April 16, 2020

The Honorable Mitch McConnell
Majority Leader
United States Senate
S-230, The Capitol
Washington, DC 20510

The Honorable Chuck Schumer
Minority Leader
United States Senate
S-221, The Capitol
Washington, DC 20510

The Honorable Nancy Pelosi
Speaker
United States House of Representatives
H-232, The Capitol
Washington, DC 20515

The Honorable Steny Hoyer
Majority Leader
United States House of Representatives
H-107, The Capitol
Washington, DC 20515

The Honorable Kevin McCarthy
House Minority Leader
United States House of Representatives
H-204, The Capitol
Washington, DC 20515

Dear Majority Leader McConnell, Minority Leader Schumer, Speaker Pelosi, Majority Leader Hoyer, and Minority Leader McCarthy:

The National Advisory Board (NAB) on Improving Health Care Services for Older Adults and People with Disabilities appreciates the continued efforts of the members of Congress to support the American people during this global coronavirus pandemic. The NAB is a diverse group of nonpartisan healthcare professionals and consumer advocates who are experts on long-term services and supports. For the past 13 years, we have been studying the populations in need of these services and the infrastructure that has evolved to meet their needs in their homes and communities. While we are sponsored by Anthem, our group functions independently in multiple arenas: internally providing guidance and advice to Anthem and their affiliates and externally conducting inquiries and studies, providing public comments and sharing pertinent opinions and advice with other consumer advocacy groups, providers, health insurers, trade associations, and industry representatives.

We have produced numerous reports of our findings, including the often-cited Declaration for Independence. This seminal document includes six foundational principles on which we believe America’s long-term service and supports service system must be based:

1. Enhance self-care through improved coordination
2. Encourage community integration and involvement
3. Expand accessibility of services and supports
4. Uphold personal preference
5. Empower people to participate in the economic mainstream
6. Invest in improved technology

We are requesting your leadership and your assistance to ensure that Congress protects the rights of people with disabilities and older adults, including access to acute and long-term care, during this pandemic. We believe it is fundamental for people with disabilities of all ages who receive assistance in the community to be able to maintain the functional services and supports they need to remain in our communities and live safely at home.

These critical services are provided by Direct Support Professionals (DSPs) and Personal Care Attendants (PCAs) who are essential to the well-being of people with disabilities and older adults. These workers are on the front line of the pandemic every day, across the nation, saving the lives of people with disabilities and older adults. They are often without personal protective equipment (PPE) and frequently work for very low wages. In most cases, without the services provided by DSPs and PCAs individuals are likely to experience unnecessary hospitalization and/or institutionalization, which is both expensive and, at this point in time, extremely dangerous.

In order to reduce the risk of tens of thousands more people of contracting the coronavirus and dying unnecessarily, the direct care workforce must be supported.

As you consider the fourth stimulus relief bill, the NAB believes it is important to reserve the capacity of hospitals and other inpatient facilities for individuals with acute care needs — especially COVID-19 patients -- and to ensure that people of all ages who are living successfully at home with the assistance of PCAs, DSPs and family caregivers are able to continue to do so.

This is both fiscally prudent and crucial for health and safety. As such, we recommend the Congress does the following:

- Designate Personal Care Attendants (PCAs), Direct Support Professionals (DSPs), and other homecare workers who assist individuals with activities of daily living (ADLs) and instrumental activities of daily living (IADLs) as “essential” and as “health care providers” for the purposes of receiving emergency resources and equipment and to continue to work during stay-at-home orders;
- Expand paid sick days and paid leave to all PCAs and DSPs, and remove state Medicaid restrictions on overtime pay for these direct care workers during staffing shortages due to the pandemic;
- Ensure that paid sick days and leave provisions include unpaid caregivers who can’t work because they are caring for an adult with a disability or aging family member whose in-home care provider is not available during the emergency (current Department of Labor rule does not include these individuals);

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• Ensure equal access to health care treatment and services by reinforcing and communicating obligations, under current law (the Americans with Disabilities Act, Section 504 of the Rehabilitation Act, Section 1557 of the Affordable Care Act) prohibiting discrimination on the basis of disability, including in decisions related to allocation of limited resources in short supply such as ventilators, hospital beds, personal protective equipment and personnel;

• Direct hospitals and other acute care facilities to provide exceptions to restrictive visitor policies to allow hospitalized people with intellectual disabilities, dementia, communication or behavioral support needs, who may otherwise be unable to fully understand and participate in their care, to have in-person support available from healthy caregivers, (family, DSPs, PCAs) to assist in the management of care and communication about treatment. This will protect both patients and hospital staff in meeting both health and safety needs; and

• Include coverage of peer support services for people with mental health and substance use disorders (MH/SUD) including telehealth and peer support groups for addiction recovery. Although most states do cover peer support services through their Medicaid programs, we support further expanded coverage of these useful services beginning immediately. Allow Medicaid and Medicare health plans to dispense a 90-day supply of medications or facilitate early and/or mail order refills of psychiatric prescriptions to reduce risk of COVID-19 exposure and promote continuity of care. Allow Medicare providers to bill for group MH/SUD telehealth services. These services support long-term recovery and decrease hospitalizations. It is the right time for full alignment of substance use privacy statute (42 CFR Part 2) with the HIPAA standard so as to not further stigmatize SUDs and be at parity with all other medical/behavioral services.

It is our wish that due consideration be given to these recommendations and the lifesaving outcomes they would yield for people with disabilities and older adults, as well as the direct care workforce who provide critical healthcare and services for them. We also support the recommendations recently submitted by America’s Health Insurance Plans (AHIP) and the National Managed Long Term Services and Supports Health Plan Association aligned with our recommendations. We are happy to provide additional information or answer any questions you may have.

Respectfully,

Lex Frieden, Convener
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