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February 6, 2023

The Honorable Kathy Hochul  
Executive Chamber  
State Capitol  
Albany, NY 12224

Dear Governor Hochul,

I write to you as the CEO of The Arc New York, the state's largest non-profit provider of services for people with intellectual and developmental disabilities (I/DD).

In your remarks during a recent press conference in the Bronx, you reflected on the past institutionalization of New York's most vulnerable citizens. You spoke specifically of the West Seneca Developmental Center near Buffalo, where thousands of New Yorkers were institutionalized. You spoke of two young people – Roger and Melanie – who your parents helped support in their transition from the Developmental Center to community living. And you spoke warmly of your own memories taking Roger and Melanie shopping, helping them learn the skills of daily living and share the ordinary experiences of life.

The focus of your press conference was to share the critical \$1 billion, multi-year investment in mental health resources included within your recently announced Executive Budget.

It is clear your personal experience with Roger and Melanie deeply influenced the policies you're implementing and the investments you're making to correct a mental health care system that has suffered from chronic underinvestment.

What may not be clear – to you, and to many New Yorkers – is that most of the residents of the West Seneca Developmental Center were not people with mental health concerns, but people with intellectual and developmental disabilities.

The West Seneca Developmental Center was one in a network of "State Schools," built to house New Yorkers with I/DD. At its height, 1,710 people were warehoused at West Seneca alone. The institutional abuses revealed

at Willowbrook State School triggered the eventual closure of all the state's Developmental Centers, including West Seneca. Advocates for humane treatment of people with disabilities – including the families of The Arc New York – established the system of integrated community supports that we provide today.

Our system of essential supports and services for New Yorkers with I/DD has suffered from the same chronic underinvestment you are seeking to correct for our Mental Health system. Yet the proposed budget does not correct the state's lack of investment in our I/DD service system. It continues it.

In the Bronx you said, "I don't know how many Melanies and Rogers were out there."

We know.

There are 140,000 citizens with I/DD in need of the state's support today. And there are 100,000 direct support professionals (DSPs) – overwhelmingly female and people of color – who are similarly sidelined and forgotten in their work to deliver essential care.

One of our long-term board members, Judy O'Rourke, is the chair of our West Seneca D.C. Chapter. Her daughter, Katie, was a resident of West Seneca Developmental Center. People like Katie, and others we serve with developmental disabilities, are often referred to as the forgotten.

We believe you are working to build a New York that invests in the needs of people like Roger and Melanie and Katie. Your experience has given you insight into the needs of New York's mental healthcare system, and you are fighting to realize them.

We would like to take this opportunity to offer you a meeting with Ms. O'Rourke and other stakeholders who have direct experience with the former developmental centers in service of their loved ones. Their experience offers similar insight into the needs of New Yorkers with intellectual and developmental disabilities, and the actions New York must take to ensure they aren't forgotten.

We look forward to hearing from you.

Sincerely,



Cc: Kerri Neifeld, Commissioner of the Office for People with Developmental Disabilities  
Jihoon Kim, Deputy Secretary for Human Services & Mental Hygiene  
Kim Hill, Chief Disability Officer  
Senator John Mannion, Senate Disabilities Committee Chair  
Assemblymember Rebecca Seawright, Assembly People with Disabilities Committee Chair