



**American Health Care Association**



**National Center For Assisted Living**

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Donald Berwick, M.D.  
Administrator  
Centers for Medicare & Medicaid Services  
U.S. Department of Health and Human Services  
Attention: CMS-2296-P  
P.O. Box 8016  
Baltimore, MD 21244-1850

**Re: File Code CMS-22296-P, Medicaid Program: Home and Community-Based Services Waivers Proposed Rule, 76 Federal Register, April 15, 2011**

Dear Dr. Berwick:

The American Health Care Association (AHCA) and the National Center for Assisted Living (NCAL) represent nearly 11,000 non-profit and for-profit providers dedicated to continuous improvement in the delivery of professional and compassionate care for our nation's citizens who are frail, elderly, or have developmental disabilities (DD) who live in nursing facilities, assisted living residences, subacute centers, and homes for persons with DD.

AHCA/NCAL appreciates the opportunity to comment on the proposed rule revising the regulations implementing Medicaid home and community-based services waivers under Sec. 1915(c) of the Social Security Act. While we strongly support efforts to support and enhance person-centered care, we have deep concerns that the proposed definitions of community-based settings in this proposed rule could have devastating consequences for Medicaid beneficiaries by eliminating important choices of settings in which to receive long term care services and supports. We also have concerns that combining existing waiver target groups could jeopardize the health and safety of residents if done inappropriately.

One of the major challenges that our country faces is providing long term care for the large number of Baby Boomers that will need assistance in the future. About 13 percent of the American population is currently 65 or older with the number expected to grow to 20 percent (or 72 million people) by 2030. Many will be poor and need financial assistance as they age to cover the costs of care and services not provided by Medicare. Assisted living facilities are a large part of the answer to this challenge because they provide services in a homelike setting at a

much lower cost to Medicaid than services available in a nursing home. It's a double win. Residents live in a home-like environment that respects their independence, privacy and choice – and the system saves money. For many seniors, assisted living is the least expensive Medicaid alternative and also the most integrated into the community. Unfortunately, this proposed rule heads in the wrong direction and may end up costing Medicaid more money. We understand CMS' goal of ensuring community integration but this proposed rule is not the answer and we stand ready work with CMS to achieve this goal.

## **Executive Summary and Recommendations**

- The overly prescriptive definitions in the proposed rule conflict with Congressional intent in the legislation establishing home and community-based services (HCBS) waivers. Congress enacted HCBS waivers to provide long-term care services more cost effectively and to provide individuals who are elderly and disabled with more flexibility and choice of how to receive their care. Congress intended to allow states the greatest possible flexibility under HCBS waivers in establishing plans with respect to comprehensive assessments, plans of care development, and the provision of services. In contrast to Congressional intent, the proposed rule would reduce state flexibility, reduce beneficiary choice of care settings, and significantly raise costs.
- CMS' attempt in this proposed rule to define what constitutes an “integrated setting” appears to us to contradict the *Olmstead v. L.C.* decision. In *Olmstead*, the Supreme Court references the “integration regulation” in Title II of the Americans with Disabilities Act. This regulation requires a “public entity [to] administer... programs...in the most integrated setting appropriate to the needs of qualified individuals with disabilities.” Clearly, integration is a relative term and flexibility to meet the needs of all individuals is key. Yet the proposed rule is prescriptive and best suited for only a small segment of the HCBS population. The *Olmstead* decision also notes that for some individuals, the most integrated setting is an institution.
- AHCA/NCAL recommends that for purposes of this rule, CMS utilize the definition of HCBS currently in law while exploring a clarification that focuses on services available and provided by the setting, and ensures that processes, such as care planning, promote choice. For example, the care planning process could include, if appropriate, a discussion about all housing options available to the beneficiary receiving Medicaid services. This process, where choice rests with the beneficiary, could be repeated at regular intervals as appropriate, when the care plan is updated. In addition, the care plan could specify how the access to the larger community will be provided to a resident, including the transportation and support services needed.
- AHCA/NCAL recommends that CMS convene stakeholder meetings as it works on a definition of HCBS settings in order to reduce the potential for such a definition to result in negative, inadvertent consequences for Medicaid beneficiaries.
- We recommend that CMS ensure that any clarification of the definition of HCBS or settings does not eliminate important community-based options for Medicaid

beneficiaries, including assisted living communities, group homes for individuals with DD, and other settings.

