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April 26, 2021

The Honorable Maggie Hassan  
United States Senator  
324 Hart Senate Office Building  
Washington, DC 20510

The Honorable Bob Casey  
United States Senator  
393 Russell Senate Office Building  
Washington, DC 20510

The Honorable Sherrod Brown  
United States Senator  
503 Hart Senate Office Building  
Washington, DC 20510

The Honorable Debbie Dingell  
United States Representative  
116 Cannon House Office Building  
Washington, DC 20515

*Submitted Electronically to [HCBSComments@aging.senate.gov](mailto:HCBSComments@aging.senate.gov)*

Dear Senator Hassan, Senator Brown, Senator Casey and Representative Dingell:

On behalf of ADvancing States, I am writing to provide comments on the discussion draft of the *HCBS Access Act*. ADvancing States is a nonpartisan association of state government agencies that represents the nation's 56 state and territorial agencies on aging and disabilities. We work to support visionary state leadership, the advancement of state systems innovation, and the development of national policies that support home and community-based services (HCBS) for older adults and persons with disabilities. Our members administer a wide range of services and supports for older adults and people with disabilities, including overseeing Medicaid long-term services and supports (LTSS) in many states. Together with our members, we work to design, improve, and sustain state systems delivering long-term services and supports for people who are older or have a disability and for their caregivers.

We first would like to thank you and your staff for providing leadership regarding the redesign of Medicaid LTSS. We agree that fundamental structural changes are required to eliminate the institutional bias for service delivery that has existed in the program since its inception. We additionally appreciate the full Federal funding included in the bill in recognition that many states would not be able to finance such a significant expansion to HCBS eligibility and services.

Though we agree with the overarching goals of this legislation, to transform Medicaid and provide services in the community that enhance the quality of life of participants while reducing the reliance on institutional services, we also have some specific concerns and

questions about the legislation. We first provide comments on the legislation itself and then respond to the questions outlined in the memorandum seeking feedback. We hope that these recommendations are useful as you continue to develop and refine your legislative proposals.

### **Financing Provisions**

We support the proposal to provide full federal funding for HCBS services, including both those that are currently provided in state program as well as those that will be expanded under this Act. Such an approach promotes equity between states that already have robust HCBS and those that are still working to balance their LTSS programs. The language implementing the increased federal medical assistance percentage (FMAP) provisions in section 3(d) of the Access act specifically refers to “waivers furnished under a waiver in effect under section 1915.” Given that HCBS is authorized in section 1915 via a combination of the state plan and waivers, we recommend including a specific reference to both waivers and state plan to ensure that all HCBS is encompassed within this provision.

Although we appreciate the proposal to provide extensive Federal funding for the new service package, we have concerns that the level of federal funding provided may not be sustainable given the anticipated costs of this legislation. We are specifically concerned that, if enacted, Congress could seek budgetary savings in the future by reducing the federal share of funding and/or limiting eligibility or benefits. We do not want to create a scenario where programs drastically expand, provide supports that people utilize, and subsequently contract and leave those same individuals without their expected services. Instead, we recommend gradual increases in a manner that do not create expectations or make promises that ultimately may not be kept.

### **Financial Eligibility**

Based on our interpretation of the legislation, it appears that the bill intends to largely maintain current financial eligibility pathways while simultaneously expanding LTSS functional eligibility to additional individuals. There are several technical considerations that should be included within the financial eligibility framework. These include:

- **Katie Beckett Eligibility**: Katie Beckett eligibility is codified at Section 1902(e)(3) of the Social Security Act and would not be impacted by this legislation. However, we note that the provisions of 1902(e)(3)(B) would continue to require that an eligible child meet the institutional level of care and that the cost of services be no greater than serving the participant in such institutional setting. Given the HCBS Access Act’s attempt to decouple institutional coverage and HCBS, we recommend allowing states to align functional eligibility across LTSS programs and removing the cost neutrality requirement.
- **Special Income Group**: The provisions in this legislation appear to amend the eligibility category for individuals in the institutional special income group to include individuals eligible for this new HCBS benefit. We are unsure whether the institutional deeming rules and spousal impoverishment criteria would be applied to the newly eligible people under this provision or whether the Medicaid community rules would continue to apply. We encourage the committee to ensure that income and resources are treated equitably across settings.

