June 29, 2012

Ms. Barbara Edwards
Director
Disabled & Elderly Health Programs Group
Center for Medicaid, CHIP and
Survey & Certification
Centers for Medicare & Medicaid Services
Department of Health and Human Services
Attention: CMS-2249-P2
P.O. Box 8016
Baltimore, MD 21244-8016

RE: Medicaid Program; State Plan Home and Community-Based Services; 5-Year Period for Waivers, Provider Payment Reassignment and Setting Requirements for Community First Choice; CMS-2249-P2

Dear Ms. Edwards:

AARP appreciates the opportunity to comment on the proposed rule to implement the State Plan Home and Community-Based Services (HCBS) Option/Benefit under Section 1915(i) of the Social Security Act, setting requirements under multiple Medicaid HCBS authorities, and the five-year period for waivers including individuals who are eligible for both Medicare and Medicaid.

AARP is a nonprofit, nonpartisan organization with a membership that helps people age 50+ have independence, choice and control in ways that are beneficial and affordable to them and society as a whole. We have offices in all 50 states, the District of Columbia, Puerto Rico, and the U.S. Virgin Islands. Though our comments will focus more on how this proposed rule could affect individuals age 50 and over, we note that Medicaid HCBS authorities provide important services to people of all ages.

While we will comment on many provisions of the proposed rule, the bulk of our comments will focus on the critical issues raised by the home and community-based setting requirements. We appreciate the effort to distinguish between true "home" and "community-based" settings and institutional practices that still prevail in some types of settings receiving Medicaid HCBS funding. We support many of the requirements and note that many were improved from previous proposals. However, our comments will outline continuing questions and real concerns that in the absence of further clarification and modifications, some of these provisions could be interpreted to bar individuals of all ages who reside in a range of non-institutional settings and housing options from receiving

HCBS under various Medicaid HCBS authorities, including 1915(i), the Community First Choice (CFC) Option, and HCBS waivers, currently the largest funding stream in Medicaid for HCBS. Given that CMS-proposed language on home and community settings is generally consistent for 1915(i) and CFC, our comments on this issue apply to CMS proposals under both Medicaid HCBS authorities, unless otherwise noted. We also note CMS' intent to apply these same setting requirements to Section 1915(c) HCBS waivers; thus our comments are also applicable to setting requirements under such waivers. We also offer some additional thoughts and potential solutions for CMS' consideration. We know defining "home" and "community" raises many complicated and challenging issues, and we appreciate CMS' response to some of our previous comments on this issue, as well as CMS' solicitation of additional public input. We hope setting requirements can be addressed in a way that allows all individuals to live in the most integrated setting appropriate to their needs and consistent with their preferences.

As more states are considering or implementing managed long-term services and supports (LTSS), we assume the setting requirements would also apply to managed LTSS. CMS should consider how these requirements would work within managed LTSS and impact network adequacy, particularly as plans may have networks less extensive than fee-for-service Medicaid.

AARP also strongly commends and supports CMS' inclusion of caregiver assessment in the proposed regulatory text of 1915(i). Especially when person-centered service plans rely on the involvement of family caregivers, assessing and addressing the needs of family caregivers to support them in their caregiving role (and ultimately the individual they are caring for) is critical. We provide CMS with some additional thoughts on implementation of this provision and expanding it to other HCBS authorities. Below are AARP's comments on issues in the general order in which they appear in the text of the proposed regulation.

Section 430.25 Waivers of State Plan Requirements

This section implements Section 2601 of the Affordable Care Act allowing any waiver under subsections (b), (c), or (d) of Section 1915 of the Social Security Act, or a waiver under Section 1115, that provides medical assistance to dual eligible individuals to be conducted for five years, and upon the request of a state, extended for additional five-year periods unless the HHS Secretary makes certain determinations. Twenty-six states have submitted demonstration proposals to CMS under the Financial Alignment Initiative of the Medicare-Medicaid Coordination Office and the Center for Medicare and Medicaid Innovation. These three-year demonstrations will test two financing models to improve the quality and cost of care for dual eligibles. Some states are using waivers as part of their implementation of these demonstrations. We urge the HHS Secretary to be mindful of these demonstrations and make wise and appropriate use of her authority under this section.

Section 440.182 -- State Plan Home and Community-Based Services

AARP generally supports CMS' approach in Section 440.182(d), which outlines HCBS costs not considered room and board, and which are thus eligible for the federal Medicaid matching rate. CMS proposes that a State may claim federal financial participation (FFP) for "a portion of the rent and food costs that may be reasonably attributed to an unrelated caregiver providing State plan HCBS who is residing in the same household with the recipient, but not if the recipient is living in the home of the caregiver or in a residence that is owned or leased by the caregiver." FFP would be available only for the "reasonable additional rent and food costs of the caregiver residing in the recipient's home, not to support the cost of a caregiver's household in which the recipient resides." We suggest that CMS explore providing FFP for the same expenses reasonably attributed as a service cost to compensate a related caregiver providing State plan HCBS, just as described above for unrelated caregivers. This modification could enhance consumer choice of providers in states that opt to offer a self-directed services option.

AARP supports the broader array of services states can offer with the addition of "other services". We also support CMS' decision to allow states to offer in this category certain transition services to help individuals return to the community and that such services could begin prior to discharge.

