilities at Syracuse, said he and other researchers want to determine how much the higher death rate is related to the difficulties some people with intellectual development disorders have communicating with medical professionals.

“Historically, this is a population that has not achieved as good a care and is not as well understood by the medical community,” he said.



The Medford home quickly implemented aggressive safety protocols in response to the pandemic.

PHOTO: GABRIELA BHASKAR FOR THE WALL STREET JOURNAL

One of the virus's victims from the Medford home was Stuart Darch, a 72-year-old autistic man who suffered from anxiety and had difficulty communicating, Mr. Morgan said. He was taken to Long Island Community Hospital in late March. A nurse told his niece, Alexandra Noyes, that he was agitated and had shallow breathing.

Previously, he would have been accompanied by a caregiver such as Mr. Morgan, but the virus forced hospitals to place restrictions on such visitors.

Long Island Community Hospital declined to comment on Mr. Darch's case but said such restrictions, used across New York state, were necessary to control the spread of the virus to other patients and staff.

"I said, he doesn't understand what is going on." Ms. Noyes said. "To him, surrounded by strangers wearing masks and protective gear, it's like he has been abducted by aliens or something."

Around two weeks into his hospital stay, Mr. Darch died.

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