- Spend-Down: The Act would continue to allow individuals to spend down income to a medically needy eligibility threshold to establish eligibility. We note that this would perpetuate institutional biases for participants in the program. Most notably, individuals in institutional settings can spend-down their income for all nursing facility costs, including the room and board provided in such a setting. In contrast, participants in the community can only count medical expenses towards the medically needy requirements.
- Estate Recovery: The Act does not address estate recovery provisions in section 1917(b)(1)(B) of the Social Security Act, which require the state to seek reimbursement for medical services delivered to individuals older than 55 upon their death. We are concerned that the expansion of eligibility and services will require a significant increase in staff time to seek recovery without sufficient financial returns to justify the increased staffing. More importantly, mandatory estate recovery would create disincentives for people to apply for needed HCBS which could lead to deterioration of conditions to the point of institutionalization. We recommend making HCBS an optional, but not mandatory, category of services subject to estate recovery.

### **Functional Eligibility**

The new eligibility criteria of 2 ADLs or 2 IADLs is extremely broad and would greatly expand the number of individuals eligible for HCBS in most states. While we support changes that make HCBS available prior to institutional care, we are concerned about the implications on service delivery, provider capacity, cost, and sustainability of this measure. One potential approach that may have value would be to couple HCBS expansions with a corresponding increase in ability to limit institutional services.

We also note that the eligibility criteria utilizes the IRS definition of ADLs, which focuses on functional needs of the individuals but does not appear to sufficiently address issues applicable to cognition, Alzheimer's, or related dementias. While we recognize that the new nonfinancial eligibility criteria also maintains eligibility for individuals currently enrolled in, or eligible for, HCBS on the date of passage, it appears to be focused on grandfathering existing eligible individuals rather than extending current state eligibility requirements to this benefit package indefinitely. We strongly encourage Congress to work with states to do a thorough review of existing clinical and functional eligibility criteria across the country to ensure that certain groups of individuals who access HCBS are not inadvertently excluded in the future.

The new eligibility criteria would also establish a universal floor for eligibility and services regardless of characteristics of participants. While we agree with the need for parity across Medicaid participants, we are concerned that the provisions would remove a state's ability to waive Medicaid's comparability requirements that are codified at §1902(a)(10)(B) of the Social Security Act. Removing the ability to waive comparability and target services to specific populations will create significant challenges with program development, including establishing population-specific services as well as appropriately delegating program administration to operating agencies and providers with expertise in specific services and groups of older adults or people with disabilities. We believe that there is continued need to provide differentiation in services depending on the characteristics of the populations and a waiver of

comparability would improve the ability of states to serve the needs of the wide range of populations and people that utilize HCBS.

### **Services**

The Act would leverage a wide range of existing services and supports across the Medicaid program to create the benefits package for eligible individuals. The current construction of benefits mandates an extremely wide range of services and supports that may not be appropriate for all individuals in the Medicaid program. While actual service authorization would be subject to an individual assessment and plan of care, the broad range of available services appears likely to lead to significant expansion of interventions delivered. We agree with the philosophy that would allow a wide range of different options based on the participant's needs, goals, and preferences; however, the current benefits construction raises concerns about program integrity, financial sustainability, and provider adequacy.

One potential approach would be the creation of tiered benefits that have different functional eligibility requirements. For example, a more modest package of benefits could be available for individuals with less-significant needs. These initial benefits would focus on targeted, cost-effective, interventions that prevent the need for more significant and comprehensive LTSS in the future. Individuals with higher assessed needs would be eligible for more comprehensive services, with institutional care limited to those participants with the highest level of assessed need. Tiered benefits would enable states to tailor services that focus first on prevention and then gradually expand to meet the needs of participants and families. If an individual experiences a change in status, existing protocols would necessitate a reassessment to determine the appropriate service category.

