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April 26, 2020

VIA ELECTRONIC SUBMISSION

The Honorable Sherrod Brown
Senator
US Senate
Washington, DC 20510

The Honorable Bob Casey
Senator
US Senate
Washington, DC 20510

The Honorable Maggie Hassan
Senator
US Senate
Washington, DC 20510

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

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

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

The Medicare Rights Center appreciates this opportunity to provide feedback on the HCBS Access Act (HAA) draft. Medicare Rights is a national, nonprofit organization that works to ensure access to affordable health care for older adults and people with disabilities through counseling and advocacy, educational programs, and public policy initiatives. Each year, Medicare Rights provides services and resources to nearly three million people with Medicare, family caregivers, and professionals.

Medicaid home- and community-based services (HCBS) provide vital supports for people with disabilities and older adults that enable them to live safely in their communities of choice. But both the funding and availability of HCBS fall far below its importance, leaving too many people without services to meet their needs. The institutional bias of the Medicaid program guarantees access to nursing home care, but not HCBS, despite the latter being what people want for themselves and for their loved ones.

The optional nature of HCBS funding has led to a panoply of state laws and approaches to HCBS. Far too many callers to our national helpline want HCBS but are trapped on waiting lists or cannot get the

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specific care they need, leaving them no option but to enter nursing homes or other congregate settings. This is especially troubling during the COVID-19 pandemic, which has demonstrated yet again that congregate settings are not just less preferred by most, but can also be dangerous.

If enacted, the HAA would greatly expand access to HCBS, helping people who need supports to stay in their communities, age in place, and live the lives they choose. The Medicaid program must be made more equitable and better meet the needs of those it serves. We are fully committed to this vision and offer the following suggestions to tweak the HAA to better achieve it.

General additions

We urge the inclusion of several provisions that will help ensure people have consistent access to the care and services they need:

- Livable wages and greatly enhanced training, leave, protections, and certification for all HCBS workers.
- Inclusion of “age” in all lists of tracked demographics.
- Permanent extension of Money Follows the Person as well as language requiring data collection based on age, disability, race, ethnicity, sexual orientation, and gender identity for the program.
- Permanent extension of HCBS Spousal Impoverishment protections.
- Clarification that Medicaid retroactivity¹ applies to HCBS coverage. Long-standing practice has denied such retroactive coverage for HCBS despite the plain language of the statute making it clear that retroactive HCBS coverage is not waivable under the statute.²
- Creation of an independent HCBS-dedicated professional ombuds program to help facilitate beneficiaries to resolve issues and access needed services; and to identify and report to the state—and help address—systemic problems with enrollment, eligibility, or access to services.
- Encouragement of robust availability of resources to protect against the abuse and neglect of older adults and people with disabilities in a home care setting, to include coordination with the above-mentioned HCBS ombuds program and local adult protective services.
- Establishment of adequate reimbursement rates as well as a federal floor for service funding to ensure equal access to services and avoid dangerous variability across states.
- Elimination of prescription medication cost sharing for all HCBS recipients.
- Mandate training for HCBS recipients, family members, workers, and caregivers to identify and combat abuse and neglect, with a particular focus on those recipients who are self-directing to ensure they have the information and resources they need.

Section 2

¹ 42 U.S.C. §1396a(a)(34).

² 42 U.S.C. § 1396n(c)(3). The statute limits waivers to statewideness, comparability, and income and resource rules.

Page 3, lines 3-9: We urge you to add cognitive disabilities including Alzheimer’s and related dementias to the list of the disabilities enumerated in paragraph 5. The Alzheimer’s Association estimates that more than 6 million Americans are living with Alzheimer’s, with an expected increase to nearly 13 million by 2050. These numbers demonstrate the necessity to ensure more people with Alzheimer’s can receive care in their communities and homes rather than in institutional settings.

