November 12, 2020

The Honorable Seema Verma  
Administrator  
Centers for Medicare & Medicaid Services  
Department of Health and Human Services  
200 Independence Avenue, SW  
Washington, DC  20201

Submitted electronically to HCBSMeasuresRFI@cms.hhs.gov

Re: Request for Information: Recommended Measure Set for Medicaid-Funded Home and Community-Based Services

Dear Administrator Verma:

AARP, on behalf of our nearly 38 million members and all older Americans nationwide, appreciates the opportunity to respond to the request for information on a recommended measure set for Medicaid-Funded Home and Community Based Services (HCBS). Our comments will focus on the importance of family caregivers, HCBS, principles for HCBS quality measures, and respond to some of the specific questions CMS poses. Our comments are from the perspective of older adults who may or do use HCBS (Medicaid or not) and their family caregivers.

The vast majority of older adults want to live independently in their homes and communities. Not only is this where they want to be, but it is also generally more cost-effective. On average, for each person residing in a nursing home, Medicaid can fund three individuals receiving home and community-based long-term care. Family caregivers – broadly defined to include relatives, partners, friends, or neighbors – assist their loved ones with an array of tasks such as eating, bathing, dressing, paying bills, managing medications, medical/nursing tasks, transportation, arranging and coordinating care, and more. They are the backbone of the care system in this country, often providing essential assistance that enables their loved ones to live in their homes and communities. Forty-one million family caregivers provide an estimated $470 billion annually in unpaid care to their adult loved ones. However, in providing this help, family caregivers often take on physical, emotional, and financial challenges and need support themselves to continue in their caregiving role. Family caregivers are often the first line of assistance, but when individuals do not have family caregivers or when they need more support than family and friends can provide, they turn to HCBS. This may mean a home care worker or direct support professional, or other services and supports, whether paid out-of-pocket, through private long-term care insurance, Medicaid, or other public programs.

There is a greater need for HCBS now more than ever, due to both the growing aging population and more people looking for alternatives to congregate care due to COVID-19. Given the disproportionate number of deaths in nursing homes and other long-term care facilities, and older adults’ preference to live in their homes and communities, ensuring access to HCBS for these individuals is vital. Greater investments in HCBS will allow more older adults to age in their homes and communities where they want to be, while also helping to alleviate some of the challenges we are facing in our nation’s nursing homes. Investing in HCBS means ensuring that individuals have choices and options for HCBS that meet their needs and services that are high quality. Having quality measures for Medicaid HCBS would help measure and improve the quality of these services and enable individuals to choose quality providers, services, and plans (in states with managed long-term services and supports).

A person-and family-centered approach to service delivery is important. “Person-and family-centered care (PFCC) is an orientation to the delivery of health care and supportive services that addresses an individual’s needs, goals, preferences, cultural traditions, family situation, and values…Services and supports are delivered from the perspective of the individual receiving the care, and, when appropriate, his or her family.”

Strong quality standards are vital to the Medicaid population, including those receiving HCBS. They are particularly important as Medicaid enrollees served through waivers and state plan services have increasingly complex care needs, and states are serving more diverse populations through those mechanisms. AARP believes strong quality programs, measures, and tracking can improve beneficiaries’ health, safety, and well-being. We encourage CMS’ continued efforts to facilitate and standardize quality measurement and tracking under those programs. Having a recommended Medicaid HCBS quality measure set that is widely adopted and effective could also help spur or encourage the use and public reporting of these measures in the private sector, which would benefit individuals and their families who pay privately for HCBS. This could improve the quality of care and help consumers and their families select HCBS providers.

AARP, with the our partners the Commonwealth Fund, the SCAN Foundation, and the AARP Foundation, publishes the **Long-Term Services and Supports State Scorecard** every three years, most recently in September. The Scorecard measures state-level long-term services and supports (LTSS) system performance from the viewpoint of service users and their families across multiple dimensions. One of the challenges since the first LTSS State Scorecard in 2011 has been the lack of available and consistent quality measures for HCBS across all states. Having a national set of Medicaid HCBS quality measures would greatly improve and enable the comparison of HCBS quality within and across states.

