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April 26, 2021

The Honorable Sherrod Brown
Senator
U.S. Senate

The Honorable Bob Casey
Senator
U.S. Senate

The Honorable Maggie Hassan
Senator
U.S. Senate

The Honorable Debbie Dingell
Representative
U.S. House of Representatives

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

Thank you for the opportunity to provide comments on the HCBS Access Act (HAA). The National Health Law Program (NHeLP) strongly supports this initiative. Founded in 1969, NHeLP protects and advances the health rights of low-income and underserved individuals. We advocate, educate, and litigate at the federal and state levels to advance health and civil rights in the U.S.

We are grateful for your dedication to improving Medicaid for individuals with disabilities. This is evident in your thoughtful approach to this draft legislation, and we strongly support your goal of undoing the institutional bias in Medicaid. Below, please find detailed comments and suggestions, which we offer in hopes of strengthening the bill and services for Medicaid

enrollees. Our comments track the order of the bill, in order to facilitate review, and thus are not necessarily in order of importance.

I. Section 2 -- “Purposes”

We offer two brief edits to the purposes section. First, it is important to prioritize racial equity in this statute, but the statutory purposes would be incomplete if it did not include the need to eliminate other disparities. Thus, we suggest the following edit to page 4, to indicate both that racial equity must be singled out as an essential priority, but that the purpose of the bill includes addressing the full range of disparities.

Page 4:

Lines 8-12: (11) *To eliminate the race, ~~and gender~~, **ethnicity, disability status, age, sex, sexual orientation, gender identity, preferred language, rural/urban environment, and service setting** disparities that exist in accessing information and HCBS, and to prevent the unnecessary impoverishment and institutionalization of **people with disabilities, especially Black, Brown, Indigenous and other disabled People of Color of all ages.***

We also suggest adding the following purpose, to indicate that improving the quality of HCBS services is also a purpose of the Act:

To reinforce and promote continuous quality improvement and program integrity by all entities engaged with the organization, financing, management, and delivery of HCBS services and supports.

II. Section 3(a) -- “Definition of Home and Community-Based Services”

We support the breadth of the services included in the new definition of “Home and Community-Based Services,” and appreciate the cross-disability approach. We particularly commend the offices for including services that are often provided outside of 1915(c) waivers in the definition, including intensive community-based behavioral health services.



A. Section 1905(hh)(2)(A)

There are several areas in the list of “specified services” to be included in the new HCBS benefit where it may be beneficial to be more specific about the service that will be included (to ensure it will be both mandatory and receive increased federal funding). For example, “specified services” includes “services described in any of paragraphs (7), (8), (13)(C), (19), (20), (24), and (29)....” (Page 5, line 14-17). However, 1905(a)(19) includes both “case management services (as defined in section 1915(g)(2)) **and** TB-related services described in section 1902(z)(2)(F)” (emphasis added). While case management services are clearly integral to HCBS, the TB-related services described in section 1902(z)(2)(F) are not, and likely should not be funded at the proposed increased FMAP.

Additionally, the same paragraph includes in the definition of “specified services” the services specified in 1915(c)(4)(B). While it is necessary to pull in services included in 1915(c) waivers, we note that in addition to list of the services in 1915(c)(4)(B) (which includes “case management services, homemaker/home health aide services and personal care services, adult day health services, habilitation services, respite care,”) that section also includes “such other services requested by the State as the Secretary may approve.” While the ability to include “other services’ is appropriate for 1915(c) waivers, which are more limited in size and scope, this type of statement may be too broad for HCBS state plan services, as it would give the Secretary virtually unbridled authority to approve additional services. Instead, we believe the better path is to allow the advisory panel to recommend services for inclusion to the Secretary, who in turn could issue guidance indicating which new services meet the definition of “home and community-based services.” We address the proposed role of the panel and the inclusion of new services in more detail below, *infra* section II(B).

Thus, we suggest the following modifications:

Page 5, Lines 13-21

“(A) IN GENERAL -- For purposes of paragraph (1), the services specified in this paragraph are services described in any of the paragraphs (7), (8), (13)(C), (19) (excluding **TB-related services specified in 1902(z)(2)(f)**), (20), (24), and (29) (as applied without regard to the reference to ‘September 30, 2025’) of subsection (a) or in any subsections (c)(4)(B)(**as applied without regard to the reference to “such other**



services requested by the State as the Secretary may approve”), (c)(5), (k)(1)(A), (k)(1)(B), or (k)(1)(D) of section 1915. . . .”

Being more specific about the services intended to be included in HCBS may help reduce the overall cost of the bill and better target resources towards HCBS.

Additionally, the HAA includes a “catch-all” category of services that are not otherwise covered but necessary for an individual to remain in the home and community. This category should be modified as follows:

Page 6, Lines 20-25:

~~“(x) Necessary medical and nursing services~~ **Medical care, or any other type of remedial care recognized under State law, furnished by licensed practitioners within the scope of their practice as defined by State law, not otherwise covered** which are necessary in order for the individual to remain in their home and community, including hospice services.”

The word “necessary” unnecessarily modifies “medical and nursing service not otherwise covered which are necessary in order for the individual to remain in their home and community, including hospice services.” All services that are delivered via Medicaid must be “medically necessary,” and adding the modifier “necessary” to one service but not others could lead to an interpretation that there is some extra restriction on the service. We also suggest replacing the phrase “medical and nursing services” (which is not defined under the Medicaid Act) with the phrase “medical care, or any other type of remedial care recognized under State law, furnished by licensed practitioners within the scope of their practice as defined by State law;” which is a defined benefit under 1905(a)(6).