- AHCA/NCAL recommends that in section 441.301 of the rule, the person centered planning process should include guardian/family members of individuals with profound disabilities and other beneficiaries who are not able to make care plan decisions for themselves. In these situations, guardians/family members should be allowed to make decisions that they feel are best for their loved one; and the services, supports, and goals associated with these decisions should be included in the person centered care plan.
- Although we strongly urge CMS not to impose additional requirements as described above, should CMS choose to move forward regardless of the consequences that may ensue, and impose additional requirements for assisted living settings, we suggest that CMS pursue a measured strategy by providing states with less-formal advice first, before issuing regulations. A more gradual approach would allow for further feedback from states and other stakeholders and help prevent unintended consequences that could have negative impacts on beneficiaries.

## Comments

### Congressional Intent

Congress enacted HCBS waivers as part of the Omnibus Budget and Reconciliation Act of 1981 (OBRA of 1981). Codified at Section 1915(c) of the Social Security Act,<sup>1</sup> this statutory provision authorizes the Secretary of the Department of Health and Human Services (HHS) to waive certain Medicaid requirements so that states may provide HCBS to Medicaid beneficiaries who otherwise would require institutional care.<sup>2</sup> According to the House Report accompanying OBRA of 1981, Congress enacted HCBS waivers for two reasons: (1) to provide long-term care services more cost effectively; and (2) to provide elderly and disabled individuals with more flexibility and choice of how to receive their care.<sup>3</sup> Congress intended to allow states “the greatest possible flexibility [under HCBS waivers] in establishing plans with respect to comprehensive assessments, plans of care development, and the provision of services.”<sup>4</sup>

The Secretary clearly stated in the originally implemented HCBS waivers regulation that “[t]he purpose of these regulations is to give States the maximum opportunity for innovation in furnishing noninstitutional services to beneficiaries, with a minimum of Federal regulation. . . . [W]e are not generally mandating how the States must establish or implement their community

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<sup>1</sup> 42 U.S.C. § 1396n(c).

<sup>2</sup> Institutional care refers to care provided by a hospital, skilled nursing facility (“SNF”), or intermediate care facility (“ICF” or “ICF/MR”). See 46 Fed. Reg. 48532 (Oct. 1, 1981).

<sup>3</sup> See generally H.R. Rep. No. 97-158 (1981).

<sup>4</sup> H.R. Rep. No. 97-158, at 319 (1981).

care programs.”<sup>5</sup> Following Congress’s edict to ensure flexibility for the states when developing and executing the HCBS waivers program, the Secretary clearly articulated her intent to allow for “maximum opportunity for innovation . . . with a minimum of Federal regulation.” The overly prescriptive and restrictive provisions contained in both the preamble of the proposed HCBS waivers rule and the actual proposed rule would undercut Congressional<sup>6</sup> and HHS’s previously articulated intent.

### Definition of HCBS Settings

CMS proposes “that HCBS settings: must be integrated in the community; must not be located in a building that is also a publicly or privately operated facility that provides institutional treatment or custodial care; must not be located in a building on the grounds of, or immediately adjacent to, a public institution; or, must not be a housing complex designed expressly around an individual's diagnosis or disability, as determined by the Secretary. In addition, we propose that the settings must not have qualities of an institution, as determined by the Secretary. Such qualities may include regimented meal and sleep times, limitations on visitors, lack of privacy and other attributes that limit individual's ability to engage freely in the community. We invite comments on this portion of the regulations.”

As we noted in comments on CMS’ recently published proposed rule implementing the Medicaid Community First Choice Option Proposed Rule, AHCA/NCAL understands and agrees with CMS’ desire to assure that HCBS settings are integrated into the community. However, we do not agree with CMS’ proposal that HCBS settings “must not be located in a building that is also a publicly or privately operated facility that provides institutional treatment or custodial care; must not be located in a building on the grounds of, or immediately adjacent to, a public institution; or, must not be a housing complex designed expressly around an individual's diagnosis or disability, as determined by the Secretary.” Our strong disagreement is based on the following:

1. Proximity of an HCBS setting to an institutional setting or disability-specific housing complex has little, if any, bearing on the degree of community integration experienced by HCBS residents. In fact, geographic separation should not matter if a residence is well integrated with the larger community through transportation services combined with in-house and off-site programming. Thus, we think a better way to clarify community integration would be to look at services available and provided by the setting and to ensure that processes, such as care planning, promote beneficiary choice.
2. Depending on how such language is interpreted, this proposal could exclude HCBS settings, including assisted living communities, continuing care retirement communities

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<sup>5</sup> 46 Fed. Reg. 48532 (1981).