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We encourage CMS to consider several important principles in developing quality measures and domains for Medicaid HCBS. First, Medicaid HCBS are offered to many different types of beneficiaries who may have a large array of needs, so the measures should address the broad scope of services, settings, and populations served by the program. Medicaid HCBS covers many different types of services in a variety of settings via different delivery systems. Quality measures and domains need to both be broadly applicable to all the different types of HCBS and beneficiaries, and flexible enough to ensure measurement of important features that are unique to different settings, health care conditions, disabilities, and services.

Quality measurement in home and community-based settings must reflect the importance of quality of life as well as quality of care, and measures should adequately reflect the importance of family caregivers in these types of arrangements. As we have noted, family caregivers are critical to helping older adults and people with disabilities live independently in their homes and communities. Assistance from family caregivers helps delay and prevent more costly institutional care and unnecessary hospitalizations, saving taxpayer dollars. While most family caregivers willingly provide services and emotional support, many are strained by caregiving responsibilities that come on top of work and other family commitments, and they may also experience profound negative effects on their own physical and psychological health. According to Caregiving in the U.S. 2020, when compared to 2015, a greater proportion of family caregivers of adults report being in fair to poor health themselves (21 percent, up from 17 percent in 2015). One in five family caregivers say they feel alone, and six in ten (61 percent) report working at a paying job while caregiving, too. These factors demonstrate the need for a family caregiver assessment that asks family caregivers directly about the caregiving situation from their perspective. Measures should also be applicable in Medicaid fee-for-service and managed care (managed LTSS).

Transparency is essential for increasing accountability in the quality of care provided to Medicaid beneficiaries. When public funding is used for HCBS, the public should have access to quality assessment tools and measures and information on scoring. Quality data and evaluations must be accessible and easy to understand for consumers and families to benefit from the information. The ultimate goal is to help enable beneficiaries to access and choose services and supports, how they are delivered, providers, and settings that ensure them the best possible care.

During the current COVID-19 public health emergency, beneficiaries of Medicaid HCBS and their family caregivers may be more isolated than ever and providers are dealing with unprecedented strains on their ability to care for and support individuals. We believe these difficult times are only increasing the imperative of enabling meaningful, easy-to-understand quality measures that will help everyone—individuals and families, providers, regulators, and payers—assure the safest, highest quality services and supports possible. Below we respond to specific questions CMS asked.

- What is the value in having a standard set of recommended quality measures for voluntary use by states, managed care organizations, and other entities engaged in the administration and/or delivery of HCBS?
CMS publication of a standard set of HCBS quality measures would allow states, Medicaid managed care organizations (MCOs), and others the benefit of expert consensus in identifying valid, reliable, and feasible HCBS quality measures. Use of effective quality measures can contribute to ongoing quality improvement in care delivery and better outcomes for individuals. Standardization also offers the possibility of consistency and comparison in quality performance across and within states, MCOs, fee-for-service, and populations. Once established, the HCBS measure set will be an important resource for state and federal policymakers, advocates, consumers and caregivers, private sector purchasers, providers, researchers, and others. Consumers and their families would have information to help them compare providers. Having standardized measures across states would also help states to learn from one another and benchmark their performance against similar states or the national average. Standard quality measures could also help provide additional data regarding the cost-effectiveness of HCBS. Including measures on consumer and family caregiver experience of care, family caregiver assessment, and support for family caregivers in such a measure set would also provide critical insights into care from consumers and family caregivers and help make care more person-and family-centered.

CMS may also wish to consider whether the measure set should be mandatory. Doing so would provide important data across states, but a mandatory measure set should not become a barrier to development and adoption of better quality measures down the line, including in domains where the measure set may be sparse and measure development is difficult and potentially expensive to develop and/or collect.

