

HEALTH

Here's why NJ's first disability watchdog has hope despite scandals



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For eight years, Paul Aronsohn served as New Jersey's first ombudsman for people with developmental disabilities. He built the office from scratch, took calls at all hours, drove thousands of miles to meet families in crisis and often found himself at odds with his colleagues in state government.

Now, with the end of Gov. Phil Murphy's administration, Aronsohn, a former Ridgewood mayor, is leaving a job that motivated him and kept him on his toes.

The work was "heartbreaking and infuriating, yes, but definitely the most meaningful work I've ever done," Aronsohn, 59, said recently, days after his tenure came to an end.

New Jersey's disability ombudsman, a watchdog office designed to be a resource for families when disability services fail, has become a [national model](#) under Aronsohn's watch. U.S. Rep. Tom Kean Jr. has introduced a bill in Congress to create a federal version of the office.

An estimated one in four U.S. adults — about [70 million people](#) — reported having a disability in 2022, according to the U.S. Centers for Disease Control and Prevention.

Aronsohn came to the job with a tragic, personal view of how the system can leave people with disabilities behind. He also arrived with a long résumé in government that included stints with some of the most recognizable names in American politics. But the work that made him proudest wasn't on the world stage; it took place in living rooms, in group homes and on the streets of New Jersey.

His stakes are personal in disability fight

Aronsohn grew up in Fort Lee and attended George Washington University, earning undergraduate and graduate degrees in international affairs before taking a job with Bill Clinton's 1992 presidential campaign.

Aronsohn helped with opposition research and worked with famed Democratic campaign strategist James Carville. After Clinton won, Aronsohn moved into foreign policy, spending eight years at the State Department supporting U.S. ambassadors to the United Nations.

He was an adviser to Ambassador Madeleine Albright, supporting her efforts to ease the threat of land mines around the globe. When Clinton's vice-president, Al Gore, lost his presidential bid in 2000, Aronsohn headed back home to New Jersey.

Long before he became ombudsman, disability was personal for Aronsohn. His older sister Patti was diagnosed at age 25 with [spinocerebellar ataxia](#), a degenerative brain condition that steadily robbed her of the ability to walk, eat or speak on her own. By 45, she was nonverbal, quadriplegic and dependent on a feeding tube.

His brother, Robert "Bob" Zuckerman, a photographer prominent in the film industry, suffered from a rare genetic disease that put him in a wheelchair in his 50s. By his 60s, he was living in a Florida nursing home, where he eventually contracted COVID-19. He died at 67 in 2022, five years to the day after Patti..

It wasn't until 2006, however, that Aronsohn, then running for Congress, decided to talk publicly about his siblings' struggles. He wasn't sure if voters would relate to disability issues

until he was encouraged by Marcie Roth, a national disability advocate and family friend.

“I remember her physically grabbing me and saying, ‘Not only can you talk about disability, you have to talk about disability. The community doesn’t have enough champions out there.’” Aronsohn recalled. “From that moment on, I haven’t stopped talking about disability.”

Building access in Ridgewood

Aronsohn lost that race, but he won a Ridgewood council seat in 2008 and began putting his commitment to disability rights into action. He created a local “Access for All” committee, meant both to find disability barriers in town and to serve as a resource for families. It spotted problems no had noticed before in a society not primed to think about accessibility.

“For instance, there was an accessible spot, but there was no curb cut,” Aronsohn said. “A person had to go roll in the middle of the street down to the end of the block” to reach the parking.

He was finishing his time as mayor of Ridgewood in 2016 when he wrote an op-ed arguing that New Jersey needed a disability ombudsman to help navigate the state’s maze of services. He sent the piece to Phil Murphy, who was then running for governor in a Democratic primary. Murphy called him almost immediately.

“I want to learn more,” Aronsohn recalled Murphy saying. Aronsohn became an informal adviser, drafting language on disability for Murphy’s platform. When Murphy won and the Legislature passed a bill introduced by Kean, then a state assemblyman, to create an ombudsman, the call came back to Ridgewood. In April 2018, Aronsohn was appointed to the office, a blank slate he would need to fill in.

“It was just brand-new. None of us knew what to do at the moment,” he said.

148,000 miles across New Jersey

Aronsohn said his approach was "very personal," built around responsiveness. He wanted to be a salve for people struggling with New Jersey's bureaucracy.

That meant phone calls and availability beyond business hours. He put 148,000 miles on his state-issued Dodge SUV, driving to over 145 towns up and down the state to talk one-on-one with people struggling with unresponsive state agencies, insurers or medical providers. It was well beyond a 9-to-5 job, Aronsohn said.

He also produced a series of annual, [often-scathing reports](#) about public and private disability programs, where billions in spending routinely failed to meet the community's needs. The reports were meant to "[sound an alarm](#)" about abuse in group homes, a lack of proper autism care, [labor shortages](#) and other critical problems, he said.

The Murphy administration pumped billions of dollars into the system and oversaw wage increases for direct support professionals who staff group homes and other programs. But severe problems persist, advocates say. As documented by The Record and NorthJersey.com in investigations last year, group homes often operate with impunity, with poorly trained staff and [little accountability for resident deaths](#). Disability groups also say the state has allowed private insurers to [take over the Medicaid program](#), leading to increasing denials of health care services.

More: [NJ has a huge health care gap for people with disabilities. Dig into our series](#)

In January, the state Assembly honored Aronsohn, praising his efforts to create "a more just and equitable society replete with opportunity for all."

Advice for Sherrill

Gov. Mikie Sherrill has not yet named a new ombudsman, but Aronsohn has left a final report as a road map for the incoming administration, urging officials to chart an

"expansive" future for his office.

"The office's scope should be broadened," he said and "be more independent."

If the next ombudsman does not have the personal experience he brought, he said, then they must "hire deputies that do. Make sure most of your staff has lived experience."

Aronsohn is optimistic that the next administration could mark a turning point for New Jersey's disability community if it follows through on promises of transparency and accountability, as he outlined in a [January op-ed](#) for The Record and NorthJersey.com.

People with personal disability experience should be placed in senior government roles in Trenton, and disability policy needs to be coordinated across agencies rather than siloed, he counseled. Aronsohn suggested creating a state Department of Disability Services and called for greater public visibility into how decisions are made and taxpayer dollars are spent.

Stronger oversight, including penalties for group home providers and managed care organizations, could make the system more effective and humane, he added.

An emotional toll

Aronsohn said he has no plans for his next act yet. He offered some advice for his replacement, whoever that may be: The work takes an emotional toll, he said. Look for ways to stay grounded.

"I walk," he said. "Anytime you feel just a little overwhelmed emotionally, take time. Go breathe. Go for a walk."

He described the job in almost spiritual terms. The ombudsman gets invited into people's lives at their most vulnerable moments.

"People often thank us for the work we do, and I appreciate that. But I'm grateful to them. It's a real blessing to be invited in," he said. "It doesn't get better than that. It really doesn't."

Correction: A prior version of this story mistakenly said that Paul Aronsohn worked for Al Gore's presidential campaign. It also incorrectly described the cause of his brother's disability. It was due to a genetic disorder, not a COVID infection.