Section 441.530 -- Home and Community-Based Setting

The issue of defining or determining criteria for home and community settings raises the most challenging and complex issues in this proposed rule. We appreciate the thought and effort that CMS has put into these issues over multiple years. AARP has also engaged in thoughtful conversations with stakeholders in the aging, disability, and provider communities in order to hear various perspectives and ideas about these critical issues and inform our thinking and comments. As noted previously, CMS' proposed language on criteria for home and community settings is very similar for both Section 1915(i) and CFC. Unless otherwise noted, AARP's comments on this issue under one authority are applicable to both authorities, as well as HCBS waivers.

AARP strongly supports state compliance with the Americans with Disabilities Act and the *Olmstead* decision. As CMS noted last year in the preamble of the Community First Choice Option proposed rule, in *Olmstead* "the Court affirmed a State's obligation to serve individuals in the most integrated setting appropriate to their needs." We also strongly support a person and family-centered approach to services. AARP believes the concepts of individual choice and control and meeting individual needs and preferences, through individual assessment and person-centered planning, are vital both within Medicaid HCBS and as an overall approach to long-term services and supports in Medicaid and other programs. Older adults want to remain independent as long as possible. AARP supports the intent and goal of ensuring that HCBS provided under Medicaid HCBS authorities are indeed provided in settings that are home and community-based settings and not institutions or institution-like settings. In doing so, we believe it is important to acknowledge that the population needing HCBS is not homogenous; their needs and

preferences for where they choose to reside vary as do those of the broader population. We believe home and community-based setting requirements should not eliminate the type of innovative quality home or community residences being developed in a number of states.

In general, we appreciate that CMS has taken the approach of looking at the qualities of a setting to determine whether it is a home and community-based setting, and we appreciate some changes that CMS made since its proposed rulemaking on the issue last year, such as the removal of the term "custodial care." A determination of whether a setting is home or community-based should be made by looking at the whole picture and all of the criteria that can determine such a setting, not any one factor.

States planning to provide HCBS under Section 1915(i) or CFC would be required to include a definition of home and community-based setting that incorporates the principles outlined by CMS. CMS will review all state plan amendments (SPAs) to determine whether they propose to fund settings that are home or community-based. AARP urges CMS to provide greater clarity regarding the process by which the Secretary will interact and work with states and providers to make determinations of what settings meet the home and community-based setting requirements. The process should be reasonable, fair, consider all appropriate factors, and not be overly burdensome.

States with approved 1915(i) or CFC SPAs would be provided with a "reasonable transition period" of at least a year to comply with HCBS setting requirements promulgated in a final rule. We recommend that CMS give states more than one year to comply with final HCBS setting requirements to avoid unintended consequences in the transition that could cause individuals to lose access to vital HCBS and to ensure that states have a sufficient time to transition and ensure adequate access to HCBS providers. State LTSS service delivery systems vary and the specifics of a final regulation will impact states differently. CMS should be flexible enough in implementation to ensure as smooth as possible a transition in all states and consider state progress in the implementation period. Continuity of services and access to service providers is essential for individuals who require HCBS. CMS must ensure that implementation of the HCBS setting requirements does not have the unintended and severe adverse consequence of sending individuals into institutional settings. Affected individuals should be grandfathered in existing settings that are legitimately choosen, especially if they do not have other home and community-based setting options that meet their needs and preferences, and they are at risk of losing services. We also note the shortage of affordable and accessible housing alternatives and the time required to develop new options. Access to housing is reported by many states to be one of the challenges to successfully transitioning older individuals from institutions into the community. CMS should consider these factors in establishing transition periods in states.

The issue of "choice" is important in the consideration of home and community settings. Individuals who need HCBS should be able to make an informed and genuine choice among a full array of services, supports, and quality home and community settings to meet their individual unique needs and preferences. This includes receiving services and supports in their own homes, as well as other settings, including congregate settings that are home and community-based settings. Many individuals would choose to receive services in their own homes, and they should have the ability and supports to do so. The same should hold true for individuals who choose other home and community-based settings. Some individuals who are not eligible for Medicaid may choose to sell their homes, move to an assisted living residence or other similar setting they have chosen with home and community qualities, and pay out of their own pockets to live there and receive the services and supports they need. They may have chosen this community for a number of reasons – they may have friends who reside there, and/or they may have felt isolated in their homes and desired the social interaction and cultural activities made available to them in the assisted living residence. They may be active in their greater local community outside their residence, interacting regularly with individuals without disabilities, and they may be active in the community within their assisted living residences. This example is not a "forced" choice or an instance in which a person can only choose an assisted living residence because she did not have access to more integrated alternatives. If she later spends down her resources and becomes eligible for Medicaid HCBS and wants to remain in her assisted living residence, she should be able to do so. Her choice should be respected and supported, just as for individuals who choose to receive services in their own homes.

The concept of "community" is also critical to this discussion. We agree that an important purpose of HCBS is to assist individuals to live fully integrated in the greater community. We also note that in some cases an individual may live in their own home in the greater, non-disabled community, but lack appropriate supports and relationships with individuals in the greater community. Such individual may live alone, may infrequently leave the home or have regular visitors, may have limited transportation access, and may become depressed and socially isolated. On the other hand, this same individual who chooses to live in a congregate setting could regularly interact with her peers and be supported in her choices and efforts to socialize and pursue interactions with individuals without disabilities in the greater community. In some cases, it may be her interactions with her community of peers that reduces social isolation and depression and encourages and supports her interaction with the greater community outside her residence. While we understand and clearly value integration with the larger community, we recognize that certain residential settings freely chosen can also provide a sense of community, as persons who individuals may choose to spend time with and activities that individuals may choose to participate in may also be found in the building or the site where they live. Providers should be required to support access to the broader community, but CMS should also recognize the important obligation to foster community within the residential setting for those who seek this option. Individuals may choose to participate in activities and engage with people in the greater community, in the community of their residence, in a community accessed through electronic means, some or all of the above or none of the above. The final rule should recognize the full scope of community and range of choices.

