



**CONSORTIUM FOR CITIZENS  
WITH DISABILITIES**

April 26, 2021

The Honorable Sherrod Brown  
Senator  
U.S. Senate  
Washington, DC 20510

The Honorable Bob Casey  
Senator  
U.S. Senate  
Washington, DC 20510

The Honorable Maggie Hassan  
Senator  
U.S. Senate  
Washington, DC 20510

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

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

The Consortium for Citizens with Disabilities (CCD) is the largest coalition of national organizations working together to advocate for federal public policy that ensures the self determination, independence, empowerment, integration and inclusion of children and adults with disabilities in all aspects of society. The Long Term Services and Supports (LTSS) Task Force addresses the services and supports that enable individuals with disabilities of all ages to live in their homes and communities. In particular, the Task Force focuses on Home and Community-Based Services (HCBS), recognizing that they are the key to community integration, full participation, independent living, and economic self-sufficiency for many people with disabilities and older adults. These critical services make it possible for people with disabilities and older adults to fully exercise their civil and human rights.

We welcome the strong interest of your offices in expanding home and community-based services for people with disabilities and older adults, and we appreciate the opportunity to comment on the discussion draft of the HCBS Access Act (HAA.) Our Task Force and member organizations have been advocating for the policies described in the HAA for decades, and we are eager to ensure that the HAA is as robust and effective as possible. Our comments are extensive, and organized loosely by theme; we seek to address both the specific questions posed in the request for comment, as well as some of our additional thoughts.

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

*Self-Direction and Person-Centered Planning*

We appreciate the inclusion of services which support person-centered planning and self-direction among the list of services to be included in the proposed mandatory Medicaid HCBS coverage under the legislation. However, given the troubling variation in proper implementation of person-centered planning and self-direction principles across state Medicaid systems, we believe it is imperative to include recommendations of previously federally-funded efforts regarding the specifics around essential components that person-centered planning and self-direction should have.

### *Recommended Enhancements to Person-Centered Planning*

We are concerned about the current definition of a person-centered care plan in the draft legislation, which seems to conflate a functional assessment process with the person-centered care plan. These are two very different documents, and the processes for completing each of these are also distinct. While the person-centered care plan may be informed by the functional assessment, it also includes an intentional process of discovery, exposure, and engagement of the individual with their chosen support network to assist them in thinking through their goals for various aspects of their life.

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)(1)(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.

#### Page 14, line 2-4

“... a written plan with respect to an individual that meets the requirements **of the person-centered planning process and the person-centered plan, as defined in 42 C.F.R. 441.725, as of the date of enactment of HAA.** ~~of section 1915(i)(1)(G)(ii):~~”

As you may be aware, in 2019, CMS and the Administration for Community Living (ACL) co-invested in an 18-month convening of a National Person-Centered Planning and Practice Committee, facilitated by the National Quality Forum (NQF), charged with completing the following objectives:

- Refine the current definition for PCP;
- Develop a set of core competencies for performing PCP facilitation;
- Make recommendations to HHS on systems characteristics that support person-centered thinking, planning, and practice;
- Develop a conceptual framework for PCP measurement; and
- Conduct an environmental scan including the historical development of person-centered planning in LTSS systems to include a research agenda for future PCP research.

As a result of this work, a consensus definition of person-centered planning agreed upon by the multi-stakeholder Committee was published in the NQF final report<sup>1</sup>:

*Person-centered planning is a facilitated, individual-directed, positive approach to the planning and coordination of a person's services and supports based on individual aspirations, needs, preferences, and values. The goal of person-centered planning is to create a plan that would optimize the person's self-defined quality of life, choice, and control, and self-determination through meaningful exploration and discovery of unique preferences and needs and wants in areas including, but not limited to, health and well-being, relationships, safety, communication, residence, technology, community, resources, and assistance. The person must be empowered to make informed choices that lead to the development, implementation, and maintenance of a flexible service plan for paid and unpaid services and supports.*

Additionally, the NQF report also recommended that person-centered planning and practice reflect the following domains and indicators<sup>2</sup>:

- Focus on the person
- Choice and self-determination
- Community participation
- Availability of services and supports
- Accessible Information
- Skills, knowledge and training
- Positive expectations

To the extent that any changes are made to the suggested language above, we recommend that the NQF report serve as a resource and guiding principle.

### *Self-Direction*

Similarly, we also believe that a definition should be included under “Key Terms” in the legislation to clarify the principles around self-direction, assuring ongoing individualization, flexibility, and empowerment in the use of self-direction options. Self-direction (SD) is based on the principle of self-determination; therefore, it allows participants both employer and budget authority. However, we are aware of numerous states that have significantly diluted the intent of self-direction or have created parameters around self-direction that specifically discourages

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<sup>1</sup> As defined in the Final Report of the National Committee on Person Centered Planning and Practice entitled, “Person-Centered Planning and Practice”, p.7. July 31, 2020. National Quality Forum.

