



Talking Points: COVID-19 Risk and Response for the I/DD Population

The Issue

Individuals with I/DD are at greater risk of infection and mortality due to COVID-19 than the general population of New York.

As the state and the nation gradually resume operation, our day habilitation and employment programs have reopened, both in congregate site-based locations and in the community. Transportation has resumed, and individuals, visitors and staff are moving in and out residences again. While this change is welcome, it increases both the risk of individual exposure to COVID-19 and its transmission within our residential programs and the general population.

Cases of COVID-19 are again on the rise. Ensuring proper prevention measures is essential.

The Evidence

Recent studies conducted by Syracuse University and The Lerner Institute for Public Health Promotion found that individuals with I/DD supported in residential settings were 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.

These reports are based on data collected by The Arc New York and New York Disability Advocates (NYDA). The full papers can be found below.

- [COVID-19 outcomes among people with intellectual and developmental disability living in residential group homes in New York State](#)
- [COVID-19 Trends Among Adults with Intellectual and Developmental Disabilities \(IDD\) Living in Residential Group Homes in New York State through July 10, 2020](#)

The Arc New York Response

The Lerner study concludes that the higher number of cases among individuals with I/DD did not result in similarly disproportional death rates due, in part, to the efforts of providers and staff to mitigate the crisis.

All Chapters of The Arc New York strictly adhere to state guidelines for reducing transmission in our population and the staff that serve them. This includes:

- Strict cleaning and disinfection protocols
- Regular health screenings
- Appropriate use of personal protective equipment (PPE)
- Modification of service delivery to ensure social distancing and reduce congregate settings and community outings
- Temporary closure of day programs
- Restrictions on visitation

The Arc New York has spent well over \$3 million to independently purchase and distribute hundreds of thousands of gloves, masks, gowns, hand sanitizer and other PPE and supplies to ensure the health and safety of the people we support.

Some Chapters of opened Step-Down Units, offering recuperative medical care for individuals with COVID-19 following discharge from the emergency room or hospital. These units aim to improve recovery rates, support the complex needs of COVID-19 patients with I/DD, free up hospital capacity, and reduce transmission to other individuals in our residential programs and communities.

We have also undertaken our own data collection and analysis to better understand and respond to COVID-19 in the absence of meaningful data from the state. This critical data allows us to quickly identify hotspots and mitigate transmission in our programs and communities.

What We Need from New York

According to Lerner studies' author Scott Landes, "To address this increased risk, it is necessary to ensure that people with I/DD and those who provide for their care have access to preventive measures and the resources needed to carry them out."

Those critical resources include:

- Access to and funding for appropriate PPE
- Access to and funding for COVID-19 testing for staff and individuals
- Clear and timely guidance from the State on response protocols for our population
- Hazard pay for front-line staff
- Recognition as eligible providers for purposes of FEMA reimbursement
- Improved research and data sharing to enhance understanding of risks and best practices
- Support for right-sizing facilities where social distancing can be implemented more effectively
- Ongoing fiscal and policy support of new service modalities, such as telehealth and in-home services

Background

The Arc New York is a family-led organization that advocates and provides supports and services to people with intellectual, developmental, and other disabilities (I/DD), emphasizing choice and community engagement. With 39 operating Chapters serving 61 counties across New York state, our organization supports more than 60,000 individuals with I/DD and their families, and employs more than 30,000 people statewide. Our full breadth of supports encompasses residential services, clinic, nursing and transportation services, day programming, employment and education supports, respite and service coordination, and more.

These services often include around-the-clock care for individuals with complex medical needs. Many of the people supported in our Intermediate Care Facilities (ICFs) are non-ambulatory, 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. In our Supervised Individualized Residential Alternatives (IRA) programs, staff provide 24-hour support, often including feeding, bathing, toileting, medication administration, and other close-contact care in traditional family-style group homes for up to 14 residents, whose medical needs are overseen by Chapter nursing staff.

We also run clinic programs throughout the state, which deliver occupational therapy, physical therapy, speech and language therapy, as well as nursing, nutrition, psychiatric, counseling, and intensive behavioral services.