



**CONSORTIUM FOR CITIZENS
WITH DISABILITIES**

June 10, 2021

The Honorable Charles Schumer
Majority Leader
U.S. Senate

The Honorable Nancy Pelosi
Speaker
U.S. House of Representatives

The Honorable Mitch McConnell
Minority Leader
U.S. Senate

The Honorable Kevin McCarthy
Minority Leader
U.S. House of Representatives

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

The undersigned members of the Health and Long-Term Services and Supports task forces of the Consortium for Citizens with Disabilities (CCD) write to urge Congress to include the \$400 billion investment in Medicaid HCBS infrastructure and other critical investments to make health care more accessible and affordable for people with disabilities in the next recovery package. The CCD is the largest coalition of national organizations working together to advocate for federal public policy that ensures the self-determination, independence, empowerment, integration, and inclusion of children and adults with disabilities in all aspects of society. CCD members represent a broad range of stakeholders – people with disabilities and their families, older adults, disability service providers and workers, healthcare professionals, and state systems that provide disability services – who advocate on behalf of adults and children with all types of disabilities, including people with physical, intellectual, developmental, and mental health disabilities, chronic health conditions, and older adults.

Invest in Medicaid Home and Community Based Services

We urge Congress to prioritize robust investment in the Medicaid home- and community-based services (HCBS) infrastructure and the workforce that provides those services by including the \$400 billion investment outlined in the American Jobs Plan in the next package. This will allow states to build on the dedicated HCBS funding in the American Rescue Plan to continue to recover from the pandemic, address the gaps and inequities in access to these critical services, and support the direct care workforce.

Support and Expand Medicaid Coverage

We appreciated the American Rescue Plan provisions that further support Medicaid expansion to all adults under age 65 with income below 138% of the federal poverty level. Medicaid is a critical source of coverage for many individuals with disabilities, including many adults who do not meet the Social Security Administration's strict disability definition. It became even more important during the pandemic when many people with disabilities had to self-isolate due to being at higher risk, and may have had to stop working in order to keep themselves and their families safe.

However, the coverage gap in states that have not expanded Medicaid remains an urgent concern. Many people in this gap have chronic conditions and other disabilities that require consistent care. Most adults in the gap are Black and Latinx. These individuals have pressing health needs and should have immediate access to insurance year-round, without open enrollment periods or waiting periods. Therefore, we urge Congress to develop further policy options to close this gap. Solutions should prioritize affordability for these lower income individuals, while ensuring that they do not create perverse incentives that undermine coverage in states that have already expanded Medicaid.

We likewise urge Congress to address the Medicaid funding crisis in the U.S. territories by providing full, permanent Medicaid funding at a fixed percentage of territories' Medicaid costs without limit, as it does for the states. Without an immediate fix, nearly 2 million individuals with limited income who are primarily people of color will have their health coverage cut or eliminated completely.

To further strengthen Medicaid, Congress should pass legislation that triggers an automatic FMAP increase during economic downturns so that states can continue to provide quality and comprehensive Medicaid coverage after the current public health emergency ends and during future recessions. We also urge Congress to improve the continuity of Medicaid coverage for both children and adults by making 12-month continuous eligibility mandatory. Finally, we urge Congress to improve Medicaid for working people with disabilities by raising the maximum eligibility age for the Medicaid Buy-In to allow people with disabilities age 65 and older to pursue employment and maintain their Medicaid coverage.

Improve Medicare Coverage

Millions of individuals with disabilities rely on Medicare to access the services and devices they need to remain healthy, functional, and live independently in their homes and communities. Yet there are significant gaps in Medicare's coverage of basic health care services. Therefore, we urge Congress to improve Medicare to better serve individuals with disabilities by strengthening the benefit package to include comprehensive dental, vision (including rescinding the low-vision aid exclusion), and hearing benefits in Part B, as well as coverage of intensive community-based

behavioral health services. Lack of coverage for these critical services often contributes to complications and poorer overall health,¹ which makes maintaining independence more difficult, especially for people who cannot afford to pay for these services out of pocket. We also recommend modernizing and strengthening the Medicare home health benefit by eliminating the “in the home” restriction for coverage of durable medical equipment, including mobility devices (e.g., wheelchairs and scooters), and relaxing or eliminating the homebound and/or skilled care eligibility requirements

It is also critical that Congress expand programs that help low-income beneficiaries with their Medicare premiums and cost-sharing. Half of all Medicare beneficiaries have incomes below \$30,000, and the median income is only \$23,050 for Black enrollees and \$15,600 for Hispanic enrollees.² Congress should expand eligibility limits and simplify and align the Qualified Medicare Beneficiary program and other Medicare Savings Programs, as well as the Part D Low-Income Subsidy (Extra Help).

