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RESEARCH BRIEF #32

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COVID-19 Trends Among Adults with Intellectual and Developmental Disabilities (IDD) Living in Residential Group Homes in New York State through July 10, 2020

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KEY FINDINGS

For people with IDD living in residential group homes in New York State, COVID-19:

- Case rates were consistently 3.4 times higher than for New York State as of late April 2020.
- Case growth rates were similar to those of New York State as of May 2020.
- Case-fatality rates were consistently 1.9 times higher than for NY State as of late April 2020.

An early report warned that people with intellectual and developmental disabilities (IDD) may be at higher risk during the COVID-19 pandemic.[1] Three reasons for concern were proposed. First, people with IDD are a socially disadvantaged population that experiences comparatively higher levels of health disparities[2,3] that may be aggravated during the pandemic. Additionally, people with IDD have a higher prevalence of pneumonia, a respiratory infection initially identified as possibly leading to more severe COVID-19 outcomes.[4] Finally, a disproportionate percentage of the IDD population resides in congregate settings,[5] presenting increased challenges to physically distance and reduce the spread of the virus.[6] Results from early studies confirmed the concern that COVID-19 presents a more severe risk to people with IDD. In a study analyzing real-time electronic medical data of those with COVID-19, people with IDD had a higher prevalence of co-occurring medical conditions associated with more severe COVID-19 outcomes and higher case-fatality rates. Those conditions included respiratory, endocrine, nutritional, metabolic, and circulatory diseases.[7] A second study reported higher COVID-19 case rate, case-fatality rate, and mortality rate among a sample of adults with IDD that lived in Medicaid waiver funded residential group homes in New York State.[8]

In response to these early concerning results, a research team from Syracuse University and Upstate Medical University is collaborating with New York Disabilities Advocates (NYDA), a coalition of organizations that serve and support people with IDD in New York State, to track COVID-19 outcomes among this population over time. This report compares COVID-19 trends among 13,200 adults with IDD living in Medicaid waiver funded residential group homes in the state of New York (hereafter people with IDD) with overall COVID-19 trends in the state of New York.

Case Rates

While COVID-19 case rates increased between April 10, 2020 and July 10, 2020 for both groups, from April 10 to May 1, the case rate increased by 2.5 times for people with IDD, from 2,225 to 5,544 cases per 100,000, but only increased by 1.6 times for New York State, from 886 to 1,584 cases per 100,000. From May 1 to July 10, the case rate increased for both groups at a similar rate, 1.3 times.

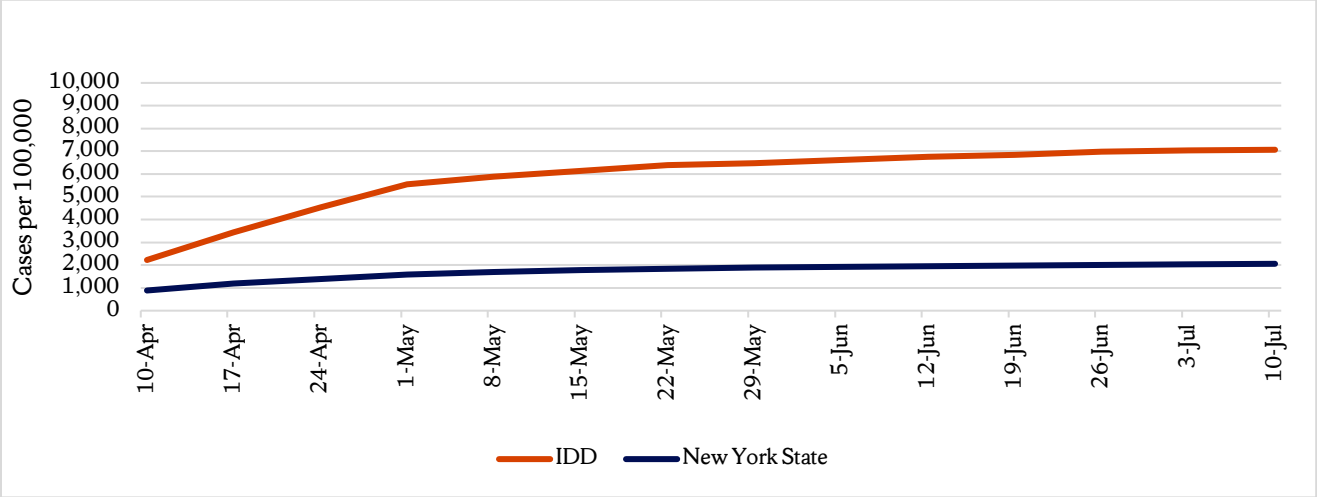

Figure 1. Case Rate People with Intellectual and Developmental Disability (IDD) and New York State Overall

Data Source: New York Disabilities Advocates (NYDA) COVID-19 Survey of Providers; Johns Hopkins' Center for Systems Science and Engineering COVID-19 Tracker

Case Growth Rates

Analysis of the case growth rate reveals a similar pattern. The rate of week over week growth in cases was higher for people with IDD (54%) than for New York State (34%) on April 17. However, there was a more substantial decrease in the case growth rate for people with IDD through early May, resulting in a similar growth rate for people with IDD (6%) and New York State (7%) by May 8. From May 15 through July 3, the case growth rate steadily declined for both groups from approximately 4% to 1%.

