



March 29, 2022

Re: Urgent need for expansion of HCBS

To the Senate Special Committee on Aging,

I am writing to request that the federal government **expand access to quality home and community-based services (HCBS) and invest more funding and resources to the direct support workforce**. I am both a researcher and a disabled person who is observing and living out this crisis in multiple ways. Our University of Cincinnati Center for Excellence in Developmental Disabilities works to improve outcomes for people with disabilities. We do this in several ways, including gathering information and increasing knowledge about the current state of Ohioans with disabilities. In Ohio, we have more than 68,000 people on a waiting list for HCBSⁱ. Unfortunately, our state also maintains the 2nd largest number of institutions that severely restrict the community integration of Ohioans with disabilitiesⁱⁱ-more than 30 years after the Americans with Disabilities Act and more than 20 years after the Olmstead Supreme Court Decisionⁱⁱⁱ.

Thank-you for facilitating last week's hearing on our country's urgent need and long-overdue investment in HCBS, including bolstering our direct support provider workforce. I appreciated the DSP perspectives shared during the hearing. Direct care providers make a median hourly wage of \$12.10 an hour or \$16,200 each year. Here in Ohio, the lowest wage for someone to meet their basic needs—like rent, food, and healthcare—is \$13.16 an hour. The staffing shortage, along with bureaucratic and administrative flaws in the systems, are creating dangerous – and in some cases, deadly – situations for Ohioans with disabilities and people nationwide.

The Better Care Better Jobs Act, which will provide more money and resources devoted to paying and retaining direct support workers that reflects just how valuable they are to millions of people with disabilities: a lifeline and a way to live independently, in our communities, and out of the institutions we have fought against for so many years. Recent analyses indicate a minimum \$150 billion and ideally a \$400 billion investment would fund



progress to matching our HCBS system's capacity with the increasing and under met needs of aging Americans and Americans with disabilitiesⁱⁱ.

In addition to increased federal investment in HCBS, Congress should compel the US Bureau of Labor Statistics to establish a Standard Occupational Classification for Direct Support professionals. The absence of this classification status has allowed states to underpay DSPs and it forgoes a path for people to make this important profession a career.

Much of my work in the last two years has studied the tragic cost of what our system lacks. More than 200,000 Americans-most with disabilities-have died in congregate settings^{iv}. Many died waiting for the lives in their communities that our laws and values uphold. People with disabilities have shown immense resilience despite disproportionate losses during the Covid-19 pandemic. Hope for these critical improvements in the system is waning but remains. We must act now in improving our HCBS infrastructure.

Thank you for your consideration and service.

Sincerely,

Kara Ayers

Associate Director of the University of Cincinnati Center for Excellence in Developmental Disabilities (UCCEEDD)

Director of the Center for Dignity on Healthcare for People with Disabilities

Assistant Professor, Division of Developmental and Behavioral Pediatrics and the University of Cincinnati College of Medicine

Kara.ayers@cchmc.org

937-305-8254

ⁱ "IDD Waiting List Enrollment for Medicaid Section 1915(c) Home and Community Based Services Waivers as of 2018," State Health Facts. Washington, DC: Kaiser Family Foundation, accessed March 28, 2022.

ⁱⁱ "The Case for Inclusion 2022: Blazing Trails for Sustainability for Community Disability Services," ANCOR Foundation and United Cerebral Palsy, accessed March 28, 2022.

ⁱⁱⁱ *Olmstead v. L.C.*, 527 U.S. 581 (1998).

^{iv} "Over 200,000 Residents and Staff in Long-Term Care Facilities Have Died from Covid-19". Washington, DC: Kaiser Family Foundation, accessed March 28,2022.