The NYS Developmental Disabilities Advisory Council (DDAC) was charged with preparing a report to the legislature assessing New York State’s response to COVID-19 for people with intellectual and developmental disabilities (IDD) and provide recommendations on improvements to better address the needs of people with IDD in future emergencies. The NYS Developmental Disabilities Planning Council (DDPC) was asked to assist the DDAC in the preparation of this report. This report was sent to the Governor and Legislature on November 17th, 2022.

The DDPC engaged a significant number of stakeholders-over 2,000 self-advocates, parents and providers-to hear their stories of how the pandemic and the state’s response impacted them. Based on this vast amount of input, as well as extensive research and analysis of data, the DDAC’s findings include the following:

1. People with IDD and family members living in the community felt largely ignored by the State in its response to COVID.
2. The Office for People with Developmental Disabilities (OPWDD) COVID guidance often fell short and was not timely to address the needs of providers and the people they serve.
3. OPWDD COVID guidance was often difficult to access and understand.
4. Underserved communities were mostly overlooked by the state in response efforts.
5. Non-profit providers were often not able to obtain necessary PPE from the state at the onset of the pandemic, putting staff and the people they serve at risk for COVID.
6. Staffing shortages and program closures had a major adverse impact on individuals with IDD and caregivers.
7. The hospital discharge policy may have inadvertently accelerated the spread of COVID for the IDD population living in congregate settings.
8. People with IDD were initially denied necessary supports while hospitalized which impacted their ability to access appropriate treatment.

To improve the State’s response efforts to the IDD population, the DDAC’s recommendations include the following:

- Create an Emergency Management Plan specifically for the IDD Community representing the racial, ethnic and linguistic diversity of NYS
- Require mandatory training for all first responders to appropriately respond to the unique needs of people with IDD
- Improve data collection and access to data during an emergency
- Address the chronic DSP workforce crisis by creating a task force to examine barriers and recommend actionable, short and long term solutions
- Reduce reliance on congregate care settings for people with IDD by examining regulatory, financial and administrative barriers to offering more independent housing options
- Make telehealth, telemedicine and virtual programming permanent, ongoing services when it is appropriate and develop best practice guidance for providers