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April 25, 2011

Ms. Barbara Edwards
Centers for Medicare & Medicaid Services
Department of Health and Human Services
Attention: CMS-2337-P
P.O. Box 8016
Baltimore, MD 21244-8016

Re: File Code CMS-2337-P, Medicaid Program: Community First Choice Option Proposed Rule, 76 Federal Register, February 25, 2011

Dear Ms. Edwards:

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 to implement Section 2401 of the Affordable Care Act (ACA) that establishes a new state option to provide home and community-based services and supports (HCBS).
We support the added opportunities that this new state option may provide to eligible individuals in need of care. We believe that all Americans should have access to the entire spectrum of long term care settings based on their individual preferences and needs. Thus, we are very concerned that this proposed rule, as currently written, would significantly limit access to settings, as opposed to opening up opportunities for individuals to receive supports and services in their settings of choice.

We provide below our recommendations followed by a discussion of our concerns.

AHCA/NCAL Recommendations

- *AHCA/NCAL recommends that CMS add a new section to the proposed rule to clarify, in accordance with the statute, that it is the individual's choice to participate in Community First Choice, and that would protect against coercion of any sort.*

- *AHCA/NCAL recommends that CMS reconsider its HCBS clarification proposed under this rule and rely on the statutory definition of HCBS for purposes of implementation of this provision.*
- *AHCA/NCAL recommends that CMS continue exploring how to clarify that certain settings are "outside of what would be considered home and community-based because they are not integrated into the community" as follows:*
    - *Consider that such clarification could be process-based and service-based and explore which processes and services characterize integration.*
    - *Convene stakeholder meetings to ensure that there are no negative, inadvertent consequences for Medicaid beneficiaries.*
    - *Ensure that clarification of the definition does not eliminate important community-based options for Medicaid beneficiaries, including assisted living communities, group homes, and settings that happen to be located near institutional settings.*
- *AHCA/NCAL recommends that when a clarification is developed, CMS should initially limit its use to one HCBS program until it is determined that there are not unintended or unanticipated problems caused by the clarification.*
- *AHCA/NCAL recommends that CMS utilize its rule for implementing section 10201(i) of the ACA, which sets forth transparency and public notice procedures for demonstration projects under section 1115 waivers, as a model for ensuring that there is transparency regarding the Development and Implementation Council.*

Discussion

Individual's Choice To Participate

According to Section 2401(k)(1) of the ACA, a state may provide HCBS to certain eligible individuals, "but only if the individual chooses to receive such home and community-based attendant services and supports…" We see nothing in the rules relating to this very important mandate that the choice to receive such services remains with the individual. The ACA is very clear that the individuals who receive these newly available services must opt to do so (i.e., make a voluntary decision). In this regard, we believe that CMS has neglected to note, let alone stress, that the choice to participate in this program is the individual's (or that of his or her authorized representative), not the state's, not a consumer advocate's, and not the service provider's.

Given that there is an economic advantage to the state in the form of a 6% enhanced federal medical assistance percentage (FMAP) for services and supports under this program, it is particularly important that CMS clarify, in its implementing rule, that the choice of whether or not to participate rests with the individual. Further, how states ensure that beneficiaries are given a free, informed, and uncoerced choice as to whether to receive these services and supports should be clearly delineated in this rule.

Therefore, AHCA/NCAL strongly urges CMS to include an additional section in the proposed rule that would clarify that it is the individual's choice to participate in this program and that would protect against coercion of any sort.

Definition of HCBS Setting, Section 441.530

Section 1915(k)(1)(A)(ii) of the ACA provides that a home and community-based setting does not include a nursing facility, institution for mental diseases, or an intermediate care facility for the mentally retarded. CMS proposes to adopt this statutory language in its regulations. AHCA/NCAL agrees that the statutory definition should be in the regulations.

CMS' Proposal To Clarify HCBS Settings, Section 441.530 (d) and (e)

AHCA/NCAL understands and agrees with CMS' desire to assure that HCBS settings are integrated into the community. CMS proposes "that home and community settings may not include a building that is also a publicly or privately operated facility which provide inpatient institutional treatment or custodial care; or in a building on the grounds of, or immediately adjacent to, a public institution or disability-specific housing complex, designed expressly around an individual's diagnosis that is geographically segregated from the larger community, as determined by the Secretary." AHCA/NCAL strongly disagrees with CMS' proposed clarification for two reasons:

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 and residences for people with DD, that operate in proximity to institutional facilities, on a campus or otherwise, as well as assisted living units in continuing care retirement communities. 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, 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.

