



American Health Care Association



National Center For Assisted Living

August 4, 2009

Ms. Cindy Mann
Director, Center for Medicaid & State Operations
Centers for Medicare & Medicaid Services
200 Independence Avenue, S.W.
Room 301.H2
HHH Building
Washington, D.C. 20201

Dear Ms. Mann:

Re: File Code CMS-2296-ANPRM, Medicaid Program: Home and Community-Based (HCBS) Services Waivers, Federal Register, June 22, 2008

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 this advanced notice of proposed rulemaking (ANPR) announcing the Center for Medicare and Medicaid Services' (CMS') intent to publish proposed amendments to the regulations implementing Medicaid home and community-based (HCB) services waivers under Sec. 1915(c) of the Social Security Act and soliciting advance public comments 1) on the merits of providing states with the option to combine or eliminate the existing three permitted waiver targeting groups and 2) on the most effective means to define home and community settings.

AHCA/NCAL has been working with CMS and other stakeholders on these issues over the past several years. Last year, we provided our input when we submitted comments to CMS' proposed rule implementing the 1915(i) HCB State Plan Services option and again when we responded to CMS' white paper on the subjects. We are appreciative of the many opportunities to offer our recommendations on these very important topics and we commend CMS for its outreach and for issuing this ANPR.

Executive Summary

In response to the ANPR, AHCA/NCAL's main concerns are as follows:

- Attempts to define what qualifies as a community based setting may limit beneficiary choice by excluding some types of assisted living providers or homes for people with DD from the Medicaid HCB program;
- Combining target populations may lead to a loss of access to Medicaid services for beneficiary groups that are less politically powerful than others; and
- Combining target populations such as persons with mental illness with persons with DD or frail seniors in waivers may increase the risk of inappropriate placement of vulnerable populations, as well as create safety issues.

AHCA/NCAL recommends that CMS should:

- *Continue gathering stakeholder input, including several stakeholder meetings, before defining what qualifies as a community-based setting so as to ensure that there are no negative, inadvertent consequences for Medicaid beneficiaries.*
- *Ensure that beneficiaries have choice of the entire spectrum of long term care settings and ensure that attempts to define community-based settings do not limit that choice.*
- *Acknowledge that assisted living communities must meet care and regulatory standards under state law that help ensure resident safety and that these standards typically do not apply to beneficiaries receiving services in their own homes.*
- *Not use the number of residents in a setting as a factor in determining whether a setting is considered institutional or community-like.*
- *Acknowledge that assisted living communities offer residents a wide variety of opportunities for community integration while maximizing independence, privacy, choice, and freedom of action, and respecting the rights and needs of other residents.*
- *Continue working with the Center for Excellence in Assisted Living (CEAL) and take into consideration a white paper on what person-centered care means in the assisted living context soon to be published by CEAL.*
- *Acknowledge that Medicaid's failure to pay for room and board in assisted living settings creates a payment gap that makes it difficult to provide private apartments in many states.*
- *Not attempt to mandate exact congruency between standards applying to 1915(i) and 1915(c) programs since the levels of care under the two programs are set at different points.*
- *Develop safeguards ensuring that politically weaker target groups do not lose access to services and that target groups are not inappropriately mixed in residential settings and thereby exposed to harm, if states are allowed to mix target populations under Medicaid waivers.*

In the following discussion, we present our concerns and recommendations in greater detail.

Discussion

I. Defining Home and Community-based Characteristics

As we have noted in previous comments, defining HCB settings is a complex undertaking and should be done in a way that does not inadvertently reduce viable options for these vulnerable populations. We are pleased that CMS understands the complexity of the undertaking as evidenced by the issuance of an ANPR that provides notice of a deliberative stakeholder process.

The Importance of Stakeholder Input

We are pleased that CMS is soliciting, in this ANPR, stakeholder input in “working with CMS to develop policy guidelines for State definitions.” AHCA/NCAL is very interested in participating in this process and recommends that CMS conduct a minimum of four stakeholder meetings over one year as part of the process to develop such guidelines. We believe that several stakeholder meetings are necessary to ensure there are no negative, inadvertent consequences for beneficiaries.

