



**CONSORTIUM FOR CITIZENS
WITH DISABILITIES**

September 16, 2021

The Honorable Chuck Schumer
Majority Leader
U.S. Senate

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

The Honorable Ron Wyden
Finance Committee Chair
U.S. Senate

The Honorable Frank Pallone
Energy & Commerce Chair
U.S. House of Representatives

Dear Leader Schumer, Speaker Pelosi, Senator Wyden, and Representative Pallone:

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.

Please consider the following comments and requests from the CCD Long-Term Services & Supports (LTSS) Taskforce co-chairs on Part 2, Subtitle G of the Build Back Better Act (BBB Act). Many of these suggestions were included previously in our July 21, 2021 comments, which are [available here](#) for reference.

I. Increase the Federal Medical Assistance Percentage Bump to 10%

We are concerned that the proposed federal medical assistance percentage (FMAP) increase dropped to 7%, from the original 10% proposed in the Better Care Better Jobs Act (BCBJA). As currently written, this proposal falls far short of both the President's stated commitment of \$400 billion as well as the estimated CBO score of \$300 billion to meaningfully implement the BCBJA. We believe that funding of at least \$250 billion is necessary to achieve the core goals of the proposed improvements. Funding below this level will not enable Congress to meet its stated dual goals of expanding access to critical services and strengthening an overstretched workforce.

While we understand that at some points in the process there will inevitably be restrictions on committee expenditures and competing interests, we urge you not reduce the FMAP increase below 10%. The 10% FMAP increase in the ARPA funding was sufficient to ultimately entice every state to take up the new funding, but advocates from some states reported needing to push strenuously with their state to ensure uptake. At a level below 10%, states will be even less likely to take up these funds. Many states will forgo participation if they determine that the cost of complying with the statutory mandates is higher than funding offered. This will be especially true of states most in need of the support offered by this legislation--which will create even more inequality and variation among state HCBS programs and supports than already exists. We continue to believe that a 10% FMAP increase creates the appropriate balance between new state obligations and new federal funding.

II. Ensure HCBS Funds Are Spent on HCBS

We appreciate the inclusion of the "supplement but not supplant" language on page 45 that mirrors the language from the American Rescue Plan Act (ARPA), Section 9817. However, ARPA also contained language that requires states to invest *all* additional federal funding for HCBS in "one or more activities to enhance, expand, or strengthen home and community-based services under the State Medicaid program." **This language is key, and is missing from the BBB Act.** Money Congress designates for HCBS should be invested in HCBS. We request that this requirement be added.

Without additional language requiring *all* new federal funding for HCBS to be spent solely on HCBS or HCBS-related expenses, a state could technically comply with the "non-supplementation" language by maintaining state spending, yet still spend some of the new federal investment on non- HCBS expenses, or potentially something totally unrelated to health care. We understand that, unlike ARPA, there are specific

enumerated actions the state must take in exchange for this funding. However, without APRA-like language to cabin the universe of things the funds could be spent on, we are still concerned that a state could meet the bare minimum for compliance with the required actions without investing all new federal funds in HCBS-related actions.

We suggest that you add language to akin to the language in ARPA to ensure that all federal funding targeted for HCBS will actually be spent on HCBS:

“The state shall use the funds attributable to the federal medical assistance percentage increase under paragraph (1)(A) to implement activities to strengthen and expand access to home and community-based services and the direct care workforce that provides such services.”

We also suggest that on page 42 you clarify that the cost of implementing and operating the ombuds program is an allowable administrative expense for which a state may claim the 80% administrative match. Otherwise, it is unclear how the ombuds program will be funded.

III. Ensure that Investments in Behavioral Health Services Are Limited to Community-Based Behavioral Health Services

One of the required uses of the additional funding is to “expand[] access to behavioral health services” (page 48). We request that this is modified as follows, to be clear that this refers to investments in *community-based* behavioral health services:

“Expands access to **home and community-based** behavioral health services,”

Without such a restriction, a state could invest HCBS funding in institutional-based services, contrary to the intent of the legislation.

Further, we note that the definition of “institutional services” is not consistent throughout the legislation. While we are pleased to see psychiatric hospitals included in the definition of institutions (page 29), the list of facilities where long-term services and supports are provided in institutional settings excludes psychiatric hospitals and thus neglects to require reporting on the individuals served in those settings (page 36). We

suggest defining institutional services consistently throughout the Act, and including all congregate settings where individuals receive long-term behavioral health services.

IV. Adopt an Inclusive Definition of Personal Care Services

We are thrilled by the requirement that personal care services authorized under paragraph (24) of 1905(a) be covered. However, given the proliferation of unduly narrow definitions of state plan personal care services at the state level that 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 to include **“assistance in accomplishing activities of daily living, instrumental activities of daily living, and health-related tasks through hands-on assistance, supervision, or cueing.”** This definition of tasks for which personal care services are available tracks the definition used in 1915(k), and is more inclusive than the definition used by most states for state plan personal care services. If this change is not made, hundreds of thousands of people with disabilities currently on waiting lists will not benefit from the relief offered by this provision.