Last, while we support efforts to ensure that services are defined by those who use services, and thus are generally supportive of the creation of the advisory panel, it may not be prudent to delegate final decision-making authority regarding covered services to the panel. While there may be times that it is appropriate to insulate Congress and CMS from certain decisions, determinations of what should and should not be included in a public insurance program need to involve broad public input. Such decisions need to be made by a government entity that is accountable to constituents. We propose instead the following language:



Page 7, lines 15-17

“(xvi) Any other services ~~specified~~ **recommended** by the panel convened pursuant to subparagraph (B) and **determined by the Secretary to be included in the services described in paragraph 1905(hh)(2)(A).**”

This change would prevent the panel from adding whole swaths of services to the definition of HCBS, including potentially services that are in no way related to HCBS. We note that all of the services that are listed on page 5, line 22 through page 7, line 17 are examples of services described in 1905(hh)(2)(A). (This is why the statute uses the word “including” before the list). Thus, any new service added would need to be a subset of services specified in 1905(a)(7), (8), (13)(C), (19), (20), (24), and (29), and certain sections of 1915. The panel should not add any services outside those parameters, and the Secretary is the appropriate authority to determine what services fall within those parameters.

B. Section 1905(hh)(2)(B)-- “Specification of Services”

As noted above, we are concerned that the legislation delegates final decision-making authority regarding additions to HCBS to the panel. We believe the panel will better serve its role (and be less subject to fewer legal and political challenges) if it remains advisory and is insulated from making the final determination. Thus, we suggest the following line edits:

Page 8, lines 1-3:

“...~~which shall~~ **to** be included as home and community-based services under this paragraph.”

Page 9, lines 23-25

“...the panel shall submit to the Secretary and to Congress a report specifying services ~~which shall~~ **recommended to** be included ...”

Page 10, line 9-16

“Services ~~specified~~ **recommended** by the panel in a report submitted under clause (iii) **and determined by the Secretary to be included in the services described in**



paragraph 1905(hh)(2)(A) shall be treated as services described in subparagraph (A)(xvi) for the calendar quarters beginning on or after the date that is 1 year after the date of such submission.”

Further, we believe it is important that this panel reflect the full diversity of the disability communities, including diversity of race and language, and suggest that the section on composition of the panel, page 8, lines 9-18 be edited to reflect this. We also recommend that the panel receive funding or staff support necessary to facilitate full participation. Many of the representatives from groups and organizations listed in 1915(hh)(2)(ii)(1)(bb) will already have paid professional support and staff, while individuals listed in (aa) -- who are actually using HCBS -- may not. It is important that all members of the panel are on equal footing to meaningfully participate.

C. Section 1905(hh)(3) -- “Eligible Individuals”

1. Grandfathering Current Recipients

In addition to meeting the level of care specified in 1905(hh)(3)(A)(i), another way individuals will become eligible for HCBS is by being a current HCBS recipient at the time of enactment of the statute. This serves the important purpose of ensuring that individuals do not lose integral, life-saving services during this transition. Currently, the definition of “eligible individual” on page 11 states that an individual is eligible if the individual is determined to have a functional impairment (as defined by subparagraph B) *or* “is an individual receiving or determined to be eligible for, as of the date of the enactment of this subsection, home and community-based services . . .” This language should be clarified to indicate that an individual will be eligible if that person:

Page 11

“is an individual receiving or determined to be eligible for home and community based services as of the date of enactment of this subsection, **and continues to meet the specified level of care, as of the date of the enactment of this subsection, for any service included in the definition of home and community-based services in (hh) . . .**”



This clarifies that the intent is not to guarantee that anyone who was ever eligible for HCBS will continue to be eligible. Such an approach does not make sense, as an individual may regain functioning and no longer need HCBS. Instead, the intent is simply to grandfather in individuals who continue to meet the functional eligibility requirement that states currently have in effect for HCBS. This will protect enrollees in the rare instance where a state's required level of care for services is currently lower than the eligibility requirement in the HAA.

2. Eligibility of Youth

The HAA does not explicitly address the intersection of the new HCBS service with EPSDT. We believe this is generally the correct approach. In general, children are eligible for services that are necessary to “correct or ameliorate defects and physical and mental illnesses and conditions...” Thus, children should not be excluded from any service listed in 1905(hh), even if they fail to meet the 2 ADL/IADL level of care. For example, pursuant to the EPSDT mandate, a child could have a need for personal care services, but only need assistance with 1 ADL. In such a situation, the child should still get the service, and the service should still be reimbursed at the enhanced FMAP. The child certainly should not be excluded from services that are only available under 1905(hh), such as respite services, because the child does not require assistance with 2 ADLs/IADLs. To reflect this, we suggest adding a clause under “Eligible Individual” to anyone eligible for EPSDT is eligible for Home and Community-Based Services under (hh) based on medical necessity. These individuals are not required to meet the functional impairment standard under (3)(A)(i).

We suggest adding a new (3)(A)(iii) that states:

“(iii) an individual receiving or eligible to receive services pursuant to 42 U.S.C. §§ 1396a(a)(10)(A), 1396a(a)(43), 1396d(a)(4)(B); 1396d(r)(5).”

Such children would not automatically get services, but could get an assessment for services pursuant to Section (4).