<sup>2</sup> Person-Centered Thinking, Planning, and Practice: A National Environmental Scan of Indicators prepared by the Human Services Research Institute as part of NCAPPS technical assistance. December 2019. pp. 4-5. [https://ncapps.acl.gov/docs/NCAPPS\\_Indicators%20Scan%20\\_191202\\_Accessible.pdf](https://ncapps.acl.gov/docs/NCAPPS_Indicators%20Scan%20_191202_Accessible.pdf)

individuals from using this option in receiving Medicaid HCBS. Specifically, we would ask that the following definition of self-direction be included in the legislation:

*“SELF-DIRECTED SERVICES” means, when participating in Home and Community-Based Services , services*

- I. For which participants or their representatives have decision-making authority over and take direct responsibility for management of the services with the assistance of a system of available supports; and*
- II. That are provided in a manner that furthers the right of individuals with disabilities, regardless of the physical or intellectual capacity of the individuals, to make choices about and direct all aspects of their lives, including through control over receipt of and funding for support services*

*SELF-DIRECTED SERVICES --*

- I. Provide individuals the decision-making employer authority to recruit, hire, train, and supervise the individuals who furnish their services; and the budget authority over how the Medicaid HCBS funds in a budget are spent.*
- II. Maximize the opportunities of individuals to live as independently as possible in the most inclusive community-based setting of their choice;*
- III. Empower individuals, with the support of their chosen team, to exercise choice and control over the long-term services and supports they receive; and*
- IV. Maintain and improve health and quality of life outcomes in the community.*

Additionally, we recommend that provisions be included in the bill that would seek to eliminate unnecessary restrictions that limit choice and control of beneficiaries who opt to use self-direction in the receipt of Medicaid-funded HCBS, in accordance with the federal HCBS regulations. Specifically, we would request that a provision be included in the legislation that reaffirms that states must fulfill the requirements under the federal HCBS rule to allow for beneficiary choice in the services provided and the individuals providing the services under self-directed options.

Finally, under the “HCBS Implementation Grants” section, we request that states be allowed to utilize grant funds for implementing or expanding evidence based practices demonstrated in the 1995 National Cash and Counseling Evaluation Demonstration to (a) allow for a broader approach to participant direction that gives participants the authority to manage an individual budget and the latitude to use the budget to purchase goods and services to meet their service and support needs; and (b) give participants the option of receiving allowances in cash to purchase services and supports, or have their funds deposited with an entity that would perform financial transactions under their direction.

### *Individualized Assessments*

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. Therefore, 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 or algorithm may not have adequately accounted for.

Recommendation: Add subclause (vi) to (hh)(4)(D) Standards (pg 15, ln 5) as follows:

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

“(vii) include a process by which individuals can request a human review of their assessments results to address needs that the assessment or its methodology may not have adequately accounted for.”

### *The HAA’s Impact on Children and Youth*

States are already obligated to provide almost all services that are included in the new mandatory HCBS service to Medicaid enrollees under 21. This is due to Medicaid’s comprehensive Early and Periodic Screening, Diagnostic and Treatment (EPSDT) benefit for children. EPSDT’s statutory provisions require states to provide and arrange for a broad range of services necessary to meet children’s medical needs, including services that are considered HCBS services and are often only offered to adults via waivers. Specifically, if a service is listed under 42 U.S.C. § 1396d(a) (the section of Medicaid statute that defines “Medical Assistance”), and the service is medically necessary, then the state must provide the service.

The HAA creates a new category of services under 1396d(a), called “home and community based services.” Children must receive these services, via EPSDT, if such services are medically necessary to correct or ameliorate a condition.<sup>3</sup> Children will be eligible for the new HCBS service, even if they do not technically meet the definition of an “eligible individual” under the statute, because states must provide them all services “described in subsection (a)” that are necessary to “correct or ameliorate defects and physical and mental illnesses and conditions...”<sup>4</sup> Because the new category of services defined in 1396d(a) includes some services not otherwise included in the definition of “medical assistance,” the HAA will add some additional services to those that are currently required via EPSDT. For example, with the HAA, families will be able to access respite services and necessary home modifications, which currently are not available via EPSDT.

The HAA does not explicitly address the intersection of the new HCBS service with EPSDT. We believe this is generally the correct approach. However, we do offer one suggested change that could clarify that nothing in the HAA is intended to limit the breadth of the EPSDT entitlement. We suggest adding a clause under “Eligible Individual” to clarify that 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 (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).

The HAA does not address the situation of children who currently receive HCBS through “Katie Beckett waivers.” States can use waivers -- or a “Katie Beckett” state *option* authorized under the Tax Equity and Fiscal Accountability Act (TEFRA) -- to provide an eligibility pathway, and thus HCBS services, for certain children with complex medical conditions, even though their families’ incomes are too high to qualify for Medicaid otherwise. Under these waivers, as opposed to the TEFRA option, states can cap the number of children eligible.

More than half the states use waivers instead of the TEFRA state *option* to create an eligibility pathway for these children. Thus, children in these states will still be subject to waiting lists for HCBS services.<sup>5</sup> With the language suggested related to maintaining eligibility for individuals

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<sup>3</sup> 42 U.S.C. §§ 1396a(a)(10)(A), 1396a(a)(43), 1396d(a)(4)(B); 1396d(r);

<sup>4</sup> 42 U.S.C. 1396d(r)(5).

<sup>5</sup> MaryBeth Musumeci & Priya Chidambaram, Kaiser Fam. Found., Medicaid’s Role for Children with Special Health Care Needs: A Look at Eligibility, Services, and Spending (June 12, 2019), <https://www.kff.org/report-section/medicaids-role-for-children-with-special-health-care-needs-a-look-at-eligibility-services-and-spending-issue-brief-2/>

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 HAA through that state's Beckett-like eligibility as it existed at the time of 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.