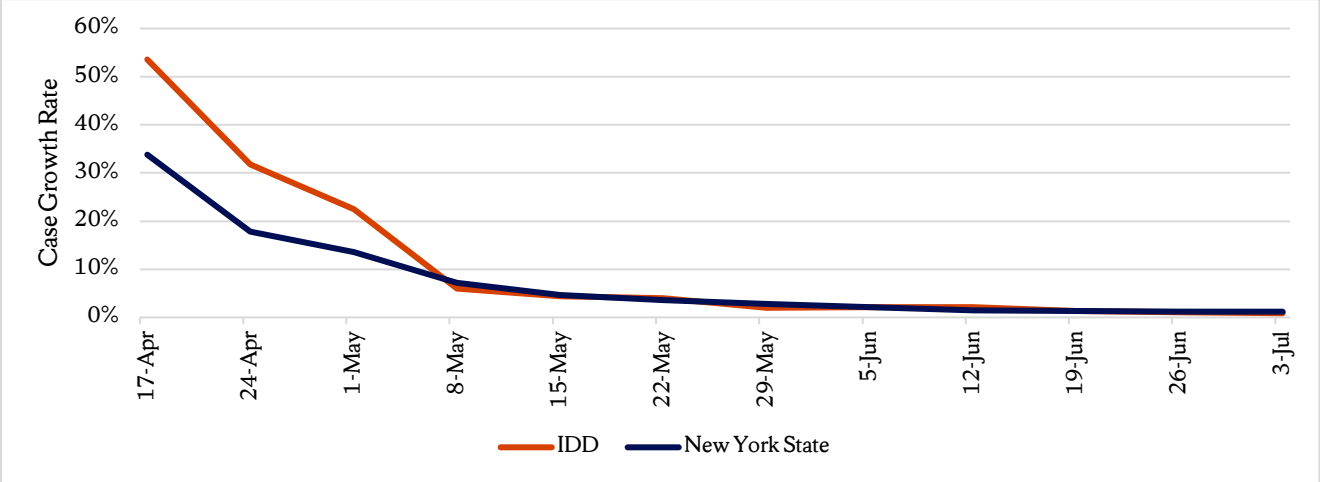

Figure 2. Case Growth Rate for People with Intellectual and Developmental Disability (IDD) and New York State Overall

Data Source: New York Disabilities Advocates (NYDA) COVID-19 Survey of Providers; Johns Hopkins' Center for Systems Science and Engineering COVID-19 Tracker

Case-fatality Rates

Case-fatality rates (the percentage of confirmed COVID-19 cases that resulted in death) were 2.7 times higher for people with IDD (19%) than for New York State overall (7%) on April 10. The case-fatality rate then dropped but remained approximately 2.0 times higher for people with IDD (~16%) than for New York State overall (8%) from April 17 to July 10.

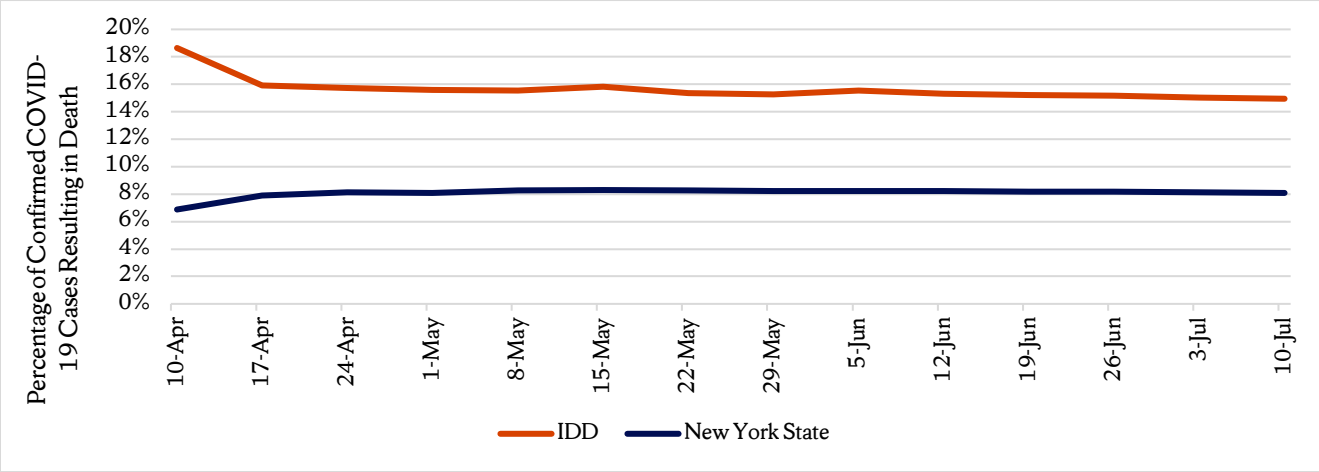

Figure 3. Case-fatality Rate for People with Intellectual and Developmental Disability (IDD) and New York State Overall

Data Source: New York Disabilities Advocates (NYDA) COVID-19 Survey of Providers; Johns Hopkins' Center for Systems Science and Engineering COVID-19 Tracker

A Call for Increased Monitoring and Data Sharing

Trends in this report show that while the growth in diagnosed cases of COVID-19 among adults with IDD initially outpaced the growth of cases in New York State overall, a shift occurred in early May. From May through early July the two groups experienced a similar pattern in cases. Although there was a slight reduction in the case-fatality rate among people with IDD in early April, case-fatality rates remained around two times higher for people with IDD from mid-April to early July.

