DRRC
Disability & Rehabilitation Research Coalition

July 14, 2021

Submitted via E-Mail

The Honorable Frank Pallone
Chair
House Committee on Energy & Commerce
2107 Rayburn House Office Building
Washington, DC 20515

The Honorable Cathy McMorris Rodgers
Ranking Member
House Committee on Energy & Commerce
1035 Longworth House Office Building
Washington, DC 20515

The Honorable Anna Eshoo
Chair, Subcommittee on Health
House Committee on Energy & Commerce
272 Cannon House Office Building
Washington, DC 20515

The Honorable Brett Guthrie
Ranking Member, Subcommittee on Health
House Committee on Energy & Commerce
2434 Rayburn House Office Building
Washington, DC 20515

Re: Hearing on "Empowered by Data" and the Need to Collect Disability Status Information

Chairman Pallone, Chairwoman Eshoo, Ranking Members McMorris Rodgers and Guthrie, and Members of the Energy & Commerce Health Subcommittee:

On behalf of the Disability and Rehabilitation Research Coalition (DRRC)[1], thank you for the Committee's work to advance equity and public health through data-driven policy initiatives, in particular the recent hearing on "Empowered by Data: Legislation to Advance Equity and Public Health." The Disability and Rehabilitation Research Coalition (DRRC) is grateful for the Committee's attention to the critical policy importance of accurate and current health data, which has been starkly highlighted by the COVID-19 pandemic.

My name is Jae Kennedy, and I am a professor of Community Health Policy at the Elson S. Floyd College of Medicine at Washington State University in Spokane, WA. I am the former president of the National Association of Rehabilitation Research and Training Centers (a professional society comprised of National Institute of Disability, Independent Living, and Rehabilitation Research grantees) and current member of the DRRC Steering Committee and have been doing research on US disability programs and policies for over 30 years.

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[1] The DRRC is a coalition of national non-profit organizations committed to improving the science of disability, independent living, and rehabilitation. The DRRC seeks to maximize the return on the federal investment in disability, independent living, and rehabilitation research and development with the goal of improving the ability of Americans with disabilities to live and function as independently as possible, in keeping with the promises of the Americans with Disabilities Act.

On behalf of the DRRC, I would like to raise our concerns about the lack of inclusion of people with disabilities in the data collection requirements examined during this hearing. Among the 13 pieces of legislation discussed during the June 24, only one (H.R. 666, the *Anti-Racism in Public Health Act of 2021*) explicitly includes disability status as a required element in federal data collection (though some of the other bills identify "race, ethnicity, age, sex, geographic region, *and other relevant factors*"). **We urge the Committee to explicitly identify "disability status" as a standard demographic group in the legislative text for these bills, and in all future legislation that requires health data collection.**

In particular, as the Committee prepares to mark up several of these bills on July 15, we urge the Committee to amend the legislative text with this minor but exceedingly meaningful change. These bills include H.R. 925, the *Data to Save Moms Act*, H.R. 2503, the *Social Determinants Accelerator Act of 2021*, H.R. 3894, the *CARING for Social Determinants Act of 2021*, and H.R. 4026, the *Social Determinants of Health Data Analysis Act of 2021*.

Congress has already recognized people with disabilities as a distinct minority group, subject to pervasive social stigma and institutional discrimination, and has passed significant civil rights law (e.g., *the Americans with Disabilities Act, the Rehabilitation Act, and the Individuals with Disabilities Education Act*) to protect this population. It should also require federal agencies like the Centers for Disease Control and the National Institutes of Health to measure and address the health and health care disparities experienced by people with disabilities.

In a recent report (attached), my co-author Elizabeth Wood and I used pre-pandemic survey data to demonstrate that adults with disabilities, compared to those without disabilities, were much less likely to be employed, less likely to graduate from high school, more likely to live in poverty, and much more likely to be in fair or poor health. They also used more health care than their nondisabled counterparts and were much more likely to report difficulties in obtaining and paying for their health care. Under these circumstances, it seems quite likely that people with disabilities would have higher rates of COVID-19 exposure, infection, serious symptoms, hospitalization, and death. They also may face significant barriers to vaccination or be at higher risk of developing "long COVID." But we do not know for sure, because the data simply has not been collected appropriately.