3. 1905(hh)(3)(B) -- Definition of “Functional Impairment”

We support the Consortium for Citizens with Disabilities’ (CCD) recommendation that the definition of “functional impairment” be clarified to include an individual who requires assistance with one activity of daily living (ADL) as *well* as with one instrumental activity of



daily living (IADL). For example, we believe that an individual who requires assistance with bathing and with meal preparation (1 ADL + 1 IADL) should be eligible in the same way as someone who requires assistance with bathing and dressing (2 ADLs) or with meal preparation and household chores (2 IADLs.)

The definition of “functional impairment” refers to the citation in the Internal Revenue Code (IRC) to define ADLs and refers to 1915(k)(1)(A) to define IADLs. With regard to ADLs, using the IRC citation includes additional language that likely was not intended to be included. Thus, we recommend the citation be narrowed so as to only reference the list of ADLs.

More importantly, there is no firm definition of IADLs in 1915(k)(1)(A). Section 1915(k)(6)(F) states “The term ‘instrumental activities of daily living’ includes (but is not limited to) meal planning and preparation, managing finances, shopping for food, clothing, and other essential items, performing essential household chores, communicating by phone or other media, and traveling around and participating in the community.” At the least, we recommend replacing the citation to 1915(k)(1)(A) with a citation to 1915(k)(6)(F). However, the definition in 1915(k)(6)(F) is still more of a list of examples than a definition. Thus, we suggest the following modifications:

Page 12, line 4-8

“...2 or more activities of daily living (as described in 7702B(e)(2)(B)(i)-(vi) of the Internal Revenue Code of 1986)... or ~~2 or more~~ instrumental activities of daily living (as defined for purposes of section 1915(k)(1)(A)). **Instrumental activities of daily living are those activities that allow an individual to live independently in the community, including those activities described in 1915(k)(6)(F).** ~~as defined for purposes of section 1915(k)(1)(A)~~”

4. 1905(hh)(4) -- Individualized Assessment & Person-Centered Care Plan

We suggest that the definition of “person-centered care plan” incorporate the language in 42 C.F.R. § 441.725, instead of the language in 1915(i)(l)(G)(ii). It is particularly important that the definition of “person-centered care plan” include a prohibition on compelling “natural supports,” and note that any services provided by family members and friends must be provided voluntarily.



“... a written plan with respect to an individual that meets the **following** requirements of **the person-centered planning process and the person-centered plan:** ~~of section 1915(i)(1)(G)(ii):~~

- (a) ***Person-centered planning process.*** Based on the independent assessment required in 1905(hh)(4), the State must develop (or approve, if the plan is developed by others) a written service plan jointly with the individual (including, for purposes of this paragraph, the individual and the individual's legal guardian or other person who is authorized under State law to represent the individual for the purpose of making decisions related to the person's care or well-being, if applicable). The person-centered planning process is driven by the individual. The process:
- (1) Includes people chosen by the individual.
 - (2) Provides necessary information and support to ensure that the individual directs the process to the maximum extent possible, and is enabled to make informed choices and decisions.
 - (3) Is timely and occurs at times and locations of convenience to the individual.
 - (4) Reflects cultural considerations of the individual and is conducted by providing information in plain language and in a manner that is accessible to individuals with disabilities and persons who are limited English proficient.
 - (5) Includes strategies for solving conflict or disagreement within the process, including clear conflict of interest guidelines for all planning participants.
 - (6) Offers informed choices to the individual regarding the services and supports the individual receives and from whom.
 - (7) Includes a method for the individual to request updates to the plan, as needed.
 - (8) Records the alternative home and community-based settings that were considered by the individual.

(b) ***Person-centered service plan.*** The person-centered service plan must reflect the services and supports that are important for the individual to meet the needs identified through an assessment of functional need, as well as what is important to the individual with regard to preferences for the delivery of such services and supports. Commensurate with the level of need of the individual, and the scope of services and supports available under the State plan HCBS benefit, the written plan must:

- (1) Reflect that the setting in which the individual resides is chosen by the individual from an array of setting options that includes non-disability specific settings. The State must ensure that the setting chosen by the individual is integrated in, and supports full access of individuals receiving Medicaid HCBS to the greater community, including opportunities to seek employment and work in competitive integrated settings, engage in community life, control personal resources, and receive services in the community to the same degree of access as individuals not receiving Medicaid HCBS.
- (2) Reflect the individual's strengths and preferences.
- (3) Reflect clinical and support needs as identified through an assessment of functional need.
- (4) Include individually identified goals and desired outcomes.
- (5) Reflect the services and supports (paid and unpaid) that will assist the individual to achieve identified goals, and the providers of those services and supports, including natural supports. Natural supports are unpaid supports that are provided voluntarily to the individual in lieu of State plan HCBS.
- (6) Reflect risk factors and measures in place to minimize them, including individualized backup plans and strategies when needed.
- (7) Be understandable to the individual receiving services and supports, and the individuals important in supporting him or her. At a minimum, for the written plan to be understandable, it must be written in plain language and in a manner that is accessible to individuals with disabilities and persons who are limited English proficient.
- (8) Identify the individual and/or entity responsible for monitoring the plan.

