JUSTICE IN AGING

FIGHTING SENIOR POVERTY THROUGH LAW

April 26, 2021

The Offices of Senators Hassan, Brown, and Casey and Representative Dingell

Re: Discussion Draft of the Home and Community Based Services Access Act of 2021 (HAA)

Submitted via: HCBSComments@aging.senate.gov

Dear Senators Hassan, Brown, and Casey and Representative Dingell,

Thank you for the opportunity to provide feedback on the Home and Community Based Services Act of 2021 (HAA). We are excited to work with you on this transformative legislation that would end the Medicaid law's institutional bias and increase access to quality HCBS for people with disabilities of all ages across America. In particular, we see this as an opportunity to end inequities in access to HCBS across all disabled populations and all states. Requiring states to cover HCBS as mandatory benefit is critical and will end cumbersome waivers, enrollment caps, and waiting lists. However, we will not be able to help all low-income individuals with HCBS needs who want to age in place to do so without also expanding and streamlining eligibility, including by making HCBS retroactively reimbursable and permanently authorizing both the HCBS spousal impoverishment protections and the Money Follows the Person program.

As data shows, despite the progress towards "rebalancing" HCBS spending overall, half of states are still spending twice as much on institutional care as on HCBS for older adults and people with physical disabilities.[1] In addition, 33 states do not have any older adults with disabilities on waiting lists despite 28 of these states spending more on institutional care than on HCBS - a reflection of the lack of HCBS options for these populations.[2] And while the number of individuals living in nursing homes has decreased over the last few decades, that decrease has been primarily among white older adults. Meanwhile, older adults of color living in nursing homes has increased in part, researchers suspect, due to unequal access to home and community-based alternatives.[3] Older adults with dementia, a disease which disproportionately affects Black and Hispanic populations, experience the starkest inequities: at age 80, 75% of people with dementia live in nursing homes.[4]

Consistent with these overarching considerations, we submit the following specific feedback and recommendations on the HAA.

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- **Ensure Equity in HCBS Access Based on Age, Disability, Race/Ethnicity**
    - **Age**. Ensure age, older adults, and the needs of older adults is included throughout the legislation, including:
        - Sec. 2. Purpose. Paragraph 5 (p. 3): add cognitive disabilities to list of disabilities to include dementia and Alzheimer's.
        - Sec. 3. Requiring Coverage of HCBS. Paragraph (a)(2)(B). Specification of Services and Composition (pp. 7-9).
            - Paragraph (aa): Substitute "elderly" and add "aging adults"
            - Paragraph (bb): add aging organizations including representation for Alzheimer's/Dementia
        - Sec. 5. HCBS Implementation Grant Program (starting p. 19)
            - (c)(3) (p.20): Add "age"
            - (c)(4) (p. 20): Add "aging agencies" to read "existing State disability and aging agencies"
            - (c)(6) (pp. 21-22): Add "Older Americans Act"
            - (c)(11) p. 22: Add "age"
            - Add new paragraphs to require states to conduct needs assessments for various populations to establish baselines.
            - Add new paragraph that requires states to describe how it will evaluate and address disparities in its plan beyond the numerical goals identified in c(3).
        - Sec. 6. Quality of Services
            - (a)(1) (p. 23) add "age" with list of demographic break downs at line 20-21.
    - **Race and Ethnicity**. Ensure equitable HCBS access based on race and ethnicity
        - **Tribal and US Territories**: Consult with stakeholders that can advise on how this legislation intersects with Indian Health Services and HCBS availability on tribal lands and in the US Territories. Ensure the legislation is drafted to facilitate expansion to HCBS on tribal lands and ensure that it can be implemented by the US Territories. We know that the capped funding for Medicaid in the territories is a major reason why they do not cover LTSS. However, this legislation should be carefully drafted not to inadvertently create additional barriers or further embed existing barriers to new HCBS programs in the Territories.
        - **Include race, ethnicity, and other demographic equity factors throughout legislation, including:**
            - Sec. 2. Purpose. Paragraphs 9 and 10 (pp. 3-4): Include inequities based on race and gender/sex for unpaid caregivers and the direct care workforce.