Although many of the services included in the HAA are already available to enrollees under 21, the importance of HAA to youth under 21 cannot be overstated. With the HAA, when a child with a disability ages out of EPSDT, he or she will no longer be faced with a "services cliff" when they reach age 21. They should no longer risk losing their HCBS simply because they grow up. Instead, youth will be able to maintain practically seamless access to services. Passing the HAA means that the structure of Medicaid will no longer prevent disabled youth from going away to college, moving for a better job, or following a partner to a new hometown. Instead, disabled youth relying on Medicaid will be free to explore their future.

### *Conforming Amendments*

Because the proposed statute sunsets several types of waiver authority, and some states use waivers to expand income and asset eligibility to individuals who are not otherwise eligible for Medicaid, it is essential to ensure that sunseting the waivers does not serve to limit Medicaid eligibility.

We appreciate section (e) on page 17 ("Conforming Amendments") but suggest that the section be amended to better ensure inclusions of individuals with disabilities who would otherwise be over-income. While these conforming amendments should permit states to continue to make income-eligible individuals who are currently only eligible for Medicaid due to the special income limits and other provisions of waivers in Section 1915, such amendments only create options for states, and do not require states to maintain eligibility categories that currently exist. As long as the HAA is funded at 100% FMAP, states will have less of an incentive to restrict eligibility. However, if 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, 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 the old waiver population to the new group that is eligible for HCBS.

Further, 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.<sup>6</sup> 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).

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 HAA] and are otherwise entitled to HCBS under (hh).”**

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 ...” (emphasis supplied). We suggest that 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).~~

We also suggest adding one additional conforming amendment to ensure that the new definition of HCBS does not inadvertently expand mandatory estate recovery. Specifically, 42 U.S.C. 1396p(b) requires states mandatory estate recovery for individuals over 55 who receive home and community based services. We suggest that, at the least, 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.<sup>7</sup>

Page 18, new subsection 5:

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

<sup>6</sup> 42 U.S.C. 1396a(a)(10)(C); (“i) the plan must include a description of ... the single standard to be employed in determining income and resource eligibility for all such groups,. . . .”); 42 C.F.R. 435.482.

<sup>7</sup> There 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>.



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 an amendment.

Last, 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 FFP for individuals who meet the special income income limit in 1902(a)(1)(A)(ii)(V) as amended by HAA.

*Grandfathering*

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 someone who

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 HAA.

*Relationship between the HAA and the Medicaid Act*

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. Because HCBS will now be a mandated service for both categorically needy and medically needy populations, the requirements in the Medicaid Act related to amount, duration and scope will apply. However, we do note that the regulations that define services that are required for the categorically needy (42 CFR 440.210) are outdated, and it may be beneficial for the HAA to direct CMS to update such regulations.

### *Eligibility*

We recommend that in the definition of an eligible individual on page 11, the text be clarified that an individual who requires assistance with one ADL *as well as* with one IADL, is an eligible individual. 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.) As written, the language seems to say that an individual would need to require assistance with either two ADLs or two IADLs, but that an individual who needed assistance with one item in each category, for a total of two areas in need of assistance, would not qualify.

Additionally, some people who require HCBS will experience fluctuations in their disability over time, such as some people with cancer, multiple sclerosis, or some mental health disabilities. We request language clarifying that these individuals will remain eligible for HCBS even if for a period of time their condition improves such that they no longer require assistance with 2 or more ADLs or IADLs. This can be done by specifying that while their service plan may change to reflect a reduced need for services, their overall eligibility should be maintained so that services may be reinstated quickly when their condition re-intensifies and function declines.

### *Mental health services*

We recommend several language changes to ensure that individuals with mental health disabilities are fully included throughout the HAA:

#### Page 2

Lines 11-13: *Eliminate (2) **shortages of and** waiting lists for HCBS, which delay access to necessary services and civil rights for people with disabilities and aging adults.*

Page 6

Lines 1-3, within “personal assistance”: *professionals, home health aides, private duty nursing, homemakers and chore assistance, **encouragement and cueing**, and companionship services.*

Page 7

Add to lines 1-3: *(xi) Home and community-based intensive behavioral health **services, including in-home supports and services, community support workers, therapeutic foster care, assertive community treatment, and mobile crisis teams and other crisis intervention services.***

Similarly, to avoid inadvertent exclusion of individuals with multiple disabilities, we recommend the following change to page 8:

Page 8

Lines 9-18, replace “OR” to “AND”:

“(aa) Individuals with disabilities receiving home and community-based services under this title and individuals with disabilities in need of such services, including those with physical disabilities, behavioral health disabilities, **AND** ~~or~~ intellectual or developmental disabilities, and including elderly individuals.

*HHS Advisory Panel*

We propose two minor but highly impactful modifications to the HHS advisory panel:

Page 9

Lines 15-18: “(II) **REQUIREMENT FOR MAJORITY EQUAL REPRESENTATION.**—~~The Secretary shall select an equal number~~ **majority** of individuals with disabilities and disability-led organizations as described in items (aa)...

