July 6, 2023

The Honorable Debbie Dingell
102 Cannon House Office Building
U.S. House of Representatives
Washington, DC 20515

The Honorable Robert P. Casey Jr.
393 Russell Senate Office Building
United States Senate
Washington, DC 20510

Dear Ranking Member Dingell and Chairman Casey:

United Spinal Association is pleased to write in strong support of H.R. 1493/ S.762, the Home and Community Based Services (HCBS) Access Act. This critically important legislation is designed to ensure eligible older adults and people with disabilities have a real choice of care and support options between home care and institutional care. The bill would, over time, eliminate HCBS waiting lists and the need for states to repeatedly apply for HCBS waivers. The safety, health, and well-being of older adults and those with disabilities can be improved significantly with the HCBS Access Act.

United Spinal, founded by paralyzed veterans in 1946, is dedicated to enhancing the quality of life of all people living with spinal cord injuries and disorders (SCI/D), paralysis, neurological conditions and other mobility disabilities, including veterans, and providing support and information to loved ones, care providers and professionals. United Spinal represents 5.5 million wheelchair users across the country, has over 61,000 members, 47 chapters, 120 support groups and 115 rehabilitation facilities and hospital partners nationwide. Additionally, we work collaboratively with Spinal Cord Injury Model (SCI) System Centers and the Model Systems Knowledge Translation Center that provide innovative research and support in the field of SCI. United Spinal Association is also a VA-accredited veterans service organization (VSO).

United Spinal shares your understanding of what this home and community-based care can mean in the lives of individuals and families. The current system fails to meet the needs of millions of people with disabilities with critical home and community supports needs. The HCBS Access Act is a prime example of what can change for these individuals on a daily basis. The overarching goals of this act are:

- Eliminate waiting lists for HCBS, which delay access to necessary services and civil rights for people with disabilities and older adults.
- Build on decades of progress in serving people with disabilities and older adults via HCBS.
- Fulfill the purposes of the Medicaid program to provide medical assistance for those whose income and resources are insufficient to meet the costs of necessary medical services, and to provide rehabilitation, long-term services and supports, and other services to help such families and individuals attain or retain capability for independence or self-care.
- Ensure that people with all kinds of disabilities and with multiple disabilities, including intellectual disability, cognitive disabilities, developmental disabilities, behavioral health disabilities, physical disabilities, and substance use disorders, and older adults, receive the services they need to live in their communities.
- Streamline access to HCBS by eliminating the need for States to repeatedly apply for waivers.
- Continue to increase the capacity of community services to ensure people with
disabilities and older adults have safe and meaningful options in the community and are not at risk of unnecessary institutionalization.

- Act on the decades of research and practice that show everyone, including people with the most severe disabilities, can live in the community with the right services and support.
- Support over 53,000,000 unpaid family caregivers who are often providing complex services and support to older adults and people with disabilities because of a lack of affordable services, workforce shortages, and other inefficiencies.
- Improve direct care quality and address the decades long workforce barriers, which have been exacerbated by the COVID–19 pandemic, for nearly 2,600,000 direct care professionals providing support to people with disabilities and older adults in their homes and communities.
- Remove race, gender, sexual orientation, and gender identity disparities that exist in accessing HCBS.

Activities like eating, bathing, transportation, access to medication, managing finances, and more are tasks that individuals with disabilities need help with daily. Individuals should not have to be forced into institutional care and away from the comfort of their own homes to access the care they need for daily tasks. The HCBS Access Act can help change the status quo.

Common themes from our community members:
“I have to rely on my caregiver for daily assistance in order to live and participate in his community.”
“My caregiver does everything I need done including clothing, meal preparation, and transporting me to medical appointments and community activities.”
“Pay rates should increase for the Medicaid community care attendants so we can keep them and not have to keep looking for new caregivers and training them all over again.”
“I am a public transportation rider and due to service area restrictions and barriers I do not have access to all of the places I have to go.”
“More funding is needed for training and maintaining highly skilled attendants to provide us with the care we need.”

Individuals, family members, care support staff, and many more need the HCBS Access Act to feel safe and assisted in whatever setting they choose. When resources are not easily accessible, individuals with disabilities and seniors can be seriously limited in their day to day lives. This can lead those and their families to feel fear and anxiety with the “what if’s” of care and support. The HCBS Access Act will provide for needed gaps in the existing care support network and United Spinal fully supports this bill.

Thank you for considering these comments. Should you need further information or have any questions please contact Rebecca MacTaggart at rmactaggart@unitedspinal.org.

Sincerely,

Alexandra Bennewith

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Vice President, Government Relations