

The Disability and Aging Collaborative

March 17, 2021

The Honorable Xavier Becerra
Secretary
U.S. Department of Health and Human Services
200 Independence Avenue, SW
Washington, DC 2020

The Honorable Chiquita Brooks-LaSure
Administrator
Centers for Medicare and Medicaid Services
7500 Security Boulevard
Baltimore, MD 21244

Subject: End of the Public Health Emergency

Dear Secretary Becerra and Administrator Brooks-LaSure,

The undersigned aging and disability organizations appreciate your recent renewal of the COVID-19 Public Health Emergency (PHE), as the pandemic continues to devastate our communities. However, we are concerned that this may be the last renewal of the PHE. We know that that U.S. Department of Health and Human Services (HHS), the Centers for Medicare and Medicaid Services (CMS), and states have been working to plan for the end of the PHE for months. Yet, several unanswered questions for people with disabilities and older adults remain that require more than a 60-day notice.

We request that HHS provide at least 120 days advance notice when it intends to lift the COVID-19 PHE. In addition, we urge HHS to not end the PHE until sufficient steps have been taken to address the direct care workforce crisis and ensure that people with disabilities and older adults are protected during the redetermination process.

Protections for People with Disabilities and Older Adults

The PHE includes several important components that have protected beneficiaries and assisted states during the pandemic. In particular, Section 6008 of the Families First Coronavirus Response Act (FFCRA) allows complying states to receive a 6.2% Federal Medical Assistance Percentage (FMAP) boost until the end of the PHE for their Medicaid programs. To comply, states must maintain continuous coverage and abide by maintenance of effort requirements (MOE).¹ These protections have meant that people with disabilities and older adults who have encountered eligibility difficulties have had time to sort those issues out. The increased funding

has helped states cover the increased costs from the pandemic and maintain previous standards under the MOE. It has also allowed HHS and states to utilize emergency authorities, such as Section 1915(c) Appendix K, 1135 Waivers, and telehealth expansion. We are extremely concerned that states are not prepared to ensure that people with disabilities and older adults are protected if the PHE ends in July.²

The Direct Care Workforce Crisis

The COVID-19 pandemic has drastically accelerated the direct care workforce crisis impacting home and community-based services (HCBS) for over 3.5 million individuals with disabilities and older adults. Low compensation³ paired with the new stresses and risks of providing close-contact services has resulted in turnover rates ranging as high as 79.5%.⁴ Nearly every HCBS spending plan narrative approved under the American Rescue Plan Act (ARPA) focuses on programs that address the workforce crisis and create, sustain, and retain a viable direct care workforce.⁵ Our networks report issues with finding and retaining staff in every state. Some programs have closed entirely because of staffing issues. While Congress authorized an additional 10% FMAP boost for HCBS specific services in ARPA, this crisis continues, and a hasty end to PHE could put individuals at risk of institutionalization due to lack of adequate direct care supports.

Part of the state response to this crisis has been the use of Appendix K emergency authorities. Every state remains reliant on at least one Appendix K waiver by virtue of the PHE to keep their HCBS programs accessible through the COVID-19 pandemic; most of which include reduced staffing ratios and incentive pay to slow the exodus of direct care workers from the field and maintain access to services through the crisis.⁶ While many of these authorities can be incorporated into the state plan or existing waivers, not enough has been done to make states aware of these options. While some states have made their plans clear,⁷ others have not, leaving beneficiaries without a clear sense of what will or will not continue. Certain authorities remain crucial, such as telehealth flexibilities, given the high risk COVID-19 status of some states and localities in the United States.

We commend HHS for its ongoing work to prepare states for the redetermination process and flexibilities available to them under the law. However, more must be done to direct and support states to address the direct care workforce crisis and incorporate permanent flexibilities prior to the end of the PHE.

Ensuring People with Disabilities and Older Adults are Protected During Redeterminations

Equally importantly, we are concerned that millions of people with disabilities and older adults may be at risk of losing their access to health care and LTSS as the eligibility protections end and states begin redeterminations. According to MACPAC, over 17.8 million individuals qualify for Medicaid on the basis of a disability or being aged 65 or older.⁸ The end of the eligibility protections places these individuals at risk of potential loss of benefits and reduced access to services. In particular, Medicaid provides access to the vital LTSS that Medicare and private

health insurance does not cover, including HCBS. Access to HCBS involves complex eligibility determinations. Many people with disabilities and older adults who rely on HCBS will likely be difficult redetermination cases for states. This means that errors are likely, a problem compounded for this population because, by definition, many may have functional limitations that make completing eligibility paperwork difficult. While assistance from legal services organizations or other assistors may be available, since all of these redeterminations will be happening at once, that assistance will be more limited than usual.

Another complication is that many of these beneficiaries receive Supplemental Security Income (SSI) benefits and their eligibility for Medicaid is linked to SSI. But the Social Security Administration (SSA), which administers SSI, has suspended their in-person services for almost two years. As a result, people, especially low-income people with disabilities, have had difficulty sorting out eligibility issues with SSA without in-person service. SSA's Inspector General recently reported that 67.8 million calls were unanswered in FY 2020⁹ and huge amounts of mail have not been opened or addressed.¹⁰ Because Medicaid relies on SSA to determine eligibility for many people with disabilities and older adults, we are extremely concerned that many people who have been trying to sort out eligibility issues for months or over a year will be incorrectly terminated from Medicaid because of these massive delays at SSA.