Section 441.530(a)(1)(i)-(v) – Home and Community-Based Setting Qualities

CMS proposes that home and community-based settings must have specific qualities, and such other unspecified qualities as the Secretary determines appropriate, based on the needs of individuals as indicated in their person-centered service plans, in order to be eligible sites for delivery of HCBS. We agree with allowing for a more individualized approach to a person's needs and preferences and involving the person-centered service plan; this seems to be a person-centered approach. However, it would be helpful for CMS to clarify how the unspecified qualities relate or not to the specified qualities and to provide some examples. We will comment on the qualities for home and community settings, the additional requirements for provider-owned or controlled residential settings, and other additional requirements or issues.

Section 441.530 (a)(1)(i) requires that the "...setting is integrated in, and facilitates the individual's full access to, the greater community, including opportunities to seek employment and work in competitive integrated settings, engage in community life, control personal resources and receive services in the community in the same manner as individuals without disabilities." AARP agrees that a home and community setting should facilitate the individual's full access to the greater community as they choose, including in the areas noted. We note, however, that individuals may vary in their choices as they seek full access to and participation in the greater community, and a home and community-based setting should facilitate such full access consistent with an individual's choices and preferences. Some individuals may not seek full access to the larger community or to all the aspects noted. Individuals should have access to information, transportation and other supports to enable them to have meaningful access to the larger community and community activities, and we strongly support the right and choice of individuals to have this freedom.

The second criteria CMS proposes is that the "setting is selected by the individual from all available alternatives and is identified in the person-centered service plan." AARP believes that the individual receiving services should select the setting from a full array of potential options, which should include the most integrated setting appropriate to the individual's needs. We note that the assessment instrument for nursing facility residents, the Minimum Data Set (MDS) 3.0, includes a question in Section Q asking the nursing home resident or their representative if they would like to talk to someone about the possibility of returning to the community. Section Q also includes a follow-up question about whether a referral was made to a local contact agency. This is one example of how nursing home residents can be made aware of community options. Regardless of the individual's situation, the individual and, as appropriate, the individual's representative should have access to information and independent options counseling free from conflicts of interest to help them make an informed and meaningful choice in selecting their setting. CMS may wish to further clarify what such options counseling should include and how Medicaid may fund such counseling.

We note that individuals in different situations may not have the same range of options available to them. We hope the setting requirements will help drive further positive change in the public and private sector delivery systems for HCBS to create more and better home and community setting options to meet the needs and preferences of individuals of all ages. At the same time, the requirements should not have the consequence of removing legitimate home and community settings and limiting choices for individuals. In the event specific settings will no longer be in compliance with the home and community setting requirements, CMS should grandfather individuals currently in existing settings if they choose to remain to prevent service disruptions, especially if they do not have other home and community setting options that meet their needs and preferences and are at risk of losing services. As noted above, allowing an appropriate transition period is also critical. Finally, we note it is not the actual selection of the setting and its inclusion in a person-centered service plan that makes it a home and community setting. Thus, it may be more appropriate to include this provision in person-centered planning.

CMS's third criteria is that an "individual's essential personal rights of privacy, dignity and respect, and freedom from coercion and restraint are protected." AARP strongly agrees that these are important personal rights that should be protected. However, we suggest that CMS reword the sentence to read "individual's personal rights of privacy, dignity and respect, and freedom from coercion and restraint are essential and are protected." As currently written, the placement of "essential" may imply that other rights are not essential and thus do not need to be protected.

Fourthly, CMS proposes "Individual initiative, autonomy, and independence in making life choices, including but not limited to, daily activities, physical environment, and with whom to interact are optimized and not regimented." This important criterion goes directly to the choice and control an individual has over his or her life. Optimizing consumer choice is a person-centered approach to service delivery and consumer choice should be optimized to the maximum extent possible. A slight modification may also be needed to reflect the involvement of an individual's representative, as appropriate, when individuals are unable to act on their own behalf. CMS should also clarify who would determine and how to determine whether the individual initiative, autonomy, and independence in making life choices were optimized.

Another criterion is that "Individual choice regarding services and supports, and who provides them, is facilitated." AARP strongly believes that individuals should have choice regarding services and supports and who provides them. However, we do want to ensure that "is facilitated" is not used to water down individuals exercising choice over services, supports, and providers. Some individuals may need assistance in exercising choice over services and providers, and other individuals may need their chosen representative to act on their behalf if they are not able to act on their own behalf. Are these the situations the "is facilitated" language is intended to address? If this is the intent, we suggest rewording this criterion to note that support should be provided, as needed, to facilitate such choices and acknowledge that an individual's chosen representatives may be acting on behalf of the individual when the individual is unable to act on their own behalf.

Section 441.530 (a)(1)(vi) – Conditions for Provider-Owned or Controlled Residential Settings

CMS proposes additional conditions for "provider-owned or controlled residential settings." In our earlier comments regarding the language in the preamble to the proposed rule for the 1915(c) waiver program related to "assisted living," AARP encouraged adoption of more generic terms because of the ambiguity surrounding the various ways that "assisted living" was defined by states. We applaud use of the more general "provider-owned or controlled residential settings," but since CMS is creating a new technical term defining a class of services, it would be prudent to offer clearer regulatory guidance regarding the reach of such a term. For example, would an elderly housing project that included service coordination and other services be subject to these provisions as a provider-owned residential setting? CMS may want to consider limiting this term to apply to state-licensed or certified settings to avoid confusion.

