

# Advocates for disabled offer fix for poor pandemic response

Gene Myers

NorthJersey.com

USA TODAY NETWORK - NEW JERSEY

Leaders in the disability community who condemned the state's COVID-19 response in a recent report said one fix is obvious to anyone with a disability and it's shocking that it wasn't to others.

Expand the office of the New Jersey "Ombudsman for Individuals with Intellectual or Developmental Disabilities and Their Families" to the "Office of the Ombudsman for People with Disabilities and Their Families," and fewer people in need will fall between the cracks, posited the report, which outlined 23 ways the state failed to protect the disabled community during the pandemic.

"If we are going to say that we are going to protect some people with disabilities, then we should protect all people with disabilities," said Javier Robles, chair of the New Jersey Disabilities COVID-19 Action Committee (DAC).

The DAC wants the existing state ombudsman office to expand its role. Change the name of the relatively new and tiny office so the man who runs it can advocate for everyone with a disability. After all, the devil is in the details, Robles said.

People with disabilities were left aside, and outside of the planning process, because of a lack of understanding of the community, how they live and the help they needed, the report stated.

The report was compiled by the DAC, which consists of people with disabilities, their families, advocates and institutions including the Center for Disability Sports, Health and Wellness at Rutgers University, the New Jersey State Independent Living Council and the New Jersey Council on Developmental Disabilities.

"More than ever, this pandemic has focused a spotlight on the marginalization of the voices, needs, and rights of people with disabilities," the report stated, adding that rights "have been abrogated" and voices "silenced."

## The ombudsman

Paul Aronsohn, a former Ridgewood mayor, is the first disability ombudsman for New Jersey. He spends most of his time zig-zagging across the state. He drove 36,000 miles in 2019 to meet with some of the same people DAC said have



Paul Aronsohn, a former Ridgewood mayor, is the first disability ombudsman for New Jersey. CHRIS PEDOTA, NORTHJERSEY.COM-USA TODAY NETWORK

been long ignored. Many times they are upset: They can't get in touch with case managers making decisions about their care, parents are concerned about the homes their children with autism live in — the problems he fields are varied and many.

Aronsohn points them to people who can help and programs available to them, and he listens to their problems. He logs what he finds and brings the stories back to Trenton, where they are discussed with legislators. He compiles each year's troubleshooting into reports he submits to the governor, lawmakers, the commissioner of human services and the commissioner of children and families.

"Advocacy" is how Aronsohn describes what he does.

By removing the qualifiers and changing the office of the ombudsman, more individuals would disabilities will have a champion in their corner.

The CDC defines developmental disabilities as "a group of conditions due to an impairment in physical, learning, language, or behavior areas. These conditions begin during the developmental period, may impact day-to-day functioning, and usually last throughout a person's lifetime."

By this definition, anyone disabled as an adult, or anyone with singular disabilities, such as vision and hearing loss, limited mobility or a host of other diagnoses,

including multiple sclerosis, falls outside the ombudsman's purview.

It's a distinction that might have been missed when the position was created, said Democratic Assemblywoman Valerie Vainieri Huttle of Englewood, who helped to draft the bill that created the ombudsman's office.

"In developing that legislation for developmental disabilities and intellectual disabilities, I would think that the other disabilities would fall under that," Huttle said. "We assumed that everything should be included. We did not intentionally disregard anybody. It was to be inclusive."

The office was signed into law by Gov. Chris Christie in 2018 and filled when Gov. Phil Murphy appointed Aronsohn later that year. The position is unique, Aronsohn said, in its independence. He reports only to the governor, a fact that allows him to move more easily between state departments.

## The state's COVID response

Many of the issues the DAC found in the way the state handled the needs of its disabled residents were made worse by siloed responsibilities and a patchwork of services and programs that are hard to find and harder still to understand, advocates said.

A myriad of programs have been de-

signed for citizens with disabilities. Some focus on jobs or public safety, others on housing or transportation; a person with a disability can often rely on more than one program. But navigating the departments that house the programs is daunting.

Both the ombudsman's 2019 report and the DAC's report released this fall pegged this scattershot approach as a contributing factor that caused people in need to get lost in the shuffle. This and a lack of understanding of who makes up the state's disability community are some of the reasons the state fell short of serving an estimated 24% of its residents said the DAC report.

When it came to the distribution of personal protective gear, better pay for workers who had to put themselves on the line taking care of "medically fragile" people with the most severe disabilities hospital rights and disseminating critical information, many needs went unmet this year, advocates said.

For lawmakers, it's been a year of learning, said Huttle and Democratic Assemblywoman Joann Downey, who also sponsored the bill that created the ombudsman's office.

"This unfortunate pandemic and emergency has exposed many cracks in the systems of care to our disability community," Huttle said.

## The future

The cracks painstakingly illustrated in the DAC's report, which outlined 23 ways the state failed to protect residents at high risk during the crisis, have shined a light that has stopped lawmakers in their tracks, said Republican Sen. Thomas H. Kean Jr.

"It is clear that the disability community doesn't have the responsiveness from government that they should have," he said. "I am 100% in favor of expanding the ombudsman's office."

So are Huttle and Downey, who independently have begun to look into crafting new legislation, following the advice of the DAC, to bring other disabilities under the umbrella of the ombudsman's office.

"We just need to make sure the priorities are being heard and being addressed

See PANDEMIC, Page 5A

## Pandemic

Continued from Page 4A

through the ombudsman," Huttle said. "We are currently looking into this idea, and we hope to draft legislation to expand the scope of the ombudsman's office, and we are also looking into additional ways to provide support."

Although Huttle said it was "unrealistic to have it voted upon by the end of the year," she is hoping to have a bill introduced by the end of the year with a vote early next year.

It's a role Aronsohn is not only willing to take on, but unofficially is already doing, because "the line between intellectual disability and developmental disability and the rest of the disability world seems arbitrary," he said.

"I have a lot of folks that contact us and they don't fall into the bucket, if you will," he said. "I always tell them, 'You are a little bit out of the lane,' but we still help them, because they need services, too."

Kean, who said he expects his colleagues in the Senate to be receptive to the idea, said he has fielded many calls from constituents through the years that back up the experiences documented in the DAC's report.

"When you look at the fissures and the gaps in the safety nets that have been exposed by the pandemic, I think it's incredibly important that we expand the scope of the ombudsman's office and bring more families under the oversight and protection of that office," Kean said.

Kean, Huttle and Downey all praised Aronsohn's work thus far.

"He's an amazing soundboard and action creator," Downey said. "I think it would be great to expand his role, change it so that he is ombudsman to all disabilities. But I think we have to be thorough and start looking into this and how we would that get done. It's only him and one other person right now. To do this he would absolutely need more assistance and a bigger office in terms of people working with him. He would need a bigger budget, too."

*Email: [myers@northjersey.com](mailto:myers@northjersey.com)*

*Twitter: @myersgene*