Recommendations

We appreciate CMS including a commitment to “ensuring that all individuals can access and maintain their coverage more easily,” as part of its strategic vision for the Medicaid program.¹¹ In order to make that commitment a reality, we urge HHS to not end the PHE until the agency can be sure that states and providers have sufficient staffing, processes, and plans in place to ensure access to HCBS and prevent individuals from being wrongly removed from benefits. This should include a letter to State Medicaid Directors on how to quantify and address the direct care workforce crisis and a plan to maintain coverage for SSI beneficiaries who are working to sort out eligibility issues with SSA. It would be better if the PHE were not ended until SSA has been reopened for several months and has had the opportunities to work through their own backlog. We also recommend that all plans to address the direct care workforce crisis and state redeterminations be made public on the CMS website. We urge CMS and states to allow for public comment on these plans to ensure that advocates can raise issues of concern.

For these reasons, we believe that at least a 120-day notice of the end of the PHE would be far more appropriate than the current commitment from HHS to provide us with a 60-day notice. We will need to continue to prepare for the end of the emergency ourselves and 60 days is insufficient notice to prepare our members and networks for the issues raised in this letter.

Thank you for your consideration of our concerns. We greatly appreciate the work you and your team have done to support individuals with disabilities and older adults during this crisis. We would like to meet with the relevant staff at CMS to discuss these issues. Please contact Bethany Lilly (lilly@TheArc.org), Senior Director of Income Policy at the Arc, with questions and to schedule that meeting.

Sincerely,

Allies for Independence
American Association on Health and Disability
American Network of Community Options and Resources (ANCOR)
Association of Maternal & Child Health Programs
Association of University Centers on Disabilities
Autistic Self Advocacy Network
Be a Hero
Caring Across Generations
CommunicationFIRST
Community Catalyst
Disability Policy Consortium
Disability Rights Education and Defense Fund (DREDF)
Easterseals
Epilepsy Foundation
Justice in Aging
Lakeshore Foundation
LeadingAge
Lutheran Services in America-Disability Network
Medicare Rights Center
National Academy of Elder Law Attorneys
National Association for Home Care & Hospice
National Association of Councils on Developmental Disabilities
National Committee to Preserve Social Security and Medicare
National Consumer Voice for Quality Long-Term Care
National Council on Aging
National Council on Independent Living
National Disability Rights Network (NDRN)
National PACE Association
The Arc of the United States
The Jewish Federations of North America
Well Spouse Association

CC: Jeffery Zients, White House Coronavirus Response Coordinator

¹ Families First Coronavirus Response Act (2021), available at <https://www.congress.gov/bill/116th-congress/house-bill/6201/text>.

² National Association for Medicaid Directors (NAMD), et al., Letter (Feb. 17, 2022), available at <https://medicaidirectors.org/wp-content/uploads/2022/02/Congressional-Medicaid-Glide-Path-Ltr-Major-Medicaid-Organizations-2-16-22.pdf>.

³ Economic Policy Institute, Domestic Workers Chartbook (2020), available at <https://www.epi.org/publication/domestic-workers-chartbook-a-comprehensive-look-at-the-demographics-wages-benefits-and-poverty-rates-of-the-professionals-who-care-for-our-family-members-and-clean-our-homes/>.

⁴ National Association of State Directors of Developmental Disabilities Services and Human Services Research Institute, National Core Indicators[®] Intellectual and Developmental Disabilities, 2020 Staff Stability Survey Report (2020) available at https://www.nationalcoreindicators.org/upload/core-indicators/2020StaffStabilitySurveyReport_FINAL.pdf.

⁵ National Association of State Directors of Developmental Disabilities Services, State Workforce Initiatives: ARPA Spending Plan Topical Analysis (2021), available at https://www.nasdds.org/all_resources/state-workforce-initiatives-arpa-spending-plan-topical-analysis/.

⁶ Kaiser Family Foundation, Medicaid Emergency Authority Tracker: Approved State Actions to Address COVID-19 (2021), available at <https://www.kff.org/coronavirus-covid-19/issue-brief/medicaid-emergency-authority-tracker-approved-state-actions-to-address-covid-19/>.

⁷ <https://medicaid.ncdhhs.gov/media/10770/open>.

⁸ MACPAC, MACStats: Medicaid and CHIP Data Book (2021), available at <https://www.macpac.gov/wp-content/uploads/2021/12/MACStats-Medicaid-and-CHIP-Data-Book-December-2021.pdf>.

⁹ Social Security Administration, Office of the Inspector General, The Social Security Administration's Telephone Service Performance (2021), available at https://oig.ssa.gov/assets/uploads/A-05-20-50999_1.pdf.

¹⁰ Social Security Administration, Office of the Inspector General, The Social Security Administration's Processing of Mail and Enumeration Services During the COVID-19 Pandemic (2021), <https://oig-files.ssa.gov/audits/full/A-08-21-51036InterimReport.pdf>.

¹¹ Health Affairs, Chiquita Brooks-LaSure and Daniel Tsai, A Strategic Vision for Medicaid And The Children's Health Insurance Program (CHIP) (2021), <https://www.healthaffairs.org/doi/10.1377/forefront.20211115.537685/full/>.