AARP
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December 21, 2016

Acting Administrator Andy Slavitt
Centers for Medicare & Medicaid Services
Department of Health and Human Services
Attention: CMS-2404-NC
P.O. Box 8013
Baltimore, MD 21244-8013

Submitted electronically to: http://www.regulations.gov

Re: Medicaid Program; Request for Information (RFI): Federal Government Interventions To Ensure the Provision of Timely and Quality Home and Community Based Services

Dear Acting Administrator Slavitt:

AARP, with its nearly 38 million members in all 50 States and the District of Columbia, Puerto Rico, and U.S. Virgin Islands, is a nonpartisan, nonprofit, nationwide organization that helps people turn their goals and dreams into real possibilities, strengthens communities and fights for the issues that matter most to families such as healthcare, employment and income security, retirement planning, affordable utilities and protection from financial abuse.

AARP appreciates the opportunity to comment on this request for information regarding Medicaid home and community-based services (HCBS). Our comments will address elements under each of the four general topics on which CMS seeks feedback. We understand CMS is looking for actions it can take within or through its statutory authority.

A. What are the additional reforms that CMS can take to accelerate the progress of access to HCBS and achieve an appropriate balance of HCBS and institutional services in the Medicaid LTSS system to meet the needs and preferences of beneficiaries?

Accelerating Balancing and HCBS Access

About 90 percent of older adults want to stay in their homes and communities. Yet, Medicaid retains an institutional bias which entitles individuals to nursing home or institutional care, but home and community-based services are optional. While about 53 percent of Medicaid long-term services and supports (LTSS) spending across populations was on HCBS in Fiscal Year 2014, for older adults and people with physical disabilities, this figure was only 41 percent. Balancing also varies greatly among states. While there has been gradual progress, we need to accelerate the pace of change.

HCBS are a critical component of an individual's ability to remain in the community and avoid unnecessary institutionalization in light of the Supreme Court's landmark decision in Olmstead v. L.C., 527 U.S. 581 (1999). Individuals depend on Medicaid HCBS each and every day to remain in their homes and in their communities, and to avoid placement in institutions such as nursing facilities; a gap of only a day without adequate HCBS can pose a threat to a person's well-being and independence. From a fiscal perspective, HCBS are generally less expensive than institutional care. On average, states can provide HCBS for older adults and adults with physical disabilities for one-third the cost of nursing home care. AARP urges CMS to work with states to leverage existing Medicaid HCBS authorities and waivers to expand access to HCBS, especially for those populations who lag behind in access to HCBS. This may include building on the learnings from the Money Follows the Person Rebalancing Demonstration.

Supporting Family Caregivers

Family caregivers are critical to helping older adults and people with disabilities live independently in their homes and communities where they want to be. Assistance from family caregivers helps delay and prevent more costly institutional care and unnecessary hospitalizations, saving taxpayer dollars. AARP strongly supports a person- and family-centered approach to LTSS. Such an approach should include family caregivers as part of the care team, when the beneficiary welcomes the involvement of family caregivers. It would also include assistance needed for the family caregiver to be a meaningful member of the care team (i.e., providing interpreter services for a family caregiver who has LEP). In a person- and family-centered care system, family caregivers are no longer viewed as just a "resource" for the beneficiary; rather, they are viewed as "partners" on the care team, and also recognized as individuals who may themselves need training and support (such as respite care). CMS should be clear that services provided by family caregivers should only be included in a person- and family-centered plan if they have agreed to provide these services (i.e., it is voluntary) and have indicated their ability to carry out the actual tasks.

Involving family caregivers and supporting their own care needs should be a key component of coordination and continuity of care in health care and LTSS/HCBS. Such an approach would promote better care, improve the experience of care for both the beneficiary and the family, and reduce costs. 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. These factors demonstrate the need for a family caregiver assessment.

AARP believes that family caregiver needs should be assessed and addressed, so family caregivers can continue in their vital caregiving role without being overstrained. Building on the regulations under the 1915(i) HCBS state plan option, we urge CMS to issue guidance to states on the 1915(i) provision that calls for a caregiver assessment if unpaid caregivers will be relied upon to implement any elements of the person-centered service plan and to extend this provision to other Medicaid HCBS authorities.

At a minimum, family caregiver assessment tools should ask family caregivers about their own health and well-being; level of stress and feelings of being overwhelmed; and the types of training and supports, such as respite care, they might need to continue in their role. Following the assessment, the family caregiver should be connected to the critical supports identified during the caregiver assessment process. Doing so could, among other things, provide much needed support to continue in their caregiving role and delay the institutionalization of the beneficiary. Family caregivers may need supports to reduce caregiver strain, provide higher quality care, and continue playing an active role in a beneficiary's service plan. Because serious illness and disability affects the individual as well as the family, including both the person in need of services and supports and the family caregiver as full partners in care and decision-making -- and improving their care experiences -- are important measures of person-centered services. We urge CMS to work with states, plans, and state Medicaid LTSS programs to better support family caregivers and share best practices in this area.

