

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

The Honorable Nancy Pelosi Speaker United States House of Representatives Washington, DC 20515 The Honorable Charles Schumer Democratic Leader United States Senate Washington, DC 20510

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

June 25, 2020

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

The undersigned members of the Consortium for Citizens with Disabilities (CCD) write in response to the recently passed H.R. 6800, The Heroes Act. 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. We strongly support several provisions related to paid family and medical leave included in this legislation and urge you to include these provisions in the next legislative package to address the coronavirus pandemic.

Many people with disabilities, older adults, and their families face impossible choices as the COVID-19 public health crisis continues. The activities and programs that people with disabilities and many older adults rely on during the day while family members are at work are closed and even as reopening begins, many of these programs must dramatically change their structure (including by limiting the number of participants) to protect the high-risk people they serve. Children with disabilities have lost the usual support services they receive in school, sometimes requiring substantial assistance from their family members during working hours. This has created a care crisis as families struggle to provide the care that people with disabilities and older adults need. Because COVID-19 is a novel virus, we do not know how the next several months will unfold, but we do know that there will be additional flare ups of the virus and we know that people with disabilities and their families will need paid sick days and paid leave.

While Congress took some steps to address this crisis in March in the Families First Coronavirus Response Act, the emergency paid sick days and paid leave authorized by that law leave out millions of people and do not address many needs of people with disabilities, older adults, or

their families. CCD has developed principles detailing what a disability-inclusive paid leave program would look like and uses these principles to assess legislative proposals. In order to work for people with disabilities and their families, paid family and medical leave must be inclusive, comprehensive, and flexible and carefully integrated into existing programs and policies. Unfortunately, these principles are not met by the existing emergency paid leave and paid sick day provisions, which are not comprehensive or inclusive.

In particular, while emergency paid sick days are available for a comprehensive list of purposes, including medical and caregiving leave, emergency paid leave is available for only one purpose, to care for children (as defined by the Department of Labor to include adult children with disabilities) who have had schools close or have lost their usual source of care. This narrow purpose fails to address the needs of adults with disabilities who rely on partners, siblings, grandparents, or other family members to fill in when they lose their usual source of care. It also excludes older adults who rely on sons, daughters, and grandchildren. And it fails to address problems that the pandemic creates, such as the need for paid leave for people with disabilities who experience complications from COVID-19 or the need for paid leave to self-isolate if the worker or a member of their household are at particular high risk of complications.

In addition, the law fails comprehensively include all workers, excluding private employers with 500 or more employees and allowing employers of health care providers and emergency responders to opt out of providing emergency paid sick days and emergency paid leave, despite the fact that health care workers are on the frontlines of the pandemic and face higher exposure risk to COVID-19. We understand the difficulties faced by industries where there are staffing shortages of particular health care professionals. The disability community faces such shortages for direct support professionals and many other of our frontline workers. However, individuals who become sick with COVID-19 should be able to take paid sick days or paid leave to ensure that they do not infect others, especially since many serve those with high risk of complications such as people with disabilities.

We are also extremely concerned with the devaluing of care work in the emergency paid leave program, excluding caregivers from the full benefits of the emergency leave and paid sick days. It is unacceptable that the wage replacement for caregiving is two thirds of the wage replacement for medical leave. Caregiving can make the difference between life and death for individuals who are receiving care--people with disabilities often rely on family caregivers for incredibly personal and important things, from help with eating to getting out of bed in the morning. Family caregiving is often in addition to or in conjunction with paid caregiving assistance from health care professionals. Now, with the pandemic impacting frontline health care workers in particular, many families are continuing to provide care without their usual help and Congress has told them that this care is not as important as other kinds of care. This is unacceptable. The wage replacement rate for caregivers must be increased to the same level as other reasons for leave.

Finally, we understand that Congress was acting quickly to address the pandemic and thought initially that leave through the rest of this year would be sufficient, but we now face continued months of uncertainty as we wait for a vaccine. We urge Congress to extend these emergency paid leave provisions until there is a vaccine. There is no other way to ensure that, as hot spots develop, people with disabilities, older adults, and their families can remain safe. We also urge Congress to continue work begun in the House earlier this year to enact a permanent paid leave program that would be available outside of the pandemic, when paid leave remains equally crucial.

We are grateful to see many of these issues addressed in the recently passed H.R. 6800, the Health and Economic Recovery Omnibus Emergency Solutions Act (HEROES Act). The HEROES Act expands the reasons for leave to cover a comprehensive list of purposes, includes all workers, and extends availability of the more comprehensive paid sick days and leave until December 31, 2021. While the HEROES Act does address the pay disparity for caregivers for paid sick days, it does not do so for leave. We urge you to fix this omission and adopt the rest of the HEROES language as you move forward with the fourth Coronavirus response package.

Thank you for your consideration of this important legislative priority to ensure that people with disabilities and their families are better financially supported during the COVID-19 pandemic. Please contact Bethany Lilly (lilly@thearc.org) with any questions.

Sincerely,

American Civil Liberties Union
American Music Therapy Association
Autistic Self Advocacy Network
Autistic Women and Nonbinary Network
Center for Public Representation
CommunicationFIRST
Epilepsy Foundation
Family Voices
National Alliance for Caregiving
National Association of Councils on Developmental Disabilities
National Respite Coalition
Paralyzed Veterans of America
RespectAbility
TASH
The Arc of the United States