



**CONSORTIUM FOR CITIZENS
WITH DISABILITIES**

June 6, 2020

The Honorable Nancy Pelosi
Speaker
United States House of Representatives
Washington, DC 20515

The Honorable Mitch McConnell
Majority Leader
United States Senate
Washington, DC 20510

The Honorable Kevin McCarthy
Minority Leader
United States House of Representatives
Washington, DC 20515

The Honorable Charles Schumer
Minority Leader
United States Senate
Washington, DC 20510

Dear Speaker Pelosi and Leaders McConnell, McCarthy and Schumer,

The undersigned members of the Consortium for Citizens with Disabilities (CCD) Health Task Force write to underscore our support for urgent legislation to help all Americans, including people with disabilities, to cope with the ongoing risks and ramifications of the COVID-19 pandemic. A fourth COVID-19 response package is necessary to provide critical resources to the disability community, which has been disproportionately affected by the disease. In particular, we support targeted funding for Medicaid, including a 14 percentage point increase in Federal Medical Assistance Percentage (FMAP) and an additional 10 percentage point FMAP boost for home and community-based services (HCBS). In conjunction with other protections and coverage enhancements listed below, these Medicaid resources will save lives, allow people to stay in their communities, and help us recover from this terrible pandemic.

CCD is the largest coalition of national organizations working together to advocate for federal public policy that ensures the self-determination, independence, empowerment, integration and inclusion of children and adults with disabilities in all aspects of society.

COVID-19 has hit the disability community particularly hard, with infection and death rates as much as five times higher than the general population.¹ Home and community-

¹ Danny Hakim, NEW YORK TIMES, *'It's Hit Our Front Door': Homes for the Disabled See a Surge of COVID-19* (Apr. 8, 2020), <https://www.nytimes.com/2020/04/08/nyregion/coronavirus-disabilities-group-homes.html>; Margaret A. Turk et al., *Intellectual and Developmental Disability and COVID-19 Case-Fatality Trends: TriNetX Analysis*, DISABILITY AND HEALTH JOURNAL (May 2020), <https://doi.org/10.1016/j.dhjo.2020.100942>; Joseph Shapiro, NPR, *COVID-19 Infections and Deaths are Higher Among Those with Intellectual Disabilities* (June 9, 2020),

based services (HCBS) programs and providers continue to provide individualized, life-sustaining daily in-home services even as they face staff shortages due to sickness, self-isolation, and low wages. These services are particularly critical now in light of the outbreaks taking place in congregate settings around the country.

Like other facets of this pandemic, the devastating effects on the disability community and their caregivers are compounded by race, age, and other systemic inequities. We need to see the issues through these compound lenses. Several studies indicate that the most affected congregate settings also have a higher proportion of residents of color.² And most of the low-wage HCBS caregiver workforce – 62 percent of all home care workers – are people of color.³ They, along with all HCBS caregivers, paid and unpaid, have struggled to get protective equipment and other resources they need, despite higher infection risk.

We strongly support additional federal supports for the Medicaid program. People with disabilities rely on Medicaid for critical health care and community-based supports and services they need to work and live in their communities. Unfortunately, because they have higher needs and resultant costs, people with disabilities are often the first to feel the brunt of Medicaid cuts. An FMAP boost of 14 percentage points until the labor market and state budgets recover, but at least through June 30, 2021, would add critical federal resources that will help states and providers to manage increased enrollment and reduced revenues and avoid gutting State Medicaid programs during an unprecedented public health emergency. The pressure on Medicaid programs and providers will only worsen over coming months as Medicaid covers millions who lose health insurance stemming from COVID-19-related job losses. We urge you to support this broad FMAP increase, included in the HEROES Act, and also to extend the FMAP increase to apply to adults covered through Medicaid expansion, which includes millions of people with disabilities.

We also urge you to maintain the strong maintenance of effort (MOE) protections that were included in the Families First Coronavirus Response Act. Any weakening of that MOE, such as the limited exemption in the HEROES Act, puts Medicaid coverage, eligibility and services at risk at a time when access to health care is absolutely crucial. The Senate should eliminate such exemptions in its COVID-4 package. Even people with disabilities who have additional insurance, such as Medicare or private coverage, rely on access to Medicaid's typically broader range of supports and services. Medicare and many private insurers offer little or no coverage for critical supports like HCBS, dental, vision, and hearing. In many states, Medicaid does.