AARP also supports allowing states to use Section 1115 demonstrations to provide limited HCBS benefit packages at higher income and asset eligibility levels as a way to prevent, delay or slow the process of persons spending down to full-benefit Medicaid eligibility. As part of these demonstrations, states could target benefits to family caregivers who help beneficiaries stay in the community, and could use cost-sharing from individuals on the upper end of income eligibility, using a sliding scale or other means, to ensure financial viability. It is important that provisions are designed to protect eligible beneficiaries and their family caregivers, as well.

B. What actions can CMS take, independently, or in partnership with states and stakeholders, to ensure quality of HCBS and beneficiary health and safety?

Both CMS (federal government) and states have an important and essential role to play in ensuring quality of care and quality of life for individuals receiving Medicaid HCBS. States and the federal government must be accountable to those on Medicaid and their family caregivers, as well as taxpayers. Currently, no federal agency require states to report on consumer and family experience with services received; adequacy of care plans; timely
delivery of services; coordination of HCBS with housing, transportation, and health services; or the cultural competency of service providers. These and other aspects of the HCBS system are important in understanding how well states are doing to ensure both quality of life and quality of care for beneficiaries. While some states measure

these or other aspects of HCBS quality, and managed care organizations may be required to report on some of these aspects, it currently is impossible to find a uniform, consistent and reliable source of data across all states for HCBS utilization and quality. As more states, currently 19 and counting, are using managed care to deliver Medicaid HCBS, continued state and federal oversight and enforcement are critical.

A More Concrete Person Centered Planning Process and Greater Enforcement

Currently, federal regulations require a written person-centered plan (PCP) for people receiving HCBS provided through the Medicaid State Plan or through a waiver program. If CMS and states were to strengthen the person centered planning process, it could greatly improve compliance with health and safety issues by ensuring that plans meet the individualized needs of each person.

Care plans drive service delivery. Consistent with the person-centered planning regulations, the service or care plan should be driven by the individual and their family caregivers (as appropriate). The federal regulations require that PCPs be developed periodically, in consultation with the beneficiary (even led by the beneficiary), and be based on the most recent assessment of the individual's physical, psychosocial and functional needs. The PCP must consider the formal and informal supports that a person has or needs and identify the amount, duration, and scope of the services required. The PCP must indicate the individual's preferences for types of providers and services that will be provided and can identify other service needs that the beneficiary may have. (42 U.S.C. § 1915(i)(1)(G) and §1929 (d)(1)).

All too often, the PCP process breaks down if assessments are delayed, are done by unqualified people, or are otherwise of poor quality. The PCP process also breaks down if the beneficiary is not able to direct his or her own care or is otherwise uninformed about the person-centered plan. CMS should require reassessments of changes in particular areas that are indicative that changes could relate to an urgent need. For example, providers should be required to document and assess changes in cognitive status, mobility, behavioral symptoms, living arrangements and the need for palliative care planning. Further, federal regulations should require that PCPs address how the HCBS provider will monitor safety issues related to the risk of elder abuse including but not limited to physical, sexual, financial, isolation or abandonment issues.

To ensure that the PCP process is adhered to and meets the needs of the beneficiaries, it is essential that enforcement provisions are sufficiently aggressive to incentivize compliance.

Quality Measures

AARP supports the provision from the Medicaid managed care final rule (CMS-2390-F) requiring states to identify "standard performance measures relating to quality of life, rebalancing, and community integration activities for individuals receiving long-term services and supports." At least in part to measure this goal, CMS should use its discretion to require states to assess the experience of beneficiaries receiving HCBS,

including family caregivers if they are part of the person-centered service plan. This is also an important part of measuring implementation of the PCP. We urge CMS to require all states to use the HCBS Consumer Assessment of Healthcare Providers and Systems (CAHPS) survey endorsed by the National Quality Forum to assess the experience of beneficiaries receiving HCBS. AARP strongly advocates for plans to be assessed using standardized measures that are valid and reliable. CMS can and should use the results of such surveys to develop performance improvement projects that focus on the consumer experience of care. Ultimately, as in Medicare Advantage, survey results should be used to drive payment policy.

Outcomes measures such as functional status and quality of life are highly desirable. However, given the lack of standardized HCBS quality measures, structure and process measures (especially when there is a known relationship to the outcome) may be used. The future development of additional meaningful quality measures that can be used uniformly across models of care and states is important for evaluation, consumer comparison, benchmarking, and defining success. There is also a need to develop measures for individuals who self-direct their own care if they so choose.

While there is a need for improved measures, AARP recommends that CMS consider balancing measures, as it is critical to measure if, and to what extent, delivering LTSS through managed care improves balancing. We suggest the following balancing measures for consideration for all managed LTSS states and note CMS could require these measures:

- Number and proportion of beneficiaries receiving LTSS in the community along with number and proportion of beneficiaries receiving LTSS in an institution;
- Total HCBS and institutional expenditures as a percentage of total LTSS expenditures;
- Number and proportion of beneficiaries who transitioned to the community from an institution and did not return to the institution within a year;
- Increase or decrease in the authorization of personal care hours; and
- Percentage of new Medicaid LTSS users first receiving services in the community.

