



**CONSORTIUM FOR CITIZENS
WITH DISABILITIES**

March 14, 2020

The Honorable Mitch McConnell
Majority Leader
U.S. Senate
Washington, DC 20515

The Honorable Charles Schumer
Minority Leader
U.S. Senate
Washington, DC 20515

Dear Leaders McConnell and Schumer,

The Consortium for Citizens with Disabilities (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 write in response to the growing outbreak of COVID-19 across the United States. People with disabilities are, and will be, particularly at risk as COVID-19 spreads across the country, facing high risk of complications and death if exposed to the outbreak and needing to isolate themselves for protection. We urge Congress to focus on people with disabilities and their needs in legislation in response to the outbreak.

We are pleased to see that the package that passed the House includes increased reimbursement for state Medicaid programs, emergency requirements for all health insurers to cover COVID-19 testing, paid sick days and paid leave, and expanded nutrition assistance. All of these are crucially important parts of a federal response to the outbreak. As the legislation moves forward, we urge Congress to ensure that the workforce needs within Medicaid are considered, that the caregiving covered by both paid sick days and paid leave includes all caregiving that might be necessary for adults and children with disabilities, that it include sufficient resources for the Social Security Administration to administer any paid leave programs, and that steps are taken to ensure people with disabilities have access to a 90-day medication and medical supply fills. In addition, we urge Congress to provide states with resources they need to ensure that even during this crisis, people with disabilities have the

supports they need to remain in the community and are not forced into institutional or other congregate settings in violation of their rights and at risk to their health.

1) Ensure Medicaid Has Sufficient Resources for this Major Health Crisis

Millions of people with disabilities rely on Medicaid services to access basic health care services as well as services that ensure their functioning, independent living, and well-being, including: nursing and personal care services, specialized rehabilitation and other therapies, intensive mental and behavioral health services, prescription medications, special education services, and other needed services that are often unavailable through other insurance. Access to these services is often a matter of life, death, independence, and civil rights for the millions of people with disabilities on Medicaid. Given the major health crisis we face, we are extremely concerned that the service demand on Medicaid will rapidly increase. The 71.2 million people who rely on Medicaid will need access to comprehensive treatment for COVID-19, as will the over 27 million uninsured individuals in the United States, and the untold numbers of people who may become eligible for Medicaid due to economic challenges stemming from the outbreak.

We strongly supported the original 8% bump to the Federal Matching Percentage for Medicaid included in the House legislation, despite knowing that a larger bump would do more good for state systems and for people with disabilities. Therefore, we are alarmed and dismayed that this has now been reduced to 6.2%. We urge Congress to restore the earlier 8% rate, and to consider expanding to 10% or above to ensure that states truly have all of the resources they will need. As you know, because Medicaid is a joint federal-state partnership, the federal government pays a fixed share of a state's Medicaid costs, while states contribute the remainder. As service demand increases, we know that states will face intense budgetary pressures and we are very concerned that these pressures will negatively impact people with disabilities via cuts to eligibility or necessary services or decreased reimbursement. We strongly urge Congress to pass substantially increased funding for Medicaid, easing the burden on states and ensuring that people with disabilities can still maintain access to the services they need.

In addition, as Congress acts on this package, we want to highlight the particular issues facing the Medicaid workforce that supports people with disabilities. The workforce that supports people with disabilities and aging adults to live in the community is already at a point of crisis, with over 50% turnover and over 10% standing vacancy nationwide, low wages at less than \$10 per hour nationally, and over half of the workforce reliant on public assistance programs. In addition, many workers do not receive basic benefits such as paid sick days, putting both workers and the people with disabilities they support at risk.

We strongly support expanding sick days for these workers, but that alone is not enough. Because their wages and benefits are tied to Medicaid reimbursement rates, we urge Congress

to consider this workforce not only when thinking of paid sick leave, but to also consider mandating a specific rate increase to ensure that relief for the states is shared with this essential workforce. In particular, there will be a need for overtime and hazard pay and increased fringe benefits. If urgent attention is not paid to this workforce, and steps are not taken to ensure there are sufficient workers to handle the increased sick days and quarantine, we expect the spread of COVID-19 to accelerate among the over 4 million Americans who rely on homecare workers, as well as the workers themselves.

Additionally, we fear that, as the workforce crisis deepens in the face of the pandemic, people with disabilities may be forced into institutional and other congregate settings due to worker shortages. Those settings *increase* risk to the health and wellbeing of people with disabilities, as well as individuals who have to work in such settings. As we have seen in nursing facilities, controlling this epidemic is extremely difficult in congregate facilities. Such a move would also represent a serious violation of their well-established right to live and receive services in the community. The only way to prevent such an outcome is to ensure that states have the resources they need to support workers and those relying on them, before it is too late.