<sup>6</sup> The House Report accompanying OBRA of 1981 stated, “There is considerable variation among the States with respect to the organization of health and social services with respect to sophistication in dealing with long-term care, and other pertinent factors. Recognizing this, the Committee intends to allow states the greatest possible flexibility in establishing plans with respect to comprehensive assessments, plans of care development, and the provision of services, with certain exceptions outlined above which are intended to prevent conflict-of-interest.” H.R. Rep. No. 97-158, at 319 (1981).

(CCRCs), and residences for people with DD, that operate in proximity to or in the same building as institutional facilities, on a campus or otherwise, as well as assisted living units in CCRCs. This could create serious hardships for beneficiaries. For example, it is reasonable for a spouse who receives HCBS to want to live close to a nursing facility in which the other spouse resides in order to make visiting together easier. Likewise, elderly parents of an adult child with DD might be delighted to learn of a HCBS setting located adjacent to a disability-specific senior housing complex that would thus allow the elderly parents to be near their adult child while enjoying the benefits of senior housing. Many assisted living communities that are co-located on campuses with nursing facilities offer entirely different environments to residents. In addition, the proximity of rehabilitation services may allow assisted living residents to stay in their homes as they recover from surgery instead of having to move to an institutional setting. Some assisted living communities have rehabilitation facilities in the same buildings as residential units.

3. It is important to understand that seniors frequently become isolated from the community when living in their own homes. Lack of transportation, loss of family members, and other factors can lead to social isolation that assisted living communities are designed to address. Such individuals frequently re-connect with their communities upon moving into assisted living.
4. Depending on interpretation, the requirement that a HCBS setting “must not be a housing complex designed expressly around an individual’s diagnosis or disability” could exclude important options for Medicaid beneficiaries including assisted living dementia/Alzheimer’s units, group homes for people with DD, and residential care centers and units specializing in care for traumatic brain injuries, multiple sclerosis, Parkinson’s disease, and other specific injuries and conditions related to diagnoses or disabilities. About 40 percent of assisted living residents have Alzheimer’s disease or related dementias, for example, and many assisted living communities specialize in their care. Indeed, most states place additional requirements on facilities that hold themselves out as providers of care for people with Alzheimer’s, which further distinguishes them as specialized toward a diagnosis.
5. The use of the term “custodial care” as one of the exclusionary characteristics also is troublesome. Historically in health care, custodial care means (or is commonly interpreted as meaning) assistance with activities of daily living (ADLs) and instrumental activities of daily living (IADLs). We doubt this is the intent of CMS, because using this term could be construed as meaning that any setting that provides the care and services that Medicaid waivers are designed to pay for (assistance with ADLs and IADLs) would potentially be excluded as an HCBS setting. Therefore, the term “custodial care” should be eliminated.

The definitions above could easily eliminate more than half of the assisted living settings that currently provide services to about 131,000 Medicaid beneficiaries nationwide (by excluding settings located on or near institutional settings and housing complexes designed around specific diagnoses or disabilities). Clearly, these definitions should not be included in the final rule.

AHCA/NCAL agrees with CMS on the next part of the definition, subject to reasonable availability of staff and resources: “...we propose that the settings must not have qualities of an

institution...Such qualities may include regimented meal and sleep times, limitations on visitors, lack of privacy and other attributes that limit individual's ability to engage freely in the community." Regardless of where care is provided in the community, Medicaid beneficiaries should not be subjected to regimented meal and sleep times and unreasonable limitations on visitors and they should be able to freely engage with others both within the residential setting and with the community at large. In assisted living and other settings, while meals are typically served at set ranges of times, snacks and other food should be available to residents at all times, subject to reasonable staff availability if assistance is needed. Beneficiaries have the right to privacy, subject to the practical limitations of sharing a unit or room with another person if a shared unit is the living situation they have chosen within the range of options available to them under a state's Medicaid program.

As we stated in recent comments on the Community First Choice Option proposed rule, excluding assisted living from HCBS is particularly problematic because it occupies an important middle ground in the long term services and supports spectrum between nursing facility care and receiving care in one's home. As state policymakers seek cost-effective alternatives to providing services in nursing facilities, assisted living settings "provide oversight and access to services that are difficult to schedule for people living in their own home," according to a report by Robert Mollica ("State Medicaid Reimbursement Policies and Practices in Assisted Living," AHCA/NCAL, 2009).

