

Congress of the United States

Washington, DC 20510

May 13, 2020

The Honorable Alex Azar
Secretary
U.S. Department of Health and Human Services
200 Independence Avenue, SW
Washington, DC 20201

Dear Secretary Azar:

On April 23, the Paycheck Protection Program and Health Care Enhancement Act was passed by Congress and signed the next day by the President. Included in that law is the requirement that the Secretary of Health and Human Services provide Congress with a report on novel coronavirus (COVID-19) testing and diagnosis within 21 days of the passage of the Act. The report must contain information on testing and diagnosis of COVID-19 by “race, ethnicity, age, sex, geographic region and other relevant factors.” We strongly request that the report include disability status as one of the “other relevant” variables detailed in the report. We recommend HHS use the disability categories from the American Community Survey or the definition of disability from the American’s with Disabilities Act (ADA).

It is vitally important that key data are collected to understand the impact of the COVID-19 public health emergency on those at the greatest risk of infection. This includes tracking the number of COVID-19 tests administered and number of people diagnosed; treatment, including admissions and denials to hospitals and intensive care units, denials of needed accommodations, virus interactions with chronic disease and disability, and recovery patterns; and outcomes, including morbidities, mortalities, rehabilitation, and recovery attributed to the virus. People with disabilities are at elevated risk for complications from COVID-19 because they often have underlying medical conditions or need close contact with health care professionals and personal care attendants to meet their basic needs. Therefore, it is essential that disability is included in all COVID-19 related data collection.

Accurate, reliable data regarding testing, hospitalizations and deaths related to COVID-19 is necessary as states begin to relax shelter-in-place orders. The data collected must capture risk factors that can be used to identify important trends of infection and should follow the best practices for data collection published by the Office of Minority Health.¹ It is critical to understand the safety risks to specific populations and geographic locations. If disability status is not included, the experiences of over 53 million² people with a disability in the United States, whose lives are at risk, will not be captured.

¹ <https://minorityhealth.hhs.gov/omh/browse?lvl=3&lvlid=53>

² <https://www.cdc.gov/ncbddd/disabilityandhealth/features/key-findings-community-prevalence.html>

Early reporting showed that the number of COVID-19 related deaths in group homes or long-term care facilities increased at a rapid rate.³ This resulted in the Centers for Medicare and Medicaid Services (CMS) announcing new regulatory requirements to publicly report cases and deaths in nursing homes.⁴ Due to a lack of data, the severity of COVID-19 on the disabled population living in group settings is unknown. It is essential to closely monitor the impact of this pandemic on people with disabilities. People with disabilities, particularly those who live in group homes or long-term care facilities, are at an increased risk for infection and these types of living conditions have shown to lead to rapid spread of the virus.⁵

It is imperative for the health and safety of our country to collect data that will help us better understand the broad impact of COVID-19. Only with this information will we be able to effectively combat this public health emergency while continuing to prepare for future outbreaks. By including disability status in all COVID-19 related data collection, including testing and diagnoses, treatment and outcomes, you will ensure that this high-risk population is counted and that their needs are included in public health planning. We look forward to a response from you on this request no later than May 18, 2020.

Sincerely,

Robert P. Casey Jr.
United States Senator

James R. Langevin
Member of Congress

Elizabeth Warren
United States Senator

Ayanna Pressley
Member of Congress

³ <https://nypost.com/2020/04/23/coronavirus-deaths-at-us-nursing-homes-reach-over-10000/>

⁴ <https://www.cms.gov/newsroom/press-releases/trump-administration-announces-new-nursing-homes-covid-19-transparency-effort>

⁵ <https://www.nytimes.com/2020/04/08/nyregion/coronavirus-disabilities-group-homes.html>