A standard quality measure set for HCBS is also consistent with the previous establishment of adult and pediatric core measure sets showing the quality of care and health outcomes for adults participating in Medicaid, and children enrolled in Medicaid and the Children’s Health Insurance Program.

- What benefits or challenges would result from the release of a recommended set of quality measures?

States, MCOs, HCBS providers and others would benefit from the measure recommendations in considering the best tools for promoting HCBS quality improvement. States generally find it easier to use measures already developed. A recommended set of measures could also drive private sector adoption of measures that could help consumers choose providers. In some cases, it may take time to replace HCBS quality measures already in use with recommended measures. Some measures also still need to be developed and will take longer to incorporate into a recommended measure set. See also our answer to the previous question.

- Do you think that the measure set should be organized into a base set and an extended set? Why or why not?

Yes, even for voluntary measures, distinguishing a set of core measures is helpful because it guides users to a minimum set of recommended measures across the domains as a starting point. Further, some HCBS measures are targeted to specific populations, services, or more state
specific needs. Having a core set of measures that apply broadly and an extended set that include targeted measures is a reasonable approach. The core measure set can be modified over time based on experience with measures in the extended set.

- **Do you agree with organizing the measures by NQF domain? If not, is there a different organizing framework that you would recommend?**

Yes, the National Quality Forum (NQF) serves as a consensus-based organization that prioritizes, endorses, and maintains valid quality performance measures. The eleven measure domains that NQF established as part of the conceptual framework for HCBS in its 2016 report have since informed measure development and quality improvement efforts. Therefore, it is reasonable and will reduce confusion and competing frameworks to use them for the recommended HCBS measure set.

- **Which domains in the NQF report are most important to address through the recommended measure set?**

The recommended measure set should prioritize balance across all domains to the extent practicable, recognizing that measure gaps remain. All 11 measure domains identified by NQF are important, and it is more important that all domains be addressed than that any particular domain get special focus.

Currently available measures are not uniformly distributed across measure domains. Concentrating the recommended measure set too much in one domain or a few domains may be misinterpreted as a statement that these domains are more important than others, when in fact they may just be easier to measure.

Regarding the workforce domain, AARP urges that CMS address a misalignment between the draft measures recommended for the workforce domain and the workforce measures included in the 2016 NQF report. In particular, the NQF report includes subdomains and/or measures pertaining to the size, appropriateness of training and demonstrated competencies, compensation, cultural competence, and support of the workforce. Measures of workforce adequacy are essential to ensuring good quality of care, an ingredient of a high-performing LTSS system, and need to be added to the CMS HCBS recommended measure set. The draft recommended measure set for initial implementation includes only measures pertaining to consumer perception of the workforce, such as whether workers are respectful. Consumer experience is important to include, as recommended in the NQF workforce domain, but it is insufficient to limit the measures to consumer experience and exclude direct measures of workforce adequacy, support, and engagement.

Further, it is critical to address the gap in measures with respect to the caregiver support domain. There are currently no recommended potential measures for initial implementation. All four subdomains identified by NQF are important in assessing support of caregivers: family caregiver well-being, training and skill-building, caregiver involvement, and caregiver access to resources. It is essential that any family caregiver assessment measures ensure the care manager or other
appropriate individual asks questions directly of the family caregiver. If a caregiver assessment does not do this, it is not a family caregiver assessment. Asking questions of the care recipient is not appropriate in a family caregiver assessment. Questions for care recipients should be asked in the assessment of their needs to determine the services and supports that are best for them.

- Are there changes that CMS should make to the measure selection criteria?
- Which of the criteria are most important and should be prioritized?

CMS should make clear that in the context of categorizing structural, process and outcome measures, consumer and caregiver experience is an outcome. In addition, in selecting measures, CMS should use achieving balance in the number of measures across domains to the extent practicable as a criterion. It is important that the measure set span all 11 domains.

