



Community Options, Inc.

Supporting People with Disabilities since 1989

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Robert Stack
President/CEO

December 14, 2020

Seema Verma
Administrator, Centers for Medicare & Medicaid Services
7500 Security Boulevard
Baltimore, MD 21244

Dear Administrator Verma,

In October, members of the Senate Committee on Health, Education, Labor, and Pensions (HELP) formally requested that the Centers for Medicare & Medicaid Services (CMS) 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.

Unfortunately, public and policymaker understanding of the danger facing this vulnerable group is just as opaque today as it was nearly two months ago. The senators' October deadline came and went without action from CMS. On behalf of patients and advocates across the country, we request an update on the Centers' progress.

With the pandemic entering a pivotal stage this winter, a lack of actionable data will undoubtedly cost lives. The little data we have shows a grave risk for disabled individuals in large institutional settings.

In November, the nonprofit FAIR Health released a report finding that people with intellectual and developmental disabilities are three times more likely to die of COVID-19. Earlier this year, 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.

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. Without a federal mandate, there is little hope we will ever know the full extent of this tragedy – certainly not soon enough to enact the necessary policy changes.

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 Now these crowded, outdated forms of care are literally costing lives among a population particularly vulnerable to the pandemic.

While we support the recently issued 66-page toolkit to encourage and help states rebalance long-term care offerings for people with disabilities to favor home and community-based services, it is simply too little, too late.

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.

This is especially unforgivable given the relative safety of community-based settings. 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 CMS to mandate proper data collection and accelerate the transition of people with disabilities from large institutions to community-based settings.

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

Sincerely,

Robert Stack
President and CEO
Community Options, Inc.

cc: 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.