October 23, 2020

Seema Verma
Administrator
Centers for Medicare & Medicaid Services
200 Independence Avenue S.W.
Washington, DC  20201

Dear Administrator Verma,

The undersigned member organizations of the Consortium for Citizens with Disabilities (CCD), Disability and Aging Collaborative (DAC), and other state organizations write to raise some concerns about flexibilities that have been vital to state systems in the face of the COVID-19 pandemic, and to encourage you to make allowances for them to continue.

First, it is our understanding that CMS is considering options for timelines for the expiration of Appendix K waivers that have been invaluable to states. We share concerns about the application of twelve-month limits to states’ 1915 (c) Appendix K submissions. The flexibilities afforded state HCBS programs through these Appendix Ks have been crucial to maintaining state capacity to effectively serve individuals in need of long term supports and services throughout the pandemic. As you know, Secretary Azar recently extended the COVID-19 Public Health emergency to January 23, 2021. Since a number of the Appendix Ks submitted in response to the COVID-19 pandemic have been in effect since January 27, 2020, this means that many Appendix Ks will extend only a few days after the current end of the PHE—and if the PHE is extended, these Appendix Ks will still end despite the ongoing emergency.

We urge you to permit states, at their discretion, to extend their Appendix Ks to remain in effect for up to twelve months after the end of the Public Health Emergency. As you know, CMS initially developed a timeline for Appendix K expiration of one year from initial start date as a recognition that, after a cataclysmic event, it may take a year to re-establish “typical” services and to shore up the infrastructure of the state’s HCBS service system. Allowing Appendix Ks to be in effect for a year is sufficient when the event triggering the need for the flexibilities
afforded by an Appendix K is a time limited natural disaster. However, applying the same rationale to Appendix Ks created to deal with a months-long Public Health Emergency suggests that CMS should consider the cessation of the PHE as the beginning of the one year post-disaster period. We also note that CMS’ instructions state that a transition plan is necessary for waiver participants who might be adversely affected when the temporary changes cease and the waiver reverts back to its original form. CMS should add that, for such individuals, their person centered plan should also address how and when their services will be changed, and what alternatives may be available beyond the end of the PHE.

A second issue for many states and for providers of services for people with disabilities and aging adults is the continued availability of retainer payments. These payments are an indispensable tool for states to keep their HCBS provider networks afloat during periods when they are unable to provide services. We appreciate that CMS clarified that states were eligible for three, 30-day periods of retainer payments. However, we are now entering a new phase of the pandemic, and some states are seeing new spikes. It is still not safe for typical services to resume in many areas, and many states have already used their three retainer payment periods. This poses significant risk to the stability of HCBS provider networks, which are made up of agencies that often operate on little to no margin. We encourage you to review this determination and to extend to states the ability to provide retainer payments beyond the three 30-day periods.

We appreciate your consideration of these issues and would be happy to provide additional information and examples if it would be helpful. To set-up a meeting on the contents of this letter, please contact Nicole Jorwic, at jorwic@thearc.org or 630-915-8339.

Sincerely,

AARP
Ability Network of Delaware
ACCSES
Accessible Resources for Independence Incorporated
ADAPT National
ADAPT of Texas
Aging and Disability Professionals Association of Wisconsin (ADPAW)
Alabama Disabilities Advocacy Program
Alabama Service Providers Association
Allies for Independence
Alpha One, Center for Independent Living
American Association on Health and Disability
American Network of Community Options & Resources (ANCOR)
American Physical Therapy Association
Association of University Centers on Disabilities (AUCD)
Autism Society of North Carolina
Autistic Self Advocacy Network
California Down Syndrome Advocacy Coalition
Center for Public Representation
Community Based Care
Community Catalyst
Directions in Independent Living, Inc.
Disabilities Law Program, CLASI
Disability Rights Center of Kansas
Disability Rights Florida
Disability Rights Iowa
Disability Rights Maryland
Disability Rights Mississippi
Disability Rights Nebraska
Disability Rights North Carolina
Disability Rights North Carolina
Disability Rights Oregon
Disability Rights Pennsylvania
Disability Rights Wisconsin
Disabled In Action of PA
Down Syndrome Alliance of the Midlands
Down Syndrome Association of Connecticut, Inc
Down Syndrome Association of Middle TN (DSAMT)
Down Syndrome Network of Montgomery County
Easterseals
Epilepsy Foundation
Hawaii Disability Rights Center
Illinois Council on Developmental Disabilities
Independence Northwest: Center for Independent Living of Northwest CT, Inc.
Kansas ADAPT
Lakeshore Foundation
Lutheran Services in America
Maryland Developmental Disabilities Council
MassADAPT
National Academy of Elder Law Attorneys
National Association of Councils on Developmental Disabilities
National Association of Area Agencies on Aging (n4a)
National Association of State Head Injury Administrators
National Council on Independent Living
National Council on Aging
National Consumer Voice for Quality Long-Term Care
National Disability Rights Network
National Down Syndrome Congress
NCPA ADAPT
ND Protection & Advocacy Project
North Dakota State Council on Developmental Disabilities
Northwest Iowa Down Syndrome Society
Oregon Developmental Disabilities Coalition
Partnership for Inclusive Disaster Strategies
Personal Attendant Coalition of Texas
Placer Independent Resource Services
Progressive Independence
Protection & Advocacy System, Inc.
Protection and Advocacy for People with Disabilities, South Carolina
RAIL In-Home Support Care, Inc.
Roads to Freedom Center for Independent Living
Rural Advocates for Independent Living, Inc.
Service Employees International Union (SEIU)
Southeast Kansas Independent Living Resource Center
The Arc Georgia
The Arc Michigan
The Arc New York
The Arc of Central Alabama
The Arc of Colorado
The Arc of Connecticut, Inc.
The Arc of Delaware
The Arc of Indiana
The Arc of Massachusetts
The Arc of Maryland
The Arc of Nebraska
The Arc of North Carolina
The Arc of Oklahoma
The Arc of Oregon
The Arc of South Carolina
The Arc of Washington State
The Arc of West Virginia
The Arc Wisconsin
The Jewish Federations of North America
The Statewide Independent Living Council of Illinois
Washington State Developmental Disabilities Council
Wisconsin Board for People with Developmental Disabilities
Wisconsin Association of People Supporting Employment First (WI APSE)
World Institute on Disability