Make Health Insurance Premiums and Cost-Sharing More Affordable

The Affordable Care Act (ACA) Marketplaces and related insurance reforms provide crucial access to coverage for people with disabilities. We appreciate the expansion of subsidies in the American Rescue Plan and urge you to make those permanent. We also ask Congress to better account for out-of-pocket expenses like deductibles and cost-sharing and to allow those with unaffordable employer-sponsored coverage to access Marketplace plans with subsidies. In addition, the “family glitch” must be fixed to ensure access to Marketplace plans when employer-provided insurance is unaffordable for a family.

Ensure Prescription Drug Pricing Reforms Address Consumer Costs & Prohibit Discrimination

Prescription drugs are an essential aspect of daily life for many people with disabilities and chronic conditions. We continue to strongly support the language that bars the Secretary from using measures that devalue the lives of people with disabilities. We also strongly support creating an out-of-pocket cap in Medicare Part D. A cap, combined with smoothing, would greatly simplify the benefit and make it easier for enrollees to navigate. In addition, Congress should improve and simplify the Part D appeal process and empower Medicare enrollees with more timely information about their plan’s coverage decisions. Finally, we ask Congress to improve access to prescription drugs for low-income enrollees by expanding and simplifying the

¹ See Ctr. on Budget & Policy Priorities, Medicaid and Medicare Enrollees Need Dental, Vision, and Hearing Benefits (Dec. 8, 2020), <https://www.cbpp.org/research/health/medicaid-and-medicare-enrollees-need-dental-vision-and-hearing-benefits>.

² Kaiser Family Foundation, Medicare Beneficiaries’ Financial Security Before the Coronavirus Pandemic (Apr. 24, 2020), <https://www.kff.org/medicare/issue-brief/medicare-beneficiaries-financial-security-before-the-coronavirus-pandemic/>.

Low-Income Subsidy (Extra Help) program and eliminating cost-sharing on generics for LIS enrollees.

Support Multidisciplinary Care for People Experiencing Long-COVID

The COVID-19 pandemic has highlighted existing gaps in our health care, including those in rehabilitation care. Between 10% and 30% of people who were infected with SARS-CoV-2 may experience Post-Acute Sequelae of SARS-CoV-2 infection (PASC), including those who have had mild or asymptomatic cases.

Currently, health care in the United States lacks the infrastructure and funding to meet this crisis. Newly opened multidisciplinary post-COVID clinics that can act as a comprehensive care center, providing access to multiple physician specialists, therapists, psychiatric services, and social work seem to be best at helping patients not only recover, but better understand their new diagnosis. These multidisciplinary clinics have started opening in academic medical centers, which have resources to support them, but are not available throughout the country. We urge Congress to direct resources to support multidisciplinary clinics to support patients and provide expert care. Additionally, this care must be supported through appropriate reimbursement to ensure clinicians are able to provide care to PASC patients consistently. All patients need timely and local access to multidisciplinary care to ensure that broad and varied symptoms are addressed.

We appreciate your attention to these priorities. Please contact Natalie Kean (nkean@justiceinaging.org) and David Machledt (machledt@healthlaw.org) with any questions.

Sincerely,

American Academy of Physical Medicine & Rehabilitation
American Association on Health and Disability
American Association on Intellectual and Developmental Disabilities (AAIDD)
American Council of the Blind
American Medical Rehabilitation Providers Association (AMRPA)
American Music Therapy Association
American Network of Community Options & Resources (ANCOR)
American Occupational Therapy Association (AOTA)
American Physical Therapy Association
American Therapeutic Recreation Association
Autistic Self Advocacy Network
Brain Injury Association of America
Center for Medicare Advocacy
CommunicationFIRST
Disability Rights Education and Defense Fund (DREDF)

Easterseals
Epilepsy Foundation
Family Voices
Justice in Aging
Lakeshore Foundation
Lutheran Services in America - Disability Network
National Alliance on Mental Illness
National Alliance to End Homelessness
National Association of State Head Injury Administrators
National Center for Parent Leadership, Advocacy, and Community Empowerment (National PLACE)
National Health Law Program
National Respite Coalition
TASH
The Arc of the United States