Assisted living communities typically emphasize person-centered care, and provide care while promoting resident independence, dignity, privacy, and choice. The assisted living profession continues to promote these values and put them into practice. As part of this ongoing effort, the Center for Excellence in Assisted Living (CEAL), whose members include consumer groups, providers, and long term care professionals, published a white paper in June 2010 entitled "Person-Centered Care in Assisted Living: An Informational Guide." (The white paper is available at: <http://www.theceal.org/assets/whitepapers/Person-Centered%20Care%20in%20Assisted%20Living.pdf>.)

In 2007, 38,373 state-licensed assisted living/residential care facilities with 974,585 units/beds were providing care to their residents ("Residential Care and Assisted Living Compendium 2007," Robert Mollica & Kristin Sims-Kastelein, U.S. Department of Health and Human Services, 2007). In 2009, about 131,000 low-income frail elderly Americans were receiving services in assisted living/residential care communities under Medicaid state plans and various types of waivers. ("State Medicaid Reimbursement Policies and Practices in Assisted Living," Robert Mollica, AHCA/NCAL.) Because all states license or certify assisted living providers, Medicaid beneficiaries living in these communities receive services with greater government oversight than those receiving services in freestanding homes. In recent years, as residents' levels of disability and the proportion of residents with Alzheimer's and other related diseases have increased, states have responded by increasing regulatory standards applying to assisted living communities. (See "Assisted Living State Regulatory Review 2009," NCAL.) AHCA/NCAL believes that any definition of HCBS settings applied across the Medicaid program should include assisted living communities, as well as group homes and noninstitutional settings providing services for individuals with DD.

### *Medicaid Coverage for Assisted Living Residents Needs To Be Expanded, Not Diminished*

In part due to the fact that Medicaid cannot pay for room and board in community-based settings, the extent of Medicaid coverage in assisted living already is much more limited than Medicaid coverage for nursing homes and other long term care options in the community. In 2010, for example, of the \$123 billion in Medicaid spending on long term care, \$52 billion was paid to nursing facilities, \$13 billion to intermediate care facilities, and \$59 billion for HCBS. Only an estimated \$2.5 billion of the Medicaid spending on HCBS went toward services provided in assisted living communities. During a March 15, 2011 roundtable discussion convened by the U.S. Senate Special Committee on Aging that explored issues relating to assisted living, the only point of consensus among the diverse group of panelists was that demand for “affordable assisted living” was far greater than supply, and that the nation needs to expand the availability of affordable assisted living for Medicaid beneficiaries and other low-income groups. Rather than expanding this option, the proposed rule would dramatically constrain the supply of assisted living available to Medicaid beneficiaries.

A recent U.S. Department of Health and Human Services study tracking how people used long term care (LTC) insurance benefits can serve as a “natural experiment” and provides insight into where people choose to receive care when they have financing. The study found that a major impact of having LTC insurance is enabling claimants to exercise preferences for alternatives to nursing home care and it also found that they frequently chose assisted living over other options including their own homes. Titled “Private Longterm Care Insurance: Value to Claimants and Implications for Long-term Care Financing,” the study was recently published online by the Gerontological Society of America. (See: <http://gerontologist.oxfordjournals.org/content/early/2010/03/18/geront.gnq021>.) Researchers took a random sample from 10 LTC insurance companies of 1,474 individuals receiving benefits who were interviewed in-person by a trained nurse and then by telephone every four months for a 28-month period. About 96% of those filing claims were approved for payment. At baseline, 37% received home care, 23% assisted living, 14% were in a nursing home, and 26% had not yet begun receiving care. Researchers found that “despite the oft-cited preferences of the elderly individuals to remain at home with paid services if required, LTCI claimants frequently chose assisted living rather than paid home care or nursing home care.” The study found that the most disabled claimants resided in nursing homes and the least disabled in assisted living settings. However, nursing home and assisted living residents studied had comparable levels of cognitive impairment (64 % and 63 %, respectively), significantly greater than paid home care users (28 %). The overwhelming majority were satisfied with their service providers, including nursing home providers, although nursing home residents were less highly satisfied than assisted living residents or paid home care users.

### *Person-Centered Planning a Hallmark in Homes for People with Developmental Disabilities*

Person-centered care planning generally is a hallmark of homes for persons with DD, where individualized care plans reflect what is important to the individual and important for their health and welfare. Through an interdisciplinary team process that includes the individual or their agent, the individual’s strengths, needs, preferences, and desired outcomes are identified and a plan of care is built.