- Sec. 2. Purpose. Paragraph 11 (p. 4): Suggest moving paragraph on racial disparities higher to reflect the need to address disparities in access to HCBS.
- Sec. 3. Requiring Coverage of HCBS: Paragraph (a)(2)(B). Specification of Services and Composition (pp. 7-9): Suggest a new paragraph (cc) to include equity as a factor in the panel composition that represents age, disability, race, ethnicity, sexual orientation, gender identity, and geographic equity.
- Sec. 3(a)(4)(B). Individualized Assessment. Presumption (p. 13): strongly recommend changing language that the presumption that services are rendered in an "individual's own home and community." This could be interpreted to deny services to unhoused individuals or individuals not living in their "own home." Revised language could state: "individual's own home and community, including services provided to unhoused individuals."
- Sec. 3(a)(4)(D). Standards: Add text regarding language assistance services and compliance with all other federal non-discrimination requirements, including specific text requiring use of plain language and accessibility in the assessment tools themselves; accessible assessments for individuals who are blind or have low-vision, for deaf and hard of hearing individuals, and for individuals who cannot rely on speech to communicate; and that assessments be conducted in the individual's primary language or with a qualified interpreter. All such assessment tools and language should be tested on consumers beforehand.
- Sec. 5. HCBS Implementation Grant Program (starting p. 19)
    - (c)(2) (p. 20): Define living wage (possibly pull from Domestic Workers Bill of rights)
    - (c)(3) (p.20): Add "primary language, sexual orientation, gender identity."
    - (c)(11) p. 22: Suggest federal baseline for data collection.
    - As noted above: add new paragraphs to require states to conduct needs assessment for various populations to establish baselines.
    - As noted above: add new paragraph that requires states to describe how it will evaluate and address disparities in its plan.
    - Add requirement for states to consult with tribes.

- **Additional Provisions to Ensure Elimination of the Institutional Bias**
    - **Initiate HCBS Coverage Promptly**. Due to federal Medicaid policy, HCBS services cannot be covered until a service plan is formally approved. By contrast, nursing home services can be covered from the first day, through retroactive approval. This discrepancy forces individuals to choose nursing home care in order to get immediate assistance. To address this problem, the HAA could include HCBS in the same retroactive coverage provision that applies to nursing home care and many other Medicaid services.
        - **Possible Amendment (could be incorporated under Section 3(a)(4) Individualized Assessment (p. 12))**. Medicaid's general rule — that coverage be possible up to three months prior to the application month — is set by 42 U.S.C. § 1396a(a)(34). We recommend that section 1396a(a)(34) be amended as follows to ensure that its requirements are applied to home and community-based services:
          [A state's Medicaid plan must] provide that in the case of any individual who has been determined to be eligible for medical assistance under the plan, such assistance will be made available to him for care and services included under the plan and furnished in or after the third month before the month in which he made application (or application was made on his behalf in the case of a deceased individual) for such assistance if such individual was (or upon application would have been) eligible for such assistance at the time such care and services were furnished. <u>If care or services are provided through a service plan or any similar document, including but not limited to services provided under the authority of any provision of 42 U.S.C. §§ 1315 or 1396n, medical assistance must be available pursuant to this subsection without regard to whether the service plan or similar document was developed before or after the care or services were provided.</u>
    - **HCBS Cost Sharing**. The ACA eliminated cost sharing for Part D prescription drugs for certain dually eligible individuals enrolled in specific HCBS waivers.[5] We recommend including language in the HAA that ensures that anyone receiving HCBS pursuant to this legislation would be eligible for the cost-sharing protection. This language should be broad. The ACA language is very confusing and leaves out some HCBS provided under certain waivers. Consequently, some states have not implemented this protection properly (or at all for years) and low-income HCBS recipients have been paying for prescription drug costs when they shouldn't be.
        - **Cross reference**: Section 3309 of the ACA, those" who would be such an institutionalized individual or couple, if the full-benefit dual eligible individual were not receiving services under a home and community-

based waiver authorized for a State under section 1115 or subsection (c) or (d) of section 1915 or under a State plan amendment under subsection (i) of such section or services provided through enrollment in a Medicaid managed care organization with a contract under section 1903(m) or under section 1932'' after ''1902(q)(1)(B))''

- **HCBS Settings Rule**
  - Cross reference HCBS Settings Rule in Section 5: HCBS Implementation of HCBS Grant Program. Ensure that HCBS Settings Rule is incorporated to apply to all HCBS.
- **Make Spousal Impoverishment and Money Follows the Person Permanent**
  - Add new paragraphs to make MFP and HCBS Spousal Impoverishment protections permanent.
  - Require states to collect data based on age, disability, race, ethnicity, sexual orientation, and gender identity for Money Follows the Person program enrollees.
- **Eliminate Medicaid Estate Recovery.** Today, states are required to seek recovery from the estates of deceased recipients for costs of nursing home services and HCBS for services rendered to recipients age 55 years or older. This policy not only perpetuates poverty and racial inequities, it deters individuals eligible for HCBS from seeking services, placing them at higher risk for hospitalization and institutionalization, and strains the economic security of families who step in to act as unpaid caregivers. The law should be amended to eliminate Medicaid estate claims. Alternatively, HAA could implement the three recommendations put forth by MACPAC to limit estate recovery.[6]
- **Include Specific Requirements for Medicaid Managed Long-Term Services and Supports.** About half of states have opted to deliver HCBS and long-term care through managed Medicaid plans. Little data is available in how well these plans are providing HCBS and there is evidence that HCBS being delivered through these models are overly medicalized and fail to provide HCBS that is person-centered and provides full access to community living as set forth in the HCBS Settings Rule.[7]

