

July 19, 2021

The Honorable Chuck Schumer
Majority Leader
U.S. Senate
Washington, DC 20510

The Honorable Mitch McConnell
Minority Leader
U.S. Senate
Washington, DC 20510

The Honorable Nancy Pelosi
Speaker
U.S. House of Representatives
Washington, DC 20515

The Honorable Kevin McCarthy
Minority Leader
U.S. House of Representatives
Washington, DC 20515

Dear Leaders Schumer and McConnell and Speaker Pelosi and Leader McCarthy,

The undersigned organizations are writing to express support for the FULL \$400 billion for Medicaid Home and Community Based Services (HCBS). This level of investment is essential for building a sustainable HCBS infrastructure that can *begin to address the magnitude of need in our communities*, both increasing access to Medicaid HCBS *and* addressing the direct care workforce crisis--creating more direct care jobs to support people with disabilities and aging adults, and making those jobs better.

To address the long-standing inequities the pandemic exposed and exacerbated, this investment is critical to fortify a workforce that must continue to expand to meet a rapidly increasing level of need. The HCBS workforce provides vital services, and yet these workers--who are primarily women of color--have been devalued and underpaid for decades, leading to severe staff shortages that can result in crucial gaps in service availability, lengthy waiting lists, service line closures, and additional obstacles to achieving a high quality of life for workers and recipients alike.

Due in large part to a long history of inadequate funding at the federal level, the system itself is not serving everyone who needs HCBS, even though 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. Further, people with disabilities of all ages have a legal right to receive services and supports in the most integrated setting, regardless of the source of payment for services. Yet, 31 years after the passage of the Americans with Disabilities Act, over 800,000 people with disabilities are currently on waiting lists for the Medicaid-funded services needed to make that possible, and many more are entering institutions against their wishes because they do not have qualified and trained direct care staff to support them in the setting of their choice. These waiting lists leave people with disabilities,

aging adults and their families waiting years and even decades for services. The investments in the Build Back Better Agenda are crucial to reach this as yet unrealized goal of the Americans with Disabilities Act.

When older adults who want to age in place and people with disabilities who need support to work, live independently, and be a part of their communities are left waiting, the responsibility for care and support often falls on unpaid family caregivers, who also need financial assistance. The costs of this inadequate system fall disproportionately on people of color with limited income and wealth. The workforce and earnings losses related to unpaid family caregiving are significant and well-documented.

We once again thank you for your leadership and urge that you continue to include and prioritize the full \$400 billion investment in the infrastructure of Medicaid HCBS, and the workforce that provides them, as you negotiate recovery legislation. We stand ready to assist you in any way we can. If you have any questions, feel free to contact Nicole Jorwic (jorwic@thearc.org)

Sincerely,

AARP
ABA Center for Excellence
Alliance for Aging Research
Alliance for Retired Americans
Allies for Independence
American Academy of Pediatrics
American Association for Psychoanalysis in Clinical Social Work
American Association of People with Disabilities
American Association on Health and Disability
American Civil Liberties Union (ACLU)
American Civil Liberties Union of WV
American Council of the Blind
American Foundation for Suicide Prevention
American Geriatrics Society
American Music Therapy Association
American Network of Community Options & Resources (ANCOR)
American Occupational Therapy Association
American Psychological Association
Anxiety and Depression Association of America
The Arc of the United States

Association for Ambulatory Behavioral Healthcare
Association of Assistive Technology Act Program
Association of University Centers on Disabilities
Autism Society of America
Autistic Self Advocacy Network
Bazelon Center for Mental Health Law
Brain Injury Association of America
Broward for Progress
California State Council on Developmental Disabilities
Caring Across Generations
Center for Medicare Advocacy
Center for Popular Democracy
Christopher & Dana Reeve Foundation
Clinical Social Work Association
Coalition of Texans with Disabilities
CommunicationFIRST
Community Catalyst
CRR Behavioral Services
Cure SMA
Depression and Bipolar Support Alliance
Disability Policy Consortium
Disability Rights Education & Defense Fund (DREDF)
disABILITYsa
Disabled Queers in Action!
Down Syndrome Association of Northern Virginia
Easterseals
Epilepsy Foundation
Families USA
Family Voices
Georgia Council on Developmental Disabilities
Goodwill Industries International, Inc.
Groundwork Action
Health Care Voices
Idaho Council on Developmental Disabilities
Illinois Council on Developmental Disabilities
International Society for Psychiatric Mental Health Nurses
Jews for Racial & Economic Justice
Justice in Aging
Lakeshore Foundation
Legal Action Center
Little Lobbyists
Lutheran Services in America

Maryland Developmental Disabilities Council
Maternal Mental Health Leadership Alliance
Maternal Mental Health Leadership Alliance
Medicare Rights Center
Mental Health America
Michigan Developmental Disabilities Council
Mind Life Balance, LLC
MomsRising
NACBHDD and NARMH
National Academy of Elder Law Attorneys
National ADAPT
ADAPT Georgia
ADAPT Gulf Coast
MassADAPT
ADAPT Montana
ADAPT of Texas
National Adult Day Services Association (NADSA)
National Alliance for Direct Support Professionals, Inc.
National Alliance on Mental Illness
National Alliance to End Homelessness
National Association of Councils on Developmental Disabilities
National Association for Home Care and Hospice
National Association of Area Agencies on Aging (n4a)
National Association of Nutrition and Aging Services Programs
National Association of Pediatric Nurse Practitioners
National Association of Social Workers (NASW)
National Association of State Directors of Developmental Disabilities Services
National Association of State Head Injury Administrators
National Association of State Mental Health Program Directors
National Center for Learning Disabilities
National Center for Parent Leadership, Advocacy, and Community Empowerment (National PLACE)
National Consumer Voice for Quality Long-Term Care
National Council for Mental Wellbeing
National Council on Aging
National Council on Independent Living
National Disability Rights Network (NDRN)
National Domestic Workers Alliance
National Down Syndrome Congress
National Federation of Families
National Health Care for the Homeless Council
National Health Law Program
National League for Nursing

National Multiple Sclerosis Society
National PACE Association
National Register of Health Service Psychologists
National Respite Coalition
National Women's Law Center
Partnership for Inclusive Disaster Strategies
Personal Attendant Coalition of Texas
Postpartum Support International
R2H Action [Right to Health]
RespectAbility
REV UP Texas
Rights & Democracy (New Hampshire & Vermont)
SEIU
SMART Recovery
Social Security Works
SPAN Parent Advocacy Network (SPAN)
Spina Bifida Association
Stand UP Alaska
Tennessee Justice Center
The Advocacy Institute
The Jewish Federations of North America
The National Alliance to Advance Adolescent Health
TIME'S UP Now
TN Council on Developmental Disabilities
Treatment Communities of America
United Cerebral Palsy
United Spinal Association
United State of Women
US International Council on Disabilities
Well Being Trust
WI Board for People with Developmental Disabilities
World Institute on Disability
WV FREE