



ASSOCIATION OF UNIVERSITY CENTERS ON DISABILITIES  
THE LEADERSHIP, EDUCATION, ADVOCACY & RESEARCH NETWORK

May 27, 2021

The Honorable Patty Murray, Chair  
Senate HELP Committee  
United States Senate  
Washington, DC 20510

The Honorable Richard Burr, Ranking  
Member  
Senate HELP Committee  
United States Senate  
Washington, DC 20510

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Dear Chair Patty Murray and Ranking Member Richard Burr,  
The Association of University Centers on Disabilities (AUCD) writes in response to the request for stakeholder comments on Public Health and Medical Preparedness and Response Programs as informed by the COVID-19 pandemic. AUCD supports and promotes a national network of university-based interdisciplinary programs with the mission to advance policies and practices that improve the health, education, and social and economic well-being of all people with developmental and other disabilities, their families, and their communities by supporting our members in research, education, health, and service activities that achieve our vision.

While the COVID-19 pandemic has impacted healthcare, employment, services, community, and quality of life for individuals worldwide, people with disabilities have been particularly hard hit. This is especially true for those at the intersection of disability and race, ethnicity, poverty, and immigration.

The disproportionate impact is evidenced in multiple areas:

- [Elevated COVID-19 Mortality Risk Among Recipients of Home and Community based Services: A case for prioritizing vaccination for this population](#) from Disability Rights Education & Defense Fund (DREDF) – demonstrates the increased mortality risk for people with intellectual and developmental disabilities from COVID-19.
- [Health Disparities by Race and Ethnicity During the COVID-19 Pandemic: Current Evidence and Policy Approaches](#)
- [America at a glance: Social isolation and loneliness during the first wave of COVID-19](#)

There are numerous examples of system failures:

- [New obstacles and widening gaps: A qualitative study of the effects of the COVID-19 pandemic on U.S. adults with disabilities](#)
- [Examining How Crisis Standards of Care May Lead to Intersectional Medical Discrimination Against COVID-19 Patients](#)
- [COVID Vaccine Websites Violate Disability Laws, Create Inequity for the Blind](#)
- [Direct Support Workforce and COVID-19 National Report: Six-month Follow-up](#)
- [COVID-19 Vaccine Access for People with Disabilities](#)

AUCD's recommendations to address some of those barriers and build additional supports are listed below:

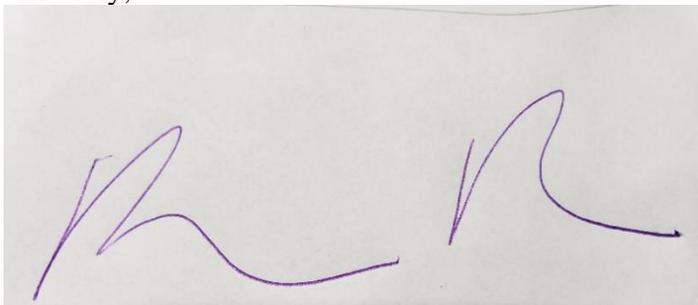
- **Expand the consideration of PWD in emergency response planning.**
  - State and local public health departments should be held accountable for the full inclusion of people with disabilities in planning, policy, and response initiatives. We recommend that public health and public emergency management entities develop and maintain ongoing communication and engagement with disability advisors at the local and state levels. To be most effective, this expertise should be embedded in the organizational decision-making structure, rather than existing solely in an advisory capacity.
  - The Disability and Health Programs – an underfunded existing state-based program at the Centers for Disease Control (CDC), National Center on Birth Defects and Developmental Disabilities (NCBDDD) – should be leveraged to respond to the emergent health threat of COVID-19 and to provide coordination of outcomes and significantly improve future plans. Action is needed to fund all states and major jurisdictions to contribute to a national surveillance system at the CDC for data on people with disabilities; to build state- and local-based networks to prepare, maintain, and distribute critical health communications for people with disabilities in all necessary formats; and to ensure state and local response capacity is prepared to provide public health services to people with disabilities in a public health emergency.
  - Accessible public health communication should be an explicit component of programs. Appropriate language use, accessible formats and innovative (and flexible) dissemination channels and strategies must be expected. This is critical in rural/remote areas of the U.S. where typical strategies (e.g., TV, print, billboards, etc.) don't appear to be as effective. We recommend that adequately defined accessible public health communication (e.g., what is accessible/plain language; what is accessible web formatting, etc.) be a measured and overt component of preparedness and response programs. While the ADA and Sections 504/508 clearly state expectations, they continue to be misunderstood and/or ineffectually met.
  - Pass the Disaster Relief Medicaid Act. As introduced in the 116<sup>th</sup> Congress, DRMA would ensure that individuals eligible for Medicaid who are forced to relocate due to a disaster are able to continue to access their Medicaid supported services.
  - Pass the READI for Disaster Act. As introduced in the 116<sup>th</sup> Congress, READI would establish a National Commission on Disability Rights and Disasters to study the needs of individuals with disabilities, older adults and others with access and functional needs throughout emergency preparation and planning, disaster response, recovery, and mitigation. Additionally, it would provide financial support to develop and provide technical assistance and training to disaster relief agencies and state and local emergency managers.
    - The May 13, 2021, announcement of the National Advisory Committee on Individuals with Disabilities and Disasters (NACIDD) from the Office of the Assistant Secretary for Preparedness and Response (ASPR) in the Department of Health and Human Services (HHS) Office of the Secretary is an important step in this area, but lacks the needed legislative authority provided by READI.
- **Improve inclusion of PWD in data collection.**
  - Data, including that from congregate care, testing, and other sources, should be disaggregated by disability status. Such a practice would improve estimates of disability in the community.
    - In general, comprehensive disability data is not being collected locally. Group home information is often used as a proxy for disability data, but this results in a significant underestimate by leaving out those living in the community, those on waiting lists, and those not connected to services.
    - SSDI receipt rates are also often used as proxy, but this is also significantly limited as many PWD do not receive SSDI.
  - We recommend that improved data representation be achieved at all levels of data collection: defining data priorities; identifying data disparities; measurement development;