We do know that death rates among nursing home residents (nearly all of whom have significant disabilities) jumped by 32% in 2020. While most people with disabilities do not live in institutions, they do share many of the same COVID-19 risk factors. All people with disabilities, regardless of their living circumstances, require accessible and affordable health and support services, particularly in a public health crisis. Real-time data collection and disclosure of disability disparities in health and health care is the first step towards developing appropriate and just public health programs and policies to support this vulnerable population. Included as an attachment to this statement is a May 2020 letter from the DRRC sent to the Administration regarding the importance of including disability status data across all COVID-19 data collections, as well as an appendix detailing the disproportionate burdens faced by people with disabilities that are under-recognized and under-addressed due to inconsistent data.

I would note that June 24th hearing emphasized the importance of uniform measures of race and ethnicity in federal data collection efforts. This information is clearly necessary to document the disproportionate impact of the pandemic on people of color, and to develop appropriate federal policies to mitigate immediate and long-term health disparities. But disability rates also vary by race and ethnicity, as well as by age, gender, and geographic area. Understanding these intersectional relationships will be critical to building a more resilient and responsive public health system for all Americans.

Thank you for considering our request to recommend the government-wide collection and reporting of data on COVID-19 testing and diagnoses, treatment, and outcomes (including rates of recovery and long-term illness) disaggregated by disability status, in addition to future inclusion of disability status with all federal health data collection efforts. If I or any other members of the DRRC can be of any assistance, please do not hesitate to contact the DRRC coordinators, Bobby Silverstein, Peter Thomas, and Joe Nahra, at 202-466-6550 or by email at Peter.Thomas@PowersLaw.com, Bobby.Silverstein@PowersLaw.com, and Joseph.Nahra@PowersLaw.com.

Sincerely,

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DISABILITY AND REHABILITATION
RESEARCH COALITION
1501 M STREET, N.W. SUITE 700 WASHINGTON, D.C. 20005

May 15, 2020

The Honorable Alex M. Azar, II
Secretary
U.S. Department of Health and Human Services
Hubert H. Humphrey Building
200 Independence Avenue, SW
Washington, DC 20201

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

Dear Secretary Azar:

On behalf of the Disability and Rehabilitation Research Coalition (DRRC)[1] and the undersigned disability and rehabilitation stakeholder organizations, we urge you to ensure that the Centers for Disease Control and Prevention (CDC) and other program operating components (POCs) within the Department of Health and Human Services (HHS) collect and report data on demographic characteristics, de-identified and disaggregated by disability status, to better inform the COVID-19 pandemic response. We strongly support the letter on this issue to your office from Senators Bob Casey and Elizabeth Warren and Representatives James Langevin and Ayanna Pressley, dated May 13, 2020 and included as an attachment to this letter. The data should, among other things, address:

- Testing and diagnoses;
- 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).

Without collecting data disaggregated by disability status associated with COVID-19, people with disabilities will remain at greater risk of disease and death. Health data collected regarding disability status will boost the pandemic response, more efficiently direct critical resources, and inform risk communication development.[2] In the appendix below, we outline some of the ways

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[1] The DRRC is a coalition of 25 national non-profit organizations committed to improving the science of disability, independent living, and rehabilitation. The DRRC seeks to maximize the return on investment in these fields with the goal of improving the ability of Americans with disabilities to live and function as independently as possible. The coalition plays a leadership role in increasing and leveraging federal resources devoted to disability, independent living, and rehabilitation research.

[2] As you know, the recently passed Paycheck Protection Program and Health Care Enhancement Act (P.L. 116-139) includes provisions requiring the regular reporting of demographic data on individuals tested for COVID-19, as well as diagnoses, hospitalizations, and deaths. The legislative text specifically references "race, ethnicity, age, sex,

in which people with disabilities are experiencing additional, disparate impacts of the COVID-19 crisis beyond the infection itself. These only serve to reiterate the importance of widespread and comprehensive data collection to understand these and other burdens faced by the disability community.

