

# Fighting for disability rights should be bipartisan

BY BRYAN DOOLEY

Guest columnist

In the mid-1800s, the famous social reformer Dorothea Dix described living conditions in one of our country's earliest asylums: "More than nine-thousand idiots, epileptics, and insane in these United States, destitute of appropriate care and protection. Bound with galling chains, bowed beneath fetters and heavy iron balls, attached to drag-chains, lacerated with ropes, scourged with rods, and terrified beneath storms of profane execrations and cruel blows; now subject to jibes, and scorn, and torturing tricks, now abandoned to the most loathsome necessities or subject to the vilest and most outrageous violations."

More than 100 years after Dorothea Dix's observation — and 45 years ago this January — reporter Geraldo Rivera found similar horrifying conditions at a place called Willowbrook.

The Willowbrook State School in Staten Island, N.Y., was one of the largest institutions in the world housing people with all types of disabilities. As many as 6,000 people with disabilities lived there at one time.

The conditions in this facility were well below those in regular prisons of the time. It was overcrowded and very much understaffed. Less than 20 percent of the patients received an actual education. The place was often permeated with the stench of urine, feces and infection.

One of my favorite axioms from college journalism is, "Sunlight is a great disinfectant." This means if you bring public attention to a problem, it often improves the situation because of mounting pressure. That's what happened with Willowbrook and the entire system serving people with disabilities.

One brave doctor who had been recently fired from Willowbrook for encouraging the families to demand better conditions for their loved ones reached out to the local ABC affiliate. Rivera, then a young reporter, took the story. He produced a series of investigative exposés about the conditions of the facility, which aired in January 1972. The images shocked the citizens of New York and the nation.

Congress responded by creating the Protection and Advocacy (P&A) System in

1975. P&As — as the agencies that make up the system are called — exist to protect the civil rights of those with disabilities.

They also have a sweeping power to advocate for people with every type of disability whose rights have been violated.

Every U.S. state and territory has a P&A, although they go by different names. North Carolina's P&A is Disability Rights North Carolina, a nonprofit organization that will celebrate its 10th anniversary this year. The staff changes lives every day for the better.

Not that long ago, I would have been considered a good candidate for an institutional placement. I have a disability that affects my ability to communicate and necessitates that I use a power chair to get around. For generations, that would have meant being locked away somewhere. Disability Rights North Carolina works to keep people like me out of institutions and in the community instead. To remain active in my community, I need services provided by the state through a Medicaid-funded program called the Innovations Waiver.

Recently, the state of North Carolina tried to implement a new policy that would have indirectly reduced services for people who received the Innovations Waiver. Disability Rights NC sued and eventually reached a settlement with the state that expands protections for waiver recipients.

Thanks to the settlement, people like me are empowered to request the services they need, in the amount they need them — without arbitrary limits. We now have stronger due process rights, so if our services are cut, we have the right and the opportunity to fight back.

Although we have made progress, Disability Rights NC must keep fighting against unnecessary institutionalizations and for the rights and independence of people with disabilities. For example, the organization recently worked with the N.C. Council on Developmental Disabilities to find individuals with developmental disabilities who are in adult-care homes and want to move into community settings and they are facilitating those moves.

P&As have been working for four decades under Democratic and Republican administrations. Much of their funding comes from the federal government. As



the new administration takes the reins,  
it's vital to the disability community that  
P&A funding is protected.

Disability is a bipartisan issue. We  
all need to remember that as we move  
forward.

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