



**CONSORTIUM FOR CITIZENS
WITH DISABILITIES**

July 21st, 2021

The Honorable Ron Wyden
Finance Committee Chair
U.S. Senate
Washington, Dc 20510

The Honorable Frank Pallone
Energy & Commerce Chair
U.S. Senate
Washington, Dc 20510

The Honorable Bob Casey
Aging Committee Chair
U.S. Senate
Washington, DC 20510

The Honorable Debbie Dingell
Representative
U.S. House of Representatives
Washington, DC 20515

Dear Senators Wyden and Casey and Representatives Pallone and Dingell,

The Consortium for Citizens with Disabilities (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. The undersigned member organizations of the CCD Long-Term Services & Supports (LTSS) Taskforce write to share our overwhelming support for the full \$400 billion investment included in the Better Care Better Jobs Act to support access to Medicaid Home and Community-Based Services (HCBS) and support the direct care workforce. Throughout our almost 50 year history, our coalition has advocated strenuously for public policies that provide the opportunity for people with disabilities to live, work, and play in their communities along with their families and peers. We are overjoyed to see such a strong proposal, and eager to support its passage.

Our task force has identified a few places where this legislation could be strengthened by some modest adjustments and clarifications. We believe these proposed edits are in keeping with the

purpose, scope, and likely process of this legislation, and have endeavored to keep our comments as narrow and targeted as possible.

Data Collection

The BCBJA contains numerous critical provisions regarding data collection. CCD has developed standard language we believe should be included in all legislation regarding data collection and HCBS. We request that every item in the BCBJA which deal with data collection and measurement explicitly emphasize the importance of stratification and cross-tabulation of data by race, ethnicity, disability status, age, sex, sexual orientation, gender identity, primary language, rural/urban environment, and service setting. With regards to workforce demographic data specifically, we request that data also be collected on the disability status of workers. Additionally, for data collection regarding HCBS services users, we request that data be collected as to the communication methods used by the person with a disability.

Definition of Direct Care Worker

We request that the definition of a direct care worker be modified as below (recommended language in bold) to explicitly include employment support professionals:

- (2) *DIRECT CARE WORKER; DIRECT CARE WORKFORCE.* —*The terms “direct care worker” and “direct care workforce” mean—*
- (A) *a direct support professional, **including an employment support professional;***
- (B) *a personal care attendant;*
- ~~(C) *a direct care worker;*~~
- (C) ***behavioral health community support worker;***
- (D) ***peer support specialist***
- (E) ***a home health aide;***
- (F) *and any other relevant worker **necessary to achieve positive HCBS outcomes, including community inclusion, supported employment services, and case management services, as determined by the Secretary.***

Further, we note that “direct care worker” is listed as part of the definition of “direct care worker,” and therefore suggest deleting it. Instead, it may be helpful to specify that behavioral health community support workers and peer support specialists are included in the list, to ensure that those workers who generally provide similar services to DSPs, but for individuals with behavioral health diagnoses, are sufficiently included.

Presumptive Eligibility

Currently, individuals needing institutional care are able to receive prompt and retroactive Medicaid coverage for institutional services while their applications are pending. Meanwhile people seeking HCBS must wait until their applications are approved to begin receiving Medicaid HCBS, leading to disruptions to their care and unnecessary institutionalization. We propose clarifying that the presumptive eligibility requirement in Section 102, (B) Access to Services is for both functional and financial eligibility and should include allowing for services to be provided under a provisional plan of care. We also recommend allowing the federal government to share in the financial risk if the person is ultimately found ineligible, ensuring that providers are not bearing all of the risk.

Ombudsman

Additionally, we propose the following text edits to strengthen the role of the ombudsman program in the bill so they serve similar functions as nursing home ombudsman under paragraph (B) in Section 102 (recommended language in bold):

(B) The State designates an accessible HCBS ombudsman office with publicly available and accessible contact information including phone number, address, website, and email address that—

“(i) operates independently from the State Medicaid agency and managed care Entities, and is free from any conflicts of interest as defined by Section 712(f) of the Older Americans Act;

“(ii) provides direct assistance and support to beneficiaries and their families, including assistance with appeals and complaints; and

“(iii) tracks, identifies, and reports its activities and systemic problems to State officials, the public, and the Secretary with policy recommendations to remedy systemic problems.”

While we agree that states will need some flexibility to identify the appropriate organization, the legislation should include measures to ensure the ombuds is adequately resourced to fulfill its responsibilities.

Maintenance of Effort and Ensuring HCBS Funds are Spent on HCBS

We appreciate the inclusion of a robust maintenance of effort (MOE) in BCBJA. However, we are concerned there are not sufficient safeguards in place to ensure that the entirety of the FMAP bump will be used to improve HCBS workforce or services. As the bill is written now, there is a potential for a state to spend some of the federal investment on non HCBS expenses, and potentially on something totally unrelated to health care. Since we assume that the intent of the statute is that money Congress designates for HCBS should be invested in HCBS, we suggest that the following language be included along with the MOE:

Page 18, new section 1(E).

(i) The State shall use the federal funds attributable to the increase under (1)(A) to enhance, expand, or strengthen home and community-based services.