data collection and distribution; data analysis and knowledge translation; and development of data-driven policy, strategy and solutions.

- At a minimum, HHS should collect disability status systematically in the same way that race and ethnicity are in any health-related data endeavor. A goal could be to develop a reporting system, like the civil rights data collection at Department of Education, for any health care entity receiving federal funding. This would allow better evaluation of civil rights statutes' implementation.
  - The lack of data collection/consistent data collection across HHS makes it extremely challenging to enforce civil rights statutes and have a transparent health care system. There is missing data on all fronts and minimal demographic data collected. Further, this would allow for an annual report (HHS OCR does not currently produce an annual report like the ED OCR annual report).
  - A fuller understanding of children's disability statuses should be integrated into the Title V Block Grant data system. The outdated siloing of that work (a mandated 1/3 of Maternal and Child Health Block Grant dollars in each state) as Children and Youth with Special Health Care Needs (CYSHCN), instead of children with disabilities, is a barrier. This could be a prime time to address this as HRSA MCHB focuses on an updated 15-year plan for this population.
- As you know, the education space includes some of the most robust data around disability.
  - We support the continuation of the seclusion and restraint initiative that has begun making changes and updating the processes for how schools enter seclusion and restraint data (not allowing for zeroes in certain cases, checking for misinformation, etc.). This work needs to continue for all the data and rapidly get underway before the '21-'22 data collection begins so the data is not in question, as was the '15-'16 and '17-'18 data.
  - In higher education, challenges exist as data does not clearly identify students with ID/DD and the language used to describe disability categories is different across datasets (RSA911, American Community Survey, NCES survey data).
    - It may be helpful to reach clarity about disability categories and definitions to drive better services.
- In employment, the Wage and Hour 14(c) certificate data collection system is significantly outdated, and the required information and review process must be updated. While the administration was recently working on updating the process to online, they did not update the information collected or the review process for when employers submit information. Some historical information should be maintained for longitudinal data collection purposes, but new information and updated information should be collected with triggers in place to flag if a non-compliant certificate is submitted. Even in states where the use of certificates is phased out, accurate, timely data to address compliance issues during that phase out period will still be needed. Data should include wage information as well.

AUCD and our network stand ready to engage and support your efforts to ensure the Public Health and Medical Preparedness and Response Programs meet the needs of all, including those living with disability.

Sincerely,



Rylin Rodgers  
Policy Director