Individuals with DD who reside in group homes participate in the community through volunteer work, social events, running errands, etc., and these activities can be incorporated into their personal care plan. In addition, many of these individuals work for local businesses and enrich their community's culture and economy. To participate in these activities, they often use the same transportation supports used by individuals who reside in private homes. It is clear that "choice" is abundant in the lives of individuals with DD who reside in group homes, and their lifestyle largely mirrors that of individuals who reside in private homes; the setting is the only difference. Therefore, applying restrictions on the definition of HCBS settings to individuals with DD in group homes clearly is not appropriate.

### *Persons with DD May Require Legal Guardians and Family Member Assistance in Decision Making*

Individuals with DD who reside in HCBS settings often have as profound cognitive disabilities as individuals who reside in ICFs/MR; thus, they may *completely* rely on the decision making support of legal guardians or family members. AHCA/NCAL finds it inappropriate that, in the proposed rule, CMS does not discuss the importance of guardians/family members in the care planning process, especially regarding the most important aspect of the care plan—the determination of what defines an "integrated" setting for the individual and the subsequent choice of residence.

### *AHCA/NCAL Recommends that CMS Reconsider its Proposed Definition*

Ultimately, parts of CMS' proposed definition of HCBS settings appear to us to be discriminatory and we believe they would harm America's seniors and citizens with DD who have limited resources. Therefore, we strongly urge CMS to reconsider the definition. For purposes of this rule, we recommend that CMS utilize the definition currently in law and explore a clarification that relies on services available and provided by the setting, and ensure that processes, such as care planning, promote choice. For example, the care planning process could include, if appropriate, a discussion about all options available to the beneficiary for receiving housing and Medicaid services. This process, where choice rests with the beneficiary or legal guardian, could be repeated at regular intervals when appropriate, as the care plan is updated. The care plan could specify how access to the larger community will be provided to a resident, including the transportation and support services needed. Ultimately, individuals' choice of residence is a major part of the "personally defined outcomes" that are established in the care plan. Unfortunately, CMS' proposed definitions of what constitutes an integrated setting could have the unintended consequence of decreasing individuals' choice of residence if Medicaid funding for a particular residence, due to its arbitrary location, is no longer available.

### Proposed Conditions for Inclusion of Assisted Living Settings

In the preamble, but notably not in the proposed regulatory language, CMS states: "For the purposes of this regulation, we note that ALS (Assisted Living Settings) for persons who are older, without regard to disability, would not be excluded from home and community-based settings when the following conditions are met..." and goes on to list eight conditions.

As stated above, we do not think that assisted living and other major options in which Medicaid beneficiaries receive long term services and supports should be singled out and potentially excluded by means of additional requirements. We also have concerns that the list of requirements will make it difficult for states and providers to maintain current levels of access to assisted living settings for Medicaid beneficiaries. Put simply, we believe these requirements would unnecessarily force tens of thousands of assisted living residents into nursing homes. It is important to remember that people who move into assisted living do so after they have determined that receiving services at home can no longer meet their needs.

However, if CMS decides to proceed and impose such conditions regardless of the potential consequences, it would be prudent to provide states with less formal directions before including such conditions in regulatory language, while at the same time soliciting feedback from states and a broad range of stakeholder groups. Such a measured course of action could provide the opportunity to minimize unintended consequences before more formal guidance or a final rule is issued.

Though we strongly urge CMS to strike this section, our comments on particular conditions for ALSs to qualify are as follows:

*“Individual has a lease.”* Comment: Requiring that an individual have a lease is problematic for two main reasons: (1) this requirement would implicate a state’s landlord-tenant laws; and (2) this requirement could run contrary to some state’s assisted living facility licensure rules.

First, the condition that an individual receiving HCBS in an assisted living setting have a lease with the assisted living facility would implicate landlord-tenant laws, which differ by state. The implication of landlord-tenant laws would result in another layer of statutory and regulatory requirements to which assisted living facilities must adhere. The application of the statutory and regulatory guidelines associated with landlord-tenant laws would result in a host of cumbersome compliance issues for assisted living facilities and would create barriers for Medicaid beneficiaries, as well. For example, it is possible that an assisted living facility resident may not have the capacity to enter into a legal agreement, such as a lease. Thus, the assisted living facility would face the burden of ensuring that it had legally enacted a lease with any incapacitated residents.

Further, in some cases, landlord-tenant laws could make the procedure for discharge due to an individual’s non-payment of room and board challenging. This, in turn, would discourage many providers from participating in Medicaid and reduce access for beneficiaries. For example, in New Jersey, there are eighteen different causes for eviction, including non-payment of rent.<sup>7</sup> In order to evict an individual, however, a New Jersey landlord must follow each of the steps in the eviction process, and a judge must be convinced that there is cause for eviction under New Jersey’s Anti-Eviction Act. A tenant can defeat an eviction complaint by showing that the steps in the eviction process were not correctly followed, or that cause for eviction does not exist, or that the landlord has not met other duties under the law.<sup>8</sup>

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<sup>7</sup> N.J. Stat. Ann. § 2A:18-61.1

<sup>8</sup> N.J. Stat. Ann. § 2A:18-59.1.