Subsection (B) – Private Units

We comment on Subsection (B) first, because it may affect the guidance required under Subsection (A). Subsection (B) requires that individuals have "privacy in their sleeping or living unit," which Subsection (B)(2) defines as "Individuals share units only at the individual's choice." AARP has long advocated for a requirement of private rooms in residential settings providing LTSS. Sufficient provisions for paying for private rooms are a critical element for ensuring that individuals have meaningful choice and their dignity and privacy are honored.

AARP believes that a private room should be considered an essential service. Part of the CMS review of state applications under any of the HCBS authorities should include a requirement that states make adequate provisions to pay for this service. As we noted in our previous comments, requiring a private room can be an empty promise if states are not required to make some provision for paying for the added cost. When individuals receive Medicaid assistance, the state requires a portion of their incomes be used to pay for the Medicaid benefits. To pay for the room and board costs that are not included in waiver services, states establish maintenance allowances, which are typically set at the Supplemental Security Income level (SSI) or SSI plus a modest amount. In most states, the income that beneficiaries are allowed to retain to meet these needs is substantially below the amount needed to pay for a private room, meals, and other non-covered costs such as heating and cooling. If the Medicaid HCBS program is to achieve a minimally necessary level of privacy for individuals receiving services, then states must make adequate provision to cover the costs. At a minimum, states should be required to set their maintenance allowance at a level sufficient to pay for room and board. Optimally, states should also provide supplements for those with SSI level incomes to enable them to live in private units.

The requirement that "Individuals share units only at the individual's choice" may require some clarification regarding the permission to share units. Clearly, the rule should allow spouses, partners, and friends to share rooms if they choose. But failing to require states to make any provision for paying for a private room could be interpreted as permitting inadequate maintenance allowances that effectively mean that the real "choice" facing individuals is to share a room for financial reasons or to seek some other type of service. Requiring private units without requiring the funding would likely result in more people being forced into institutional settings that include reimbursements for room and board costs – clearly contradictory to the goal of expanding consumer choice through HCBS options. We do note that the proposed regulation's cost estimates do not include any provision for private units.

Subsection (B) also requires units to have lockable entrance doors, with appropriate staff having keys to doors, and that individuals have the freedom to furnish and decorate their sleeping or living units. We support lockable entrance doors with appropriate staff having keys to doors, since there are also provisions under the individual modification of requirements discussed below that can be used for individuals with cognitive impairments for whom lockable doors and free egress may present safety and other issues. In such cases, alternative means for assuring meaningful individual privacy should be required (e.g. knocking and waiting for a reply before entering a person's private space, respecting private possessions, etc.). We strongly support individuals having the freedom to furnish and decorate their own sleeping or living units.

Subsection (A) – Legally Enforceable Agreements

Subsection (A) requires that a beneficiary's "unit or room is a specific physical place that can be owned, rented or occupied under another legally enforceable agreement by the individual receiving services, and the individual has, at a minimum, the same responsibilities and protections from eviction that tenants have under the landlord tenant law of the State, county, city or other designated entity." This requirement presents two major issues that may require further clarification or modification in the context of residential settings funded with HCBS funds. The first set of issues relates to the requirement of "a specific physical place." In general, AARP supports the idea that residents in such settings should have agreements for a specific room or unit and should not be arbitrarily moved around by providers. Several areas still need clarification, such as those affected by the interpretation of Subsection (B) discussed above, because landlord tenant laws vary tremendously by state and their application to specific residential arrangements tend to be fact specific and subject to complex statutory and judicial interpretation. For instance, if residents are forced to share rooms because states do not make adequate provisions to pay for private rooms, then policies must be developed to deal with the inevitable roommate conflicts certain to arise. In such circumstances, who has claim to the unit? Are such circumstances covered by normal landlord tenant laws?

In addition, federal, state and local fair housing and human rights laws will apply to the residential setting being evaluated and the home and community services to be provided. The federal Fair Housing Act prohibits discrimination in almost all housing activities based on disability and requires housing providers to make reasonable accommodations to rules and policies when such accommodations are needed for the individual to use and enjoy the housing. The application of the fair housing laws to residential settings that are also subject to state licensure and regulatory schemes can be complex, and the law in this area is continuing to develop. These regulatory schemes may require actions by the housing provider based on the medical status or level of disability of the resident, or may set out admission or termination requirements on such bases. Such instances can place the state's "level of care" licensure standards that require the discharge of residents with certain types or acuity of conditions at odds with civil rights protections designed to allow consumers to live and receive services in places they choose.

Decisions made about a person's continued ability to remain in assisted living, for example, must be made based upon individual assessments of the person's ability to remain in place, with or without an accommodation, and not on the basis of the type of disability or condition. Providers are not required to make accommodations where to do so would result in an undue financial and administrative burden or would fundamentally alter the nature of the provider's operations. However, providers **and** state licensing agencies are required to make reasonable accommodations to enable people to remain in the homes that they choose if the accommodations meet those tests. State plan amendments should specify processes by which they would make "reasonable accommodations" decisions without forcing residents to make claims in court or forcing providers to jeopardize their licensure by reasonably accommodating residents whose service needs have intensified, for example. Reasonable accommodations processes should provide plenty of notice and be easily used. A number of states have enacted interactive processes to provide appeals and individual determinations of the ability to remain, even if their continued residency represents a violation of the level of care requirements.

