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May 28, 2008

Ms. Gale Arden
Centers for Medicare & Medicaid Services
Department of Health and Human Services
Attention: CMS-2249
P.O. Box 8016
Baltimore, MD 21244-8016

Re: File Code CMS-2249-P, Medicaid Program: Home and Community-Based State Plan Services Proposed Rule, 73 Federal Register, April 4, 2008

Dear Ms. Arden:

The American Health Care Association (AHCA) and the National Center for Assisted Living (NCAL) are committed to performance excellence and Quality First, a covenant for healthy, affordable, and ethical long term care. AHCA/NCAL represents 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 frail, elderly and disabled citizens who live in nursing facilities, assisted living residences, subacute centers and homes for persons with mental retardation and developmental disabilities.

AHCA/NCAL appreciates the opportunity to comment on this proposed rule, which will implement section 6086 of the Deficit Reduction Act (DRA) of 2005 and define and describe home and community-based state plan services.

Executive Summary

This proposed rule would amend the Medicaid regulations to define and describe home and community-based state plan services implementing the new section 1915(i) of the Social Security Act (the Act) as added by section 6086 of the DRA. Section 1915(i) of the Act allows states, at their option, to provide home and community-based services (HCBS) under their regular state Medicaid plans while using certain limits previously available only under Medicaid waivers.

Under section 1915(i) of the Act, states can provide HCBS to individuals who require less than an institutional level of care and who would therefore not be eligible for HCBS under 1915(c) waivers. Section 1915(i) of the Act does not link HCBS under the state plan to an institutional level of care nor does it require cost savings compared with institutional services.

AHCA/NCAL's two major concerns regarding this proposed rule relate to vulnerable individuals receiving inadequate or no services and CMS' attempt to define HCBS settings:

- **Vulnerable Individuals Receiving Inadequate or No Long Term Care (LTC) Services**

Individuals who previously qualified for institutional LTC services and now qualify only for the HCBS state plan benefit might not receive the HCBS services because either the individual is on a waiting list or the state, under its adjustment authority, makes the needs-based criteria more stringent. Since fragile individuals with complex conditions could fall into a gap in which they receive inadequate care or no care at all until such time that their health deteriorates and their level of care (LOC) needs increase to meet a higher eligibility criteria, it is incumbent upon CMS to propose implementation procedures that consider this critical risk and offer safeguards to protect these vulnerable individuals.

- **Defining HCBS Settings**

The task of defining and describing HCBS settings is extremely difficult. Especially as this is CMS' first attempt to define Medicaid HCBS settings, CMS should be very careful that the definitions and processes it designs to determine HCBS eligibility do not inadvertently disqualify particular types of community residential settings and thereby unduly constrain beneficiary choice of places in which to live and receive services. Furthermore, the definition of HCBS settings designed for this provision may influence Medicaid policy more broadly in years to come through the precedent that is set.

As CMS states in this proposed rule, there are significant variations in individualized support needs and preferences and what may be homelike and community-integrated for one individual may not be for another individual. In order to accommodate the range of needs and to overcome the subjective nature of the determination, CMS provides guidance that is complex, confusing, vague and unclear. AHCA/NCAL offers recommendations to provide more clarity and we suggest that CMS continue its effort to define HCBS. This effort should take place in a transparent manner that includes the long term care community's involvement.

AHCA/NCAL Recommendations

Background Section – Overview of the State Plan HCBS

- *AHCA/NCAL recommends that the background section and the regulatory language define cognitive impairment and clarify that states' needs-based*

criteria, assessments, and care plans must address cognitive impairments and behavioral issues in addition to mental health conditions and intellectual disabilities.

- *AHCA/NCAL recommends that CMS should ensure that medication management and medication administration are services that can be covered under the state plan option benefit package.*

Safety Net and Transition Issues

- *AHCA/NCAL recommends that CMS include, in this rule, a safety net provision that would allow vulnerable individuals who were previously eligible for facility-based care and who are deteriorating due to insufficient adequate HCBS a means to receive adequate care in a facility before their health and well-being become so deteriorated that they become eligible for facility care under the more stringent needs-based criteria.*
- *AHCA/NCAL recommends that the exemption that allows facility-based individuals to continue to receive facility services be extended to allow individuals who transition to HCBS care the option to return to facility care.*