We also note that some of the services included in the proposed bill are very vague, and we are unsure how they would be effectuated at the programmatic level. Examples include those that would be codified at:

- 1905(hh)(2)(A)(iii) Services that enhance independence, inclusion, and full participation in the broader community.
- 1905(hh)(2)(A)(vi) Caregiver and family support services

These are important benefits, though the extremely broad nature of potential interventions would create challenges with state implementation as it would be difficult to create reasonable parameters around allowable activities within the service definition. We recommend defining specific activities that can be allowed under these services with a state option to expand further. The lack of clarity around what is included creates the risk of disputes between states, providers, and participants around appropriate service definitions and coverage limits. It would make more sense to provide specificity and enable state flexibility to develop additional services utilizing the Secretary approved "other services" option provided via 1915(c)(4)(B).

Further, while we believe that there would be options for states to continue covering a wide range of services in the HCBS system, we do not want changes made to inadvertently limit individual choice. The

legislation starts with a presumption that individuals can live independently in the community. We agree with this approach, though are concerned that an aggressive interpretation could limit options for living arrangements. We recommend explicit language that ensures access to a wide array of HCBS settings, including group homes, assisted living, memory care, and other HCBS settings that provide individual choice and autonomy but are not specifically a single family home or apartment.

We are also concerned about the potential impact on innovation in the HCBS system. Due to Medicaid's prominence in HCBS financing, many successful models for service delivery have been developed through state activities and demonstrations. Though the legislation does incorporate state-proposed, Federally-approved services by reference to 1915(c)(4)(B), we are concerned that the extensive list of services, the inability to target services to specific populations, and the changes to eligibility and Federal financing could lead to strict limits on what CMS will allow states to include.

The legislation also does not address one of the largest components of the Medicaid institutional bias: the ability to pay for room and board in institutions but not in home and community settings. Although the legislation does provide for "Housing support and wrap around services," this is generally interpreted to mean assistance with accessing housing supports and not to subsidize living costs. Medicaid programs should be provided the option to support community living expenses when budget-neutral to the cost of institutional care.

The Act should also further address Medicaid's institutional bias through service designs. As we mentioned earlier, legislation that creates a nationwide entitlement to HCBS should be coupled with changes to the nursing facility benefit. Such a significant expansion of HCBS is a laudable goal, but must be approached in a thoughtful manner that takes into account all of the other required benefits within the Medicaid program. If HCBS becomes a mandatory entitlement, we recommend allowing states to establish waiting lists and prioritization for institutional services.

Lastly, we appreciate that Advancing States is recognized as an important partner in the legislation and is included in the Advisory Panel to specify additional services for inclusion in the mandatory benefits package. We agree that there must be a process for ongoing evaluation and update of the benefits package to account for innovations and new services that may arise after the enactment of any legislation. However, we are concerned that the services only appear to be additive and that there is no process to evaluate the value of continuing benefits already listed in the statute. We also believe that the potential for future service additions could further dissuade CMS from approving "other" services that provide states with options to extend the benefits beyond those listed in the statute.

In summary, there is a delicate balance between overprescribing service inclusion while also providing states with flexibility to test new models of care and new services. We believe that a more targeted minimum benefits package coupled with extensive authority for states to expand above that floor would be a preferable approach.

### **Transition and Phase Out**

The legislation proposes a five-year transitional period for states to eliminate existing HCBS waivers and implement the required mandatory services established in this Act. We believe that this timeline is extremely aggressive and largely unachievable. If enacted, this bill would represent one of the largest changes to Medicaid since its inception and a complete overhaul of the LTSS coverage and delivery system. Though the bill does allow states to request a waiver from CMS to extend the implementation timeline, we anticipate that the vast majority of states would need to do so. This would create an unnecessary administrative hurdle in the midst of a labor-intensive overhaul of the program. We recommend a longer period for transitioning the services.

We also are unsure if certain components of the Medicaid HCBS system would be eliminated. The bill would create a new section of the Social Security Act at 1915(m) that eliminates 1915 provisions as long as “such provisions relate to a waiver for home and community-based services.” As mentioned earlier, section 1915 contains a combination of HCBS waivers and HCBS state-plan options. The language is unclear as to whether state-plan HCBS, such as those authorized by section 1915(i) and 1915(k) of the Act, would be maintained. If these programs are maintained, it is unclear whether any state would continue to utilize the options given the significantly lower Federal matching rate that would be provided.