The Importance of Access to the Entire Spectrum of Long Term Care Services

AHCA/NCAL believes that all Americans should have access to the entire spectrum of long term care services and settings based on their individual preferences and needs. Assisted living occupies a middle ground in the long term care spectrum between nursing facility care and receiving care in one’s own home.

Assisted living is an important component of the long term care system. 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 draft report by Robert Mollica (“State Medicaid Reimbursement Policies and Practices in Assisted Living,” AHCA/NCAL, forthcoming.)

Assisted living communities typically emphasize person-centered care and provide care while promoting resident independence, dignity, privacy, and choice. In 2007, states reported that 38,373 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 120,000 low-income frail elderly Americans are 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, forthcoming.) 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 their own 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.) Assisted living providers strive to provide person-centered services while adhering to appropriate standards of

care. The presence of state regulatory standards is a factor that some Medicaid beneficiaries and their families consider as they determine where to live and receive services.

Assisted Living Well Positioned To Meet Standards

In the ANPR, CMS states that “(S)tandards for community living are to optimize participant independence and community integration, promote initiative and choice in daily living, and facilitate full access to community services.” AHCA/NCAL believes that assisted living communities are well positioned to meet these goals. Assisted living communities strive to provide residential environments where people live with the maximum level of independence and ability to choose daily activities and lifestyles while providing needed services such as assistance with activities of daily living, medication management, and care for populations with specialized needs such as people with Alzheimer’s disease and other dementias. As in the community at large, residents’ freedom of action is not absolute and should acknowledge, and not impinge on, other residents’ needs, rights, and freedoms.

While many small facilities can and do provide home-like environments, AHCA/NCAL does not agree with CMS’ implication in the ANPR that larger communities are more institutional in nature simply because of their size. Smaller settings do not necessarily mean more individualized services and could even mean fewer services. Individualized person-centered care has much more to do with staff training and the culture espoused by leadership than with physical characteristics of buildings, though the latter does play a role. We are encouraged by the comment on p. 29455 of the ANPR that CMS is trying to avoid “indirect indicators such as number of residents” in efforts to define HCB settings.

Extensive Community Integration Offered by Assisted Living Communities

As we noted in our comments on the 1915(i) proposed rule, assisted living facilities, including larger communities, may actually provide more opportunities for community integration than living in a single-family residence, as evidenced by the ability to eat together with friends and to participate in a variety of group activities. Assisted living communities offer residents extensive opportunities for social integration that are generally not available through provision of services at home. New residents often note that the social interaction they find in assisted living settings provides a key missing link in their lives. Dining becomes a social opportunity, for example. Unfortunately, some frail elderly living at home are virtually shut in and lack contact with others, especially if they have outlived their spouse, and friends and family members do not live nearby. While assisted living facilities typically have set periods of time each day in which most people are served their meals, many provide opportunities for residents to obtain snacks and other choices of food upon request 24 hours a day. In addition, many residents keep snacks and beverages in their apartments. Likewise, some larger group homes for people with DD provide more opportunities for community integration than are offered to individuals living in smaller residences.

Person-Centered Care Can Be Fostered in All Types of Settings

While we have no objection to CMS identifying methods that states may follow to identify appropriate financing mechanisms for reducing the size of existing larger residences and

promoting smaller, more individualized settings, methods for funding larger facilities to make internal changes in physical plant and staffing to further culture change and person-centered care also should be identified. AHCA/NCAL believes that person-centered care can be provided in a community of any size. In fact, person-centered care originated in intermediate care facilities for persons with mental retardation (ICFs/MR) and ICFs/MR have been practicing person-centered care for years. In addition, the "culture change" movement in nursing facilities is transforming nursing facility care to much more person-centered and individualized care in many places. In the culture change model, which has gained momentum over the past decade, nursing facility residents enjoy much of the privacy and choice they would experience if they were still living in their own homes. Residents' needs and preferences come first; facilities operations' are shaped by this awareness. (See "Culture Change in Nursing Homes: How Far Have We Come? Findings from the Commonwealth Fund 2007 National Survey of Nursing Homes.")

