



October 21, 2021

Dear Director Knackstedt,

My name is Maria Town, and I serve as the President and CEO of the American Association of People with Disabilities (AAPD). AAPD is a national, cross-disability civil rights organization that works to increase the political and economic power of people with disabilities. We advocate for full civil rights for the over 60 million Americans with disabilities by promoting equal opportunity, economic power, independent living, and political participation.

On behalf of AAPD and the millions of disabled Americans we work on behalf of, I'm writing to express our urgent support for ensuring the maximum amount of funding possible for Medicaid Home and Community Based Services (HCBS) in the Build Back Better reconciliation negotiations. AAPD and the coalition of disability, labor, and gender justice groups that have joined together to fight for our nation's care infrastructure have consistently maintained that a minimum investment of \$250 billion is necessary to build a sustainable HCBS infrastructure in all 50 states that can begin to address the magnitude of need in our communities.

Due in large part to a long history of inadequate funding at the federal level, our current state HCBS systems leave behind those who these systems were intended to serve. Over 800,000 people with disabilities are currently on waiting lists for the Medicaid-funded services. In some states the waiting lists for services are decades long. Many more people with disabilities are entering institutions and other congregate settings not because they want to but because they have to because they can neither get the funding nor the setting of their choice. At AAPD, we have heard story after story of individuals sleeping overnight in their wheelchairs during gaps in care, or symptoms worsening significantly because someone could not receive regular support. People with disabilities and their families are forced out of the workforce and into poverty because they cannot access the support they need to meet their basic needs, and even with these sacrifices, sometimes the only option available to an individual is to leave the home they love and enter a congregate setting.

The long-time inadequate funding for HCBS has not only resulted in a lack of access to care but a crisis among the availability of direct support workers. Direct support professionals, often called home care workers, are disproportionately women, people of color, and immigrants. Nearly 9 in 10 workers are women, while 62 percent are people of color (compared to 38 percent of the U.S. labor force), and 31 percent are immigrants. Home and community-based services must, by definition, be provided in person, with intimate contact between the worker and client. These workers have had to balance their own child care and family care obligations, and have been given little federal support for personal protective equipment, sick leave, or hazard pay. On average direct support workers earn \$12.00 an hour and must work multiple



jobs to make ends meet and often leave the care workforce for jobs with higher pay and benefits.

These deeply concerning trends existed long before the COVID-19 pandemic, and they have only grown more dire since the virus began to spread. With less than 1% of the country's population living in congregate settings like nursing homes, groups homes and psychiatric facilities, these settings have comprised almost 40% of COVID deaths. This is not just a human tragedy – it is a civil rights violation. Under the Americans with Disabilities Act of 1990 and under the Supreme Court's 1999 *Olmstead* decision, people who want to live at home, and who could safely live at home with the proper supports, have a right to live in the community rather than an institution.

Yet, in the midst of a pandemic, our funding priorities have not strengthened the ability to stay safely at home, and have largely ignored the workforce that is key to preventing people with disabilities and seniors from being forced into some of the most dangerous congregate living situations in the country. This problem will only get worse as mounting state budget crises make Home and Community Based Services (HCBS) programs difficult, if not impossible, to maintain without additional federal help. Over-reliance on congregate care settings and underinvestment in HCBS continues to lead to needless infections and avoidable deaths.

Most people far prefer to remain in their homes as they age, and research has shown that quality of life is significantly improved when individuals are able to live in the community. For the build back better agenda to truly achieve its goals of an equitable, resilient recovery from this deadly pandemic, we need as large of an investment in home and community based services as possible. Investing in HCBS will spur increases in disability employment, care worker employment, and the employment of our family members. Reducing our nation's reliance on congregate care will prevent future deaths and make our nation better prepared to confront future disasters.

I once again thank you for your leadership and urge that you continue to prioritize getting as close as possible to a \$250 billion investment in the infrastructure of Medicaid HCBS, and the workforce that provides them, as you negotiate recovery legislation. AAPD stands ready to assist you in any way we can. If you have any questions, please contact me at mtown@aapd.org.

Sincerely,

Maria Town

President and CEO, American Association for People with Disabilities