Further, we are concerned that requiring states to provide PCS as a state plan service may upend waiver service arrays that are carefully constructed to ensure that a waiver participant’s PCS needs are being met. Many waiver services that provide benefits beyond PCS also include elements of personal care. The longstanding Medicaid rule that state plan services pre-empt waiver services could lead to situations where, because a waiver participant is receiving state plan PCS, these services are deemed duplicative. This could lead to wasteful spending on duplicative services, or worse, waiver participants losing much needed services because the state has included a personal care component in the service. We suggest requiring that states provide state plan personal care, with the added requirements in the paragraph above, or be able to demonstrate that all such personal care needs are being met for all eligible waiver recipients through other services.

V. Close the Loophole for Compliance with the MOE

On page 56, the legislation says that a state will cease to be eligible for an increase in its FMAP “at any time or beginning with the 29th fiscal quarter that begins on or after the first date on which the State is an HCBS program improvement state if the State is found to be out of compliance with paragraph (2)(B) or any other requirement of this subsection...” Read literally, this appears to mean that a state could be out of compliance with the MOE (contained in paragraph (2)(B) for up to **nine years** (two years where a state has an HCBS planning grant, and then another 7 years or 29

quarters) before risking any funds. This certainly cannot be the intent. We request that this be modified to clarify that a state can lose its FMAP for any time period it is found to be out of compliance with the MOE or other mandatory requirements of the legislation.

We also request that the effective date(s) for the MOE be clarified. On pages 45-46, the legislation states that a state may not:

1. Reduce the amount, duration, or scope of HCBS available *as of the date on which the State was awarded a planning grant...*;
2. Reduce payment rates for HCBS lower *than such rates that were in place on January 1, 2021...*, or
3. Adopt more restrictive standards, methodologies, or procedures for determining eligibility, benefits, or services for receipt of HCBS, including with respect to cost-sharing, than the standards, methodologies, or procedures applicable as of *such date*.

Does “such date” in number 3 refer to the date which the state was awarded the planning grant or January 1, 2021?

Further, permitting a state to reduce the amount, duration and scope of HCBS up to the date the state is awarded a planning grant, which could take place up to 12 months after the enactment of the BBB Act, could create two classes of states: those states that have expended all of their ARPA funds and those states which are still bound by the ARPA MOE. Pursuant to ARPA, a state could spend all its ARPA funding soon after the funding ends in March 2022, and then drastically reduce services prior to getting an improvement grant. However, states do have the option to expend ARPA funding until March 2024, and states that take this option would still be under the ARPA MOE at the time the BBB Act MOE took effect. At the very least, states should not be incentivized to spend ARPA funding faster than is in the state’s interests, and even if they do, those states should not have an incentive to cut services in any gap of time between the end of the ARPA MOE and the new MOE. This is yet another reason we are advocating that the FMAP remain at 10%, so states can move seamlessly from one MOE to the next.

Last, we suggest that the MOE not only apply to cost-sharing, but also to premiums, as some HCBS programs require premiums. Thus, the MOE requirement on page 46, lines 22-23 would be: “including with respect to cost sharing **or premiums...**” On page 47, lines 16-17, we suggest also prohibiting states from imposing “increased cost-sharing **or**

premiums” adding a restriction on increasing premiums related to the guardrails on “flexibility to support innovative models.”

VI. Improve Equity

Disaggregated data regarding the availability and use of HCBS is crucial for improving health equity. If we do not know which groups are receiving HCBS, then we cannot appropriately target initiatives to improve inequitable gaps in services. As the legislation makes clear, investments in HCBS must not simply improve HCBS in the aggregate, but must also reduce disparities in HCBS.

While we understand that initially not all states will be able to report this data immediately, allowing states to simply opt out of reporting disaggregated data for the foreseeable future if such data is not available actually rewards states that do not actively seek to track disparities, as such states would not be subject to the reporting requirement because the data is only required to the “extent available.” However, the current legislation seems to do this, requiring reporting and oversight on the availability and utilization of HCBS to be “disaggregated (*to the extent available* and as applicable) by age groups, primary disability, income brackets, gender, race, ethnicity, geography, primary language, and type of service setting” (page 55) (emphasis supplied). Similar language is included regarding the plans states must submit to monitor and report on access to HCBS and the proportion of funding for HCBS versus long-term services and supports (page 37-38), and again on regarding HCBS quality measures (page 68). At no point are states explicitly required to address deficiencies in their data reporting infrastructure or build capacity to ensure that this does not remain a long-term state of affairs.

We suggest adding a requirement for any state that reports that disaggregated data is not available. Those states should be required to report on the steps it is taking to ensure that it is able to collect such data in the future, along with a date by which the state will have implemented a system to collect and report on the required data. States could use the 80% administrative match to plan and implement the data collection systems.

We also note that the requirement to collect disaggregated data regarding “sexual orientation and gender identity” was included in the BCBJA and is now absent. We request that it be reinserted into the data that is required to be reported.

Last, to promote transparency and stakeholder engagement, we suggest adding in a requirement that states not only report on their progress regarding their HCBS program

improvement plan, but that states also publicly share such reports. On page 55, line 1, we suggest adding the bolded language: “State reports to the Secretary **and reports publicly** on the state”

VII. Conclusion

We appreciate your consideration of these concerns, and your commitment to moving this landmark HCBS legislation forward. If you have any questions or concerns, please feel free to contact Jennifer Lav at lav@healthlaw.org.

Sincerely,

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Autistic Self Advocacy Network

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