In considering or pursuing the above measures, we urge CMS and states to collect data by population to better determine the effect that managed care programs have on Medicaid's traditional bias toward institutional care and whether increasing managed care enrollment, especially for older adults, improves the balance between the use of HCBS and institutional care as this is a population that historically has lagged behind in states' balancing efforts.

C. What program integrity safeguards should states have in place to ensure beneficiary safety and reduce fraud, waste, and abuse in HCBS?

Medicaid LTSS programs should be designed to protect consumers, guard against fraud and abuse, offer appropriate training, and provide sufficient oversight to ensure high quality services. Both the state and federal governments have a role to play in providing oversight, supporting state Medicaid fraud and abuse units, and investigating and prosecuting providers in any services and supports setting who defraud Medicaid or abuse beneficiaries. There should also be whistleblower protections for staff and others who report fraud and low-quality care to the appropriate authorities. CMS should act within its authority to address these issues, including working with ACL, the Department of Justice, states, Medicaid Fraud Control Units, state attorneys general, adult protective services, long-term care ombudsman programs, law enforcement, and other appropriate entities.

A qualified, well-trained workforce is needed to ensure that quality care is provided in home and community based services. People who have a record of abuse or serious crimes in one state can simply travel to another state to find work because no national registry of abusive workers exists. They can also move from working in nursing facilities to home health agencies or supportive housing without ever undergoing a criminal background check.

AARP recommends that screening requirements be more consistent across the states, in particular with regard to criminal background checks and state licensure sanctions. Although the federal government does not require criminal background checks of HCBS workers, increasing numbers of states do. State laws vary considerably in terms of who is screened and exempted, what convictions preclude employment and for how long, what provisional employment is permitted while checks are conducted, and who pays for screening. Some state laws exempt screening for workers hired directly by the care recipient.

AARP recommends that nationwide criminal background checks be conducted on all workers who provide HCBS or who are employed in HCBS settings prior to employment.[1] Individuals who have been convicted of burglary, larceny, violent crimes or crimes involving abuse or neglect of vulnerable individuals should be prohibited from employment in HBCS settings.

AARP also recommends that criminal convictions and licensure sanctions are promptly reported to the Office of Inspector General (OIG). OIG exclusion authorities provide for exclusion of providers from participating in federal health care programs for certain crimes and licensure sanctions, so prompt reporting ensures that exclusion proceedings can be undertaken at the earliest opportunity. Prompt reporting is especially important in situations where staff or others are convicted of abuse and neglect of vulnerable people.

D. What specific steps could CMS take to strengthen the HCBS home care workforce?

[1] Background checks need not be required for parents, spouses, partners, close relatives, or close friends when hired through self-directed programs.

The benefits of having sufficient numbers of community-based providers to individuals and family caregivers will become ever more important as the Baby Boomer generation ages. People age 80 and over are "the most likely to need LTSS." As this age group increases in the future, the "number of people in the primary caregiving years (ages 45-64) is projected to remain flat." Thus, the "caregiver support ratio" – the number of potential family caregivers aged 45-64 for each person aged 80+ - shrinks. In 2010, the ratio was more than seven potential caregivers for every person 80-plus. By 2030, this ratio is projected to decline sharply to 4 to 1 and to less than 3 to 1 in 2050.[2] This shrinking caregiver support ratio will put greater strains on family caregivers in the future.

Direct care workers, including home care workers, provide most paid LTSS, yet even people who can afford home care services often have difficulty locating competent, trained people to do the job. Low wages (and few benefits) contribute to high staff turnover and low-quality care. Until recently, home care workers were not covered by federal minimum wage and overtime protections.

CMS and states should ensure that Medicaid and reimbursements paid by private contractors with government agencies (such as Medicaid managed care plans) for providers' labor costs are sufficient to pay wages that will attract and retain home care workers. Wages and salaries should be commensurate with others in the region and with the time, skill, and effort required to render high-quality services and supports. Federal minimum wage and overtime protections for home care workers should also be maintained. Adequate benefits, educational opportunities, and career ladders can encourage recruitment and retention of home care workers.

AARP appreciates the opportunity to comment on this request for information. We look forward to working with CMS to accelerate the balancing of LTSS nationally and at the state level. Older adults and people with disabilities should have the help they need – including well-supported family caregivers – to enable them to live independently in their homes and communities. If you have questions, please contact me or Rhonda Richards (rrichards@aarp.org) on our Government Affairs staff at 202-434-3770.

Sincerely,

David Certner
Legislative Counsel & Legislative Policy Director
Government Affairs

[2] D. Redfoot, L. Feinberg, & A. Houser, *The Aging of the Baby Boom and the Growing Care Gap: A Look at Future Declines in the Availability of Family Caregivers* (AARP PPI, 2013), available at http://www.aarp.org/content/dam/aarp/research/public_policy_institute/ltc/2013/baby-boom-and-the-growing-care-gap-insight-AARP-ppi-ltc.pdf.