

COVID Management for people with IDD

June 8, 2022

Ms. Keri Neifeld
Commissioner
New York State Office for People with Developmental Disabilities
44 Holland Avenue
Albany, NY

Dear Commissioner Neifeld:

Given the rapid succession of COVID waves and the predictions for new variants, the Care Design NY Individual & Family Advisory Board would like to raise some pressing concerns regarding COVID management for people with IDD and to offer recommendations for protecting the health of our loved ones.

Current NYS guidelines do not recommend 2nd boosters for people with IDD, whether they live independently or in congregate settings. The official guidelines include only people who are moderately or severely immunocompromised or who are over age 50. IDD is omitted as an inclusion criterion even though the NYS Department of Health and the CDC identify it as an “underlying condition with evidence” for higher-risk of severe COVID-19 outcomes. Because of this omission, some members who would benefit from the second booster have been turned away by pharmacies while others have received the vaccine.

This is counter-productive when we know that increasing numbers of group homes have been under quarantine for 14 days due to a resident’s exposure. These quarantines, many of which could be avoided by increasing rates of 2nd boosters, reproduce the adverse lockdown conditions of the early pandemic. There is also a baffling inconsistency in not recommending a 2nd booster for people with IDD while confining them to a longer duration of quarantine than the state recommends for the general public.

We should also be mindful that individuals may soon be going to camp or travelling, or spending more time indoors to avoid the summer heat -- activities that will increase their exposure to the virus at a time when waning immunity from their last vaccine makes them more susceptible to symptomatic infection and hospitalization.

We urge you to advocate to DOH that because of their high risk for severe disease from COVID as a cohort, people with IDD should be eligible for the second booster.

Additionally, many individuals and staff who have completed their primary vaccination series have yet to receive their 1st booster. The most recent data released by OPWDD on May 7, 2022, indicate that the rate of booster administration is 10-20% lower than it is for the original vaccine and remains alarmingly low for staff in certified programs. This low rate increases the risk of infection for all residents and program participants. **We urge OPWDD, CCOs and service providers to promote first booster administration more strongly among individuals with IDD and their staff** and to support their eligibility for second boosters so that providers can get shots into arms, similar to efforts made with the initial vaccine.

To improve these outcomes and create more awareness of the impact of COVID on people with IDD, **we recommend that OPWDD resume reporting infection, mortality and vaccination data to stakeholders more frequently, and also include the number of group homes under quarantine.**

Thank you for considering our input on these critical issues. We eagerly await your response to these concerns.

On behalf of the Care Design NY individual & Family Advisory Board,

Karen Azarian
Carlene Braithwaite
Rachelle Kivanoski
Susan Platkin

Cc: Mr. Jihoon Kim, Deputy Secretary for Human Services & Mental Hygiene