Page 10

Lines 1-6: *home and community-based services under this paragraph. Such services shall be so specified with the goal of increasing community integration and self-determination for individuals with disabilities receiving, **or eligible for** such services.*

*Emergency management*

Finally, with respect to services supporting individuals with disabilities in emergency situations, we propose the following amendments throughout:

Page 2

Line 17, insert as a new paragraph **(4) to eliminate institutionalization of people with disabilities as a primary housing strategy during and after disasters.**

Page 7

Add new Section (xvi) between lines 14 and 15: **(xvi) Services, supplies and equipment to support people with disabilities before, during and after public health emergencies and disasters. These services including personal preparedness assistance, evacuation and sheltering supports, personal assistance services, home modifications, and transition services to support transition from a temporary institutional placement back to permanent community living,**

Page 8

Lines 19-23: **“(bb) Representatives of beneficiary-led disability rights organizations, disability organizations representing individuals with disabilities, families and providers, aging organizations,...**

Page 20

Lines 1-5: **A description of the State’s plan to ensure a stable and highly qualified workforce and how the State plans to ensure a living wage for individuals furnishing home and community-based services and identify and address any additional workforce issues, including a regularly exercised plan (in alignment with the requirements in the Stafford Act and the Centers for Medicare and Medicaid Emergency Preparedness Rule) that ensures continuity of all services during and after disasters and public health emergencies. These plans should anticipate and address workforce shortages due to members of the work force’s personal disaster impacts, lack of connectivity; inability to secure transportation, childcare, or as a result of illness or injury.**

Line 16: **... access for populations in need of such services including during public health emergencies and disasters of all types and kinds.**

Line 21: **... services address all functional impairments including during public health emergencies and disasters of all types and kinds.**

Page 21

Lines 10-13: **(7) A plan for how such services will be coordinated with other relevant State agencies, such as housing, transportation, child welfare, food and income security, emergency management, public health, and employment agencies.**

Line 21: **... (1) of section 1905(hh), during steady state and in the event of a disaster.**

Page 24:

Lines 1-6: ...facility for individuals with intellectual disabilities, institution for mental disease, or other similarly restrictive or institutional setting, disaggregated by the type of facility or setting, race, ethnicity, primary language, disability status, age, sex, sexual orientation, and gender identity, and emergency **or disaster placement.**

Add **Section 8- Before, During and After Disasters**

**Services before, during and after disasters shall be provided to ensure that people with disabilities will continue and, as necessary, begin to receive HCBS to prevent institutionalization. FEMA and the Department of Health and Human Services shall support states through their state emergency management, health, public health, and/or human services agencies to develop state plans that address the needs of people with disabilities before, during and after disasters including but not limited to providing equally effective communication, equal opportunities for preparedness, equal access to all disaster related programs and services, accommodations and modifications necessary to participate in all disaster related response and recovery systems of support.**

**HHS shall eliminate the practice of waiving three-day hospital stays and direct admissions before placement of people with disabilities who do not require skilled nursing level of care in congregate non-acute care facilities under Section 1135 of the Social Security Act. HCBS shall be the preferred provision over placement of people who do not require skilled nursing level of care in congregate non-acute care nursing and other facilities.**

**When an individual with a disability who is eligible for Medicaid must relocate out of their Medicaid service area due to an emergency or disaster evacuation, all HCBS and their Medicaid supported services shall continue by porting their Medicaid coverage to the relocation area (as described in the Disaster Relief Medicaid Act).**

**Whenever an individual is admitted to a congregate non-acute care facility during and after disasters there must be collection of disaggregated data tracking changes of residence of disabled persons in and out of congregate care facilities, whether the change is intended to be temporary or permanent. The state plan shall assume that all placement of people with disabilities who do not require hospital level of care in permanent non-acute care facilities during a disaster is a temporary housing strategy and re-integration into HCBS is a measure of recovery in survivor tracking and case management. State plans must include transition of individuals who have been temporarily institutionalized back into the community with provision of adequate HCBS that allows individuals to return to their pre-**

***disaster home and community living, either by returning to their previous home or in a new home when necessary..***

***The state emergency operations plans, corresponding agency plans, and standard operating procedures shall establish a mechanism for providing DME, CME, PAS, and other necessary accommodations that are not reliant on FEMA disaster assistance and do not require FEMA Individual Assistance eligibility for disaster acquired disabilities.***

***The State Plan shall address methods of continuing to provide HCBS to meet the needs of individuals with disabilities participating in or eligible for HCBS. HCBS shall be the preferred able practice. Individuals living in the community prior to a disaster shall remain in the community after a disaster when this is their preference.***

***Should an individual participating in HCBS before a disaster, be referred to a permanent non acute care facility, HCBS must continuously be an available relocation option post disaster. People whose needs have increased during and after a disaster, whose disability has been exacerbated, or people who acquired a disability due to the disaster must be provided HCBS or increased HCBS during disaster response and throughout disaster recovery.***

***Minimum data set data collections and Preadmission Screening and Resident Review (PASRR) shall never be waived and must be revised to track movement in and out of institutions during and after disasters.***

***Disposition of an individual into a congregate non-acute care facility during disaster evacuation, sheltering or temporary housing must be treated as a temporary disaster related shelter placement and tracked accordingly. Final disposition of post disaster housing for previous or new HCBS participants must prefer and prioritize return to community based living with any necessary support provided. Retention of individuals in a congregate non-acute care setting as a permanent placement must never preclude the possibility of re-entry into community living and must always be at the individual's request only.***

#### **Ensuring adequate rates:**

The federal government must clearly define what should be included in a state's rate methodology and establish a minimum funding level for different services to ensure that rates are sufficient. CMS should also enforce these so that rates may better reflect the actual cost of providing services, state rate setting bodies should be created that include consumers, DSPs, providers, state officials, and other stakeholders. Many states do not offer adequate rates to cover provider overhead and assume that providers can cover any shortfalls with charitable

donations. Rates should include realistic overhead. Additionally, the cost of training should be funded and not wrapped into administrative overhead funding.

CMS must approve rates and determine that the process the state used is reasonably designed to ensure compliance with statewideness and reasonable promptness.

As part of the state plan amendment process, the legislation should require CMS to analyze, confirm, and work with all state Medicaid agencies whose current HCBS reimbursement rates do not reflect wages consistent with geographically-specific living wage scales to update their reimbursement/payment methodologies.