Similarly, one area upon which CMS has solicited comment is a potential criterion that would include a "requirement that receipt of any particular service or support cannot be a condition for living in the unit." AARP supports such a limitation to ensure that HCBS are provided in the most integrated settings appropriate to individuals' needs and that the individualized needs of the Medicaid beneficiary drive the services delivered. Similar to the description above, if situations exist where an individual does not need all the services offered by a provider or the individual is below a minimum level of care need for living in a particular setting, there should be a process such as the one described above to provide reasonable accommodations.

Finally, a legally enforceable agreement under this subsection should include a right to appeal decisions affecting tenancy. Agreements should clearly specify the conditions that would trigger a termination, including conditions related to the person's health status or level of disability that would necessitate a move. The individual should have the right to appeal termination decisions to an objective third party in a timely manner, such as 30 days, which should be defined in the state's waiver application. This appeals process should be accompanied by the reasonable accommodation process noted above.

Subsections (C), (D), and (E) -- Control Schedules and Activities, Food Access, Visitors, and Physical Accessibility

Subsection (C) requires individuals to "have the freedom and support to control their own schedules and activities, and have access to food at any time." Subsection (D) requires that individuals "are able to have visitors of their choosing at any time" and Subsection (E) requires the setting to be "physically accessible to the individual." AARP supports these home and community setting requirements. They address individuals' choice and control over their own lives, which individuals of all ages value.

Individual Modifications of Requirements

The preamble specifically solicits comments on a proposal to permit modifications to the requirements associated with provider-owned or controlled residential settings as long as they are "supported by specific assessed needs and documented in the person centered service plan." In general, AARP supports this approach. Rather than take a rigid approach that may not account for the needs of every individual who requires HCBS, CMS proposes an approach that is more person-centered and can be tailored to the well-being and needs of specific individuals. The goal of making such modifications would be to balance protecting individuals' "independence and freedom" with the need to protect the "safety and welfare" of those whose disabilities make the requirements unworkable or dangerous. For example, lockable doors may not work for a person with moderate to severe dementia. We would note, however, the extensive list of proposed requirements associated with such modifications may be excessive in some circumstances. For example, requiring "regular collection and review of data" or "periodic reviews" related to removing the lock from the door of a person who can no longer use it because of dementia would seem excessive. The requirements should be easy enough to manage and related to the likelihood of the person no longer needing the modification after a period of time.

The logic of making individual exceptions to the setting requirements through the person-centered service plan is consistent with our suggestion above regarding reasonable accommodations processes. As in the instances cited in the preamble, the goal of requiring reasonable accommodations regarding licensure requirements related to eviction is also to balance individual "independence and freedom" with the state's responsibility to protect the "safety and welfare" of those who reside in licensed settings.

CMS gives the good example of addressing the safety needs of an individual with dementia as one potential reason for modifying the additional conditions and may require some additional clarifying flexibility in the proposed rule. Dementia care settings typically control egress, because wandering is an increased risk associated with dementia. Indeed, some states require such controlled egress in settings that characterize themselves as providing specialized dementia services. Not everyone with dementia is a wandering risk – but it is not possible to make individual determinations for an egress system that obviously affects all residents. Not all residents may be at risk for wandering at a given time, but given the progressive nature of dementia, a person who isn't a wandering risk today may be a wandering risk next week. This example indicates that modifications to the setting conditions should be allowed to address the known risks that affect some but not necessarily all of the residents in a setting. CMS should clarify the process settings would undergo in such situations. Clearly, at least one resident in this example would need to demonstrate a risk for wandering, and most likely more than one resident would have such a demonstrated risk. However, setting modifications of this sort should not necessitate a modification to every resident's service plan in the setting, regardless of their wandering risk. Individuals, as appropriate, should have their risk for wandering assessed, but CMS should provide guidance on what reasonably should and should not be required of providers in such a situation.

Finally, CMS may also want to consider whether this authority to make individual modifications would be more appropriate in the sections related to privacy and dignity, as placing it in the setting requirements section may inadvertently narrow its scope to particular settings.

Section 441.530 (a)(2) – What Home and Community-Based Settings Do Not Include

CMS proposes that home and community-based settings do not include a "nursing facility", "an institution for mental diseases", "intermediate care facility for the mentally retarded" (the outdated technical term in the law), or a "hospital providing long-term care services". As cited in the CFC statute, the first three settings are not home or community settings and we agree.

We would agree with CMS that a long-term care hospital would not be a home or community setting. CMS acknowledges that people with disabilities use personal attendant services and supports for help with activities of daily living (ADLs) and instrumental activities of daily living (IADLs) and may have a continued need for such assistance while in a short-term stay in general acute hospital settings. CMS notes that while services provided in such a setting are not CFC services, "individuals who have an assessed need for assistance with IADLs may continue to receive such services while an inpatient in an acute hospital setting." We agree that individuals in an acute care hospital who need services, such as assistance with IADLs, should not be prevented from receiving such services while they are in an acute hospital setting. In fact, the ability to receive these services, as needed, while in the hospital could enable a smoother transition after hospital discharge back to a home or community setting and help prevent institutionalization.

