

# The Disability and Aging Collaborative &



**CONSORTIUM FOR CITIZENS  
WITH DISABILITIES**

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](mailto: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