Page 3, lines 13-17: We suggest clarifying that the goal is to avoid unnecessary and unwanted institutionalization. While most people with disabilities and older adults would prefer to remain at home and in their existing communities, there are others who prefer and would choose congregate settings.

Page 4, lines 8-12: We suggest revising this section to make it clear that the disparities in access and outcomes are the major focus, with the disparity of access to information as a related disparity. A suggested edit:

To eliminate the race and gender disparities in HCBS that affect outcomes as well as access to care, services, and information and to prevent the unnecessary impoverishment and institutionalization of black and brown individuals with disabilities and aging adults.

Section 3

Page 5, line 12: We encourage the addition of “safety monitors” or “safety supervisors” who can ensure that people with Alzheimer’s or related dementias can remain in their homes if they require supervision at night. In our experience, people living with dementia may be more likely to be institutionalized because they may not need around the clock assistance with activities of daily living (ADLs) or instrumental activities of daily living (IADLs) but do require other assistance to ensure their safety.

Page 6, lines 14-16: We urge the inclusion of training for care managers to include identification of abuse and neglect. In addition to care management, we also urge the inclusion of “care coordination” to ensure people receive appropriate help navigating multiple kinds of coverage. For example, a beneficiary may need assistance getting a power wheelchair covered by Medicare with custom parts covered by Medicaid.

Page 7, line 4: We applaud the inclusion of peer support services which are life saving for some of our clients.

Page 7, lines 5-6: We urge the inclusion of food and nutrition services as one of the wrap-around services.

Page 7, lines 20-21: We have concerns that a 10-year gap between convenings of this advisory panel is too long to ensure that HCBS will meet the needs of people who rely on the services. Adaptive technologies in particular can evolve quickly. We urge a convening at least every five years to ensure appropriate coverage of services.

Page 8, lines 5-8: We urge the inclusion of language to make clear that equity is a factor in panel composition, to include age, disability, race, ethnicity, sexual orientation, gender identity, and geographic equity. We also have concerns that the size of this panel would be impracticable.

Page 8, line 18: We suggest the term “aging adults” or “older adults” instead of “elderly.”

Page 8, line 23: We encourage the specific inclusion of organizations focused on Alzheimer’s and dementia.

Page 12, lines 3-8: We suggest including language that makes clear that a combination of one ADL and one IADL would satisfy the requirement for a qualifying functional impairment.

Page 13, lines 5-7: We suggest adding language that establishes standards for keeping person-centered care plans up-to-date and reflective of the current needs of the individual and making them readily available to the individual upon request.

Page 13, lines 19-20: We suggest modifying the language from “the individual’s own home and community” to “the individual’s home and community, not to exclude unhoused individuals.”

Page 13, lines 21-23: We suggest adding that services may be self-directed or directed by the individual’s authorized representative.

Page 14, lines 5-10: We urge the inclusion of 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; and accessible assessments for individuals who are Deaf or hard of hearing. We urge that all such assessments, notices, and other communications go through consumer testing prior to implementation. We also urge that all assessments be conducted in the individual’s primary language or with a qualified interpreter, and that the right to appeal an assessment is clearly conveyed.

Page 15, lines 1-4: We urge the creation of processes for the public to challenge assessment methodologies.

Page 19, lines 18-20: We suggest adding several requirements to this section for states to explain how they will

- Increase oversight to combat abuse and neglect, including coordination with adult protective services.
- Conduct needs assessments for various populations to establish baselines.
- Evaluate and address disparities in its plan.
- Consult with tribes where applicable.

Thank you again for this opportunity to provide comment on this transformational legislation. For further information, please contact Lindsey Copeland, Federal Policy Director at LCopeland@medicarerights.org or 202-637-0961 and Julie Carter, Senior Federal Policy Associate at JCarter@medicarerights.org or 202-637-0962.

Sincerely,

A handwritten signature in cursive script that reads "Lindsey Copeland".

Lindsey Copeland
Medicare Rights Center