

Buffalo News, November 13, 2023

Another Voice | Health care

Another Voice: Those with disabilities can live independently as long as there is a support system

Max Donatelli

Nov 13, 2023

On a trip to Albany recently for the Developmental Disabilities Planning Council Advocacy Institute, I had the opportunity to watch the documentary "The Path **Forward: Looking Back at Willowbrook**" with fellow advocates. As a parent of a young man, Craig, with Down syndrome, I can't tell you the emotions I felt watching this film.

It reflected on the so-year-ago point when Geraldo Rivera exposed the horrendous conditions at the Willowbrook State School in Staten Island. The school that became a residential program for children and adults with intellectual and developmental disabilities had been built to house 4,000 residents but reached its peak of 6,200; and because of underfunding of staff, food and the basic necessities, its conditions were horrific. These people were hidden away from their loved ones and the general public.

It was the largest institution for people with developmental disabilities in the U.S. Families back then had been encouraged by the medical community to place their loved ones there because they were told they would get the help they needed, that they couldn't get in their own communities. Unfortunately, it became, out of sight: out of mind, for many families and communities.

In 1972, thanks to staff, parents, resident Bernard Carabello, Geraldo Rivera, and writer Jane Kurtin, Willowbrook's inhumane conditions were exposed. This documentary tells the story of how the conditions worsened to the point that the facility was referred to as a "snake pit."

As a parent and family advocate, this film was disturbing, but fortunately our son Craig and so many others are now living in their communities with support staff assisting them. Some people still require certified group living so may not be in their communities where their families live. Support staff is critical for many people with developmental disabilities; some need 24/7 care, while others may help with things like budgeting and getting out in the community.

Underfunding for the salaries of these direct support professionals remains a major concern, as my wife, Joyce, and I have written about before. This is still a significant issue that needs immediate attention given the workforce crisis. This documentary tells a story that I believe will shock you when you watch it. We pray that our elected officials will watch it and recognize that more needs to be done to improve our current system. Direct support professionals need to be paid more so we don't go backward.