Congress should instruct CMS to include HCBS under the equal access rule, which would require that Medicaid reimbursement rates are set to ensure adequate access to services. Access to services and DSP turnover should be added as measures of rate adequacy (or inadequacy).

Congress should consider directing CMS to automatically set starting DSP wages to a fixed percentage (e.g. 150%) above the prevailing minimum wage; require states to provide evidence that increased rates to pay DSPs at or above the federal/state minimum wage are passed onto DSPs at the wage level that was factored into the state's updated reimbursement methodology; assure that wage levels and rates for DSP-services are equitable across agency-rates and self-direction options, so long as DSPs hired under self-direction deemed proficient in validated competency areas; and require an annual COLA adjustment for all DSP wages and HCBS rates.

Finally, the legislation must clearly mandate that state Medicaid agencies must assure that all HCBS contracts are compliant with state and federal minimum wage requirements in the pay of all personnel providing HCBS (and that the SMA increases HCBS reimbursement rates accordingly).

### **Ensuring a robust workforce:**

#### *Create a standard occupational classification for DSPs*

Congress should direct the Bureau of Labor Statistics to create a federal designation specific to DSPs to recognize the profession and gather data that can inform policy making.

#### *Formalize communications between DOL and HHS*

Since Medicaid providers also fall under the jurisdiction of DOL, we strongly encourage Congress to incentivize and/or encourage formal processes and communications channels between DOL and HHS. This would ensure that providers can comply with new labor regulations that result in increased costs and interdepartmental outreach on apprenticeships and other programs.

### *Paid training programs*

Direct and fund state workforce investment systems to provide competency-based DSP training as a part of a “High Growth Industry.” Through the dislocated workers program, direct states to shift efforts from congregate settings to community placements. Direct states to fund education grants for DSPs to obtain further career pathways, credentialing, specialized trainings, degrees, etc. to stay in the HCBS field. Expand pipeline programs by increasing training programs at IHE, career and tech education programs, Service Care Corps, etc. with low barriers to entry.

With respect to the responsibility of state Medicaid agencies in supporting capacity building efforts among the DSP workforce, we recommend that states be required to pay for the competency-based training that leads to certification of DSPs from an accredited DSP educational programs, and to be able to use increased FMAP dollars to fund this requirement. We also believe that state Medicaid agencies should also be required under self-direction options to pay for competency-based training available outside of individual’s self-direction budgets in parity with TA/training funded by the state for DSPs within provider agencies.

We also believe that in order to professionalize the DSP field, it is critical that states provide credentialing opportunities, career pathways, and ongoing competency-based training and mentoring, embedded in public policy and sufficiently funded to create incentives for DSP participation. As such, we recommend that the legislation confirm that states can use the increased FMAP to administer a statewide career advancement pathway for DSPs based on the completion and demonstration of CMS’ core competencies, with career lattices (with corresponding increased wages) for individuals who have been deemed by a neutral third-party as proficient in demonstrating competency areas. Further, the legislation should allow states to reimburse for front-line peer mentoring to allow seasoned DSPs deemed proficient in demonstrating competency areas to work with less experienced DSPs in learning how to effectively implement evidence-based practices in direct support provision in real-time.

### *Expand self-directed models*

Increase access to/utilization of self-direction, paid family caregivers, shared living, and other relationship-based models or models with longer retention.

### *Technology and data*

Congress should provide funding and authority to facilitate states and providers to address technology deficits that impact job satisfaction and retention (e.g., paper reporting). Congress should ensure that the HCBS program created by the HAA has adequate funding and authority for states to explore appropriate technologies that alleviate pressure on the workforce (e.g., remote monitoring where appropriate). And, the HAA should include funds for training people leveraging services, their families, direct care workers, and others on the use of the



aforementioned technology. The goal should be to allow for adequate oversight of program integrity without adding undue burden to providers or beneficiaries.

Additionally, in light of what we have learned as a part of the COVID pandemic, we believe it would be sensible to allow states to reimburse for virtual communications and technologies to support service provision and address DSP workforce shortages under certain circumstances (but not substitute necessary in-person supports that lead to inclusion). Some examples include incidental/episodic events that occur and require urgent guidance/support (employment, housing, welfare & safety, transportation). We also believe the sponsors of the HAA should consider a provision that incentivizes state Medicaid agencies to work with their state Assistive Technology Coalitions and provider associations to conduct ongoing implementation and evaluation of the use of technologies as a universally-designed option for support while simultaneously providing relief to the increased demand for support and support workers. Such an incentive could be written into the HCBS Innovation Grants section.

#### *Ensuring Adequate Training of Frontline DSP Supervisors*

States must also invest in and implement educational requisites to DSP front-line supervisors to demonstrate proficiency in the Front Line Supervisory Competency areas developed by the University of Minnesota that also leads to nationally accredited certification. The National Frontline Supervisor Competency Areas for supervisors, focus on high-quality provision of direct supports; health, wellness and safety; support of plan development, monitoring and assessment; facilitating community inclusion across the lifespan; promoting professional relations and teamwork; staff recruitment, selection, and hiring; staff supervision, training, and development; service management and quality assurance; advocacy and public relations; leadership, professionalism and self-development; and cultural awareness and responsiveness. We suggest that the legislation be amended to clarify that states may use increased FMAP resources to provide educational requisites and certification by a national accreditation entity for front-line supervisors of direct support professionals to demonstrate proficiency in the National Front-Line Supervisory Competencies.

