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Hidden Crisis: Advocates Support Call by US Senators For Improved COVID-19 Data Collection on All Congregate Care Facilities

***Research by U.S. Senate HELP Committee Staff Reveals “Substantial Lack of Data”
for Children and Adults with Mental Illness and Disabilities***

Princeton, NJ – November 9, 2020 – Several U.S. Senators have called upon the Centers for Medicare and Medicaid Services (CMS) to 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. [In a letter to CMS](#) the Senators noted that a review of state-level data reporting ***“reveals a substantial lack of data for congregate care settings for children and adults with mental illness, children and adults with disabilities, and older Americans.”***

“For the past 30 years, we have raised concerns about the warehousing of people with disabilities in large institutions, as opposed to community-based housing programs. And now this outdated form of care is costing lives,” stated Robert Stack, President and CEO of Community Options. The organization, headquartered in Princeton, NJ, with 17 offices across New Jersey, provides housing and employment support for people with disabilities throughout 10 states. “It is nothing more than absolute neglect for the federal and state governments to not even care enough to even monitor such facilities – let alone during a world-wide pandemic.”

U.S. Senators Elizabeth Warren (D-MA), Patty Murray (D-WA) and Margaret Wood Hassan (D-NH) penned the letter to CMS following a report compiled by staff of the U.S. Senate Committee on Health, Education, Labor & Pensions. They conducted a review of all 50 states’ and DC’s coronavirus public data websites for reporting on congregate care settings and current guidance from federal health agencies to determine the type of settings included in COVID-19 reporting and the type of settings included in federal guidance.

During the pandemic, the Department of Health and Human Services recommended that state regulators address outbreaks in nursing homes by imposing new reporting requirements, conducting inspections to ensure that infection controls and other procedures are in place, and providing facilities with PPE for staff. ***However, no new federal requirements have been implemented to help other congregate care settings improve their response to the pandemic, though they serve similar populations.***

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The letter to CMS also noted that ***current public health guidance indicates a high spread of the virus in congregate living conditions and among high-risk populations.*** These facilities typically serve children and adults with disabilities, children and adults with mental illness, and older Americans. The letter further described these facilities as sites where “care is provided in one location where many people – often more than 10 – are located.”

No immediate response to the senators’ letter by CMS has been made public. However, late last week, CMS issued a [66-page toolkit](#) designed to encourage and help states rebalance long-term care offerings for people with disabilities to favor home- and community-based services over institutions

“The CMS toolkit comes at a critical time as we have seen the devastation that the coronavirus pandemic has had on people with disabilities who live in institutional settings,” stated Stack. “Residents experience a much lesser quality of life in these large institutions, and there are limited opportunities for growth and employment. It is our hope that a new administration will develop incentives to transition more people with disabilities out of these facilities.”

According to Stack, large institutions in some states have realized mortality rates as high as 14% (Pennsylvania) and 16% (New York) due to the pandemic - compared to 8% of those infected among the general public. And, those numbers are based only on available data – it could be higher. Community-based housing programs, however, have witnessed far less mortality rates across the board. Community Options for example has realized only a .1% mortality rate across 40 offices in 10 states.

“We applaud these senators for taking the initiative and the interest to call out this issue and to seek some action,” added Stack. “Families and advocates consistently have challenged the concept of large facility congregated care – and now, unfortunately, federal and state authorities only are waking to this reality after the cost of so many human lives.”

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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. The organization, headquartered in Princeton, NJ, with offices in Woodbury, Elmwood Park, Moorestown, Lawrence, Edison, Montville, Forked River, Hillsborough, Springfield, Wayne, Morristown and Flanders in NJ, provides housing and employment support for people with disabilities. 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.