We appreciate the recognition that the transition will require extensive planning, and request that the legislation specify the amount of funding available to states under the grants authorized by section five of the bill. We also recommend specifying the length of time the funding is available. We further agree that community networks, particularly Aging and Disability Resource Centers (ADRCs) and No Wrong Door (NWD) networks, should be leveraged to assist with outreach, education, and assistance to program participants during the transition. We request specific funding to support these networks during the transitional period.

We are concerned about the transition plans required by the legislation. CMS’ 2014 HCBS Regulations<sup>1</sup> required states to submit transition plans that described the implementation of changes to promote community integration of HCBS participants. This final rule was promulgated over seven years ago and several states have not yet received final approval of their transition plan.<sup>2</sup> We do not want a similar process to unfold that would place significant administrative burden on the states while simultaneously delaying work needed to effectuate the transition. If the legislation continues to require CMS approval of the transition plan, we recommend establishing firm parameters regarding requirements and timelines for Federal review and approval of the transition plans.

### **Quality**

We agree that the HCBS system should continue to develop quality and outcomes measures that focus on the experience of participants rather than administrative oversight and process measures. We appreciate

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<sup>1</sup> CMS-2249-F/CMS-2296-F

<sup>2</sup> <https://www.medicaid.gov/medicaid/home-community-based-services/statewide-transition-plans/index.html>

the recognition of this need and the proposed allocation of resources to assist with the endeavor. We would like to highlight the National Core Indicators – Aging and Disabilities project that Advancing States and our members have developed.<sup>3</sup> Similarly, our partners at the National Association of State Directors of Developmental Disabilities Services manage the National Core Indicators project, which performs similar outcomes measurement and evaluation for intellectual and developmental disabilities HCBS. We request that the legislation include specific reference to building upon existing HCBS quality initiatives rather than establishing a new project or program for this purpose.

### **HCBS Delivery System Considerations**

We encourage Congress to consider whether Medicaid should remain the primary source of HCBS and LTSS in the nation. If this legislation is enacted, it would represent a drastic expansion of the Medicaid HCBS delivery system but would not implement changes to financial eligibility requirements. As such, Medicaid would remain a largely poverty-based program that requires individuals to have limited income and spend down resources to access services.

If Congress is interested in establishing standardized HCBS eligibility and service packages and is also able to finance 100% of the cost with Federal money, we recommend consideration of a multifaceted approach that does not rely solely on Medicaid. We recommend that Medicaid remain a safety-net program for participants while also establishing alternate ways to access LTSS without meeting Medicaid's strict income and asset requirements. One potential approach would be to couple Medicaid HCBS expansion with the addition of a targeted Medicare LTSS benefit that includes HCBS. Medicare participants that meet the functional eligibility for LTSS could access certain services without divesting income and assets and the Medicaid benefit would remain the comprehensive approach for individuals with higher service needs and meet income eligibility requirements for Medicaid.

### **Requests for Feedback Highlighted in the Memorandum**

Below, we address the questions outlined in the March 16<sup>th</sup> memorandum soliciting comments from stakeholders.

#### *The minimum services and standards to be provided by state HCBS*

As discussed earlier in this comment letter, we recommend that Congress include a more limited benefit package that establishes a core mandatory HCBS benefit and provides with the state flexibility to expand further based upon specific needs and state dynamics. This minimal package could include:

- Personal assistance, including personal care attendants, direct support professionals, home health aides, private duty nursing, homemakers and chore assistance, and companionship services.
- Community-based habilitation services, including supported employment and integrated day habilitation.

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<sup>3</sup> <https://nci-ad.org/>



- Adult day health and adult day social services.
- Physical and psychosocial rehabilitation services.
- Respite services.
- Caregiver and family support services, defined as:
  - Assessment of Caregiver needs and activities.
  - Provision of services to temporarily replace assistance generally provided by the caregiver.
  - Caregiver training and education to help them learn and improve skills that enable them to care for their loved one
  - Specialized medical equipment and/or supplies that are needed to help the caregiver continue providing support.
  - Behavioral health services, such as therapy, to help manage stress and other challenges with caregiving.
  - Physical therapies and other interventions to maintain overall wellness and ability to provide assistance.
- Case management, including intensive case management, fiscal intermediary, and support brokerage services.