Adjustment Authority

- *AHCA/NCAL recommends that CMS include, in this rule, a safety net provision that would allow vulnerable individuals who lose their HCBS under the state's adjustment authority to receive adequate care before their health and well-being becomes so deteriorated that they become eligible under the more stringent needs-based criteria.*
- *AHCA/NCAL recommends that when states adjust needs-based criteria in a way that would make individuals receiving the HCBS benefit ineligible, the minimum time period for individuals to continue to be eligible for services be increased from 60 days to 120 days.*

Enrollment Limitation

- *AHCA/NCAL recommends that for those individuals on waiting lists, CMS ask states how they plan to address a beneficiary's declining health, and family caregiver burden.*
- *AHCA/NCAL recommends that to assist those individuals on waiting lists, CMS ask states to conduct environmental scans of potential resources.*

Determining HCB Settings

- *AHCA/NCAL recommends that states develop, with public input, clear guidance on defining HCB settings and that such guidance is used in the assessment process to promote consistent interpretation among evaluators.*

- *AHCA/NCAL recommends that in accordance with using the HCBS waiver program as a model for the HCBS benefit program, CMS provide guidance to the states that encourages the inclusion of the full range of state licensed, certified or registered assisted living/residential care communities that demonstrate individual choice and respect to their residents under the new HCBS benefit.*
- *AHCA/NCAL recommends that CMS include as an applicable factor in determining whether a residence is institutional or in the community “the right to assume risk without placing others at risk.”*
- *AHCA/NCAL recommends that the Secretary’s minimum standards for community living facilities be developed with public input and involvement, and released initially as a proposal with a comment period.*

Plan of Care

- *AHCA/NCAL recommends that 441.565(a) (1) be reworded to acknowledge the important role, under normal circumstances, of families, guardians and representatives as follows: “The plan must be developed in consultation with the individual’s health care or support professionals, or other appropriate persons, as determined by the state, and with the individual’s family, spouse, caregiver, guardian, or representative unless the individual has reason to exclude any of these individuals.”*
- *AHCANCAL recommends that 441.565(a)(i) be reworded to clarify that only natural support that is voluntary and appropriate is included in the plan of care and that the plan of care considers the potential that natural support may not last.*

Discussion

Background Section – Overview of the State Plan HCBS Benefit

Throughout the background section and the regulatory language, the following terms are used: “mental impairment,” “mental condition,” “mental health condition,” and “intellectual disabilities.” The first three terms generally are associated with mental health conditions such as depression and schizophrenia. “Intellectual disabilities” encompass conditions such as Down’s syndrome and other forms of developmental disabilities. None of the terms refer to the cognitive impairments that stem from various forms of dementia, including Alzheimer’s disease. We believe it is important that CMS make clear that the HCBS state plan benefit includes individuals with dementia. Therefore, we provide the following recommendation:

- *AHCA/NCAL recommends that the background section and the regulatory language define cognitive impairment and clarify that states’ needs-based criteria, assessments, and care plans must address cognitive impairments and behavioral issues in addition to mental health conditions and intellectual disabilities.*

CMS states that services under the HCBS benefit “are intended to prevent progression to institutionalization...” Medication management and medication administration are essential services for that goal. About 90 percent of assisted living residents, for example, need help taking their medications. On average, they take 9-10 medications daily. In, *Prevalence of Potential Medication Problems Among Dually Eligible Older Adults in Medicaid Waiver Services*, Alkema, et al found that 49% of the study sample had potential medication problems. In an article published by the Hartford Institute for Geriatric Nursing titled *Medication: Nursing Standard of Practice Protocol; Reducing Adverse Drug Events*, authors Zwicker and Fulmer state that adverse drug events leads to serious outcomes for older adults. Clearly, the inclusion of medication management and medication administration under the HCBS benefit is essential. Therefore, AHCA/NCAL provides the following recommendation:

- *AHCA/NCAL recommends that CMS should ensure that medication management and medication administration are services that can be covered under the state plan option benefit package.*

Proposed Rule 42 CFR 441.559(b) More Stringent Institutional and Waiver Needs-Based Criteria

As required under the DRA, CMS proposes in 441.559(b) that the state plan HCBS benefit is available to a state only if individuals demonstrate a lower level of need to obtain state plan HCBS than is required to obtain institutional or waiver services.