- (9) Be finalized and agreed to, with the informed consent of the individual in writing, and signed by all individuals and providers responsible for its implementation.**
 - (10) Be distributed to the individual and other people involved in the plan.**
 - (11) Include those services, the purchase or control of which the individual elects to self-direct,**
 - (12) Prevent the provision of unnecessary or inappropriate services and supports.**
 - (13) Document that any modification of the conditions for a community-based service as defined in 1905(hh)(1) must be supported by a specific assessed need and justified in the person-centered service plan. The following requirements must be documented in the person-centered service plan:
 - (i) Identify a specific and individualized assessed need.**
 - (ii) Document the positive interventions and supports used prior to any modifications to the person-centered service plan.**
 - (iii) Document less intrusive methods of meeting the need that have been tried but did not work.**
 - (iv) Include a clear description of the condition that is directly proportionate to the specific assessed need.**
 - (v) Include a regular collection and review of data to measure the ongoing effectiveness of the modification.**
 - (vi) Include established time limits for periodic reviews to determine if the modification is still necessary or can be terminated.**
 - (vii) Include informed consent of the individual; and**
 - (viii) Include an assurance that the interventions and supports will cause no harm to the individual.****
- (c) Reviewing the person-centered service plan. The person-centered service plan must be reviewed at least every 12 months, when the individual's circumstances or needs change significantly, and at the request of the individual.**

Additionally, there is a requirement in the new 1905(hh)(4)(v) that the assessment take place no later than 30 days after eligibility has been determined, but no timeframe is included for the development of the person centered plan. It would be reasonable to also define a timeframe for

the person centered plan to be developed (either measuring from the date of an eligibility determination or from the date of assessment) so that service delivery is not delayed.

With regard to functional assessments and their relationship to the person-centered planning process, we recommend that the HAA include language that clarifies that data derived from the individualized assessment can never fully capture all aspects of a person's condition and living situation that contribute to their service needs. This may be especially true for children when an assessment is structured on the HAA benefit and may not take into consideration all that may be provided to a child under EPSDT to meet their needs. Therefore, it must be clear that the assessment required in the HAA it is intended as a guideline and may not be used as the sole evidence determining an individual's level of service needs. The assessment process should also include a built in exceptions pathway where an individual, having reviewed their results and the determinants of their score, can request a human review to address needs that the assessment questions, methodology, scoring, or algorithm/automated decision system may not have adequately accounted for.

Page 15, line 5: we suggest adding subclause (vi)

“(vi) ensure an assessment results may be considered as a guideline only and may not be the sole piece of evidence in determining the level of needed services.”

III. Sections 3(b) “Mandatory Benefit” and 3(c) “Ensuring Coverage of HCBS for All Medicaid-Eligible Individuals”

The HAA is carefully drafted to ensure that the new service fits squarely within the structure of the Medicaid Act. Basic requirements of the Medicaid Act, such as the requirements around statewideness, amount, duration, and scope, and due process will apply to this benefit. This will allow the new benefit to be administered within the well-defined contours of the Medicaid program, and for CMS and the states to draw on the fifty-year history of Medicaid to inform implementation of the new benefit.

We specifically agree with the decision to place the requirement for home and community based services in a new section 1902(a)(10)(D)(ii), after the current home health benefit. This placement makes sense. The home health benefit operates much like the new HCBS benefit will: just as home health is currently only mandated for those who are entitled to nursing facility services, HCBS will only be mandated for those who meet the eligibility criteria. We further



agree that it is helpful to include HCBS in the list of services that must be required to mandatory populations, as was done by amending 1902(a)(10)(A) to include HCBS.

IV. Section 3(d)-- Federal Medical Assistance Percentage

We appreciate that the FMAP for HCBS is set at 100%. However, we are concerned that if the HAA is amended so that the FMAP drops below 100%, some states may want to restrict eligibility because they will no longer be able to control costs by limiting the number of individuals who receive HCBS via waiver enrollment caps.

Thus, if the offices reduce the FMAP or taper it in the proposed statute, it is essential that a strong maintenance of effort (MOE) provision be added to the HAA. Such an MOE should require states to maintain the same asset and income eligibility requirements that were applied to under the waivers that are in effect at the time of enactment to the new group that is eligible for HCBS. To protect the integrity of HCBS, a three-pronged approach is necessary: 1) an MOE and corresponding individual right to continued eligibility suggested on page 16 of these comments, 2) a requirement to grandfather in individuals who meet the current functional level of need for HCBS as suggested on page 6 of these comments, and 3) a high quality assessment process.

As currently drafted, states will receive the 100% FMAP immediately upon enactment, but will not need to start providing any new services until five years after enactment. We suggest tailoring the increased FMAP and increasing it as states come into compliance with the new requirements. States could be required to meet certain benchmarks and requirements in implementation in exchange for predetermined increases in FMAP. We also recommend considering an enhanced administrative match near the beginning of implementation, to assist states with the important task of implementation, and taper this administrative match down as states start providing services and the FMAP for HCBS services increases. We also suggest that states receive an enhanced FMAP, equal to the FMAP for HCBS services, for administrative activities related to the HCBS ombuds program, adoption of HCBS quality measures, including consumer and other stakeholder engagement, data and quality infrastructure, expanding the sample size for beneficiary experience surveys such as HCBS CAHPS, NCI, NCI-AD and CQL-POMS, and public reporting of quality data.



V. Section 3(e) -- Conforming Amendments

A. General Comments and Technical Amendments

We strongly recommend that the offices ensure that all individuals currently meeting the income and resource limits that states are able to define via 1915 waivers will be able to access the new HCBS service. For example, it appears that some states use 1915(c) waivers to combine both a special income limit of up to 300% of SSI (as permitted under 1903(f)(4)(C), *and* some level or type of spenddown or income disregard to allow individuals to reach the 300% of SSI threshold. Absent these waivers, states would be bound by the general rule that the state must use a single income eligibility standard across all medically needy categories. We request that the offices draft a solution that allows for states to create a separate, higher income standard for medically needy individuals who meet the definition of an “eligible individual” under 1905(hh)(3), and ensure that a statutory pathway exists for any other income or resource limit that may exist solely via waivers, so that current enrollees do not lose access to Medicaid.