We also would urge Congress to pass permanent reauthorization of the Money Follows the Person (MFP) Program. The COVID-19 epidemic may lead to individuals with disabilities and aging adults being unnecessarily institutionalized, adding to the problem of individuals already waiting to be transitioned back to the community. More must be done to support people in their homes and in the community, but permanent MFP would provide funding to states to transition people back home and away from the congregate settings that are so especially dangerous to aging adults and people with disabilities right now. Spousal Impoverishment protections should also be made permanent so that aging adults can stay in their homes.

2) Ensure Access to Necessary Health Care, including Medications and Medical Supplies for People with Disabilities

We are glad to see that the House legislation includes a requirement that all payers cover the testing and associated office visits for COVID-19 without ANY cost-sharing. We are concerned that the same protections are not extended to the treatment of the virus, even for those who might be captured by the new state Medicaid option for uninsured individuals. If an individual is tested for a virus, but does not have access to health insurance coverage for the treatment of the virus, will they then be liable for costs of any quarantine or treatment? This seems likely to discourage uninsured people from seeking testing at all, since they may be unable to afford any prescribed treatment. We would urge Congress to include coverage of treatment for uninsured individuals to ensure that they will seek testing and treatment as soon as possible and not increase the community-spread. Congress should also consider additional cost-sharing

protections for all individuals in response to this new and novel disease to encourage testing and treatment.

In addition, the Center for Disease Control recommends that people with disabilities take several actions to reduce risk of being exposed and catching COVID-19, including having extra necessary and life-saving medications and other health-related supplies on hand and self-isolating. The recommendations explicitly suggest that people with disabilities utilize mail order pharmacies rather than visiting pharmacies, a protective step that we support. Unfortunately, there are barriers that prevent people with disabilities from taking such protective steps to be taken. These barriers include medications with particularly short fill terms (often those who fall under the Controlled Substance Act prohibitions, such as anti-seizure medications), strict prior authorization requirements, or other bureaucratic barriers. There are also limitations that would place people with disabilities at risk of exposure to the virus in order to access necessary medication, including limits on refills authorized via telehealth visits and restrictions on mail order pharmacies across state lines.

We urge Congress to require, on an emergency basis, that all payers cover up to a 90 day stockpile supply of medications and supplies and to allow for partial fills of medications. We also would urge Congress to allow all payers to cover refills authorized by telehealth visits and utilize mail order pharmacies, including those out of state. Critically, we urge Congress to ensure that controlled substances are included in these provisions.

3) Paid Sick Days and Paid Medical Leave

We support the Paid Sick Days provisions in the earlier House legislation. We were particularly glad to see that paid sick time under this provision can be utilized to care for loved ones who are “otherwise in need of care” since this will capture situations where people with disabilities have lost their primary source of care due to COVID-19 and need a loved one to step into that role. We are concerned that the latest language is more restrictive, and would not cover a family member or other individual stepping in as a caregiver if COVID-19 results in someone losing their usual source of care, and that it does not apply to caring for adults with disabilities. We expect this to be a major issue due to the workforce issues described above, and urge that this provision be broadened once again.

We also support the legislation’s recognition that paid family and medical leave is also needed to address the COVID-19 outbreak as sometimes longer leave will be required than that provided by sick days. This is especially true for people with disabilities who may have complications from COVID-19 due to their pre-existing conditions. We strongly support the hold harmless provisions related to both Title II and Supplemental Security Income benefits. We are

concerned, however, that the use of this leave for caregiving purposes is limited to caring for someone with a COVID-19 diagnosis or those caregiving for children or adults who are unable to attend school or other care programs as usual. Adults with disabilities may work or be involved in other activities in their communities outside of a “care program” and may in fact live on their own, but due to shortages of health care workers, require caregiving from loved ones. We urge Congress to broaden this definition.

We are very concerned that rather than passing a comprehensive paid leave program, the government is placing the burden on employers, who are already struggling under the economic burden of the crisis, to figure out how to pay for this leave and then claim a tax credit. Employers should not be placed in that situation and the federal government should use its resources to administer a real paid leave program.