Scientific acceptability should be prioritized, to assure that the recommended measures meet standards of validity and reliability. AARP believes that NQF endorsement should be part of this consideration, as scientific acceptability and consensus is part of the endorsement process. Measure importance should also be prioritized. As defined, this criterion emphasizes measures that address areas of opportunity for improvement of poor performance or variation in performance. AARP supports consideration of whether measures can be applied at the statewide, delivery system, and/or population levels.

- Should the base and extended measure sets only include measures that have undergone testing and validation?
- How important is it for measures in the base set and/or extended set to be endorsed by a consensus-based entity, an accreditation body, or other independent entity?

In selecting measures, CMS should give priority to those that are endorsed by NQF and have undergone testing and validation. These features demonstrate that the measure has been reviewed by experts and stakeholders and tested in a real-world setting where flaws in measure specification can be identified and corrected. However, where there are measure gaps CMS should consider recommending measures that do not meet these criteria if there is good reason to believe that they will ultimately do so. It may take additional time for some measures to be tested, validated, and endorsed.

- Should there be differences in how the measure selection criteria described above are applied to measures that are important to measure and/or are in wide use by states and/or managed care organizations?
- Should the base and extended measure sets cross all HCBS populations? If no, what special populations should be addressed in the extended set? What types of measures, if any, would apply only to a suggested population(s)?

It is appropriate to apply the selection criteria differently to measures that are important to measure or are in wide use by states or MCOs. The recommended measure set should take into account the existing landscape of measure use and should recognize the measures most important to improving the quality of HCBS.
In its totality the recommended HCBS measure set should include measures that cross all HCBS populations. However, it would be too limiting to require that each recommended measure apply uniformly across populations. For example, measures related to employment may be highly relevant to community inclusion for younger adults with disabilities, but not for older adults who are of typical retirement age, or children who are not typically in the workforce. Some measures may be more important to some populations than others and/or some measures may be assessed differently by different populations.

- Should the base set and/or the extended set only include measures that are in the public domain and are available at no charge?
- Is it important to offer publicly available measures that are free of charge as alternatives to any proprietary measures included in the base set?
- Should publicly available measures be offered as alternatives to any proprietary measures included in the extended set?

Ideally, all recommended measures should be in the public domain and available at no charge. A publicly available alternative should be identified for any recommended proprietary measures. The offering of a publicly available alternative is most important for any proprietary measures in the recommended base measure set.

- How important is it to include experience of care survey measures in the measure set?

Consumer and family caregiver experience of care is a particularly important component of assessing the quality of life and quality of care for individuals receiving HCBS and should be included in the recommended base measure set. The literature supports the view that consumers value what other consumers have to say about their experiences with the health care and support systems. Quality measurement has limitations and including the voices of those who are receiving services and supports helps provide a complete picture. In the case of HCBS, this is particularly important because the planning and delivery of these services should be person-and family-centered.

Prioritizing consumer experience is reflected throughout the Medicare quality reporting and pay-for-performance programs involving hospital care, physician visits and other services. For example, performance on consumer experience of care measures account for one-quarter of a hospital’s total score for the Inpatient Hospital Value-Based Purchasing Program payment adjustment.

- Are there any measurement domains or areas for which it is important to have population specific measures?

It is important for community inclusion measures to be population-specific. While community inclusion is important for all groups, the construct (what inclusion means to the person) varies significantly between populations, and the measures must also be population-specific to
appropriately measure it. Population-specific measures should be considered for all domains, as appropriate.

- **How important is it for measures included in the base set to be applicable across delivery system types (e.g., fee for service, managed care, self-direction)?**

Many Medicaid beneficiaries receive HCBS as MCO enrollees, although others do so through traditional fee-for-service payment or in systems of self-directed services. It is important that the recommended measure set apply to all these delivery system types. As states move toward managed LTSS, it is important to compare managed LTSS to fee-for-service to ensure that managed LTSS provides comparable or better quality and the quality is not sacrificed to meet financial targets. Measurement should allow for comparisons within systems (e.g., comparison of MCOs) and across them (e.g., comparison of HCBS quality under fee-for-service and managed care). In some cases, there may be measures that are unique to managed care.