In addition to the myriad state requirements that an assisted living facility would be required to meet under states' landlord-tenant laws, this condition contradicts certain states' licensure rules for assisted living facilities. For example, in some states, the lease of a portion of the facility constitutes a change of ownership; therefore, having individual "leases" would be treated as multiple changes of ownership and would be inconsistent with the actual ownership of the assisted living facility.<sup>9</sup>

As another example, certain states require that an assisted living community have a "resident agreement" with residents.<sup>10</sup> The "resident agreement" combines apartment rental and care services into one agreement, thereby disallowing a lease as defined under state law.<sup>11</sup>

While some states use leases for Medicaid residents, most use residency agreements or other forms of contracts. Leases, residency agreements, or other forms of contractual agreements need to allow transfer to another setting if a resident requires a level of care that either is not allowed under state law in an ALS or that a particular provider is not capable of providing, given limitations posed by its staffing, physical plant, and other characteristics. To prevent uneven or unfair application of such move-out decisions, there should be a mechanism for timely appeal of decisions. We strongly believe that states should be able to use residency agreements or other forms of agreements as well as leases.

*"Setting is an apartment with individual living, sleeping, bathing and cooking areas, and individuals can choose whether to share a living arrangement and with whom."* Comment: Requiring apartments will exclude ALSs in many states as would requiring individual living, sleeping, bathing, and cooking areas. Even innovative design models such as Greenhouse cannot meet these requirements.

Over the years, the primary factors constraining access to Medicaid coverage for assisted living have been economic. And this is even more the case today as many states facing huge budget shortfalls contemplate cuts in programs serving low-income Americans. Under the Medicaid program, because assisted living is currently considered a HCBS setting, Medicaid does not pay the cost of housing, utilities, and food. These gaps in Medicaid financing mean that states must consider a number of design decisions to finance costs that Medicaid does not cover. Of states providing Medicaid coverage in ALSs, only 23 require apartment style units. Forty states allow units to be shared and 24 states allow sharing by choice of the residents (Mollica, 2009).

Requiring cooking areas is problematic for residents with Alzheimer's disease and other cognitive impairments. To prevent injuries and accidents, it is not prudent for many people with Alzheimer's disease and other dementias to have working stove tops under their control. Some providers may not be able to find insurance that allows such individuals to have rooms with a stovetop or may not be able to meet state health and safety regulations designed to protect this population.

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<sup>9</sup> See e.g. 175 Neb. Admin. Code § 4-004.04; Kan. Admin. Regs. § 26-39-101.

<sup>10</sup> See e.g. Ohio Admin. Code § 3701:17-57.

<sup>11</sup> See e.g. *id.*

This proposed condition provides no guidance on what consists of an individual “living” and “cooking” area. Without that guidance, it is difficult to determine what sort of settings might be excluded by this condition. Even so, this proposed condition, specifically the requirement that there be individual “living” and “cooking” areas, is overly restrictive and likely would exclude a number of assisted living and other residential settings. For example, this proposed condition would exclude assisted living facilities developed under the Greenhouse Project, where “[t]he elders’ rooms allow ample sunlight and are clustered around a shared living room with a hearth, an open kitchen and dining area.”<sup>12</sup> The shared living room and kitchen of a facility developed pursuant to the Greenhouse Project model would result in the disqualification of this assisted living facility if it was deemed to not be “integrated in the community” under the proposed 42 C.F.R. § 441.301(b)(1)(iv).

*“Individuals have lockable access to and egress from their own apartments.”*  
Comment: For residents with Alzheimer’s or other dementias, staff often need to have access as well. Perhaps a more reasonable standard for people with Alzheimer’s disease would be “closable” doors. Fire safety standards for institutions like nursing homes are based on the assumption of high staffing and having doors open at night to facilitate evacuation, while fire safety standards for residential settings like assisted living assume relatively lower staffing, closed doors (creating privacy), smoke detectors in units, and thicker separation walls between units.