CMS also addresses the issue of services provided in a hospital in Section 1915(i). However, the proposed preamble and regulatory text are inconsistent and require clarification, and this provision is also different from the regulatory text in the CFC Option. In the 1915(i) preamble, CMS recognizes the potential value of "ongoing support through the HCBS State Plan for physical needs over and above such services available in a hospital, to ensure smooth transition from clinical setting to home, and to preserve a sense of continuity and normalcy...", while noting that these services "must be exclusively for the benefit of the individual... and must not substitute for services that the hospital is obligated to provide..." However in the proposed regulatory text for 1915(i), CMS includes "a hospital" in Section 441.656(a)(2)(iv) in its proposed list of settings not home and community-based. This language does not have the long-term care hospital clarification in the CFC Option and seems inconsistent with the language of the 1915(i) preamble. As CMS is trying to take a consistent approach on the setting issue across HCBS authorities, we are unsure why this difference exists and wonder if it is because of the "hospital" reference in the 1915(i) statute as institutionalized care (see Section 1915(i)(1)(B) as one example). To the extent possible, we encourage CMS to be consistent across authorities as it intends to clarify this difference.

In subsection (a)(2)(v), CMS notes that any "other locations that have qualities of an institutional setting, as determined by the Secretary" are not home and community-based settings. In the preamble, CMS notes that characteristics that could cause it "to consider a setting as 'institutional' or having the qualities of an institution include "settings which are isolated from the broader community, do not allow individuals to choose whether or with whom they share a room, limit individuals' freedom of choice on daily living experiences such as meals, visitors, and activities, or limit individuals' opportunities to pursue community activities." Many of these are reasonable considerations, and it is important to consider multiple factors when determining if a setting is institutional.

In addition, subsection (2)(v) lists types of settings that would receive heightened scrutiny and would be subject to a rebuttable presumption that they do not qualify as home and community-based settings, specifically "any setting that is located in a building that is also a publicly or privately operated facility that provides inpatient institutional treatment, or in a building on the grounds of, or immediately adjacent to, a public institution, or disability-specific housing complex." While the rebuttable presumption is a small improvement over the blanket disqualification of the types of settings listed in this section, AARP continues to have a number of concerns and questions regarding this issue. In the first place, we continue to have concerns about the range of housing and service types that may potentially be presumed to be ineligible.

- Would the term "disability-specific housing complex" preclude the provision of HCBS services in
    - any Section 202, Section 811, or other public or private housing that specifically serves older persons or persons with disabilities,
    - a residence that provides dementia care or other diagnosis specific services, or
    - any other housing that requires individuals to have a disability to live there?

- Is a "disability-specific housing complex" any building or buildings where people with disabilities or older adults who need help with daily activities reside?
- What is a "public institution?" Would this provision presumptively exclude HCBS services in publicly funded housing for older persons if a nursing home happens to be located on the same campus?
- What is "inpatient institutional treatment" and does "provides" mean direct provision of services by the facility, any provision of services in the facility, or facilitating the provision of such services?

AARP is also concerned about the nature of the heightened scrutiny and lack of guidance regarding what would constitute adequate rebuttal of the presumption against eligibility. The proposed rule already creates a set of requirements specific to provider-owned and controlled residential settings receiving HCBS funding, which effectively create heightened scrutiny for such settings. If residential settings meet these standards, what additional evidence must they provide that they qualify as HCBS settings by virtue of their location or whom they serve? What will constitute adequate "rebuttal" of the presumption that these settings do not qualify as HCBS settings? What procedural safeguards will be in place to allow appeals of decisions, and who will make the final determinations? What are the additional administrative burdens placed on states and providers to add this additional layer of heightened scrutiny? If a setting meets an individual's needs and preferences and meets the other criteria for home and community-based settings, who should bear the burden of proof to demonstrate that a setting is not home and community-based?

AARP is concerned that the presumptive ineligibility of certain congregate settings and disability specific housing may have a chilling effect on the development of innovative service delivery approaches designed to meet the preferences of and provide a wider array of options to people with limited income and resources. For example, continuing care retirement communities (CCRCs) and dementia-specific assisted living have been important options for older persons who want to plan for a future in which increased disability is likely. But most of such settings and services are very expensive – well out of the reach of people who are likely to need Medicaid assistance. In response, some innovative providers of subsidized housing are co-locating assisted living settings on the same location or converting parts of their buildings to assisted living. If such approaches would mean that these settings were presumptively ineligible to participate in Medicaid HCBS programs, it could have a chilling effect on developing such innovations – effectively restricting them to those consumers who have substantial resources.

One potential solution would be to recognize what the Fair Housing Amendments Act of 1988 has recognized in civil rights law – namely that "housing for older persons" is desired by a substantial number of people age 55 and older and that it is not considered discriminatory. It is relevant to recall that assisted living and CCRCs emerged largely as private pay options, reflecting strong consumer demand for age-specific housing with services that enable older people to live more independently than they would in a nursing home. This history stands in contrast to state mental hospitals or institutions for those with intellectual or developmental disabilities, where state policies created segregated

environments for people with such disabilities. The history of age-specific housing with service approaches also contrasts with the history of nursing homes, which grew dramatically after the enactment of Medicaid with its institutional funding bias. In correcting the history of state and federal actions that have segregated people with disabilities, CMS should not prevent the ability of older persons with low incomes to access innovative approaches to housing and services that have demonstrated strong consumer demand and are permissible under civil rights law.

Section 441.656 -- State Plan Home and Community-Based Services Under the Act

See our comments regarding home and community-based settings under CFC. Those comments are applicable to 1915(i). Note our comments around "hospital" as an institutional setting, as that is one area of difference between CFC and 1915(i) proposed regulation text. We also appreciate CMS' statement that "States are not prohibited from funding institutional care under Medicaid" and that "HCBS should be available to assist individuals to leave an institution".

Section 441.659 – Needs-Based Criteria and Evaluation

If states establish needs-based criteria for each specific service that an individual receives, this would add to the complexity of the assessment and service planning, the overall costs of program administration, and potential beneficiary and family caregiver confusion. Such variability in Medicaid across states could become extremely difficult to track and monitor.

