

The Disability and Aging Collaborative

March 16, 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 Disability and Aging Collaborative (DAC) is a group of over 40 national Disability and Aging organizations that work together to promote policies to support the unique needs of people with disabilities and aging adults. The undersigned members of the DAC write to urge the Senate to pass H.R. 6201 as quickly as possible in response to the growing outbreak of COVID-19 across the United States.

People with disabilities and older adults are 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 to protect themselves. Going forward, we urge Congress to prioritize people with disabilities and older adults and their needs in legislative responses to the outbreak.

We strongly support the provisions in the package passed in the House early Saturday that provides increased reimbursement for state Medicaid programs, emergency requirements for all health insurers to cover COVID-19 testing free of charge, paid sick days and paid leave, and expanded nutrition assistance. All of these are crucially important parts of a federal response to the outbreak and will help keep people with disabilities and older adults safe.

As this, and any future, legislation moves forward, we write to urge Congress to ensure that:

- The workforce needs within Medicaid are considered and additional resources are made available to states and communities to reduce institutionalization;
- Caregivers of individuals across the lifespan are covered by both paid sick days and paid leave, with additional resources for respite care and Title III E caregiver supports under the Older Americans Act (OAA), along with sufficient resources for the Social Security Administration; and
- People with disabilities and older adults have access to a 90-day medication and medical supply fills.

Congress must take steps to provide states with resources they need to ensure that even during this crisis, people with disabilities and older adults have the supports they need to remain in the community and that they are not forced into institutional or other congregate

settings in violation of their rights and at risk to their health. We urge Congress to pass permanent reauthorization of the Money Follows the Person (MFP) Program and protections from spousal impoverishment for married individuals receiving HCBS. The COVID-19 epidemic may lead to individuals with disabilities and older 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 married couples can afford to stay together at home when a spouse develops a chronic illness or disability.

In addition, Congress must ensure that states and providers have sufficient resources to address underlying chronic conditions or serious injuries, such as falls, at the same time it combats the effects of the virus. As the disease spreads, the healthcare system will come under increasing strain. Without increased resources, patients may not receive adequate care needed to treat underlying or non-virus related conditions.

We also support efforts to ensure that low-income Medicare beneficiaries receive the help they need. Since millions of eligible beneficiaries have not enrolled to receive this premium and cost sharing assistance through Medicare Savings Programs and Extra Help, consideration should be given to auto-enrollment and enhanced outreach and assistance, so that they can afford necessary treatments related to COVID-19.

Following are five areas that require Congress's attention both immediately and throughout the response to ensure our response, health, and support systems are equipped to meet the needs of people with disabilities and older adults who are at particular risk from COVID-19.

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

We strongly support the 6.2% increase to the Federal matching percentage for Medicaid included in the House legislation. Millions of people with disabilities and older adults 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 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 and older adults on Medicaid. In addition, as Congress acts on this package, we want to highlight the particular issues facing the Medicaid workforce. The workforce that supports people with disabilities and older adults to live in the community is already at a point of crisis, with over 50% turnover 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 and older adults they support at risk. We also urge that consideration be given to providing grants to state for

workforce and unpaid caregivers, consistent with the infrastructure implementation grants for home and community-based services under S. 3277.

We strongly support expanding sick days for these workers, but that alone is not enough. Because their wages and benefits are tied to Medicaid rates, we urge Congress to consider this workforce not only when thinking of paid sick leave, but to also consider a specific FMAP increase to support this workforce. If urgent attention is not paid to this workforce, 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 and older adults 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 and older adults, and 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.

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

We are glad to see that H.R. 6201 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 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 risk of these individuals. As part of the solution, Congress must make clear that Medicaid COVID-19 testing and treatment services are fully covered as both “emergency services” and core benefits in Medicaid. We also encourage Congress to consider additional cost-sharing protections for all individuals in response to this new and novel disease to encourage testing and treatment.

In addition, the Centers for Disease Control recommends that people with disabilities and older adults 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 and older adults utilize mail order pharmacies rather than visiting pharmacies, a protective step that we support. Unfortunately, there are barriers that prevent people with disabilities and older adults from accessing a long-term supply of necessary medications or health-related supplies that would allow for 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 place people with disabilities and older adults 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 urge Congress to require 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) Expanded Nutrition Assistance

We strongly support the expanded nutrition assistance included in the House legislation, especially provisions to provide additional resources for senior congregate and home-delivered meals, waive the work requirements in SNAP for the duration of the emergency, and address needed flexibilities related to congregate meals as schools and other meal sites close. People with disabilities and older adults, and their families, are at high risk for experiencing 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. As more and more people with disabilities and older adults 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 have concerns that there is no funding in H.R. 6201 for the SNAP ABAWB suspension and emergency waiver authority, and urge that consideration also be given to investing in the Commodity Supplemental Food Program (CSFP) under USDA.

4) Paid Sick Days and Paid Medical Leave

We were disappointed to see that the paid sick and paid leave provisions were narrowed from earlier versions from “otherwise in need of care” since this will capture situations where people with disabilities and older adults have lost their primary source of care due to COVID-19 and need a loved one to step into that role. We expect this to be a major issue due to the workforce issues described above and it is imperative that the definitions are clearer that people who are caregivers to adults with disabilities and aging adults are included.

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 and older adults 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 of who can use the enhanced paid family and medical leave.

We also must express our concern about the lack of funding for the Social Security Administration (SSA) to administer this new program. While we value the hold harmless provision protecting the Trust funds, as the Consortium for Citizens with Disabilities Paid Leave Principles state, “[SSA] cannot afford to repurpose existing limited resources to implement a new program and even with its own funding, any new program would further burden the agency, creating additional and unacceptable delays.” We urge Congress to include resources for SSA beyond simply the resources required for this program to address the agency’s existing delays.

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

Finally, 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 and older adults 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. In addition to the related recommendations above, one of the most important steps that Congress can take at this point to avoid institutionalization is to invest in Administration for Community Living programs, such as those under OAA Title IIIB, that support the Aging and Disability Networks, which are the backbone of the nation’s non-Medicaid home and community-based services systems.

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 DAC co-chairs Nicole Jorwic (jorwic@thearc.org) and Howard Bedlin (Howard.Bedlin@ncoa.org)

Sincerely,

Disability and Aging Collaborative