#### *Require a DSP Code of Ethics*

We suggest that states be required to adopt the National DSP Code of Ethics and train all DSPs statewide on how to incorporate the principles into everyday practice as a condition of working in the field of direct support provision with respect to Medicaid-funded HCBS.

#### *Innovations Funds to Support New Models of DSP Workforce Development and Career Advancement*

We recommend that the HCBS Innovation Grants include an emphasis on new models for DSP workforce development that involves all stakeholders (state-payer/plan-provider-DSP-participants) to enhance the capacity, competency, workplace culture, socioeconomic advancement, and social determinants of health (SDoH) of DSPs in Medicaid-funded HCBS programs.

Additionally, we recommend the addition of a National Technical Assistance Center focused on Building Capacity of DSPs in Competency Areas. The TA Center would support the evolution of demonstrations of new models for DSP workforce development that involves all stakeholders (state-payer/plan-provider-DSP-participants) to enhance the capacity, competency, workplace culture, socioeconomic advancement, and social determinants of health (SDoH) of DSPs in Medicaid-funded HCBS programs. The TA would be based on the National Core Competencies developed by the National Alliance for Direct Support Professionals and endorsed by CMS. Suggested legislative language is included below:

*“ESTABLISHMENT OF INNOVATION GRANTS FOR BUILDING THE CAPACITY OF DIRECT SUPPORT PROFESSIONAL WORKFORCE. From the amounts appropriated to carry out XXXXXXXX, and within one year of the enactment of this Act, the Secretary of Health and Human Services shall award grants under sections XXXXXXXX, on a competitive basis and under the auspices of the Administration for Community Living, to States and eligible entities to assist State Medicaid Agencies in enhancing the capacity, competency, workplace culture, socioeconomic advancement, and social determinants of health of Direct Support Professionals in Medicaid-funded HCBS programs by –*

*(1) Providing training on validated competency areas administer a statewide career advancement pathway for DSPs based on the completion and demonstration of CMS’ core competencies, with career lattices (with corresponding increased wages) for individuals who have been deemed by a neutral third-party as proficient in demonstrating competency areas.*

*(2) Testing and validating models for improving the socioeconomic advancement and the social determinants of health of direct support professionals.*

*(3) Coordinating efforts with health plans, community based organizations, direct support professionals and beneficiaries eligible to receive Medicaid home and community based services to assure direct support professionals have access to ongoing training, technical assistance,*

*professional development and peer mentoring in the proper implementation of the National DSP Code of Ethics and National Core Competencies for Direct Support Professionals.*

ESTABLISHMENT OF A NATIONAL TECHNICAL ASSISTANCE CENTER ON DIRECT SUPPORT PROFESSIONAL WORKFORCE DEVELOPMENT. *From the amounts appropriated to carry out XXXXXXXX, and within one year of the enactment of this Act, the Secretary of Health and Human Services shall award at least one grant to eligible entities to establish a national center to provide technical assistance to State Medicaid Agencies, community-based organizations providing home and community based services, direct support professionals, and beneficiaries of Medicaid home and community based options engaged in a state's self-direction in the expansion of direct support professionals certified in the National Core Competencies of Direct Support Professionals."*

Finally, we believe the HAA represents a critical opportunity to address key gaps in national research and data collection regarding HCBS. The HAA should include requirements and funding for research and data collection, to take place at the state level, to better understand workforce issues and develop solutions. Congress should consider the National Core Indicators staff stability report as a model. And the legislation should ensure robust funding for quality reporting infrastructure to feed into states' data tracking systems.

### **Managed LTSS**

Managed LTSS is a growing delivery system for HCBS. States that use managed care as a delivery system would still be obligated to fulfill all the statutory requirements pursuant to sections 1932, 1915(a) and (b) and 1115, including all the applicable regulations under 42 CFR § 438.

We are aware that a number of states run some or all of their HCBS waiver programs via Section 1115 demonstration programs. While states may need to revise an 1115 to comply with HAA, it should be noted there are clear statutory limits to the use of Section 1115 demonstration waivers. Demonstrations (and subsequent amendments to demonstrations) must: propose an "experiment[], pilot or demonstration," waive compliance only with requirements in 42 U.S.C. § 1396a, be likely to promote the objectives of the Medicaid Act, and be approved only "to the extent and for the period necessary" to carry out the experiment. Any change to a state's 1115 to comply with HAA must also comply with the requirements of Section 1115.

We also recommend that states that utilize a managed care model in the provision of Medicaid-funded LTSS implement the following requirements in addition to requirements already spelled out in the managed care statute and regulations:

- Allowances for including provision of direct services under self-direction options for receiving Medicaid-funded home and community based services as part of network adequacy metrics, as required by the 2020 Medicaid Managed Care Rule [42 CFR Parts 438 and 457 [CMS–2408–F]].
- Allowances for health plans to select, contract with, and terminate contractual agreements with community based organizations providing home and community based services based on the compliance with quality standards defined by each health plan.
- Incorporation of costs within capitated rates associated with ongoing training, certification, mentoring and professional development of direct support professionals in validated competency areas.

### **HCBS provider network adequacy**

Ensuring that people who need a Medicaid HCBS provider 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 of provider networks.* To the extent possible, we believe standards for network adequacy should be equivalent across delivery systems. Also, passive reporting of network adequacy has proven insufficient to identify problems in managed care. The HAA should direct CMS to mandate direct testing of provider networks in both managed care and FFS delivery systems. The law should require all states and managed care plans to conduct active testing of their HCBS provider networks. For example, many states that use managed care contract with an external quality review organization, or similar entity, to conduct independent secret shopper surveys that test the accessibility and adequacy of the HCBS provider network throughout the HCBS service array and across geographically diverse regions in the state. 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. Direct testing could also measure provider turnover for different types of HCBS or for different populations.