CMS optimistically states in the preamble that it anticipates that rather than go through the complexities of raising the criteria for facility eligibility, states are more likely to adopt a simpler strategy of defining the new state plan HCBS needs-based eligibility criteria at a less stringent level than existing institutional criteria. CMS cautions that in the event that states elect to raise the criteria for facility care, the more stringent needs-based criteria may not reduce access to services mandated elsewhere in title XIX. For example, to the extent that needed health-related care and services above the level of room and board are not available in the community, the nursing facility institutional benefit must remain available to all Medicaid eligible individuals as defined in the nursing facility benefit in section 1919(a)(1)(C).

AHCA/NCAL is concerned that some cash-strapped states, rather than expanding the long term care benefit to include a population of individuals with less stringent needs, will raise the needs-based criteria for facility care. In such a situation, some individuals who no longer qualify for facility care may find that the HCBS care is insufficient to meet their long term care needs or, even worse, that they are placed on a waiting list for the services. The state’s adjustment authority (discussed more fully later in this document) to rapidly raise the needs based eligibility criteria for both HCBS and facility levels of care further exacerbates our concerns. While CMS cautions states not to reduce access to mandated services, CMS does not provide specifics on how states could provide a services safety net, such as access to facility care on a limited basis, when individuals are not faring well under the HCBS benefit or are languishing on an HCBS waiting list. The likely potential that, under this proposed rule, there will be an expansion of skilled care in unregulated community care settings further intensifies the need for a safety net.

- *AHCA/NCAL recommends that CMS include, in this rule, a safety net provision that would allow vulnerable individuals who were previously eligible for facility-based care and who are deteriorating due to insufficient adequate HCBS a means to receive adequate care in a facility before their health and well-being become so deteriorated that they become eligible for facility care under the more stringent needs-based criteria.*

Under 441.559(b)(2), CMS proposes that if states modify their institutional LOC to meet the requirement that institutional LOC be more stringent than the eligibility criteria for the HCBS benefit, individuals receiving institutional and waiver services as of the date that more stringent eligibility criteria for those services become effective would not be subject to the more stringent criteria. This exemption is indefinite, but ends when the individual is discharged from the facility or waiver, or the individual no longer meets the criteria for the applicable LOC.

AHCA/NCAL believes that this important exemption must be considered in relationship to initiatives, such as Money Follows the Person (MFP) Rebalancing Demonstration, to transition individuals from facilities to HCBS. When vulnerable individuals are encouraged to transition from a facility to any HCBS program, they should be held harmless in the event that the decision turns out not to be appropriate for them. Individuals who in good faith leave a facility must be allowed the option to return. Thus, the exemption should remain indefinite not only for individuals who remain in facilities, but also for individuals who transition to HCBS. Therefore, AHCA/NCAL provides the following recommendation:

- *AHCA/NCAL recommends that the exemption that allows facility-based individuals to continue to receive facility services be extended to allow individuals who transition to HCBS the option to return to facility care.*

Should CMS elect not to extend the exemption to transitioning individuals, we firmly believe that CMS would be obligated to assure that the states clearly, comprehensively and understandably explain to these vulnerable individuals and their families or representatives that once the individuals leaves the facility, they will lose their eligibility to return. While this information likely would have a negative impact on transition initiatives, not providing it would be unconscionable. AHCA/NCAL considered adding an alternative recommendation on the importance of communicating this loss of eligibility information, but we determined that the delivery of information, on its own, is not a sufficient alternative to extending the exemption as described above.

Proposed Rule 42 CFR 441.559(c) Adjustment Authority

As required under the DRA, CMS proposes to permit states to adjust the HCBS needs-based eligibility criteria in the event that the state experiences enrollment in excess of the number projected to be served by the HCBS benefit. The purpose of such an adjustment would be to revise the needs-based criteria in order to reduce the number of individuals in the state who would be eligible for the HCBS benefit.

In order to preserve the requirement that more stringent needs-based criteria are in place for institutional care, there is the very likely potential for the HCBS adjustment to result also in an adjustment to the facility needs-based criteria, thus reducing the number of individuals eligible for both the facility benefit and the HCBS benefit. The statute does not provide remedies for these vulnerable individuals who will lose services due to the state's adjustment in eligibility criteria for the HCBS benefit.

