



Centers for Medicare & Medicaid Services
Department of Health and Human Services
Attention: CMS- 2296-P
Mail Stop C4-26-05
7500 Security Boulevard
Baltimore, MD 21244-1850

Dear Dr. Berwick,

June 10, 2011

RE: 42 CFR Part 441
File Code CMS -22296-P
RIN 0938-AP61
Federal Register April 15, 2011 Proposed Rule

The Assisted Living Federation of America (ALFA) appreciates the opportunity to comment on the above referenced proposed regulation that would revise the rules implementing Medicaid Home and Community Based Services (HCBS) waivers under section 1915(c) of the Social Security Act. ALFA is the largest national association exclusively dedicated to professionally-managed senior living communities and the residents and families they serve. Since our formation in 1990, ALFA has advocated for choice, accessibility, dignity and quality of life for all seniors wherever they may live and wherever they may call home. As your records will indicate, ALFA commented on the earlier version of these regulations during the Advanced Notice of Proposed Rulemaking (ANPRM 74 FR 29453) in August 2009. Some of our comments presented at that time were incorporated into the April 15, 2011 proposed rule. We thank CMS for responding to our comments. *However, we still have concerns with the proposed rule.* Some components of the proposed rule could have the devastating effect of denying the opportunity for frail seniors to participate in the HCBS waiver program. This would be a departure from current practice that allows over 131,000 elderly in 48 states to participate in the HCBS waiver program.

A recurring theme throughout our comments is that the proposed rule NOT focus on the physical setting as the determination for a home and community-based environment but rather focus on the implementation of person-centered domains and attributes, i.e., the needs an individual may have and the choices they may want to make for themselves. For example, we strongly object to rules that define a home and community-based setting based on the size of the apartment or the number of people who may live in an assisted living community. Further, individuals must have the choice to live where they want to live. The core values of respect, dignity, privacy, independence, autonomy and choice are the foundation for person-centered planning. When operationalized, each individual is treated as a unique person with inherent value. Our belief is that this is the true measure of a home and community-based setting.

I. Background on HCBS Settings

Before commenting on the actual proposed rule, ALFA would like to address the background section on HCBS Settings contained in the proposal that singles out eight conditions that must be met by assisted living communities to be considered a home and community-based option under the 1915(c) waiver program. CMS states that many comments were received during the ANPRM to allow older people to choose to live together in assisted living communities and “urged CMS to allow them to exercise this preference and receive waiver services.” The background continues, “Similarly some persons who are older may desire to live in retirement communities, such as continuing care retirement communities. As a result, in accordance with a person-centered plan, we will allow such settings to be permissible under the section 1915 (c) HCBS program for older persons under certain circumstance, which are noted below.”

ALFA has four concerns with this background section.

Our first concern is that if the proposed conditions are implemented as proposed, virtually all licensed assisted living communities would be prohibited from participating in the 1915 (c) Home and Community – Based waiver program. This would mean that frail seniors would not, as required by the Olmstead Act, be entitled to live in the least restrictive and most community-integrated setting possible. They would be forced to live in a far more costly institutional facility such as a nursing home.

Our second concern is that assisted living is one of many congregate settings where waiver residents live and receive services. Therefore, we do NOT support assisted living being singled out or treated differently than other congregate living settings.

Our third concern is that the eight conditions are extremely prescriptive. Flexibility is important so that individual choices and needs can continue to be met today and in the future. We have a saying that “the best assisted living has yet to be invented.” The proposed conditions inhibit the development of innovative living arrangements.

Our fourth concern is that a portion of the language mirrors the qualified residence language in the Money Follows the Person program. That language all but eliminated the opportunity for people who choose assisted living to participate in that program. We do not want that unintended consequence to be repeated.

Below are our comments and our recommendations on the preamble and current proposed rules:

The preamble states: “For the purposes of this regulation, we note that ALS 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...”

1. Individual has a lease

Comments: ALFA finds this language not in accordance with usual practice for individuals living in congregate settings such as assisted living. In congregate settings that accommodate

individuals receiving housing and services, the agreement most commonly used is a residency agreement that includes room and board with the service package in one document. The residency agreement includes many properties of a lease, however if the word “lease” is used exclusively, it will virtually eliminate every assisted living provider from participating in the waiver program.

