December 14, 2020

Honorable Dr. Theodore Kastner
Commissioner
Office of People with Developmental Disabilities
44 Holland Ave.
Albany, NY 12229

Dear Commissioner Kastner,

As you are aware, the Centers for Medicare & Medicaid Services (CMS) issued a 66-page toolkit to encourage and help states rebalance long-term care offerings for people with disabilities to favor home and community-based services over large institutions. We urge the state of New York to take immediate action on these guidelines. As the COVID-19 pandemic surges, we need to quickly transition nearly 20,000 New Yorkers with disabilities out of crowded, congregate settings to protect their lives.

It has been more than 20 years since the U.S. Supreme Court’s historic ruling in *Olmstead v. L.C.* that found unjustified segregation of persons with disabilities constitutes discrimination in violation of title II of the Americans with Disabilities Act (ADA). But today, on the 30th anniversary of the ADA, fewer than 15 states have abolished state-funded large facilities in favor of community-based programs.

New York is unfortunately not among them. The state is also guilty of placing many individuals with disabilities under 64 years old in crowded and vulnerable nursing homes. In New York, approximately 580 persons with disabilities remain in state-run or state-contracted institutions, while nearly 19,000 are housed in nursing homes.

For the past 30 years, the disability community has raised concerns about the warehousing of people with disabilities in large institutions or nursing homes, as opposed to community-based housing programs. Now these crowded, outdated forms of care are literally costing lives among a population particularly vulnerable to the pandemic.

The nonprofit FAIR Health in November released a report finding that people with intellectual and developmental disabilities are three times more likely to die of COVID-19. Prior to that report, an adjunct professor at Syracuse University issued a similar report finding that pandemic
mortality rates for the developmentally disabled was 16% in New York and 14% in Pennsylvania, compared to 8% among the general population.

However, we in the disability community believe that mortality and infection rates likely are much higher than these reports. Data through most state health departments is inconsistent or nonexistent. This lack of information prompted U.S. Senators Elizabeth Warren (D-MA), Patty Murray (D-WA) and Margaret Wood Hassan (D-NH) to write a letter to CMS requesting that it issue guidance for mandatory comprehensive data collection and reporting on congregate care settings to better understand and address the impact of COVID-19 on people with disabilities and older Americans in these settings.

What we can say with confidence is that community-based settings are much safer for people with disabilities as the pandemic surges. Of the nearly 4,100 people in the care of Community Options nationwide, only seven have passed away due to COVID-19, or .0017 percent of the people we support.

It is time for states to finally abandon the practice of warehousing people with disabilities. We urge the state of New York to act promptly on the guidelines provided in the CMS digital toolkit to protect the lives of nearly 20,000 New Yorkers with disabilities. For their sake and their families and loved ones, we cannot afford further delays.

We are happy to provide any information or assistance we can in this effort.

Sincerely,

Robert Stack
President and CEO
Community Options, Inc.

cc: Governor Andrew Cuomo, Attorney General of California Xavier Becerra

About Community Options, Inc.:
For over 30 years, Community Options has developed housing and employment supports for people with disabilities – supporting thousands of people from over 40 offices across 10 states. Community Options provides advocacy assistance to empower people with disabilities because all people – regardless of ability level – should live and work in the community with dignity, choice and self-determination. For more information please visit our website: www.comop.org and to follow along with the #AllItTakes campaign, search #AllItTakes on Facebook, Twitter and Instagram.