*“Individuals are free to receive visitors and leave the setting at times and for durations of their own choosing.”* Comment: We generally agree with the intent, subject to reasonable interpretation when considering residents with dementia. Also, visiting hours and security could be an issue in some states where residents are permitted to share units; in such instances, the lease or residency agreements might include a statement of mutual agreement by residents sharing a unit on how these issues will be handled when receiving visitors.

*“Aging in place, or allowing individuals to remain where they live as they age and/or support needs change, must be a common practice of the ALS.”* Comment: As noted above, there are upper limits on the types and level of services that may be provided in an ALS determined under state law and also by the assisted living provider as a matter of policy or functional capacity. For example, most states do not allow 24-hour skilled nursing care to be provided in an ALS for extended periods of time. Also, this condition is worded so vaguely that it may be misleading and unenforceable. For example, what does “common practice” mean? It is also important to note that the meaning of “aging in place” is not specified.

*“Leases may not reserve the right to assign apartments or change apartment assignments.”* Comment: This requirement could severely limit the supply of assisted living to Medicaid beneficiaries if applied before residents begin receiving Medicaid services. Because Medicaid does not pay for room and board, which represents about 40-50% of total assisted living costs, providers often reserve the right to move a resident to a smaller room or apartment should he or she convert from paying with private funds to Medicaid. If providers cannot do this, they will be far less likely to accommodate Medicaid beneficiaries in single-occupancy units or

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<sup>12</sup> <http://www.thegreenhouseproject.org/about>.

to be able to provide Medicaid services at all. In New Jersey, which mandates that 10% of units be set aside for Medicaid eligible residents, the right to switch a resident to a smaller unit is often stated in the residency agreement.

An alternative policy would be to promote disclosure of a community's policy regarding housing options for residents who exhaust private funds and convert to Medicaid; several states already require such disclosure.

*“Access to the greater community is easily facilitated based on the individual's needs and preferences.”* Comment: We agree, subject to reasonable availability of staff if assistance is needed when going out in the larger community.

*“An individual's compliance with their person-centered plan (in the event that the individual has shared his/her plan or the landlord is also the provider of services) is not in and of itself a condition of the lease.”* Comment: This could pose serious problems for providers in complying with state regulations and could increase the risk of lawsuits and related costs. Because assisted living combines housing with services, in most states the landlord could be the same organization as that providing the care. While it is reasonable to accommodate some deviations by the resident from the person-centered care plan, there are limits, especially when non-compliance puts the resident, other residents, or staff at risk of injury or death. Qualification for Medicaid reimbursement should not be disallowed where state health and safety requirements require remedial actions including transfer from the ALS, if necessary. In such instances, there should be avenues of appeal for either party.

### Regulatory Impact and Impact on Beneficiaries' Lives

We disagree with the statement that this proposed rule does not reach the economic threshold of a major rule (i.e., that economically significant effects would not be \$100 million or more). The proposed definitions of HCBS and assisted living settings could easily increase costs to states by that amount by disqualifying thousands of HCBS settings, thereby causing most of the Medicaid beneficiaries in those settings to move to much more expensive institutional settings. The economic impact of such transfers, however, will pale in contrast to the impact on these people's lives, both in terms of their psycho-social well-being and health. Should CMS decide to implement these exclusionary definitions (which AHCA/NCAL strongly opposes), we recommend that CMS grandfather current beneficiaries and allow them to continue to reside in settings that become disqualified as HCBS settings, if that is the beneficiaries' choice, and that CMS continue to allow Medicaid payment in those settings for those individuals. Absent such grandfathering, any final rule implementing such definitions should also include a detailed plan, specifying sources of funding, for relocating beneficiaries living in disqualified settings in the least disruptive way possible.

### Person-Centered Planning Process

We agree with the emphasis placed on the person-centered planning process in the proposed rule and agree that the person-centered plan should “include individually identified goals, which may include, as desired by the individual, items related to relationships, community living, community participation,” and other specified factors. A care plan that includes these elements,

reviewed and updated to reflect changes in beneficiary needs and preferences at regular intervals, should be the vehicle for ensuring community integration. A solid resident-centered plan ensuring access and integration to the larger community, as well as choice of residential location, can be developed and put to work in a setting that is in the same building as an institution or next to one. Often, as we noted above, assisted living residents have greater access to the larger community than they previously had in single-family homes, and individuals with DD can thrive in group homes that are near institutions. We strongly urge CMS to eliminate the definitions of community and assisted living settings that would restrict choice of settings and instead use care planning process to ensure community integration.