We recognize that recently enacted legislation mandates the collection of race and ethnicity data regarding COVID-19 testing and morbidity. This data will be critical to document the disproportionate impact of the pandemic on people of color and to begin to develop measures to mitigate immediate and long-term issues of health disparities and access to treatment. However, we will not be able to understand the intersectionality of race, age, disability, geography, and chronic illness without collecting disability data. Current case reporting forms used by the CDC to track COVID-19 cases do not include disability identifiers, and as such, we do not know the full impact of the virus on people with disabilities. It is essential that the public health response include an understanding of the impact that disability status has on increasing risk and vulnerability for minority populations, older adults, those in high-risk geographic areas, and other populations.

Our request to disaggregate data by disability status reflects the underlying realities faced by people with disabilities. Many people with disabilities already face significant inequities in income, education, employment, housing, transportation, and community participation. Disability status is also correlated with poorer health and health care outcomes.

Populations with physical, cognitive, psychiatric, or communication disabilities have decreased access to preventative care, including wellness, fitness, smoking cessation and weight loss interventions. Deaf populations, for example, are 7 times more likely to have low health literacy compared to hearing populations; people with disabilities are 30% more likely to be obese, are over 2 ½ times more likely to develop diabetes and are around 3 times more likely to develop cardiovascular disease. People with disabilities face negative attitudes and biases; inaccessible environments and equipment; inaccessible written, verbal, and electronic health care communication; and failure to provide accommodations and other modifications to policies, practices, and procedures.

These disparities are likely to lead to decreased access to or denial of COVID-19 treatment. Even before the current public health emergency, cause of death for people with disabilities, including people with intellectual and developmental disabilities, was too often inaccurately attributed. Independent data collection efforts, including the recently released COVID-19 & Disability survey conducted by the American Association on Health and Disability, have shown that people with disabilities are already facing significant disruptions in their ability to access regular health

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geographic region, and other relevant factors." Our request is consistent with the expectations of members of both chambers of Congress, outlined in a letter to CDC Director Robert Redfield dated April 30, 2020, expecting CDC and other program operating components within HHS to include disability status in the "other relevant characteristics" category of the required reports. Additionally, Section 4302 of the Affordable Care Act requires that federal health care and public health programs collect and report data on demographic factors, explicitly listing disability status. The Office of the Assistant Secretary for Planning and Evaluation (ASPE) issued implementation guidance on data collection standards under this section in 2011.

care treatment during the outbreak.[3] This underscores the importance of a coordinated federal effort to collect and report critical data on COVID-19 and disability.

We also know that data alone are not enough. The federal government has a responsibility to direct support, information, and resources to people with disabilities, who are disproportionately impacted by this pandemic. Disability researchers, medical experts, and advocacy organizations have the necessary expertise to address these issues and are embedded in the disability community. These individuals and organizations are well-positioned, as trusted thought leaders and health care service providers, to collect data and conduct research toward creating holistic solutions to remedy the inequitable impact of this and future public health crises.

They are also well-situated to investigate how various demographic characteristics intersect to influence testing and treatment response. They can be deployed in partnership with public health departments to develop rapid response interventions to target the unmet needs of people with disabilities, such as the need for personal protective equipment (PPE), protections for their direct service workers, adequate medications and medical supplies, access to disability component mobile health units, COVID-19 testing in the community, and telehealth services, particularly for those who lack internet access.

The combination of limited resources and high needs creates a relatively thin "margin of health" and much greater vulnerability to communicable disease for people with disabilities. Additionally, people with disabilities face barriers to accessing care that are only exacerbated during the pandemic, including those outlined above. Consequently, people with disabilities appear to be at significantly higher risk of COVID-19 exposure, infection, serious and life-threatening symptoms, hospitalization, and death.

This grim reality is demonstrated most starkly in the shockingly high rates of COVID-19 deaths reported in nursing homes, psychiatric facilities, and other residential facilities throughout the U.S. It may also account for at least some of the racial and ethnic disparities observed thus far during the pandemic, because disability rates are much higher within African American, American Indian, and Native Alaskan populations. People with disabilities share many of the same risk factors of these populations. Real-time tracking of COVID-19 morbidity and mortality among people with disabilities and chronic conditions will be essential for developing targeted interventions in testing, treatment, economic support, and, ultimately, vaccination.