### **Equity**

We appreciate the HAA's commitment to ensuring HCBS is received equitably across intersectional identities, including race, ethnicity, disability status, age, sex, sexual orientation, gender identity, primary language, rural/urban environment, and service setting. We suggest the cognitive disabilities are included in the types of disabilities that are often siloed to include

dementia and Alzheimer's disorders. (p. 3). The HAA clearly expresses the need to collect data on how services are used by different demographics and requires states to provide "a description of numerical goals to increase access to such services that have barriers to access." (p. 20). While disaggregated data is greatly needed, states should provide more than just numerical data points. States should provide qualitative information identifying why some demographics may not be receiving services at the same rate of other groups, and identify issues for additional advocacy at the state level and how the state will address these disparities. For example, communities of color have disproportionate access to secure housing and transportation, which limits the services they can receive in the home and community.<sup>8</sup> The HAA should direct CMS to mandate that states create their own creative strategies, like supportive housing or targeted case management, to improve access to services for older adults and people with disabilities experiencing disparities. The HAA should also require states to conduct needs assessments for various populations to establish baselines.

Individuals on tribal lands often face additional barriers accessing HCBS. Stakeholders should be consulted to identify how the HAA intersects with Indian Health Services and HCBS availability on tribal lands. Similarly, consideration should be made to ensure that U.S. Territories can implement HCBS through their Medicaid programs and receive any enhanced funding and supports available to states.

In the interest of equity, the HAA should change language that for individualized assessments, services are presumed to be rendered "in an individual's own home or community" so that it is not interpreted as denying services to unhoused individuals (p. 13). Section 3(a)(4)(D) should include text confirm language access services for individuals with Limited English Proficiency or visual, auditory, or other impairments. (p. 14).

In addition to using state disability and aging agencies to provide outreach and education, states should also focus on programs used by dually-eligible Medicare and Medicaid beneficiaries (dual eligibles). (p. 20). Some examples for outreach include hospital discharge planners, Area Agencies on Aging, senior centers and other community-based organizations. States should also utilize Medicaid-Medicare Plans (MMPs), Special Needs Plans (D-SNPs), and other managed care plans as part of their outreach to enroll dual eligibles in HCBS and divert them from institutional settings. Dually eligible individuals are more likely to be people of color, and face worse health outcomes, particularly during the pandemic, compared to Medicare only beneficiaries<sup>9</sup> Already, 49% of dually eligible individuals receive LTSS, while 60% have multiple chronic conditions. Thus, even more of this population is likely to be eligible for HCBS under the HAA.

In addition, we propose the following brief line edits:

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<sup>8</sup> <https://www.cbpp.org/research/health/medicaid-can-partner-with-housing-providers-and-others-to-address-enrollees-social>

<sup>9</sup> [https://www.healthaffairs.org/doi/10.1377/hblog20190423.701475/full/;](https://www.healthaffairs.org/doi/10.1377/hblog20190423.701475/full/)  
<https://www.cms.gov/files/document/medicare-covid-19-data-snapshot-fact-sheet.pdf>

Page 4:

Lines 8-12: (11) *To eliminate the race, and gender, **ethnicity, disability status, age, sex, sexual orientation, gender identity, primary 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.***

Add the following purpose: ***To prioritize HCBS activities that measurably improve health equity, including tracking disparities through the stratification and cross-tabulation of data by race, ethnicity, disability status, age, sex, sexual orientation, gender identity, primary language, rural/urban environment, and service setting;***

## **Section 6 Quality of Services**

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 beneficiaries in its design and implementation. Quality metrics cannot themselves provide sufficient oversight due to inevitable gaps in reporting and to the sheer diversity of services and needs that older adults and people with disabilities use. Therefore, the mechanisms named in this section must be supplemented with network adequacy provisions and the ombuds office described elsewhere in this legislation. We also recognize that states running MLTSS programs will have a different quality measurement regulatory framework. Any HCBS quality improvement program must address both capitated managed care and fee-for-service delivery systems.

### *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 even an effective way to identify health disparities. Rightly, this failure has reenergized a push to improve data collection systems and build in the capabilities of those systems to collect, report, and verify data stratified by key demographic factors including by race, ethnicity, disability status, age, sex, sexual orientation, gender identity, primary 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 for all relevant health metrics, unless inappropriate for a particular measure. We recognize and support these efforts to prioritize demographic data collection and reporting, and 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.

### *Goals for Measuring HCBS Quality*

Each state shall develop, recognize, implement, enforce, and publicly and periodically report on multi-faceted HCBS quality and accountability mechanisms. These mechanisms aim to achieve the objectives described in Section 2 of the HAA through at least the following components:

1. 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. It includes robust, meaningful, and transparent quality metrics publicly reported annually and posted on each state's website, as well as mechanisms to address measure gaps
2. Quality advisory committees at both federal and state levels comprised of a majority of beneficiaries and their advocates, plus other stakeholders
3. Federal support of measure development
4. Federal technical assistance to states.

We also suggest adding a purpose to section 2 to indicate that improving the quality of HCBS services is also a purpose of the Act:

We propose the following brief line edits:

#### Page 4:

Line 13 -- insert

(12) 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.

