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December 8, 2020

Honorable Andrew M. Cuomo
Governor of New York State
NYS State Capitol Building
Albany, NY 12224

Dear Governor Cuomo,

New York state prides itself on a decisive and effective response to the COVID-19 public health crisis. As we partner to develop a thoughtful vaccination program to combat this pandemic and ensure the safety of our most vulnerable and high-risk citizens, New Yorkers with intellectual and developmental disabilities must not be forgotten.

I speak as the President of The Arc New York, the largest non-profit provider of services for people with intellectual and developmental disabilities in the state. I speak as a parent who knows the pain of losing a child with I/DD. I speak on behalf of my daughter, the 60,000 individuals supported by The Arc New York, and 140,000 New Yorkers with I/DD – each of whom the state has made a commitment to protect.

Individuals with I/DD are at disproportionately high risk of contracting and dying from COVID-19. It is essential that they be prioritized in an equitable plan for the distribution of the COVID-19 vaccine.

New York's pandemic response has been consistently strengthened by a focus on facts. To support this data-driven response, The Arc New York is collaborating with New York Disability Advocates (NYDA) and Syracuse University on an ongoing project to collect and analyze COVID-19 data from voluntary I/DD providers to inform our understanding of the risks of COVID-19 for people with I/DD, strengthen our pandemic response, and support our advocacy efforts.

A study from the Lerner Institute analyzing that data found that individuals with I/DD supported in residential settings were nearly four times as likely to contract COVID-19, and two times as likely to die from the infection than the general population of New York.

Individuals in group homes are at the highest risk, in part due to the congregate care settings of our residential service system. When there is a case of COVID in one of our homes, with shared bedrooms, bathrooms and common areas, it is incredibly challenging to limit the spread within the home. Our experience echoes the crisis of nursing homes early in the pandemic. A crisis that must not be repeated.

In our residential programs, staff provide 24-hour support, often including feeding, bathing, toileting, medication administration, and other close-contact care. The individuals we support often have comorbidities, may be non-ambulatory, non-verbal, have seizure disorders, behavior problems, mental illness, visual or hearing impairments, or a combination of the above. All qualify for Medicaid assistance, and receive medical and nursing care through our services.

These vulnerable New Yorkers are our families. Our loved ones. They are nearly four times more likely to contract COVID-19. Two times as likely to die.

Cases are surging. Across the state, entire residential homes for people with I/DD are under quarantine. Staff report 24-7 to care for the people they support in COVID-positive homes, despite the extreme risk to themselves and their families. These front-line workers deserve the same respect as New York's hospital staff, and the same commitment to their safety.

Yet to date, providers of services to individuals with I/DD have not been included on priority lists for securing personal protective equipment. We are no longer being reimbursed for PPE to run our programs safely in the COVID environment. Federal emergency funding has been withheld from our sector, and we face drastic funding cuts as we shoulder the skyrocketing expenses of maintaining staff and critical health and safety protocols necessary to protect the people we support. The vaccination program is an opportunity to reverse this pattern of neglect.

Scott Landes, author of the Lerner Institute studies clearly linked the higher case rates to under-resourcing of providers and a historic and ongoing lack of prioritization of quality health care for New Yorkers with I/DD.

This needs to change. Our pandemic response can no longer leave vulnerable citizens neglected and unprotected. The state must ensure priority vaccination for New Yorkers with I/DD and the dedicated staff who support them.

The Arc New York has a statewide presence and the expertise necessary to implement a vaccination program for our field. We appreciate your partnership to date on this critical issue and are prepared to work with the state to distribute the vaccine to the people we support.

We need the state's commitment that our loved ones will be a priority as we face this crisis together.

Governor Cuomo, we call on you to ensure that people with I/DD served in New York's residential programs, and the Direct Support Professionals who support them, are included in Phase 1 of New York's COVID-19 vaccination plan. It is essential that New York classify people with I/DD living in residential programs as residing in a long-term care facility, and that direct support professionals be considered health care workers for the purpose of COVID-19 vaccine distribution.



Dr. John Kowalczyk
President
The Arc New York

cc: Senate President Pro Tempore and Majority Leader Andrea Stewart-Cousins
Assembly Speaker Carl Heastie
Assembly Majority Leader Crystal Peoples-Stokes
Senate Minority Leader Robert Ortt
Assembly Minority Leader William Barclay
Assemblywoman Aileen Gunther, Chair, Assembly Mental Health Committee
David Carlucci, Chair, Senate Mental Health & Developmental Disabilities Committee
Dr. Theodore Kastner, Commissioner, Office for People With Developmental Disabilities
Dr. Howard Zucker, Commissioner of Health
Kerri Neifeld, Assistant Secretary for Human Services & Mental Hygiene
Robert Mujica, Director of Budget