*Methods to ensure state Medicaid rates are sufficient to support required services and supports and to provide adequate pay for direct care workers, including personal care attendants and other in-home care providers*

As noted in our comments to CMS in 2015, it is extremely challenging to measure rate adequacy in HCBS and LTSS due to the wide range of interventions provided and lack of comparable wage/income data for many of the covered services.<sup>4</sup> Instead, we recommend focusing on measuring access to services and supports based upon the individualized plan of care for participants. Information regarding services that were included in the plan but not delivered could provide important information about areas where there are potential shortages of providers. We note, however, that simply increasing Medicaid rates does not necessarily result in increased provider capacity. There must be multifaceted approaches to recruiting and retaining sufficient HCBS workers.

*Workforce development and support, including but not limited to, wages and benefits for direct service workers and personal care attendants, as well as recruitment, organizing, training and retention strategies.*

Even states with higher-than-average reimbursement rates for HCBS struggle with securing sufficient providers of care. Congress must address financial stability, career ladders, self-direction mechanisms, and

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<sup>4</sup> [http://www.advancingstates.org/sites/nasquad/files/CMS\\_Access\\_regulation.pdf](http://www.advancingstates.org/sites/nasquad/files/CMS_Access_regulation.pdf)



other structures that recruit, retain, and support a robust workforce to effectively deliver services. This should include:

- Demonstration and grant programs to experiment with different strategies.
- Research to evaluate how the different strategies are working.
- Identifying large-scale investments beyond Medicaid that can assist with workforce issues such as education initiatives, scholarships, loans, loan forgiveness, work visa programs.
- Additional Federal data for direct-care workers to help understand what is happening nationally and locally with workforce issues.

*HCBS infrastructure in states that support family caregivers, provider agencies and independent providers.*

There is a wide range of infrastructure important to HCBS service delivery. First and foremost, we recommend ongoing investments in and emphasis on development of information technology (IT) infrastructure that incorporates LTSS into the broader care delivery system. For example, the HITECH Act provided significant investments in health information technology (HIT) but did not include HCBS providers as eligible grant recipients. We recommend Federal initiatives to support adoption of HIT at the state and provider level and to ensure access to this infrastructure for caregivers, providers, and participants. We further suggest Federal initiatives to strengthen the IT related to monitoring and responding to issues of participant health and welfare, including improved ability to coordinate across multiple systems such as adult and child protective services, law enforcement, Medicaid, and operating agencies.

We also encourage the strengthening and expansion of ADRCs and NWD systems to ensure that family members and individuals have access to information and resources to make informed choices about LTSS options. Providing comprehensive up-front information can assist with accessing a wide range of LTSS, including both Medicaid and non-Medicaid interventions, that can often lower future programmatic costs and improve participant quality of life and satisfaction.

Lastly, there should be increased Federal funding to support state HCBS staffing. Any extensive overhaul of the LTSS system will require significant regulatory and programmatic changes, which will likely necessitate increased staff to enact. Prior budget reductions led states to reduce workforce levels, yet improved finances from economic growth are largely consumed by service expansions, increasing caseloads, and growing costs. As a result, many previous state FTE reductions have not been restored. We believe that Congress should work with states to identify ways to recruit, train, and retain program staff that can provide increased oversight and assistance with the HCBS benefits across the country.

*An HCBS infrastructure that*

- *Supports workforce development and activities to address workforce shortages, recruitment, turnover, career development and the provision of qualifications and on-going professional development;*

- *Ensures direct service workers are provided a voice in policy decisions and are able to join a union and collectively bargain;*
- *Facilitates communication among those receiving services, Medicaid HCBS program staff, and direct care workers in order to strengthen the delivery system and respond to emergencies; and*
- *Enables eligible Medicaid recipients to connect with qualified home care workers who fit the needs of older adults and people with disabilities, and provides other supports to those navigating the long-term care systems.*

Many of the recommendations provided in prior answers are applicable here as well:

- Workforce development and retention in LTSS must be addressed in a multifaceted manner that includes providing career opportunities for workers, improving quality of life and wages for providers, and engages various parts of the Federal government to identify strategies across labor departments, education, and the LTSS system.
- Expanded state infrastructure, including employees, would strengthen the ability to engage with workers and solicit feedback for policy decisions as well as communicate across all stakeholders to improve service delivery, respond to emergencies, and collaborate on issues related to HCBS and LTSS.
- The ADRC and NWD networks across the country provide a strong foundation to connect Medicaid participants and their loved ones with information and assistance with navigating the LTSS system. We recommend further investments to strengthen and expand the reach of these networks across the country.