Additionally, we offer the following suggestions as technical amendments:

Page 17, lines 5 through 7

The amendment to 1902(a)(10)(A)(ii)(V) should read “**or who are eligible individuals as defined in section 1905(hh)(3)**” and not 1905(kk)(3). We believe the reference to 1905(kk)(3) is a typographical error.

We also believe that an additional conforming amendment may be necessary in 1903(f)(4)(C) to allow states to collect federal funding for individuals who meet the special income limit in 1902(a)(1)(A)(ii)(V) as amended by the HAA.

We encourage the offices to be more specific as to which waivers would sunset. As the HAA is now drafted, Section 3(e) adds a new section (m) to 1915, which states that “the preceding provisions of this section, insofar as such provisions relate to a waiver for home and community-based services, shall not apply beginning with the first calendar quarter ...” We suggest that the HAA be specific as to which provisions of 1915 shall sunset, and specify that 1915(a) and 1915(b) are excluded from sunset.



Page 17, lines 18-19

“...insofar as such provisions relate to a waiver or state plan amendment ~~for home and community-based services~~ **granted pursuant to Section 1915(c), 1915(d), 1915(e), 1915(i), 1915(j), and 1915(k).**

B. Protecting HCBS recipients from additional mandatory estate recovery

To ensure that the new definition of HCBS does not inadvertently expand mandatory estate recovery, we also suggest adding one additional conforming amendment. Specifically, 42 U.S.C. § 1396p(b) requires states mandatory estate recovery for individuals over 55 who receive home and community based services. At the least, we suggest that 42 U.S.C. § 1396p(b)(1)(B) be modified to strike the phrase “home and community based services,” thus exempting all HCBS from mandatory estate recovery.¹

Page 18, new subsection 5:

(5) in section 1917(b)(1)(B), by striking “home and community based services”.

It is particularly important to exclude HCBS from estate recovery because the new definition of HCBS greatly expands the services that are considered HCBS, and thus could greatly expand mandatory estate recovery if this language is not amended.

VI. Section 4: Medicaid Eligibility Modifications

A. Youth in 1915(c) waivers.

While some have voiced concerns that the HAA would prevent children who could be eligible for Medicaid via “Katie Beckett waivers,” we believe that this is primarily based on a misunderstanding of which provisions would sunset under the HAA. The HAA only sunsets

¹ here have been multiple calls for estate recovery to be made optional. See MACPAC, Medicaid Estate Recovery: Improving Policy and Promoting Equity (March 2021), <https://www.macpac.gov/wp-content/uploads/2021/03/Chapter-3-Medicaid-Estate-Recovery-Improving-Policy-and-Promoting-Equity.pdf>; Justice in Aging, et al, Medicaid Estate Claims: Perpetuating Poverty and Inequality for Minimal Return (April 2021), <https://justiceinaging.org/wp-content/uploads/2021/04/Medicaid-Estate-Claims.pdf>.



waivers in section 1915. The Katie Beckett option is in 1902(e)(3), and thus will not be changed by the HAA.

However, many states use HCBS waivers to create an eligibility pathway for youth with disabilities in families that are over-income for Medicaid. These waivers would sunset with the HAA. With the language suggested below in Section VI(B) that would maintain eligibility for individuals who are currently or would otherwise meet the income levels in states at the time of enactment must continue to be eligible, we believe this would protect continued eligibility of youth in 1915(c) Beckett-like waivers. The Katie Beckett eligibility criteria in place at time of passage would be ongoing, meaning new youth could become eligible for the HAA through that state's Beckett-like eligibility as it existed at the time of the HAA enactment. However, if this is not sufficient, the offices could add a new eligibility category that makes 1902(e)(3) a mandatory eligibility category.

B. Protecting Access to HCBS

In addition to the MOE articulated above, to further ensure that states do not seek to limit access to HCBS by reducing income eligibility or make more restrictive the treatment of resources after the HAA is enacted, we suggest adding the following or similar language to Section 4 of the HAA.

Page 19

Section 1902(a)(10)(A)(i) of the Social Security Act is amended by adding: “(X) who meet the HCBS income and resources requirement in the state on [at the time of enactment of the HAA] and are otherwise entitled to HCBS under (hh).”

VII. Recommendation for an Independent HCBS Ombuds Program

While a robust HCBS core measure set (see comments below, section IX “Quality of Services) can provide valuable information to guide quality improvement and strengthen health equity, quality measures alone will never be able to capture the full scope of care quality. A core quality measure set is necessarily limited and cannot cover every service type or subpopulation. Also, substantial data lags required for measure collection, verification, and analysis may lead to long delays before some problems even get identified.



For this reason, we recommend that the HAA mandate states to designate an independent ombuds office with the dual purpose to facilitate beneficiaries to resolve issues and access needed services and to identify and report systemic problems with enrollment, eligibility, or access to services up to the state. The Medicare-Medicaid Coordination Office's (MMCO) dual eligible financial alignment initiative created long term care (LTC) ombuds programs charged with fulfilling both these purposes. In that initiative and in Medicaid managed care beneficiary support systems for LTSS, the most effective ombuds programs function as an advocacy program, helping individuals understand their rights and providing assistance in resolving issues without infringing on an individual's right to appeal or file a grievance. Referral and education are also important functions of an ombuds program, but serving as an advocacy resource for individuals will ensure that individuals continue to bring problems to the attention of the program as they seek assistance. The program should be able to serve those receiving HCBS and those who are seeking such services.