There are a couple of plausible explanations for the differences in cases in the early part of this study. People with IDD have not historically, nor during this pandemic, been granted the same priority for health care afforded to the general population.[9] This disparity has been most obvious as residential group homes for people with IDD were not prioritized for testing at the same level as nursing homes. The marked increase in cases observed from early April to early May might reflect this lack of prioritization and delayed access to testing for people with IDD.

The differences observed in confirmed cases in the early part of this study may also reflect the positive effects of policies enacted by the group home providers and by New York State.[10] For instance, by mid-March, policies were in place to ensure that group home residents did not participate in community-related outings or day programs, and outside visitors were no longer allowed in group homes. By early April, policies were in place requiring COVID-19 positive residents to quarantine and residential group home employees were required to wear facemasks. Reduction in the growth of cases among people with IDD from mid-April to early May possibly resulted from policies like these attempting to protect residents and contain the spread of the virus.

While it is promising that trends in COVID-19 cases for people with IDD were in line with those of New York State by early May, the persistently higher case-fatality rate calls for further investigation. To date, there is not sufficient data to determine the degree to which this disparity is a result of the group residential setting or the prevalence of pre-

existing health conditions among this population. Continued collection and reporting of robust data are crucial in identifying the factors that contribute to poorer outcomes for people with IDD, as well as in further monitoring of this particularly vulnerable population.

Data and Methods

Data for people with IDD living in residential group homes are from the New York Disabilities Advocates (NYDA) COVID-19 Survey of Providers. Data for New York State are from the Johns Hopkins' Center for Systems Science and Engineering COVID-19 data github. Case rate was calculated as (number of cases/number served) * 100,000. Case growth rate was calculated as a three-week rolling average. Case-fatality rate was calculated as the number of deaths/number of cases.

References

1. Landes, S.D., Stevens, J.D., & Turk, M.A. (2020, April 27). *COVID-19 and pneumonia: Increased risk for individuals with intellectual and developmental disabilities during the pandemic*. Syracuse University, Lerner Center for Public Health Promotion. https://lernercenter.syr.edu/2020/04/27/covid-19-and-pneumonia-increased-risk-for-individuals-with-intellectual-and-developmental-disabilities-during-the-pandemic/.
2. Krahn, G.L., & Fox, M.H. (2014). Health disparities of adults with intellectual disabilities: What do we know? What do we do? *Journal of Applied Research in Intellectual Disabilities*, *27*(5), 431-446.
3. Krahn, G. L., Hammond, L., & Turner, A. (2006). A cascade of disparities: Health and health care access for people with intellectual disabilities. *Mental Retardation and Developmental Disabilities Research Reviews*, *12*(1), 70-82.
4. Centers for Disease Control and Prevention. (2020). *Interim clinical guidance for management of patients with confirmed Coronavirus Disease (COVID-19)*. Retrieved April 23, 2020, from https://www.cdc.gov/coronavirus/2019-ncov/hcp/clinical-guidance-management-patients.html
5. Braddock, D., Hemp, R., Tanis, E.S., Wu, J., & Haffer, L. (2017).*The State of the states in developmental disabilities: 2017*. American Association on Intellectual and Developmental Disabilities.
6. Solis, J., Franco-Paredes, C., Henao-Martínez, A.F., Krsak, M., & Zimmer, S.M. (2020). Structural vulnerability in the United States revealed in three waves of novel coronavirus disease (COVID-19). *The American Journal of Tropical Medicine and Hygiene*.
7. Turk, M.A., Landes, S.D., Formica, M.K., & Goss, K.D. (2020). Intellectual and developmental disability and COVID-19 case-fatality trends: TriNetX analysis. *Disability and Health Journal*, *13*(3), 1-4.
8. Landes, S.D., Turk, M.A., Formica, M.K., McDonald, K.E., & Stevens, J.D. (2020). COVID-19 outcomes among people with intellectual and developmental disability living in residential group homes in New York State. *Disability and Health Journal*, 100969.
9. Sabatello, M., Landes, S.D., & McDonald, K,E. (2020). People with disabilities in COVID-19: Fixing our priorities. *The American Journal of Bioethics*, *20*(7), 187-190.
10. Office for People with Developmental Disabilities NYS. (2020). *COVID-19 Guidance*. https://opwdd.ny.gov/coronavirus-guidance/covid-19-guidance-documents

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