

STATE

Disability community wants more from Trenton, commemorates COVID deaths



Gene Myers

NorthJersey.com

Published 4:15 a.m. ET Sept. 20, 2022 | Updated 3:39 p.m. ET Sept. 20, 2022

The disability community and its advocates met in Trenton on Monday to commemorate people with disabilities who died of complications from COVID.

A small group of people commiserated outside the Statehouse.

“We lost a lot of people,” said Javier Robles, a Rutgers University professor and organizer of the event. “If we had some better precautions in place, a lot of them would still be here today. We have to change a lot of our thinking around people with disabilities.”

Over 200,000 residents and staff members in long-term care facilities in the U.S. have died from COVID-19, according to the Kaiser Family Foundation, a nonprofit organization that focuses on national health issues. That’s a low estimate, Robles said, because disability stats aren’t reliably collected.

One speaker for whom the loss was all too real was Regina Costantino Discenza, who lost both of her parents during the pandemic. Both were residents of the Menlo Park Veterans Memorial Home.

For subscribers: After a million deaths, COVID testing remains broken. These secret systems hide the fix

“My father passed away about 30 days after the families were locked out,” she told the crowd, referring to their isolation. “I knew my parents weren’t going to survive without my visits. They were disabled with dementia.”

Both were diagnosed with COVID-19. Although her mom survived COVID, she died six months after her husband.

Paul Aronsohn, the state ombudsman for individuals with intellectual or developmental disabilities and their families, called the ceremony “an important event.”

“Professionally as well as personally I have witnessed the disproportionate and sometimes devastating impact COVID has had on people with disabilities,” Aronsohn said. “This includes my brother, Robert Zuckerman, whose disabilities landed him in a Florida nursing home, where he contracted the deadly virus this past summer and died from it only days later.”

Aronsohn’s 2020 report to Gov. Phil Murphy stated “the pandemic has exposed and deepened the fault lines in our state’s system of care for people with disabilities.”

Now, as a chill returns to the air, the community wants leaders to make changes to the emergency response apparatus that failed them, before winter sets in and another variant or public emergency hits.

The New Jersey Disability Action Committee (DAC), New Jersey Statewide Independent Living Council, Alliance Center for Independence, New Jersey Disability Collective, New Jersey Council on Developmental Disabilities and Latino Action Network were in attendance.

They took turns at the podium remembering injustices, loved ones and colleagues lost. First, people with disabilities were left out of emergency planning in the pandemic’s first wave. Then came the scramble for protective gear as the state advised the community that it was on its own. Disability advocates warned of discriminatory care practices in hospitals while state policymakers failed to recognize who was most vulnerable in the health emergency. Millions were vaccinated ahead of the relatively small group of about 9,000 people living in homes overseen by the state.

Robles, who spearheaded the DAC, which published a scathing report in 2020 that outlined the ways in which the state failed to protect its disabled residents, said if there was one underlying theme in all of these problems it was that leaders didn’t understand people with disabilities, their needs or how they live their lives, Robles said.

High-tech hats, remapped buttons: Gaming got more accessible to those with disabilities

Representatives of the community “should be at the table” when planning for emergencies, he said.

Last year, the DAC called for establishing four full-time positions at the state Office of Emergency Management devoted to the needs of people with disabilities in emergencies and disasters. The bill has been reintroduced in the state Legislature this year.

Gene Myers covers disability and mental health for NorthJersey.com and the USA TODAY Network. For unlimited access to the most important news from your local community, please subscribe or activate your digital account today.

Email: myers@northjersey.com

Twitter: [@myersgene](https://twitter.com/myersgene)