*The role of managed care in providing HCBS, in particular, issues such as network adequacy standards and ensuring that consumers can retain maximum autonomy to direct their care.*

Managed care is an important part of the HCBS and LTSS delivery system, with 25 states currently delivering some or all of their LTSS through managed care.<sup>5</sup> States report a variety of reasons for leveraging managed care for LTSS, such as:

- Rebalancing Medicaid LTSS Spending.
- Improving Member Experience, Quality of Life, and Health Outcomes.
- Reducing Waiver Waiting Lists and Increasing Access to Services.
- Increasing Budget Predictability and Managing Costs.<sup>6</sup>

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<sup>5</sup> <http://www.advancingstates.org/initiatives/managed-long-term-services-and-supports/mltss-map>

<sup>6</sup> [http://www.advancingstates.org/sites/nasquad/files/FINAL%20Demonstrating%20the%20Value%20of%20MLTSS%205-12-17\\_0.pdf](http://www.advancingstates.org/sites/nasquad/files/FINAL%20Demonstrating%20the%20Value%20of%20MLTSS%205-12-17_0.pdf)

As with all aspects of Medicaid, managed care has specific benefits as well as considerations that must be addressed for the program to be effective. States must actively monitor the service delivery and engage with managed care organizations (MCOs) to ensure that contractual obligations are being met and that identified issues are resolved in a meaningful and timely manner. CMS issued guidance regarding necessary components of effective managed LTSS programs (MLTSS), and we believe that this framework provides a strong foundation for effective program development and implementation. We believe that ongoing support that builds upon the CMS framework, such as dedicated technical assistance for MLTSS, to help states effectively manage their programs would continue to strengthen the LTSS system. Managed care will likely continue to play a significant role in the HCBS system regardless of any Federal expansions or modifications and should be approached as a useful tool that needs appropriate skills and strategies to effectively utilize.

*Other related policies and programs, such as Money Follows the Person, the Program of All-Inclusive Care for the Elderly (PACE), and spousal impoverishment protections.*

- Money Follows the Person is a valuable program that has demonstrated success with transitioning individuals to community based LTSS instead of institutional services. We are appreciative of the recent Congressional extension and believe that the program should be made permanent, though its role may need to be reevaluated if the HCBS Access Act is enacted. Regardless of other changes to HCBS, we believe that Congress should streamline MFP reporting to reduce burden on states.
- Our states support PACE but note that it is a limited program that, by its very nature, cannot be drastically scaled to serve all individuals that may be eligible. We believe that PACE should be maintained, but that there should be parity across PACE and MLTSS policies, particularly as it relates to payment, requirements on providers, and beneficiary protections.
- The Spousal Impoverishment protections in HCBS that were extended nationally by the Affordable Care Act have been extended numerous times and remain in effect in every state. As discussed earlier, we believe that ongoing work should be done to decouple HCBS from poverty-related criteria more broadly, potentially by establishing mechanisms to access LTSS beyond Medicaid. In addition to broader changes to LTSS financing, we support extending the existing protections in HCBS programs.

## **Conclusion**

We believe that there are numerous opportunities to expand the availability of HCBS across the country. We are encouraged by the national dialogue that is occurring which is placing an emphasis on expanding access to HCBS and improving the service delivery system. We look forward to ongoing discussions around opportunities to extend HCBS to more individuals and, hopefully, enact broader reforms to LTSS that improve participant choice, quality of care, and overall quality of life for participants and providers. If you have any questions about this letter, please contact Damon Terzaghi of my staff at [dterzaghi@advancingstates.org](mailto:dterzaghi@advancingstates.org).

Sincerely,

*Martha Roherty*

Martha Roherty  
Executive Director  
ADvancing States

Cc: Members of the U.S. Senate  
Members of the U.S. House of Representatives