### *Establishing a federal HCBS Quality Committee*

The Secretary of Health and Human Services, in collaboration with the Administration for Community Living, the Agency for Healthcare Research and Quality, the Centers for Medicare and Medicaid Services, the Substance Abuse and Mental Health Services Administration, and other agencies designated by the Secretary, shall establish a federal multi-stakeholder HCBS Quality Committee.

The committee shall consist of at least 51 percent 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. The beneficiaries must represent the diversity of those receiving HCBS across the nation. The remainder of the committee will include other stakeholders involved in quality measurement, such as health plans, measure developers, measure steward organization, and

relevant national associations of state officials. The quality committee will define and regularly update the HCBS quality measure set and act as an advisory body for other elements of the HCBS quality program. HHS will provide staff support, training and other supports, such as transportation and stipends to the individual beneficiaries participating.

#### *Establishing a Core Set of Home and Community-Based Services Quality Measures*

Not later than one year after the date of enactment, the Secretary of Health and Human Services shall 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.

Not later than 3 years after enactment, CMS shall 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 retain the authority to add additional reported measures appropriate for their programs.

#### *State HCBS Quality Consumer Advisory Committees*

This committee shall consist of at least 51 percent 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. The beneficiaries must represent the diversity of those receiving HCBS in the state (including diversity by race/ethnicity, primary language, gender, gender identity, sexual orientation, age, disability status, geography, and service setting). The state must consult with the leadership of the organizations listed in selecting beneficiaries. 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.

This committee will advise the state on selecting state-level HCBS quality measures and assist in developing new initiatives to promote health equity and quality improvement in the state's HCBS program.

#### *Core set parameters*

The development of the HCBS core set should be the product of a collaboration between CMS, ACL, AHRQ, SAMHSA and key stakeholders, with a priority on beneficiary representation. 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.
- Within 2 years after enactment, require states to collect and report data on HCBS core measures disaggregated by race, ethnicity, disability status, age, sex, sexual orientation, gender identity, primary language, rural/urban environment, and service setting, unless the Quality Committee determines that such disaggregation would be inappropriate for a given measure.

### *Annual Public Reporting of HCBS core measure results*

States will post at least annually on a public website an independent report on HCBS core measure performance. The State must arrange for an annual report produced by an independent quality organization free of conflicts-of-interest with the state, such as an external quality review organization. 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 Quality Committee, and a written explanation of any measures that a state fails to report according to data stratification requirements or where there is evidence of flawed or incomplete demographic data.
- 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.
- Non-duplication: To the extent that the above requirements can be accomplished as part of the external quality review process, the Secretary can deem EQR as fulfilling those requirements

### *Accountability and Oversight*

Within one year of enactment, the HCBS quality committee, in consultation with federal agencies and subject matter experts, will 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 will be posted on CMS website within 30 days of its completion. Based on findings of this report, CMS will 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

### *Measure Development*

The Secretary of Health and Human Services, in collaboration with the Administration for Community Living, the Agency for Healthcare Research and Quality, the Centers for Medicare and Medicaid Services, the Substance Abuse and Mental Health Services Administration, and other agencies designated by the Secretary, shall work with the HCBS Quality Committee named earlier in this section 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.
- Make recommendations for quality measure development to assess the adequacy of the HCBS workforce, including revisions in classification of HCBS workers.

Such sums as necessary shall be provided to the Secretary for rapid development and testing of HCBS quality measures based on the recommendations of the HBCS Quality Committee, in coordination with CMS, ACL, AHRQ, SAMSHA, DOL, and other relevant agencies.

#### *Technical assistance with quality assessment and accountability programs*

Such sums as necessary shall be provided to 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.
- Initiatives to promote health equity, 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,

#### *Enhanced FMAP for quality activities.*

States shall receive 100% FMAP for administrative activities related to 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 measures.

### **Independent HCBS Ombuds Program**

While a robust HCBS core measure set 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 MMCO's dual eligible financial alignment initiative

created successful long term care ombuds programs charged with fulfilling both these purposes. In that initiative, 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, and should include an enhanced administrative FMAP to fund its operations.

Finally, we recommend that the independent ombuds office post periodic 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 shall 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;
  - Refer and connect 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
  - Creating periodic (quarterly) public reports on problems encountered

## **Conclusion**

We appreciate the enormous opportunity represented by the HAA to end Medicaid’s institutional bias and promote community living for people with disabilities. We look forward to working with your offices to refine, introduce, and pass this bill as quickly as possible.

Sincerely,

American Association on Intellectual and Developmental Disabilities (AAIDD)  
 American Network of Community Options & Resources (ANCOR)  
 American Occupational Therapy Association  
 American Therapeutic Recreation Association  
 Autism Society of America  
 Autistic Self Advocacy Network  
 Bazelon Center for Mental Health Law  
 Center for Public Representation  
 Christopher & Dana Reeve Foundation  
 CommunicationFIRST  
 Cure SMA  
 Disability Rights Education and Defense Fund (DREDF)  
 Easterseals  
 Epilepsy Foundation  
 Family Voices  
 Justice In Aging  
 National Academy of Elder Law Attorneys  
 National Alliance for Direct Support Professionals, Inc.  
 National Association of Councils on Developmental Disabilities  
 National Association of State Head Injury Administrators  
 National Disability Rights Network (NDRN)  
 National Down Syndrome Congress  
 National Health Law Program  
 National Multiple Sclerosis Society  
 TASH  
 The Arc of the United States

The Partnership for Inclusive Disaster Strategies  
World Institute on Disability