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Thank you for considering our request to collect and report data on COVID-19 testing and diagnoses, treatment, and outcomes (including recovery) disaggregated by disability status. We support the difficult and important work of HHS during this unprecedented public health crisis and stand ready to provide political and technical support for your efforts in disability

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[3] Drum, C.E., Oberg, A., Cooper, K., & Carlin, R. (2020). "COVID-19 & Adults with Disabilities: Health and Health Care Access Online Survey Summary Report." Rockville, MD: American Association on Health and Disability. https://www.aahd.us/initiatives/dissemination/covid-19-disability-survey/

measurement, needs assessment, program development, and evaluation. If the DRRC can be of any assistance, please do not hesitate to contact the DRRC coordinators, Bobby Silverstein, Peter Thomas, and Joe Nahra , at 202-466-6550 or by email at Peter.Thomas@PowersLaw.com, Bobby.Silverstein@PowersLaw.com, and Joseph.Nahra@PowersLaw.com.

Sincerely,

The Undersigned Members of the Disability and Rehabilitation Research Coalition

American Academy of Orthotists and Prosthetists
American Academy of Physical Medicine and Rehabilitation
American Association on Health and Disability
American Congress of Rehabilitation Medicine
American Medical Rehabilitation Providers Association
American Music Therapy Association
American Occupational Therapy Association
American Physical Therapy Association
American Speech-Language-Hearing Association
American Therapeutic Recreation Association
Association of Academic Physiatrists
Association of Rehabilitation Nurses
Association of University Centers on Disabilities
Brain Injury Association of America
Christopher and Dana Reeve Foundation
National Association for the Advancement of Orthotics and Prosthetics
National Association of Rehabilitation Research and Training Centers
National Association of State Head Injury Administrators
National Multiple Sclerosis Society
Paralyzed Veterans of America
United Spinal Association

Supporting Organizations

American Foundation for the Blind
American Psychological Association
Autistic Self Advocacy Network
Center for Public Representation
CommunicationFIRST
Disability Rights Education and Defense Fund
Easterseals
Justice in Aging
Lakeshore Foundation
RespectAbility
National Association of Councils on Developmental Disabilities
National Center for Parent Leadership, Advocacy, and Community Empowerment

CC:
Adm. Brett Giroir, Assistant Secretary for Health, Department of Health and Human Services
Eric Hargan, Deputy Secretary, Department of Health and Human Services
Dr. Robert Redfield, Director, Centers for Disease Control and Prevention
R. Adm. Anne Schuchat, Principal Deputy Director, Centers for Disease Control and Prevention
Seema Verma, Administrator, Centers for Medicare and Medicaid Services
Lance Robertson, Administrator, Administration for Community Living
Mary Lazare, Principal Deputy Administrator, Administration for Community Living
Kristi Hill, Acting Director, National Institute on Disability, Independent Living, and Rehabilitation Research
Phillip Beatty, Director of Research Sciences, National Institute on Disability, Independent Living, and Rehabilitation Research
Dr. Francis Collins, Director, National Institutes of Health
Dr. Alison Cernich, Deputy Director, National Institute of Child Health and Human Development
Lisa Kaeser, Chief, Office of Legislation and Public Policy, National Institute of Child Health and Human Development
Dr. Theresa Cruz, Acting Director, National Center for Medical Rehabilitation Research

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Appendix: Need for Disability Status Data Collection - Burdens Faced by People with Disabilities

We believe that people with disabilities are experiencing **disproportionate and unique burdens from COVID-19 that are currently under-recognized and, therefore, under-addressed.** Without systematic data collection regarding disability status, we cannot hope to mitigate or address these burdens in any meaningful way. For example:

1. People in congregate living facilities are experiencing exorbitant rates of COVID-19 infections, and in many states about half of the reported COVID-19 deaths occurred in these facilities.[4] Overwhelmingly, we believe these cases represent people with disabilities who require personal care, supervision, or mobility assistance. People who require intimate personal care from direct service workers are unable to follow social distancing guidelines. Improved data collection would allow us to explore questions such as:
    a. How many individuals reside in these facilities as their "home" and how many have been placed there temporarily as a result of acute illness and a need for subacute rehabilitation or wound care?
    b. Which individuals would be able to live in the community if they had adequate accessible housing or personal assistant services?
    c. How many of these infected individuals have multiple chronic illnesses, and what are they?
2. We are learning from post-acute rehabilitation providers that people who were not disabled before COVID-19 infection are experiencing significant functional problems due to the virus.[5] We need to be able to track this population of "newly disabled' patients to document their "long tail" of rehabilitation and recovery, and to consider the potential for permanent disability even when the initial infection has passed.
3. Direct service workers who care for people with disabilities in nursing homes and the community have been an "invisible" workforce during the COVID-19 emergency.[6] Getting access to proper personal protective equipment (PPE) and infection control training has been slow to non-existent, especially for those who are independently contracted by Medicaid waiver programs to care for a single person in their home setting. This critical but low-paid workforce may be the single most important factor that keeps people with disabilities out of emergency rooms, hospitals, and nursing homes. Without proper disability-focused data, interventions to improve the availability and safety of these workers are less likely.

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[4] Chidambaram, Priya. "State Reporting of Cases and Deaths Due to COVID-19 in Long-Term Care Facilities," *Kaiser Family Foundation,* 23 April 2020. https://www.kff.org/medicaid/issue-brief/state-reporting-of-cases-and-deaths-due-to-covid-19-in-long-term-care-facilities/

[5] Servick, Kelly. "For Survivors of Severe COVID-19, Beating the Virus Is Just the Beginning," *Science,* 8 April 2020. https://www.sciencemag.org/news/2020/04/survivors-severe-covid-19-beating-virus-just-beginning

[6] Cancino, Alejandra. "Aides Caring for Vulnerable Seniors Amid Coronavirus Still on the Job Despite Lack of Masks, Protective Gear and Social Distancing," *Better Government Association*, 8 April 2020. https://www.bettergov.org/news/aides-caring-for-vulnerable-seniors-amid-coronavirus-still-on-the-job-despite-lack-of-masks/

4. For people with intellectual/developmental disabilities (I/DD), COVID-19 appears to have a particularly outsized impact.[7] We need systematic collection of data to understand why, including the barriers to testing, risk, and adherence to infection control measures for these populations. We know, for example, that people with I/DD may have difficulty understanding the directions for tests, treatment, and other services, and they may need the support of a familiar person, take extra time, or require other accommodations. It may be difficult to quarantine a person who is COVID-positive in a group home, yet many alternative facilities being constructed for the care of COVID-19 patients who do not require hospitalization have not taken into consideration the needs of people with disabilities, leading to many being refused admission. If hospitalized, people with I/DD may need a support person to be allowed to shelter in place with them to avoid preventable problems due to poor communication, inaccurate information, or behavioral difficulties that can flare up in unfamiliar and frightening circumstances.
5. We know that people with disabilities are 30% more likely to be obese, are over 2.5 times more likely to develop diabetes, and are approximately 3 times more likely to develop cardiovascular disease. These chronic illnesses also impact COVID-19 morbidity and mortality. Better data will allow researchers to examine whether people with disabilities who have these chronic illnesses are at the same or higher risk as people without disabilities.

These examples represent only a small sampling of the burdens that people with disabilities face during the pandemic, and data collection and reporting will be the first step towards designing a comprehensive response to protect this population.

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[7] Stevens, Dalton and Scott Landes. "Potential Impacts of COVID-19 on Individuals with Intellectual and Developmental Disability: A Call for Accurate Cause of Death Reporting," *Lerner Center for Public Health Promotion, Syracuse University,* 14 April 2020. https://lernercenter.syr.edu/2020/04/14/potential-impacts-of-covid-19-on-individuals-with-intellectual-and-developmental-disability-a-call-for-accurate-cause-of-death-reporting/