Recommendation: Substitute the following language- “The individual or responsible party has a residency agreement, lease or other form of written agreement that includes the ability to appeal move out decisions to an external party in accordance with state law and includes consideration of making reasonable accommodations. The process for resolving disputes must occur within 30 days and exceptions must include non payment of fees for room and board and individuals who are a danger to themselves and others to be moved immediately for their safety and the safety of others around them.”

2. Setting is an apartment with individual living, sleeping, bathing and cooking areas and individuals can choose to share a living arrangement and with whom.

Comments: ALFA opposes the need for this overly prescriptive language because it implies that the size of the apartment or the number of rooms is in some way a condition to be a home and community- based setting. As stated throughout our comments, it is person-centered planning and services that are the heart of what CMS should use to define a home and community based setting—not the physical size or configuration. While ALFA completely agrees with CMS that the core principles of privacy, dignity and choice should be the foundation of a home and community- based setting, we know that the physical surroundings are neither a guarantee nor condition for the implementation of those principles. For example, a room may have a cooking area but if a resident does not know how to cook or does not want to cook, cooking areas will not meet their needs.

While we understand that some people believe a multi-room apartment with a private bedroom is a condition of privacy, the HCBS waiver does not pay for room and board, only services. The debate is not about the merits of a private bedroom but rather adequate reimbursement to pay for the private room. CMS must take into account the current fiscal situation where inadequate reimbursement is a reality and many providers participating in the waiver program do have two residents share a bedroom. Again, an unintended consequence of requiring a private bedroom would eliminate most assisted living providers from participating in the waiver program. Furthermore, many middle income seniors who have saved their entire lives to live in a senior living community have chosen to downsize to smaller suites or chosen to share a bedroom to make this option more affordable. We do not support bedrooms that have more than two people in a shared room but semi- private rooms must be allowed. Last but not least, there are ways to maximize privacy in a shared living situation and we completely support an assurance that privacy will be respected regardless of the setting.

Recommendation: Substitute the following language –“In congregate settings with individuals receiving services, a process shall exist for including initial and ongoing meaningful input from individuals in organizational decisions affecting choice in their living arrangements and daily living activities such as eating, bathing and sleeping.

Individuals must have the opportunity to furnish and decorate their personal living areas, and be assured meaningful privacy in their lives regardless of living in a private or semi private bedroom.”

3. Individuals have lockable access to and egress from their own apartments.

Comments: ALFA agrees with this statement with the exception of when it is not in the best interest of the individual. For example someone who is memory-impaired actually gains more independence and freedom from having their door unlocked so they can come and go as they please vs. having a lock they cannot negotiate on their own.

Recommendation: Add the following language- “...unless an exception is made in the interest of the individual and noted on the person- centered plan. However, even in such cases, all efforts to ensure privacy must be made.”

4. Individuals are free to receive visitors and leave the setting at times and for durations of their own choosing.

Recommendation: ALFA supports this statement unless the person- centered plan indicates otherwise, such as may be in the case for memory-impaired individuals.

5. 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 ALS.

Recommendation: ALFA supports this statement. Many states are adopting regulatory language that allows for aging in place provided the individual, their family and physician, and the service provider all agree the individuals needs can be met. ALFA supports this philosophy.

6. Leases may not reserve the right to assign apartments or change apartments.

Comments: We do not agree. There are valid reasons for the assisted living community to move an individual to another apartment. For example, if someone becomes memory-impaired over time, they may need to be moved to a part of the congregate setting that offers more care. Moving that person would allow them to have more freedom of choice and dignity. Another consideration might be the need for an individual to move to a smaller or shared bedroom when they can no longer afford a private bedroom and become Medicaid eligible.

Recommendation: ALFA recommends this statement would be covered under our recommended language in #2 as follows. “In congregate settings with individuals receiving services, a process shall exist for including initial and ongoing meaningful input from individuals in organizational decisions affecting choice in their living arrangements and daily living activities such as eating, bathing and sleeping.”

7. Access to the greater community is easily facilitated based on the individual’s needs and preferences.

Comments: ALFA completely agrees and believes integrating the outside community into the congregate setting and allowing the individuals in the congregate setting to participate in the community at large is very important. Not to be overlooked, however, is the community life that is also available within the congregate setting. ALFA members operate assisted living communities--not facilities. Indeed one of the main reasons individuals choose to move from their family home is for the companionship, activities, and community life available in a congregate setting.

Last but not least is the recognition that opportunities for community engagement have changed over the last decade. In a recent White House press release, "Older Americans: Connecting the Community", the President reiterated that "millions of seniors are making a significant difference in society strengthening our communities through their service." The President was also very thoughtful in recognizing that "this theme highlights how technology, including social media and assistive devices can help adults remain engaged in their communities and connect to friends and family who may live far away".