(ii) The state shall maintain at least the current level of state spending on HCBS throughout the HCBS planning period.

Additionally, similar language should be included regarding the permanent investment:

Page 22, new section 1(E).

(i) The State shall use the federal funds attributable to the increase under (1)(A) to enhance, expand, or strengthen home and community-based services.

Page 22-23, (2)(A)(i)

(III) The state shall maintain at least the current level of state spending on HCBS.

These safeguards or similar ones, taken together, will ensure that in addition to 1) requiring a state to meet all the required services and workforce benchmarks, and 2) comply with the MOE, and third goal will be met: that all federal funding targeted for HCBS will actually be spent on HCBS. Without such safeguards, a state could meet the benchmarks and comply with the MOE, and then take any additional funding leftover and spend it on anything it wanted, even if it was

wholly unrelated to HCBS or even Medicaid services. This could lead to the unintended consequence of states attempting to do the bare minimum to comply with the benchmarks, or even trying to set rates and other metrics unreasonably low, so that they may use any leftover money to fund other priorities. An MOE alone does not ensure that the entirety of this new investment is spent on HCBS.

Additionally, including language that requires a state to maintain its current level of funding will prevent a state from supplanting any portion of its current investments in HCBS with the increased federal funding. Without such a restriction, a state may be able to comply with all the benchmarks while still reducing some state investment in HCBS services and workforce. States should not be permitted to supplant any state funding with the new federal funds.

Expansion of Personal Care

We are thrilled by the requirement in section 102(a) that personal care be provided to all HCBS eligible individuals, including those on waiting lists. Given the wide variety of definitions state programs may use for personal care, and the proliferation of unduly narrow definitions that may de facto exclude some people with intellectual, developmental, cognitive, and mental health disabilities, we believe it is imperative that “personal care” be defined explicitly in the legislation, with at least a comprehensive a definition as used in 1915(k). In addition, we suggest that the language clarify that the definition of personal care applies across services, whether the service is named personal care or not.

Ensuring compliance with the HCBS Settings Rule

We recognize that, due to the nature of the reconciliation legislative process, the BCBJA is limited in the ways it can encourage states to use the additional funds to improve their HCBS services. We strongly believe that one modest but highly impactful step would be to add in explicit language tying these funds to compliance with the HCBS Settings Rule. In particular, most states are not currently truly meeting the requirement that services be available in non-disability-specific settings. Ensuring that states use enhanced funds to meet their core regulatory requirements is common sense, and the ripple effects of reaching this particular threshold are profound. The enhanced ARPA funding did not incorporate explicit language referencing the Settings Rule, and CMS and states alike have demonstrated that, absent explicit instruction, little progress will be made. Therefore, we recommend adding the following language to the list of required activities to expand access to services:

“(ii) Completing the state transition plan process and coming into full compliance with the HCBS Settings Rule, including expanding service infrastructure as needed in order to ensure that every HCBS participant has a meaningful choice to receive all services, including residential and day services, in non- disability-specific settings.

“(iii) Expanding financial eligibility criteria for home and community-based services up to Federal limits.

We strongly support the inclusion of provisions to strengthen self-determination in state HCBS programs. Providing states with funding to strengthen this service delivery method will enable HCBS participants to exercise greater control and direction over their services. However, in most states, HCBS participants that self-direct their services serve as the employer of record. Therefore, we recommend amending (G) to protect existing consumer choice and control as follows:

*(G) Ensuring that program policies and procedures allow for cooperation with labor organizations that bargain on behalf of direct care workers in the case of a State in which the direct care workers in the State have elected to join, or form, such a labor organization, or, in the case of a State in which such workers have not joined or formed such a labor organization, are neutral with regard to such workers joining or forming such a labor organization **without adopting policies that would result in fewer self-directed services, including fewer hours of self-directed services, or restrict the ability of HCBS participants to continue to act as the employer of record for their direct care workers.***

Rulemaking

Finally, we recognize that, due to the nature of the reconciliation legislative process, it is likely that many program details for this funding will need to be addressed by the HHS Secretary. To the extent possible, we strongly urge that the Secretary be directed to consult closely with stakeholders including HCBS recipients, people with disabilities and aging adults in need of HCBS, organizations led by people with disabilities and aging adults, and family caregivers in the development of all guidance, rulemaking, applications for funding, etc.

We once again thank you for your leadership on this critical issue. 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,

American Association on Health and Disability
American Dance Therapy Association
American Network of Community Options & Resources (ANCOR)
Association of People Supporting Employment First (APSE)
Autism Society of America
Autistic Self Advocacy Network
Bazelon Center for Mental Health Law
Brain Injury Association of America
Christopher & Dana Reeve Foundation
CommunicationFIRST
Disability Rights Education and Defense Fund (DREDF)
Easterseals
Epilepsy Foundation
Family Voices
Justice In Aging
Lakeshore Foundation
National Association of Councils on Developmental Disabilities
National Association of State Head Injury Administrators
National Disability Rights Network (NDRN)
National Down Syndrome Congress
National Down Syndrome Society
National Health Law Program
PVA
The Arc Of The United States