An ombuds program for HCBS should be independent of the State Medicaid agency and any managed care plans. While MMCO allowed participating states to identify the best organization to serve as LTC ombuds for the financial alignment demonstrations, some of the most effective programs used independent ombuds run by organizations outside of state government, as in New York and California. Similarly, New York's ICAN program operates as the ombuds for Medicaid managed care LTSS. North Carolina, after determining that an independent ombudsman would best achieve the goals of its ombuds program for the entirety of the managed care program, recently contracted with a consortium of legal services providers. While the ombuds programs need to provide confidential services and be able to work with the State agency, any managed care plans, providers, etc., they must not be so hampered by confidentiality and non-disclosure agreements that they cannot serve their function of reporting issues and transparency to the public about issues in the program, activities of the ombudsman, or other important function. The ombuds program should also be funded based on enrollment of HCBS so that it is properly resourced to meet the obligations of the program.

Finally, we recommend that the independent ombuds office publicly post quarterly reports summarizing its work and identifying any problems or repeated barriers to enrollment or accessing services it has encountered through its work with beneficiaries, including its recommendations to resolve these issues. The reports should include a mechanism for public disclosure to ensure transparency.



Summary

- Each state should designate an HCBS ombuds office to assist beneficiaries directly and to identify and report systemic problems to state officials and the public.
- Each ombuds office must operate independently from the State Medicaid program and from any managed care plan.
- Each ombuds office has the following responsibilities:
 - providing education regarding the rights and responsibilities of people participating in the HCBS program, including the right to file appeals or grievances and rights regarding services;
 - providing confidential assistance and advocacy to help individuals resolve problems with accessing necessary services; and
 - referring and connecting people to resources to help resolve HCBS-related issues;
- The ombuds program must not operate largely as a referral system, but should be actively helping resolve problems and referring only as part of their overall role:
 - identifying, investigating, and reporting to the state systemic problems involving beneficiaries, including problems with enrollment, eligibility, or access to services;
 - working with community partners to gather information about potential problems or other issues with HCBS;
 - working with the State and other involved entities, such as managed care plans, to resolve identified problems; and
 - creating periodic reports on problems encountered.

VIII. HCBS Provider Network Adequacy

Ensuring that people who need Medicaid HCBS can readily find an available provider is absolutely essential for any successful HCBS program. We also recognize that HCBS network adequacy oversight looks different under different care delivery systems. In Fee-for-Service, the State determines the provider rate and individuals have access to any participating provider. The legal and regulatory structure to enforce provider access relates to 1902(a)(30)(A) and the Access Rule. Under capitated managed care, the provider network is limited by a Managed Care Organization and oversight is regulated through the Medicaid managed care regulations. Both FFS and managed care are prevalent in state HCBS programs, so the HAA should address how to ensure provider availability and choice under both delivery systems.



Mandatory Direct Testing. To the extent possible, we believe standards for network adequacy should be equivalent across delivery systems. One set of oversight mechanisms that the HAA should include for both managed care and FFS is mandatory direct testing. The law should require states to conduct and report active testing of their HCBS provider networks. For example, many states that use managed care programs contract with an external quality review organization, or similar entity, to conduct independent secret shopper surveys that test the accessibility and adequacy of their HCBS provider networks. This could also be done in the context of HCBS providers. Another form of direct test could include creating a survey or interview to identify barriers to initial access of services (including for self-directed services). Or reviewing a representative sample of person-centered service plans to identify if the services met an individual's needs and if there were any problems fulfilling authorized services could be another qualitative approach to identify network insufficiencies. Direct testing could also measure provider turnover for different types of HCBS or for different populations.

While such strategies cannot by themselves ensure that HCBS services are readily available across the gamut of services used by the diverse groups of people with disabilities, they have proven highly effective checks to inaccurate and outdated provider directories reported by managed care plans, and we think they would also be effective for maintaining access to HCBS services.

IX. Quality of Services

We suggest a different approach to ensure quality of service than the one proposed in the HAA. The section on HCBS quality should create effective quality improvement programs that build on existing structures to create robust state and federal oversight of HCBS programs. This structure should incorporate meaningful quality measures, mechanisms to develop new measures to fill gaps, and strategies to hold states accountable for meeting benchmarks. To be fully effective, the quality improvement structure must center the voices of the diverse range of beneficiaries in its design and implementation. Quality metrics cannot themselves provide sufficient oversight due to inevitable gaps and lags in reporting and to the sheer diversity of services that older adults and people with disabilities use. Therefore, the mechanisms named in this section must be supplemented with other strategies to build accountability into the system, including network adequacy provisions, the ombuds offices described above, and other mechanisms already present in the Medicaid program.



We also recognize that states running MLTSS programs have an extant quality measurement regulatory framework that the HCBS accountability framework will wrap around. Any HCBS quality improvement program must address both capitated managed care and fee-for-service delivery systems.

Below, we offer a proposed framework for ensuring quality in HCBS, and suggested additions to the statute that could implement such a framework.

