

# COVID-19 Vaccine Prioritization For Individuals with I/DD in Non-Congregate Care Settings

January 11, 2020

Dear Honorable Governor Cuomo,

We are members of the Family Advisory Board of Care Design NY, a Care Coordination Organization/Health Home (CCO/HH) serving 27,000 individuals in New York State with intellectual and developmental disabilities (I/DD).

We want to express our heartfelt gratitude for including people with I/DD residing in congregate care settings and the Direct Support Professionals (DSPs) who work with them in Phase 1A for receiving the COVID-19 vaccine and for recently adding DSPs who work in community settings. This humane, evidence-based policy may help prevent even more illness and death for this very vulnerable group in our state.

However, we must ask that the approximately 80,000 individuals with I/DD who live in non-congregate settings be included in Phase 1B of New York's COVID-19 vaccination program. A FAIR Health study from November 2020 found that the case-fatality rate for people with I/DD is three times greater than it is for the general population - higher than any of the 15 conditions looked at, including heart failure, chronic kidney disease, liver disease, and cancer. A study published by the Annals of Internal Medicine found that persons with Down syndrome are four times more likely to be hospitalized and ten times more likely to die from COVID-19, even after controlling for cardiovascular and pulmonary diseases and care home residence.

People with I/DD comprise a uniquely vulnerable population. Many individuals who receive personal care have difficulty wearing a mask, washing their hands, and practicing social distancing. They are also often part of a network of critical care, receiving support not only from aging parents but also from staff who work at multiple health and community settings. The majority of individuals with I/DD access vital services in group settings with other vulnerable individuals. These risks of exposure and transmission – none of which are optional for either the individual or the staff – increase exponentially, as do the health and financial consequences of a COVID-19 illness.

We therefore endorse the joint position statement of the American Academy of Developmental Medicine and Dentistry and twenty-nine health and disability organizations on equity of vaccine allocation for people with I/DD:

*“Given increased rates of serious illness and death from COVID-19 in people with intellectual and developmental disabilities, persons with this diagnosis or condition should be explicitly included in the list of high-risk diagnoses that are used to determine vaccine priority. Individuals with I/DD as well as those who live with or provide their care must be included in the same phase of vaccine allocation, regardless of living setting.”*

We cannot afford to have one more avoidable hospitalization and death of our family members. Please help them remain safe in their homes and communities. We respectfully ask that individuals with I/DD be included in Phase 1B of New York State’s vaccine allocation program.

Sincerely,

Care Design NY Family Advisory Board Members:

Rachelle Kivanoski, RN, BSN, MA  
Susan Platkin, MD  
Lisa Fleisher, PhD  
Karen Azarian

Cc:

Robert Mujica, Director of Budget, State of NY  
Kerri Neifeld, MSW, Assistant Secretary for Human Services and Mental Hygiene  
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Roger Bearden, Executive Deputy Commissioner, Office for People with Developmental Disabilities  
Howard Zucker, M.D., J.D., Commissioner, NYS Dept. of Health  
Karim Camara, NYS Office of Faith-Based Community Development Services  
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Michael Dowling, President & CEO, Northwell Health  
Rose Duhan, President, Community Healthcare Association for NYS  
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Helen Evans, President, NYS Association of Rural Health

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**Bea Grause, President, Healthcare Association of New York State**

**George Gresham, President, 1199SEIU United Healthcare Workers East**

**Rev. Diann Holt, AME Zion Church, Doula, Buffalo area**

**Micky Jimenez, Regional Director, Capital District LATINOS**

**Bonnie Litvack, M.D., President, Medical Society of State of New York**

**Jim Malatras, SUNY Chancellor**

**Michael Martin, Executive Director, Native American Community Services of Erie and Niagara Counties, Inc.**

**Patrick Murphy, Commissioner, Division of Homeland Security and Emergency Services**

**Alicia Ouellette, J.D., President, Albany Law School**

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**Rosanna Rosado, NYS Secretary of State**

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