### Removing Regulatory Barriers to Combining Target Populations

As we stated in comments on the advance notice of proposed rulemaking in 2009, AHCA/NCAL has two major concerns about combining target waiver populations: 1) the possible loss of access to Medicaid for some populations and 2) an increased risk of inappropriate or unsafe placement. We agree that this policy change would give states more flexibility in designing HCBS waivers and we are sympathetic to the states' needs for administrative relief from operating and managing multiple waiver programs. However, we suggest that CMS either identify other means to provide flexibility and administrative relief or identify safeguards to protect beneficiaries from the risk of loss of access and/or inappropriate or unsafe placement.

#### *Possible Loss of Access to Services for Some Populations*

Combining different target populations under a single waiver could benefit some target populations but disadvantage others, especially in a climate of fiscal restraint. This could occur if a state made a certain amount of resources available to the combined target populations and some populations were better positioned, politically and otherwise, to gain access to the resources or slots available. The low-income, frail elderly, for example, often do not have robust political representation or champions. The proposed rule acknowledges this concern by stating CMS' "expectations that each individual within the waiver, regardless of target group, has equal access to the services necessary to meet their unique needs." While we appreciate CMS acknowledgement of the issue, we remain concerned that CMS will be unable to enforce this expectation.

#### *Increased Risk of Inappropriate Placement, Physical Harm*

Combining target groups under waivers may increase the likelihood of a "one-size-fits-all" approach of providing care and increase the risk of placement in inappropriate settings or with inappropriate cohabitants. In many states, different state agencies now administer programs for different waiver target groups, each with its own network of providers specialized in the care needs of the particular population served. How these agencies would reconfigure the provision of services under a combined waiver is an open question along with whether there would be a greater chance that populations would be mixed inappropriately. One concern is that housing frail elderly people or vulnerable individuals with DD alongside younger persons with mental illnesses could expose them to unnecessary risk or harm. In fact, the physical vulnerability of the frail elderly is one reason that some states do not allow residents of assisted living facilities to be below a certain age. Mixing individuals with mental illness with frail elderly is of increasing

concern to assisted living providers in terms of their ability to provide safe, high-quality care. That being said, AHCA/NCAL fully acknowledges and supports the need for all target populations to receive the services they require to live as happily and safely as possible.

If CMS were to facilitate the combination of waiver populations as a national policy, safeguards should be built into the application process, operations, and supervision of the waiver to ensure that beneficiaries are placed in appropriate settings and that all beneficiaries are safe, including from each other.

### Conclusion

Ultimately, CMS' proposed definition of HCBS settings appears to us to be discriminatory and we believe it would harm America's seniors and citizens with DD with limited resources. Therefore, we strongly urge CMS to reconsider the definition and eliminate provisions that inappropriately restrict HCBS settings. For purposes of this rule, we recommend that CMS utilize the definition currently in law and explore a clarification that relies on services available and provided by the setting, and ensure that processes, such as care planning, promote choice.

Under the logic of the landmark *Olmstead* decision, depriving Medicaid beneficiaries of a major type of housing with services – such as assisted living – would be the opposite of a reasonable accommodation or making sure they are integrated into the larger community, especially for those seniors who prefer to live in assisted living and those for whom assisted living is the least institutional option available based on their clinical and personal care needs. Denying assisted living residents Medicaid funding because their community happens to be on or near a campus with an institutional facility or cannot meet certain tests in most instances will force these people to move to an institutional setting. This also applies to individuals with DD who reside in group homes that happen to be near institutions. The location of these homes does not affect the actual integration experienced by residents. Denying Medicaid funding to individuals who choose, and need, to live in group homes simply due to the home's location could force individuals into institutions against their wishes. This proposed rule could have devastating effects by limiting Medicaid beneficiaries' access to major community-based options including assisted living, CCRCs, and residential settings for individuals with DD. Instead of such regulations, we urge CMS to work with the Department of Housing & Urban Development to expand access to these settings by finding ways to cover room and board costs for Medicaid beneficiaries living in these settings, such as the housing vouchers recently made available to the younger disabled.

As we have noted in previous comments, defining or clarifying HCBS settings is a complex undertaking and should be done in a way that does not inadvertently reduce viable options for these vulnerable populations. Assisted living and other congregate community-based settings are important options for seniors and people with disabilities. Unfortunately, this proposed rule heads in the wrong direction by eliminating many of these options and may end up costing Medicaid more money. We understand concerns that CMS has about ensuing beneficiaries are integrated into the larger community and will continue to offer our feedback and assistance as CMS deliberates this complex issue.

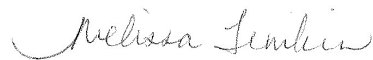
Sincerely,



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