- **Some stakeholders have indicated a preference for decreasing reliance on process measures and the focus on compliance in HCBS quality measurement programs, instead putting an increased focus on quality improvement and the use of outcome measures. Would greater focus on quality and outcomes facilitate the provision of Medicaid-funded HCBS? If so, how?**

Greater focus on outcome measurement is appropriate because ultimately the outcome of care is what matters. However, where direct outcome measures are not available it is appropriate to continue to measure whether providers are engaging in processes that are linked to better outcomes. While Medicaid-funded HCBS can operate in the absence of a focus on quality and outcomes, it is in the best interest of program beneficiaries to measure quality and outcomes. Doing so will encourage HCBS quality improvement, inform program design, and help beneficiaries identify high quality providers.

- **What specific existing process or structural measures generate the most valuable information for measuring and improving quality or outcomes?**

Some examples of existing measures may include: MLTSS-4: LTSS Reassessment/Care Plan Update after Inpatient Discharge (CMS); FASI-1: Identification of Person-Centered Priorities (CMS); and FASI-2: Documentation of a Person-Centered Service Plan (CMS). Experience with using specific measures could help determine objectively if they improve quality. Ideas for other possible measures for consideration (existing or not) include: whether a family caregiver’s needs are assessed and appropriate support is provided to the caregiver; extent to which HCBS recipients and family caregivers are actively involved in the design, implementation, and evaluation of the system; whether the beneficiary has a person and family-centered service plan that is beneficiary led and meets their goals, needs, preferences, and values; and the option to self-direct services or participation level in self-direction.

- **How often should the measure set be reviewed for potential retirement of included measures and/or addition of new measures?**
• **How often should the base set and/or the extended set be updated?**

An annual review seems reasonable and is consistent with other programs. The Medicaid adult and pediatric core measure sets are reviewed annually. Measure sets used in various Medicare quality reporting and pay-for-performance programs are subject to review as part of annual payment policy rulemaking.

• **Is there other information about the measures that CMS should include in the measure set?**

AARP recommends that CMS include a plain language description of the concept that each recommended measure is intended to assess. A simple and accessible description of the measure would enable a better understanding of the universe that the measure set is addressing and the essential factors that are being measured. The descriptions would help users identify opportunities for improvement, assist in ensuring meaningful measures, and ensure better balance among measures and domains when possible and necessary. Plain language descriptions could also help consumers and their families better understand and use the measures to select quality HCBS providers.

• **Does your organization experience any barriers with accessing data systems for quality measurement purposes?**

Obtaining quality measurement data for Medicaid managed care organizations for research purposes has been problematic. The quality data and caregiver assessment tools are generally proprietary and are not easily accessible for consumers or providers to make informed choices. Without transparency of quality information or assessment tools, there is less of an incentive for MCOs to improve their performance or for state Medicaid officials responsible for overseeing the MCOs to take measures to ensure that their performance improves. We support CMS’ current efforts to move forward on a recommended set of quality measures for Medicaid-funded HCBS but we also strongly encourage that CMS ensure that such data are available, more complete, and accessible to the public.

• **Does your organization experience any barriers to using data to improve quality?**
• **How many measures is ideal for inclusion in the base set?**
• **How many measures is ideal for inclusion in the extended set?**

While AARP cannot identify a specific number, we do recommend that the base set have a sufficient number of measures to adequately assess quality across all 11 quality domains being measured. We recognize, however, that it is important to ensure that the base set does not have too many measures, raising complexity for consumer use and diluting the incentives for HCBS providers to invest in targeted quality improvement. We recommend that a relatively smaller number of base measures will encourage greater adoption, promote research opportunities for comparisons across states, plans, and populations and minimize burden for providers and states.
There is less downside, on the other hand, of having a much larger extended set. By providing a larger extended set, CMS can help to identify additional measures that may be uniquely important to only certain types of settings, providers, or consumers. A large extended set may make it more challenging to highlight higher priority areas, but we encourage CMS to do so in its routine updates to the measure set. Measures in the extended set may also move to the base set in the future.