Recommendation: ALFA encourages the interpretation of this condition support individuals participating in activities and communities that they choose, including the community within the congregate setting, in the larger outside community and through virtual/internet opportunities.

8. An individual's compliance with their person- centered plan is not in and of itself a condition of the lease.

Comments: ALFA believes individuals living in congregate settings receiving services have the right to make their own choices. We strongly support individual control and choice in matters such as when and what to eat, routines of daily living, and health care decisions. However, there are cases when someone's non compliance with their person-centered plan could impact the safety of the other individuals residing in the congregate setting. For example, a care plan may state that an individual only smoke in an outdoor area but they may put others at risk by smoking in their own room. While we believe people have the right to make their own choices, the exception would be when that choice could compromise the safety and welfare of others.

Recommendation: "The individual's residency agreement, lease, or other form of written contract shall address consequences for actions resulting from non-compliance with the person- centered plan."

II. Provisions of the Proposed Regulation

Part 441 – Services: Requirements and Limits Applicable to Specific Services
Subpart G – Home and Community Based Services: Waiver Requirements
Section 441.301 Contents of Request of a Waiver:

(A) Person –Centered Planning Process and (B) Person – Centered Plan

A. Person- Centered Planning Process: In this section CMS conveys expectations regarding the person- centered planning process in items (1) through (7).

ALFA completely supports this section.

B. The Person-Centered Plan: In this section CMS conveys expectations in items (1) through (12) for a person –centered plan.

ALFA completely supports this section.

Comments: ALFA supports the person–centered planning process and plan and believes it will alleviate our great concern that consumer advocates, regulators and others, while seemingly well meaning, actually impose their wishes and desires on seniors. This pervasive display of ageism must not be tolerated. Ageism can work in a number of ways. One is the assumption by well meaning persons that all seniors need to do certain things. For example eat three healthy meals a day and get daily exercise. Another form of ageism is to believe seniors do not have the opportunity to make bad decisions such as refuse to take medications, be non compliant with dietary restrictions, walk without a cane etc. Another form of ageism is assuming that seniors want to do things that younger people want to do such as engage in volunteer work, cook, and be responsible for directing their own care. We must not make any assumptions about how people want to live their own lives. While difficult at times, a true person –centered planning process will give seniors their own voice.

Section 443.301 (iv)

ALFA supports Section (iv) that states a home and community based setting is integrated into the community if it provides meaningful access to the community and community activities and choice about providers, individuals with whom to interact and daily life activities.

Section 443. 301 (iv) Paragraph A

ALFA opposes Paragraph A that states a setting is not integrated into the community and cannot be considered a home and community based setting if it is located in or near a building that is part of a larger campus or provides institutional care, or is a housing complex designed around an individual’s diagnosis or disability. ALFA also opposes the use of the term “custodial care” in this paragraph.

Comments: Consumers have a right to choose where to live. As previously stated in these comments, the “sticks and bricks” do not make a setting home and community based. Some consumers want to live in continuing care retirement communities and some want to live in a building that offers independent living, skilled care, and assisted living. Consumers with these preferences should not be penalized. It is also important to recognize that in some parts of the country this may be the only option available. Again, it is the delivery of a person centered plan, not the building, that makes a setting home and community based. The last part of Section (iv) A

would discriminate against all individuals with a specific diagnosis who choose to live together. For example, individuals who are memory impaired and choose to live in a setting with others with a similar diagnosis. Using the two main CMS criteria for defining home and community-based settings, the use of a person-centered planning process and community integration, both items in (iv) A would meet the definition of a home and community based setting. Being memory impaired may change the type of community engagement but does not exclude or prohibit this type of activity. Our final comment on this section is use of the term “custodial care.” The term is not defined in the proposed rule but is defined by Medicare to include activities of daily living and other personal care assistance not provided by a skilled professional. If CMS used the same definition, all congregate settings with individuals receiving services would be prohibited from participating in the waiver program.

Recommendation: ALFA recommends that Paragraph A in Section 443.301 (iv) be eliminated.

Section 443.301 (iv) Paragraph B

Comments: ALFA opposes Paragraph B that would require the qualities of an institutional setting to be determined by the Secretary. The purpose of this proposed rule is to allow public input to guide CMS in defining what is and is not a home and community-based setting and therefore should be the guidance for the Secretary.