4) Ensure That People with Disabilities Have the Services and Supports They Need in the Community and Reduce Unnecessary and Harmful Institutionalization

We must again reiterate that Congress must take steps to ensure that states have the resources they need to ensure that even during this crisis that people with disabilities have the services and supports they need to live in the community. Between the heightened risk of transmission of the virus in institutional settings recognized in the House legislation, and the workforce issues discussed above, these civil rights are even more important in this time of crisis. With federal support, states can take steps now to ensure that their workforce is prepared and that people with disabilities can continue to be supported in their homes and communities during this crisis. We urge Congress to support those efforts and ensure people with disabilities are not placed in congregate settings in violation of their rights and at risk to their health due to the shortcomings of our service system.

During times such as these, Federal public health and medical resources may be considered or utilized to fill extreme gaps in services. These personnel are typically unfamiliar with the obligations of the government to people with disabilities and older adults living in their own homes and in the community. These government personnel will need immediate training and technical assistance on self-directed assistance, optimizing health, safety, dignity, and independence as imperatives for maintaining the civil rights of people with disabilities and older adults whether they are at home, in community-based settings, or institutional facilities. The government resources that may be under consideration whose staff who will need training include:

- National Disaster Medical System- Disaster Medical Assistance Teams
- Medical Reserve Corps

- Public Health Service
- National Guard

5) Prohibit Discrimination Against People with Disabilities in Medical Decision Making

Proposals have been made to prioritize patients without pre-existing disabilities in the allocation of scarce resources, abandoning the principle of "first come, first serve". Denying or de-prioritizing access to care for those with co-occurring conditions would represent disability discrimination. While providers have the ability to determine a treatment is quantitatively futile --unlikely to be effective at accomplishing its goals--they should not be given the ability to deny or give lower priority to people likely to benefit from treatment on the grounds that their disabilities, chronic conditions, or age are associated with a higher fatality rate. Similarly, though patients with disabilities may require more intensive resources, it would be inappropriate and discriminatory to deny them access to care they would benefit from on those grounds. In times of resource scarcity, it is particularly important to emphasize that the lives of people with disabilities have value, even in the presence of severe intellectual disability, the need for ongoing long-term services and supports, dementia, mobility impairments and other conditions that have historically been used to call into question the value of the lives of people with disabilities.

6) Recognize that Housing is Health Care

Congress *must* ensure that any emergency spending package includes resources to ensure housing stability for people with the greatest needs. Extremely low-income renters and people experiencing homelessness are often seniors, people with disabilities and/or people with underlying health conditions, making them vulnerable to severe illness from the coronavirus. It is not only a moral imperative that Congress address their needs, but also a public health imperative. These same families and individuals are likely to live in close-quarters with others, be unable to implement social distancing mechanisms, and have no ability to self-isolate should they be exposed to the virus. Therefore, CCD strongly supports the recommendations of the National Low Income Housing Coalition's Disaster Housing Recovery Coalition, and urges that these recommendations be incorporated into any legislative efforts to address COVID-19.

7) Expanded Nutrition Assistance

We strongly support the expanded nutrition assistance included in the House legislation, especially provisions waiving the work requirements in SNAP for the duration of the emergency, addressing needed flexibilities related to congregate meals as schools and other meal sites close, and the increase in funding. Compared to people without disabilities, people

with disabilities and their families are significantly more likely to experience hunger and food insecurity. Similarly, people experiencing food insecurity have increased likelihood of chronic illness and disability. Studies have also consistently found high rates of food insecurity in households that include children with disabilities and that older adults and seniors with disabilities are also much more likely to experience food insecurity, compared to their peers without disabilities. Nutrition is also foundational to supporting a strong immune system, and should be considered a necessary component of an effective pandemic response. As more and more people with disabilities self-isolate to avoid becoming infected, this food support will become more and more important and we are glad to see Congress addressing these needs.

We know that we must act now to prevent much of the worst impact of this outbreak, and we are grateful for the House's prompt action. We urge the Senate to act quickly as well, making the updates suggested by this letter and promptly passing this crucial legislation. If you have any questions, feel free to contact Nicole Jorwic (jorwic@thearc.org)

Sincerely,

Emergency Management Co-Chairs:

Susan Prokop,
Paralyzed Veterans of America

Health Co-Chairs:

Dania Douglass,
Lutheran Services of America

Dave Machledt,
National Health Law Program

Rachel Patterson,
Epilepsy Foundation

Julie Ward,
The Arc of the United States

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Alison Barkoff,
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Dan Berland
National Association of State Directors
of Developmental Disabilities Services

Jennifer Lav
National Health Law Program

Sarah Meek
American Network of Community Options
And Resources (ANCOR)