States must define the state plan HCBS needs-based eligibility criteria at a less stringent level than institutional criteria, and a purpose of 1915(i) is to expand access to HCBS to individuals who are not at an institutional level of care (LOC), rather than to reduce access to institutional and waiver services. States can also provide 1915(i) services to individuals who are eligible for waiver services. If a state modifies its institutional level of care criteria to ensure that such criteria are more stringent than 1915(i) needs-based criteria, states "may continue to receive FFP for individuals receiving institutional services or waiver HCBS under the LOC criteria previously in effect." CMS should encourage states to exercise this important provision, so that individuals eligible for waiver or institutional care services under the previous LOC criteria do not unnecessarily lose access to services. States should also be mindful of maintenance of effort requirements. We believe the intent of the state plan HCBS option is to offer HCBS to more individuals and not reduce services that individuals receive. We also note that language in the 2008 proposed rule seemed more protective of beneficiaries on this point, and we encourage CMS to act within its authority to help prevent individuals from losing services.

States have flexibility to prospectively change the needs-based criteria under the HCBS state plan option. This section provides important consumer protections, including at least 60 days notice of a proposed modification to the Secretary, the public, and "each individual enrolled in the State plan HCBS benefit", as well as protections of continued eligibility for individuals who were eligible for the state plan HCBS benefit before modification. AARP supports these important protections and encourages the inclusion of language to provide

notice to an individual's authorized representative, as appropriate. AARP generally supports the independent evaluation and determination of eligibility provisions in subsection (d).

Section 441.662 – Independent Assessment

AARP generally supports the direction of this section (including the face-to-face assessment and consultation with the individual), strongly supports the inclusion of a caregiver assessment, and suggests some additional modifications. CMS notes that an evaluation of ability to perform two or more activities of daily living (ADLs) is a required element of the assessment, but only a suggested element of the eligibility evaluation and that "...partial or complete inability to perform two or more ADLs is not a statutory prerequisite to receive State plan HCBS..." The statute does not set any specific needs-based or ADL criteria as a standard for eligibility for any HCBS services. CMS should clarify that states should not interpret the two ADLs evaluation criteria in the assessment to mean that two ADLs is the standard for eligibility for the state plan option or for any specific services under the state plan option.

Importantly, CMS should broaden its interpretation of the individual's needs that are to be assessed to encompass cognitive impairment. Language should be added that specifically addresses the need to assess cognitive impairment. Individuals performing assessments will need to be sufficiently trained to do this. Many individuals with dementia need supervision and cueing or are unable to perform instrumental activities of daily living (IADLs).

Consultation with responsible persons appropriate to the individual often includes family, a spouse, partner, guardian, health care and support providers, authorized representative, or other individuals. **AARP strongly applauds and supports CMS' inclusion in the proposed regulatory text of a caregiver assessment "when unpaid caregivers will be relied upon to implement the service plan" and we urge CMS to include this provision under other Medicaid HCBS authorities.** Recognizing the vital role of the family caregiver is enormously important in promoting a person- and family-centered approach to providing services. Such an assessment should identify the family caregiver's needs, strengths, and preferences, and connect the caregiver to critical supports, such as respite, training, and other assistance. Doing so could, among other things, enable the caregivers to continue in their caregiving role and delay institutionalization for the individual. Family caregivers may need supports to reduce caregiver burden, provide higher quality care, and continue playing an active role in a beneficiary's service plan. Because serious illness or 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 experience, are important measures of person-centered services.

Section 441.665 – Person-Centered Service Plan

AARP strongly supports person-centered planning. We concur that determining the level of services required by an individual should be done only according to assessment of the individual's need – not available funds. We also agree that individuals may choose among qualified providers in the planning process and agree with including information in the service plan about back-up plans, the individual's choice of setting, and other alternative home and community-based settings considered.

CMS states the person-centered service plan must include the "services and supports (paid and unpaid) that will assist the individual to achieve identified goals, and the providers of those services and supports, including natural supports." When the individual welcomes the involvement of family or other informal caregivers, family members should be engaged as part of the care planning and caregiving teams. Services to be provided by family caregivers should only be included in the person- and family-centered plan if they have agreed to provide these services and feel prepared to carry out the actual tasks. While most family caregivers willingly provide services and emotional support, many are overburdened by caregiving responsibilities that come on top of other work and family commitments, and they may also experience profound negative effects on their own physical and psychological health. These factors demonstrate the need for family caregiver assessment.

In the preamble, CMS says "individuals with equivalent needs for support but differing levels of family or other natural supports may be authorized for different levels of HCBS…we conclude that the statute requires that the service plan should neither duplicate, nor compel, natural supports. (emphasis added)" In the proposed regulatory text, CMS notes "Natural supports cannot supplant needed paid services unless the natural supports are unpaid supports that are provided voluntarily to the individual in lieu of State plan HCBS." We agree that unpaid supports should be provided voluntarily and not compelled. CMS should include in regulatory text the specific language about not compelling natural supports and define what it means, in addition to the above proposed language.

Section 441.668 – Provider Qualifications

We support the conflict of interest standards to help ensure the independence of individuals performing the independent evaluation of eligibility and the independent assessment, and developing the service plan. Regarding the training section, we note individuals performing assessments will need to be sufficiently trained to assess cognitive impairment.

