

# DISABILITY AND REHABILITATION RESEARCH COALITION

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June 11, 2020

The Honorable Mitch McConnell, Leader  
United States Senate  
317 Russell Senate Office Building  
Washington, D.C. 20510

The Honorable Chuck Schumer, Leader  
United States Senate  
322 Hart Senate Office Building  
Washington, D.C. 20510

The Honorable Nancy Pelosi, Speaker  
United States House of Representatives  
1236 Longworth House Office Building  
Washington, D.C. 20515

The Honorable Kevin McCarthy, Leader  
United States House of Representatives  
2468 Rayburn House Office Building  
Washington, D.C. 20515

**Re: Mandating Collection of Disability Status Data in Reporting Regarding  
COVID-19 Testing, Diagnoses, Treatment, and Outcomes**

Dear Speaker Pelosi and Leaders McConnell, Schumer, and McCarthy:

On behalf of the Disability and Rehabilitation Research Coalition (DRRC), we would like to call your attention to the attached letter to Health and Human Services (HHS) Secretary Alex Azar calling for the Department to collect and report disability status data in all COVID-19 related data collections. As you know, bipartisan legislation including the Paycheck Protection Program and Health Care Enhancement Act (P.L. 116-139) mandates the collection and reporting of certain demographic data on testing, diagnoses, hospitalizations, and deaths due to COVID-19. The legislative text of these requirements specifically references “race, ethnicity, age, sex, geographic region, and other relevant factors.” Additionally, the sponsors of these provisions have stated their intention that the Centers for Disease Control and Prevention (CDC) and other program operating components within HHS include disability status in the “other relevant characteristics” category of the required reports.

We have not yet received a response from the Department, and so far, guidance on data collection, including the CDC’s recently released guidance for laboratories conducting COVID-19 tests, has not explicitly required that disability status data be collected. As the attached letter makes clear, without collecting disability status data associated with COVID-19 testing, diagnoses, treatment, and outcomes, people with disabilities will remain at greater risk of disease and death. People with disabilities have longed face serious health inequities and disparities, which are only exacerbated by the current pandemic. Collecting and reporting data disaggregated by disability status is a crucial first step to developing and enhancing the federal pandemic response to begin to address the needs of this population. **As Congress continues to deliberate regarding future legislative action to address COVID-19, we urge you to ensure these needs are met by explicitly requiring the collection of disability status information in all mandated reporting of COVID-19 demographic information.**

Thank you for your consideration of our requests. We look forward to continuing to work with your offices and the entire Congress to advance this goal and other public policy impacting people with disabilities. If you have any questions, please contact the DRRC coordinators listed below.

Sincerely,

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