- **Are there other measures that should be included in the base set or the extended set?** In particular, CMS would be interested in feedback on measures that can address gaps related to specific NQF domains, including recommendations for measures that assess access to HCBS, such as measures of potential access (e.g., provider supply and participation in Medicaid), realized access (e.g., % of people who receive what is authorized in their service plan), and perceived access (e.g., beneficiary experience). CMS would also be interested in recommendations for HCBS measures that are relevant for people with behavioral health conditions.

AARP recommends that CMS add a measure of the percentage of those in congregate care settings who are in private rooms. In addition, we recommend that for measures that reflect a consumer’s response, that measure includes an indication of whether the response came directly from the beneficiary, the caregiver, or from another source.

Overall, we recommend that CMS ensure that there are measures that can be applied to both managed LTSS as well as to services provided under fee-for-service delivery systems. This would enable better comparative quality studies and information for consumers and providers.

Further, as noted above, the measure set should include measures of caregiver assessment. Caregivers’ health and well-being, training and other needs could be identified. Measures should also address whether caregivers received the services and supports they need based on the assessment. In addition, caregivers’ feedback and involvement should be included in LTSS plan evaluations to help ensure better quality of care.

For measures of access to HCBS, CMS could consider the percentage of LTSS beneficiaries receiving HCBS, the percentage of LTSS expenditures spent on HCBS, and the percentage of people who receive what is authorized in their service plan. These measures should be broken down by older adults, individuals with physical disabilities, and individuals with intellectual and developmental disabilities to look at HCBS access across populations. These measures should also be stratified across race and ethnicity, as this data would be helpful in identifying disparities to ensure that all individuals have equal access to HCBS. There must also be sufficient measures to address the equity domain in general and equity within the context of other domains.

We also suggest consideration of a discharge measure -- such as percentage of people who felt comfortable and supported enough to go home after being discharged from a hospital or rehabilitation facility in the past year -- and encourage consideration of a similar potential measure for family caregivers -- such as percentage of family caregivers involved in care who felt they had the necessary support and training and felt comfortable enough for their loved one to go home after being discharged from a hospital or rehabilitation facility in the past year. These measures would
address care transitions – critical points in care – and the experience of consumers and their family caregivers during these potentially challenging times in care delivery. See our other answers for additional relevant feedback to this question.

- **Are there measures you think would be most useful to a beneficiary when choosing a managed care plan, a provider, or a self-directed service delivery model?**

Measures that would be useful to a beneficiary include measures that address the choice, control, and direction they have over their services and supports, including choice of provider; their ability to easily access the services and supports they need and when, how, and where they need them; timely, easy-to-understand policies, materials, and other communications; ease of navigation to access services and supports and find needed information; consumer and family caregiver experience of care; communication with providers/experience with providers; availability of culturally competent care; access to and consumer success rates with grievances and appeals; the accessibility of back-up workers when a consumer’s regular direct care worker is unavailable; percentage of individuals receiving services in their homes and communities; meaningful options for self-direction; ability to pay family caregivers to provide care; services and supports for family caregivers; complaints against providers or plans; ease of beneficiary feedback process (i.e. does the plan/provider make it easy or strenuous for beneficiaries to provide feedback?); and presence of important consumer protections such as appropriate timeframes for consumers to meet deadlines and having an ombudsman program in managed LTSS plans. Measures that address these issues would be helpful to consumers in selecting a plan, provider, or self-directed service delivery model.

AARP appreciates the opportunity to comment on this important request for information for individuals using HCBS and their family caregivers. Consumers and their families are essential users of quality measures and any measures must meet their needs and be easily understandable. If you have questions, please feel free to contact me or Rhonda Richards on our Government Affairs staff at rrichards@aarp.org or 202-434-3770.

Sincerely,

David Certner
Legislative Counsel and Legislative Policy Director
Government Affairs