- **Enumerate Additional Specified Services**
  - HCBS Services Specified, Sec. 3, paragraph 2 Services Specified (pp. 5 - 7):
    - Add Assisted Living Services
    - Add Nutrition Services
    - Add Housing Linkages
    - Add Options Counseling
- **Improve Quality and Oversight**
  - **Establish an Independent HCBS Ombuds Program.** The HAA should establish an independent ombuds program to provide direct assistance to individuals, identify systemic issues, and work with state agencies and CMS to implement

policies to address systemic problems. This program should follow the model used in the Financial Alignment Demonstrations for dual-eligible individuals.[8]

- **Require Robust Intersectional Data Collection.** As noted above, robust HCBS data collection across all HCBS as well as Money Follows the Person is needed to track disparities in access based on race, ethnicity, age, disability, sexual orientation, gender identity, and geographic location. Such data collection is fundamental to ensuring quality.
- We also support the ideas suggested by the Disability and Aging Collaborative.

- ***NFIB v. Sebelius* considerations**
  - Consider whether other benefit/eligibility expansions could inform this expansion, including:
    - Examples of benefits expansions:
      - Medicaid Home Health—1970 as an option and became mandatory in 1993/94
      - Medicaid Retroactive Coverage—1972 (including for nursing homes but not HCBS)
      - NEMT—not the best example because it was interpreted as mandatory in the regs but officially added to statute in Dec. 2021
    - Examples of eligibility expansions:
      - SLMB (Omnibus Budget Reconciliation Act of 1990 (P.L. 101-508); was later expanded)
      - QI (Balanced Budget Act of 1997 (BBA 1997, P.L. 105-33); was scaled back in 2002)
  - Consider whether a Managed Care Organization (MCO) provider tax is feasible for certain HCBS providers and how the current provider tax on institutional long-term care providers disincentivizes states from expanding HCBS.

Again, thank you for the opportunity to provide feedback on this critical legislation. If you have any questions, please contact Amber Christ, achrist@justiceinaging.org. We look forward to continuing the discussion.

Sincerely,

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Directing Attorney

[1] Justice in Aging, "Medicaid Home and Community-Based Services for Older Adults with Disabilities: A Primer," April 2021, available at https://justiceinaging.org/wp-content/uploads/2021/04/HCBS-Primer.pdf.
[2] Id.

[3] Feng, Z., (et al.), "Growth of Racial and Ethnic Minorities in US Nursing Homes Driven by Demographics and Possible Disparities in Options," Health Affairs (July 2011), available at https://www.healthaffairs.org/doi/abs/10.1377/hlthaff.2011.0126.

[4] Alzheimer's Ass'n, "Fact Sheet: Race, Ethnicity, and Alzheimer's," (Mar. 2020), available at https://www.alz.org/aaic/downloads2020/2020_Race_and_Ethnicity_Fact_Sheet.pdf

[5] 42 U.S.C. 1395w-114(a)(1)(D); 42 C.F.R. 423.782(a). *See also* Justice in Aging, FAQ: Low Income Subsidy ("Extra Help") for Dual Eligibles Receiving Home and Community-Based Services (Sept. 2019), https://justiceinaging.org/wp-content/uploads/2019/09/Updated-Part-D-HCBS-Fact-Sheet-2019.pdf.

[6] MACPAC, Report to Congress on Medicaid and CHIP, ch. 3 (Medicaid Estate Recovery: Improving Policy and Promoting Equity), at 72 (March 2021).

[7] In 2017 and 2018, of the 10 states that did not report LTSS expenditure data, 9 were managed LTSS states: Illinois, Kansas, Massachusetts, New York, North Carolina, Tennessee, Texas, Vermont, and Virginia. CMS, "Medicaid Long Term Services and Supports Annual Expenditures Report: Federal Fiscal Years 2017 and 2018" (Jan. 2021), www.medicaid.gov/sites/default/fles/2021-01/ltssexpenditures-2017-2018.pdf.

[8] ICRC, State Approaches to Developing and Operating Ombudsman Programs for Demonstrations under the Financial Alignment Initiative, https://www.integratedcareresourcecenter.com/sites/default/files/Ombudsman%20Programs%20brief.pdf