Excluding assisted living is particularly problematic because it occupies an important middle ground in the long term supports and services 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).

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. 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 HCB settings applied across the Medicaid program should include assisted living communities, as well as group homes and non-institutional 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 2010, 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 HCB services. Only an estimated $2.5 billion of the spending on HCB services 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.

HHS Study Shows Assisted Living Is a Major Option for Seniors

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 Long-term 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 in homes for persons with developmental disabilities, 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 built.

Furthermore, individuals with DD who reside in group homes participate in the community through volunteer work, social activities, running errands, etc. 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 developmental disabilities 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, the extension of HCBS to individuals with DD in group homes clearly is appropriate.

Conclusion

Ultimately, CMS' proposed clarification appears to us to be discriminatory and we believe it would harm America's seniors with limited resources, as well as our citizens with DD and limited resources. Therefore, we strongly urge CMS to reconsider its clarification. For purposes of this rule, we recommend that CMS utilize the definition 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, could be repeated at regular intervals when appropriate, as the care plan is updated.

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. We have offered our comments and suggestions to CMS in the past and we will continue to offer our feedback and assistance as CMS grapples with this complex issue.

Consistency across the Medicaid Program (Preamble)

AHCA/NCAL understands CMS' desire to strive for consistency in definitions across Medicaid programs. But consistency has limits. Different Medicaid programs serve distinct populations with different needs, and any clarification that CMS develops could have inadvertent and serious ramifications because it could lead to vulnerable individuals losing their HCBS benefits.

CMS states, in the proposed rule, that the section 1915(k) benefit does not diminish the state's ability to provide any of the existing Medicaid HCBS. If the clarification as currently proposed were to be utilized across all Medicaid HCBS programs, the state's ability to provide these services certainly would be diminished as we would envision a number of assisted living communities and homes for persons with developmental disabilities no longer eligible to provide HCBS services.

Indeed, 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, 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 in most instances will force them to move to an institutional setting.

AHCA/NCAL suggests that when a clarification is agreed upon—even if it is different from the current proposal—CMS initially utilize such clarification only for the specific Medicaid HCBS program for which it is developed. Once it is established through experience that there are not unintended or unanticipated problems caused by the clarification, CMS could proceed to use the clarification in other HCBS programs as appropriate.

Thus, we recommend that any clarification that CMS develops be limited to the one program under rulemaking at least until it is determined that the clarification does not inadvertently restrict benefits and that is appropriate to all populations.

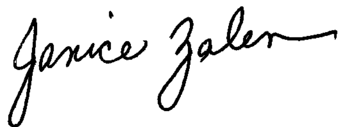
Development and Implementation Council (Section 441.575)

AHCA/NCAL agrees that the Development and Implementation Council will be an important opportunity for stakeholder collaboration. Therefore, it is critical that the process for selecting Council members and activities be transparent. For consistency purposes, we suggest that CMS look to its rules for implementing section 10201(i) of the ACA, which sets forth transparency and public notice procedures for demonstration projects under section 1115 waivers. The proposed rules were released on September 17, 2010.

Although that final rule is not yet released, we believe, based on the proposed rule, that it will ensure that the public has opportunities to provide meaningful input. The proposed rule, for example, establishes a 30-day comment period. While we would prefer 60 days and hope the final rule is so adjusted, we believe that, in a similar vein, a reasonable period of time in which to nominate someone to the Council or comment on a Council activity would help to provide the transparency needed to make the Council a truly representative stakeholder group. Public hearings, another element of the proposed rule for transparency, would work well to explain the Council, its work, and how to submit nominations.

In conclusion, we appreciate CMS' efforts to move Medicaid toward expanding options for the provision of long term services and supports. We look forward to working with you on this important undertaking.

Sincerely,



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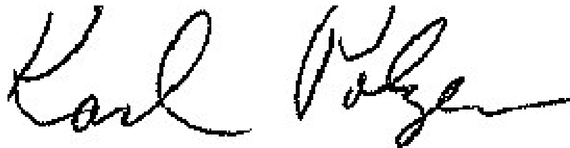

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