A. Goals for measuring HCBS Quality

The HAA should be clear about the goals of accountability mechanisms to ensure access to quality care. Each state must develop, recognize, implement, enforce, and publicly and periodically report on multi-faceted HCBS quality and accountability mechanisms. The mechanisms we propose for the HAA aim to achieve the objectives described in the purposes section (Section 2) of the HAA. The aim is that these would complement, not replace, other extant Medicaid accountability mechanisms, such as Quality and Performance Assessment Improvement programs and external quality review in managed LTSS. The HCBS quality initiatives would include at least the following components:

- a HCBS core and supplemental quality measure set and benchmarks established at the federal level to assess performance at multiple levels, including state, health plan, and provider levels; the set should include robust, meaningful, and transparent quality metrics publicly reported annually and posted on each state's website, as well as mechanisms to address measure gaps;
- quality advisory committees at both federal and state levels comprised of a majority of beneficiaries and their advocates, plus other stakeholders;
- federal support for measure development;
- federal technical assistance to states; and
- A required state quality strategy: each strategy would include the State's plan for improving the quality of its HCBS program and the state's plan to identify and reduce health disparities for people with disabilities from various demographic backgrounds; this could parallel the managed care quality strategy that is already in place for managed care states, but should apply to states that use FFS delivery services, including for HCBS services.



B. Establishing a Federal HCBS Quality Committee

We recommend that the Secretary of Health and Human Services (HHS), in collaboration with the Administration for Community Living (ACL), the Agency for Healthcare Research and Quality (AHRQ), the Centers for Medicare and Medicaid Services (CMS), the Substance Abuse and Mental Health Services Administration (SAMHSA), and other agencies designated by the Secretary, establish a federal multi-stakeholder HCBS Quality Committee. This committee would be separate from the panel which recommends additional services, as ensuring quality of services is a significantly different task from advising on the inclusion of new services.

The committee should consist of a majority of individuals receiving or in need of Medicaid HCBS, and representatives of beneficiary rights organizations, disability rights organizations, aging organizations, Protection and Advocacy organizations and Centers for Independent Living. Committee participants must represent the diversity of those receiving HCBS across the nation and represent the interests of multiply marginalized people with disabilities. The remainder of the committee would include other stakeholders involved in quality measurement, such as health plans, measure developers, measure steward organizations, and relevant national associations of state officials.

The quality committee's role would be to define and regularly update the HCBS quality measure set and act as an advisory body for other elements of the HCBS quality and accountability program. HHS should provide staff support, training and other supports, such as transportation and stipends to the individual beneficiaries participating.

We also recommend that HSS, in collaboration with ACL, AHRQ, CMS, SAMHSA, the Office of Civil Rights, the Office of Minority Health, and other agencies designated by the Secretary, work with the HCBS Quality Committee to:

- review the HCBS core measure set, identify gaps in HCBS measurement, and prioritize measure concepts for development of new HCBS measures on an ongoing basis; and
- make recommendations for quality measure development to assess the adequacy of the HCBS workforce, including revisions in classification of HCBS workers.



C. Establishing a Core Set of Home and Community-Based Services Quality Measures

We recommend that within one year after the date of enactment, the HAA would direct the Secretary of Health and Human Services would issue regulations on a core set and supplemental set of home and community-based services quality measures. HHS has already received comments on a proposed HCBS Core and Supplemental Measure Sets, so the bill should reinforce that process. We support the domains chosen through that process.

We recommend adding a provision requiring CMS, not later than 3 years after enactment, to issue regulations that require States to annually report on a mandatory base set of measures from the core set. Required measures should reflect, to the extent practicable, the full array of HCBS services and HCBS recipients. States would retain the authority to add additional reported measures appropriate for their programs, based on the recommendations of state-level quality advisory committees described below.

D. Core Set Parameters

The development of the HCBS core set should be the product of a collaboration between CMS, ACL, AHRQ, SAMHSA and other key stakeholders, with a priority on beneficiary representation and perspectives through, among other things, input from the HCBS quality committee. The following elements should be part of legislative requirements for the Core and Supplemental Measure Set. CMS, in consultation with the multi-stakeholder HCBS Quality Committee will:

- select appropriate measures for each domain in the core measure set;
- set benchmarks for each core measure;
- determine the set of mandatory measures;
- annually review and update the core measure set and mandatory measures; and
- within 3 years after enactment, begin phasing in requirements that states collect and report data on HCBS core measures disaggregated by race, ethnicity, disability status, age, sex, sexual orientation, gender identity, preferred language, rural/urban environment, and service setting, unless the Secretary, based on recommendations from the HCBS Quality Committee, determines that such disaggregation would be inappropriate for a given measure. We recognize that a phase in period may be necessary for data disaggregation, but stress the urgency of prioritizing the



development of this reporting capacity. Adequate resources and political will need to be exerted to make such data disaggregation feasible.

E. Annual Public Reporting of HCBS Core Measure Results

We recommend that the HAA require states to post at least annually on a public website an independent report on HCBS core measure performance. As with external quality review, the State would have to arrange for an annual report produced by an independent quality organization free of conflicts-of-interest with the state. States may not substantively revise the content of the annual report without evidence of error or omission. The report should include at least:

- relative performance against the benchmarks established by CMS;
- recent trends in the state's HCBS measure performance, including at least the prior three years;
- stratified performance data, at least to the minimum standard set by the Secretary. Where there is evidence of flawed, incomplete, or unreported data, the report should require a written explanation of the error and the state's plan and timeline to correct the problems;
- a narrative explaining significant health disparities identified in the data;
- a set of recommendations for specific corrective actions the state will take to ameliorate disparities or measures that fail to meet established benchmarks;
- a narrative responding to each recommendation from prior reports explaining actions taken to implement that recommendation and evaluating the effect of the actions taken; and
- a non-duplication provision -- to the extent that these requirements can be accomplished as part of the external quality review process, the Secretary could deem EQR as fulfilling those requirements