<https://www.npr.org/2020/06/09/872401607/covid-19-infections-and-deaths-are-higher-among-those-with-intellectual-disabili>.

² See, e.g., Joseph Shapiro et al., NAT'L PUB. RADIO, *In New York Nursing Home, Death Comes to Facilities with More People of Color* (Apr. 22, 2020), <https://www.npr.org/2020/04/22/841463120/in-new-york-nursing-homes-death-comes-to-facilities-with-more-people-of-color>; Hannah R. Abrams et al., *Characteristics of U.S. Nursing Homes with COVID-19 Cases*, J. AM. GERIATRICS SOC. (June 2, 2020), <https://doi.org/10.1111/jgs.16661>.

³ PHI, U.S. Home Care Workforce: Key Facts (2019), <https://phinational.org/resource/u-s-home-care-workers-key-facts-2019/>

To ensure continued access to the HCBS that help many people with disabilities remain in their own homes – and safer from COVID-19 – we also urge Congress to dedicate an additional 10 percent FMAP increase specifically to Medicaid HCBS, as is included in the HEROES Act. Prior funding packages have largely overlooked HCBS, despite the extra burdens and risks that COVID has created for the disability community. Dedicated funds are needed to immediately address these unique challenges. The enhanced FMAP approach builds on existing Medicaid infrastructure to allow states to quickly and flexibly transfer resources to HCBS programs and providers that desperately need it. We look forward to working with you to make an important clarification in the HEROES Act: the definition of HCBS must clearly include community-based services for all people with disabilities and older adults, including community-based mental health services.

We also urge Congress to enact provisions that support improved coverage and access to health care through a variety of approaches, including:

- Data collection requirements that include stratification of reporting by key demographic groups, including disability, age, sex, sexual orientation, gender identity, race, ethnicity, primary language, and treatment setting. While the HEROES Act included disability in several data collection provisions, we ask you to include it as a standard part of any data stratification requirement. Congress should be clear that data stratification should allow for intersectional comparisons. For example, researchers and advocates should be able to examine data not only by disability *or* by race/ethnicity, but also disability *and* race/ethnicity;
- Special enrollment periods for Marketplace insurance for uninsured individuals and for Medicare Parts A & B to allow for immediate access to coverage during the health emergency;
- Nondiscrimination protections that prohibit providers of services and supports funded by HEROES and the healthcare provisions of earlier COVID response legislation from turning people away due to their age, disability, sex (including sexual orientation, gender identity, and pregnancy, childbirth, and related medical conditions), race, color, national origin, immigration status, or religion;
- Federal subsidies for COBRA coverage that will help some workers who lose their jobs from also losing insurance during the pandemic;
- A withdrawal and reconsideration of the proposed Medicaid Fiscal Accountability Regulations. These vaguely drafted proposed regulations would introduce tremendous uncertainty and could hinder states ability to generate the nonfederal share of Medicaid funding, exactly at the time of tremendous job losses when Medicaid provides a crucial lifeline.

For decades, the disability community and Congress have worked together to ensure that people with disabilities of all ages have access to health care and HCBS that allow them to live, work, go to school, and participate in their communities instead of living in institutions. Please continue to support these goals by including the resources and protections for Medicaid and other key programs outlined above in your COVID-4

legislation. We remain ready and willing to work with you to do so. Please reach out to Rachel Patterson at the Epilepsy Foundation at rpatterson@efa.org with any follow up.

Sincerely,

The undersigned members of the CCD Health Task Force:

American Association on Health and Disability
American Medical Rehabilitation Providers Association (AMRPA)
American Music Therapy Association
American Occupational Therapy Association (AOTA)
American Physical Therapy Association
American Speech-Language-Hearing Association
Association of People Supporting Employment First (APSE)
Brain Injury Association of America
Center for Medicare Advocacy
Center for Public Representation
Disability Rights Education & Defense Fund (DREDF)
Easterseals
Epilepsy Foundation
Family Voices
Justice in Aging
Lakeshore Foundation
National Alliance on Mental Illness
National Alliance to End Homelessness (NAEH)
National Association of State Head Injury Administrators
National Center for Parent Leadership, Advocacy, and Community Empowerment
(National PLACE)
National Disability Rights Network
National Down Syndrome Congress
National Health Law Program
Paralyzed Veterans of America
Special Needs Alliance
The Arc of the United States