It is also worth noting that the Center for Excellence in Assisted Living (CEAL) has convened a panel of long term care experts from a variety of disciplines to discuss and define what person-centered care means in the assisted living context. This effort will result in CEAL's release of a white paper on person-centered care later this year. We encourage CMS to take this white paper into consideration.

Concern that Possible Exclusion of Some Settings Could Reduce Beneficiary Choice

We are greatly concerned that new federal guidelines might disqualify, either intentionally or inadvertently, some types of assisted living settings or residential HCB settings for people with DD currently providing Medicaid services that residents need and like. Given the ongoing economic downturn, it does not make sense to remove viable housing-with-services settings. It is important that as many setting choices as possible are available to the population needing long term care.

Inadequate Payment for Housing under HCB Programs Exacerbates Issues

Furthermore, it is somewhat ironic that CMS is seeking to develop guidelines for different types of housing when Medicaid does not and cannot under current law pay HCB providers for room and board. Because states largely rely on residents' Supplemental Security Income (SSI) payments to cover room and board costs, assisted living providers are typically paid far below their costs for these items. From a survey of NCAL members, we estimate that providers are underpaid by about \$10,000 annually for each resident served under Medicaid for the room and board component alone, though a fraction of this shortfall may be filled through SSI supplements that vary greatly from state to state. The payment distortion caused by Medicaid's failure to cover room and board costs has numerous detrimental impacts including causing private-pay residents to face higher rates needed to cross-subsidize neighbors covered by Medicaid; this places private pay residents at greater risk of spending down their assets and becoming impoverished themselves. The payment distortion raises a number of other issues including whether residents should share apartments in order for them to be affordable. If person-centered care means that each Medicaid resident should live in a private apartment, then additional funds need to be provided to pay for it. In the absence of such funding, regulatory changes that restrict Medicaid funding to "community settings" that meet high standards for physical privacy may simply drive away providers and ultimately lead to more, not less, institutional use.

Congruency between 1915(c) and 1915(i) Settings May Be Difficult To Achieve

While beneficiaries should be able to expect consistent levels of service between the 1915(c) waiver program and settings approved under the recently enacted 1915(i) provisions, it should be pointed out that absolute congruency between the two programs is probably not a reasonable expectation. For one thing, the levels of care triggering eligibility are different in the two settings: under 1915(c) waivers, beneficiaries must have a nursing facility level of care need, while under 1915(i) the bottom end of the level-of-care range must be below the state's nursing facility level of care. This difference in care level might engender differences in the types of settings needed to meet beneficiaries' needs – for example, beneficiaries served under 1915(i) programs likely will have more moderate care needs that could be more easily met in their own homes or less supervised settings. It also should be noted that 1915(i) is a new program option that so far has not been used for the frail elderly, while 1915(c) waivers provide care for the majority of assisted living residents receiving Medicaid coverage for long term care. Given the history of the two programs, it seems odd that policies developed to implement 1915(i) would be the basis for major changes to 1915(c) policies.

II. Removing Regulatory Barriers to Combining Target Populations

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 HCB 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.

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 departments 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 departments 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.

We understand that waivers have already been combined in New Jersey but the on-the-ground impact of the arrangement has not been gauged. 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.

In conclusion, we appreciate the opportunity to comment on the ANPR and CMS' openness to gathering further public input. We commend CMS for its intent to conduct a deliberative stakeholder process on these very important issues and we pledge our full support and participation.

We look forward to working with you on these and other important issues impacting the Medicaid program and its ability to deliver high-quality services in as economic and efficient way possible.

Sincerely,



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