Recommendation: ALFA recommends that Paragraph B in Section 443.301 (iv) be eliminated.

Section 441.302 State Assurances

This section allows states to serve more than one target group under a single waiver.

Comments: ALFA is supportive of the language in section 441.302 (a) (4) that if the target groups are combined “states must assure CMS that each individual in the waiver has equal access to all needed services” and that “states must continue to assure health and welfare of all participants when target groups are combined under one waiver.”

Recommendation: ALFA remains concerned that if combining waiver programs results in the comingling of different populations in one setting, it could pose a threat for frail seniors who could be living with younger individuals that are physically stronger.

Section 441.304 Duration, extension and amendment of a waiver

Recommendation: ALFA supports (f) that the agency must establish and use a public input process for any changes in the services or operation of the waiver.

ALFA also supports section (3)(i) and (ii) that CMS employ strategies to ensure compliance that may include a moratorium on waiver enrollments or other corrective strategies and that CMS provide states with a written notice of the impending strategies and an opportunity for a hearing.

III. CMS Request for additional information: Characteristics of settings that are NOT Home and Community-Based

The CMS proposal is seeking information to help clarify what is **not** a home and community based setting. Physical attributes found in institutions such as hospitals, skilled nursing facilities and nursing facilities are what ALFA believes would **NOT** be considered home and community-based. A few of these items include:

- Long, wide sterile hallways,
- Grab rails,
- Food served on plastic trays,
- Plastic name tags by the door with resident names,
- Medical furniture,
- Staff wearing uniforms and
- Public address systems.

Conversely, ALFA believes a home and community –based congregate setting should be an accessible usable environment that is designed to empower the individual receiving services to maximize and maintain their independence to the best extent possible. **ALFA strongly opposes the artificial use of the size of a setting as an indicator of a home and community- based setting.** How many people individuals choose to live with is a completely personal preference. A building with 100 individuals living with choice privacy and dignity is just as much a residential setting as a building with 4 individuals. The size of the setting is irrelevant and the focus needs to be on the person setting planning process and care. However, as mentioned earlier, ALFA supports no more than two people sharing a bedroom.

However it is not only the physical environment that makes a setting institutional but the lack of person-centered planning and care and focus instead on provider centered care. A few examples of institutional care include:

- Everyone sitting down to a glass of cranberry juice whether they want it or not because some doctor decided it was healthy,
- “Patients” sitting in the hallway so the nurse can keep an eye on them,
- “Patients” all being awakened at 7:00am for a shower
- “Patients” being taken to the activity room to play bingo whether they want to or not.

The core principles of person-centered care are dignity, choice and independence to allow people to have a quality of life they choose. It is these core principles that define what is or is not a home and community based setting. Individuals have the control and right to make decisions, good or bad, to live life the way they want. People are not told what time to get up, go to bed, what to eat, what to wear or how to spend their leisure time.

Community integration is a major component in a home and community based setting. Community integration can be the Boy Scouts, Girl Scouts or local elementary school coming into the community or the residents going out and participating in their church life or civic organizations. Congregate communities have vans and depending on the desires of the

individuals, there may be trips to the theatre or the zoo. The internet and use of computers are now widely used to stay connected to the larger community culture, friends and family.

The interesting part of trying to define home and community- based setting is that the benchmark or comparison is always made to one's family home. However, in actuality a family home where someone has lived for years can over time become less of a home and community-based setting. In fact these "homes" can become "institutions of one," if someone no longer drives and they are not participating in their church, visiting friends, or engaging in the community. Not being able to cook or not having someone to prepare meals for you leaves little choice in what to eat. Spending all day and night in the living room because the bedroom is on the second floor and a disability prohibits someone from going up and down the steps is not a dignified way to live.

A national satisfaction survey conducted in 2007 by Public Opinion Strategies, one of the nation's leading public opinion research firms, polled individuals living in assisted living. Their findings confirmed overwhelming satisfaction (95% and higher) with the level of personal independence individuals had in their community and with their personal living space.

Congregate settings for people receiving services that implement person centered planning, such as assisted living; allow individuals the opportunity to thrive. It is critical that the proposed rules does not intentionally or unintentionally limit the choice for seniors and others to select the place they call home.

Sincerely,

A handwritten signature in black ink that reads "Richard P. Grimes". The signature is written in a cursive, flowing style with a large initial "R".

Richard P. Grimes
President & CEO
Assisted Living Federation of America