F. Accountability and Oversight

While collecting robust and accurate data on HCBS quality and health disparities is a core function of an effective quality improvement program, data alone are not sufficient to make needed changes happen. Effective accountability for HCBS quality and equity in access to services requires transparency, a multi-faceted approach to evaluation, and at the end of the day, some kind of incentive or enforcement mechanisms to spur policy changes. There are currently many pilots and demonstrations experimenting with new payment methodologies,



from quality withholds to full accountable care initiatives that pay capitated rates directly to providers. The relative efficacy of these approaches with regard to HCBS quality remains unknown. For these reasons, we call for a focused study to evaluate how HCBS accountability mechanisms, including ombuds office reports, core measures, external quality review activities, direct testing, and other tools can be effectively linked to financial incentives or, potentially, corrective action plans and sanctioning authorities.

Within one year of enactment, the HCBS quality committee, in consultation with federal agencies and subject matter experts, should explore how to establish appropriate quality improvement incentives and a system for creating and establishing corrective action plans for HCBS programs that do not consistently achieve quality benchmarks or repeatedly show patterns of problems identified through independent ombuds offices, government accountability offices, or other oversight entities. Report of the committee's findings should be posted on CMS website within 30 days of its completion. Based on findings of this report, CMS should issue regulations within 18 months after the report is published to establish a system of incentives and corrective action plans to ensure state HCBS programs are meeting the objectives established under the purposes described in this section.

G. Technical assistance with quality assessment and accountability programs

The bill should require the Secretary to provide technical assistance to states, health plans, and providers, including assistance with:

- meaningful use of HCBS measures in the core set to improve quality and outcomes, including the use of measures to address equity, including disaggregation by race, ethnicity, disability status, age, sex, sexual orientation, gender identity, primary language, rural/urban environment; and
- initiatives to promote health equity that are informed by quality measurement.

H. State Quality Strategies for HCBS

Quality strategies encourage states to develop a concerted plan to drive quality improvement. States have to identify clear priorities, often in line with federal priorities, and then develop specific, quantifiable mechanisms to mark progress toward those goals. The strategy also functions as a transparency and accountability tool whereby a state has to identify measures it will report on, contracted quality entities, and performance improvement projects in a single document.



Currently, only states operating Medicaid managed care programs are required to develop a state quality strategy. However, the 2015 NPRM for Medicaid managed care proposed a new requirement that all states, including FFS states, would develop a quality strategy. While that requirement was never finalized, we think the HAA should require a regularly updated quality strategy for all states, including those that use FFS delivery systems. Managed care penetration in HCBS is far lower than in other areas of Medicaid, and states that use this delivery system should also demonstrate a commitment to a transparent quality improvement program.

Like the managed care quality strategy, states should have to include the core measures they will report, including HCBS core measures, and a well-developed plan to address health equity, including identifying and reducing health disparities, in their quality strategies. They should also have to include a plan to increase the capacity and quality of their HCBS programs.

We also recommend that the HAA require each state to establish a quality advisory committee, in addition to the federal committee suggested above. This committee will advise the state on selecting quality measures, developing and revising the state quality strategy, and developing new initiatives to promote health equity and quality improvement in the State's HCBS program. Membership should comprise a majority of individuals receiving or in need of Medicaid HCBS and should at least include representatives of beneficiary rights organizations, disability rights organizations, aging organizations, Protection and Advocacy organizations, and Centers for Independent Living. The members must represent the diversity of perspectives of those receiving HCBS in the state (including diversity by race, ethnicity, disability status, age, sex, sexual orientation, gender identity, preferred language, rural/urban environment, and service setting.). The remainder of the committee will include other stakeholders involved in quality measurement, such as health plans and providers. The state will provide staff support, training and other supports, such as transportation, interpretation and translation services, accessible materials and stipends to the individual beneficiaries participating.

X. Data Stratification

The COVID-19 pandemic has reemphasized the longstanding structural inequities of our health systems. Moreover, the pandemic has exposed major holes in our data systems that prevent an effective way simply to identify health disparities. Rightly, this failure has reenergized efforts to improve data collection systems and build in the capabilities to collect, report, verify and disaggregate data by key demographic factors including by race, ethnicity,



disability status, age, sex, sexual orientation, gender identity, preferred language, rural/urban environment, and service setting. Data should be collected to permit intersectional analysis across multiple demographic categories, such as race and disability.

We believe it should be the expectation that public health programs routinely incorporate the capacity to collect and report this data -- ideally at an individual level -- at every level of the program, including eligibility, assessments, and while measuring relevant health metrics, unless deemed inappropriate for a particular measure. We recognize and support the broad efforts from advocates and policymakers to prioritize demographic data collection and reporting across various public programs. But to be effective, these efforts need to be coordinated and consistent. We first encourage the HAA bill sponsors to work with CMS to identify and require standardized categories for key demographic data, so that cross-state comparisons will be possible, and further urge the HAA bill sponsors to work in concert with other Congressional offices and federal organizations who are addressing these problems across public health and safety net programs, including Social Security, Medicare and Medicaid to ensure consistent policy that maximizes interoperability.

XI. Conclusion

Thank you again for drafting the HAA and taking on the essential work of ending Medicaid's institutional bias. Please feel free to reach out to Jennifer Lav at lav@healthlaw.org with any questions and concerns. We look forward to working with you on this important endeavor in the future.

Sincerely,



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