Section 441.677 – State Plan HCBS Administration: State Responsibilities and Quality Improvement

CMS is interpreting the presumptive eligibility or presumptive payment provision as allowing a state option for up to 60 days of presumptive eligibility or payment for only the evaluation of eligibility for state plan HCBS and assessment to determine necessary services. We strongly encourage CMS to use its discretion, if possible, to include payment for HCBS themselves for which a state believed the individual would be eligible. This expanded authority is especially important in emergency situations, such as avoiding institutional care.

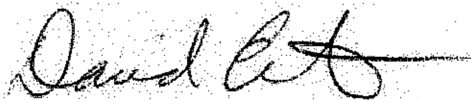
In addition, presumptive eligibility saves time and precious LTSS dollars if the individual receives needed services right away, thereby avoiding more costly LTSS or even hospitalization at a later date. Often a nursing home can take an individual right away at hospital discharge, but HCBS providers are often not able to do so, unless there is presumptive eligibility for services. Providing presumptive eligibility specifically for HCBS would help states make HCBS under this state plan option a more realistic choice for more individuals.

We believe that the rule should facilitate the adoption of these optional HCBS by States and provide financial incentives for the use of presumptive eligibility procedures. We recommend that the final rule provide FFP for presumptive eligibility services on the same basis as would be applicable to covered services under the optional HCBS benefit.
We also encourage CMS to require states to submit their quality improvement strategy to CMS at a specific frequency and consider making such information public.

Conclusion

AARP appreciates the opportunity to comment on this important proposed rule regarding home and community-based setting requirements, implementation of 1915(i), family caregiver assessment, and other issues. We appreciate your serious consideration of our comments. If you have any questions, please feel free to contact Rhonda Richards on our Government Affairs staff at (202) 434-3770 or rrichards@aarp.org.

Sincerely,



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In Brief

AARP Public Policy Institute

Listening to Family Caregivers: The Need to Include Family Caregiver Assessment in Medicaid Home- and Community-Based Service Waiver Programs

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Produced by the AARP Public Policy Institute with support from The John A. Hartford Foundation and the U.S. Administration for Community Living, Administration on Aging.

- ✓ **Family caregiver assessment is an important component of a person- and family-centered care planning process for home- and community-based services (HCBS). This In Brief summarizes findings from a 50-state survey examining how well the needs of family caregivers are assessed when states evaluate the needs of older people and adults with disabilities who qualify for HCBS programs under Medicaid.**
- ✓ **This report is the first detailed analysis of family caregiver assessment tools and processes in use by the states in Medicaid HCBS 1915(c) and 1115 waiver programs. Forty-six states plus the District of Columbia responded to the initial survey, a 92 percent response rate. Interviews with key informants were conducted in 13 states.**
- ✓ **Family support is often essential for helping older people and adults with disabilities continue to live at home and in the community. Yet the work of family caregivers can be demanding—physically, emotionally, and financially. If caregiver needs are not assessed and addressed, their own health and well-being may be at risk, which may in turn lead to burnout—jeopardizing their ability to continue providing care in the community.**

Key Findings

The concept of assessing a family caregiver's own needs is not well understood in many Medicaid HCBS programs.

We found that the term "family caregiver assessment" has mixed meanings among HCBS state officials.

Some view family caregiver assessment as simply asking the client ("care recipient") whether they have a family member involved in their care and how many hours of care that family member provides. Only a minority of states viewed family caregiver assessment to mean that questions are asked *of the caregiver* about their own health and well-being, and any services or supports they may need to be better prepared for their caregiving role.

AARP

Policy Recommendations

1. Family caregiver assessment should be a part of all assessment tools for Medicaid HCBS waiver programs, including comprehensive assessment tools developed at federal and state levels.
2. When a family caregiver assessment is conducted, family caregivers must be directly asked about their (a) own health and well-being, (b) levels of stress and feelings of being overwhelmed, (c) needs for training in knowledge and skills in assisting the care recipients, and (d) any additional service and support needs.
3. The interRAI Minimum Data Set Home Care (MDS-HC) is the most widely used assessment tool for Medicaid HCBS waivers across multiple states in our study. It should be expanded to include additional questions directed specifically to family caregivers in order to assess their service and support needs.
4. When a family caregiver is assessed, the care recipient's service plan should address the needs of the family caregiver raised during the assessment process to achieve a person- and family-centered service plan that best serves the person receiving Medicaid-funded HCBS services.
5. The family caregiver assessment should be part of the HCBS client record and coded for electronic records if available.
6. Funding should be preserved and increased for the National Family Caregiver Support Program (Title IIIE, Older Americans Act), which provides a base of family caregiver support services in local communities.
7. States should examine assessment tools in Medicaid HCBS managed care programs and for people eligible for both Medicaid and Medicare (known as dual eligible beneficiaries). These programs should add a component that assesses family caregiver needs whenever the client's care plan depends upon the family caregiver.
8. If states assign their assessments for publicly funded programs to managed care companies, the assessment tools and data should be publicly available.

The *sine qua non* of family caregiver assessment is talking with caregivers directly to better understand their needs, problems, resources, and strengths.

Both state and federal leadership is needed to come to a common understanding of what constitutes a family caregiver assessment, and to elevate the importance of assessing and addressing family caregiver needs in public programs that depend on their unpaid services—including both Medicare and Medicaid. With many states moving toward managed care and seeking to improve care for people eligible for both Medicare and Medicaid, these are opportune times to add family caregiver questions—directed to the family caregiver—as part of functional assessment for HCBS.

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A synopsis of the AARP Public Policy Institute *Research Report*, 2013-13.
A glossary of key terms and definitions are included in the full *Research Report*.
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In Brief