AHCA/NCAL is concerned about these very vulnerable individuals who rely on LTC services and lose the services because of inaccurate state projections. We believe it is incumbent upon CMS to include a safety net provision, thus, we provide the following recommendation:

- *AHCA/NCAL recommends that CMS include, in this rule, a safety net provision that would allow vulnerable individuals who lose their HCBS under the state's adjustment authority to receive adequate care before their health and well-being becomes so deteriorated that they become eligible under the more stringent needs-based criteria.*

CMS proposes that when states adjust needs-based criteria in a way that would make individuals receiving the HCBS benefit ineligible, states must continue to deem these individuals eligible for services for no less than 60 days after official notification of all required parties. AHCA/NCAL is concerned that 60 days may not be enough time to locate suitable alternative housing and services for this very vulnerable population. Therefore, we provide the following recommendation:

- *AHCA/NCAL recommends that when states adjust needs-based criteria in a way that would make individuals receiving the HCBS benefit ineligible, the minimum time period for individuals to continue to be eligible for services be increased from 60 days to 120 days.*

Proposed Rule 42 CFR 441.577(a) (1) (ii) Numbers Served

As allowed under the DRA, CMS proposes that a state may elect to set a limit on the number of individuals enrolled in the HCBS benefit. CMS does not specify waiting list requirements, but proposes to require that if a state elects to maintain a waiting list, it must do so with written and publicly published policies to ensure fairness and consistency. CMS states, in the background section, that it does not think it is appropriate to describe waiting list policies. We do not agree.

Given the seriousness of fragile individuals' health declining while on waiting lists and the well-documented negative impact on family caretakers' health when support services are minimal, AHCA believes that CMS should be more proactive in requiring specific waiting list policies. It is important to ensure that a family's ability to continue to provide care be included in waiting list policy considerations. In addition, states should assist these individuals on waiting lists to locate alternative resources. Therefore, AHCA/NCAL makes the following recommendations:

- *AHCA/NCAL recommends that for those individuals on waiting lists, CMS ask states how they plan to address a beneficiary's declining health, and family caregiver burden.*
- *AHCA/NCAL recommends that to assist those individuals on waiting lists, CMS ask states to conduct environmental scans of potential resources.*

Proposed Rule 42 CFR 441.556(a)(3) – Determining Whether Residential Settings Are Home and Community-based or Institutions

To implement the intent of Congress that the benefit be “home and community-based,” CMS would require in 42 CFR 441.556(a)(3) that individuals receiving this HCBS benefit reside in a home or community setting, and not in an institution, according to standards for community living facilities prescribed by the Secretary. CMS proposes to require that if an individual resides (or proposes to reside) in a setting with four or more persons, the independent assessment must include documentation that the individual is living in a community setting, not an institution. This process presents several potentially troubling issues that may negatively impact beneficiaries and that may constrain their choice of community living settings.

One concern is that delegating the decision (or a large part of it) about whether a setting is either institutional or community-like to contractors or other individuals performing assessments may well lead to inconsistent and sometimes unreliable judgments about what is institutional and what is not. Federal and state officials need to offer clear guidance to those performing assessments about which facilities and types of facilities may qualify as HCBS settings. Therefore, we provide the following recommendation:

- *AHCA/NCAL recommends that states develop, with public input, clear guidance on defining HCB settings and that such guidance is used in the assessment process to promote consistent interpretation among evaluators.*

CMS acknowledges that the size of a setting should not be the overriding factor in determining whether it is institutional in nature, but rather the philosophy of the care delivered and the degree to which consumers are free to exercise choice in the services they receive and their lifestyles, and that they are treated with respect and dignity. We agree. For example, there are emerging models of care where the household may be licensed, certified or registered for 15 individuals, but within the structure there are smaller individual households where individuals reside. Individuals also may choose to live in larger settings (e.g., of 100 units) because that is the environment they prefer and in which they thrive. How the community is managed is typically a more important factor in influencing the community's environment than its size.

CMS, in the background section, states that factors used in determining whether a residence is institutional or not include “opportunities for independence and community integration.” CMS points out: “Opportunities for independence and community integration in a variety of alternative living arrangements have been demonstrated for those receiving HCBS provided under section 1915(i) waivers and section 1115 demonstrations. The new Medicaid State Plan HCBS benefit should be implemented based on those practices...” We agree that the wealth of experience from Medicaid waivers should be instructive and used as the HCBS benefit is designed and

implemented. We point out that the full range of assisted living/residential care facilities operating under state law, including facilities providing Alzheimer's care, currently are included under state HCBS Medicaid waivers. Therefore, we provide the following recommendation:

- *AHCA/NCAL recommends that in accordance with using the HCBS waiver program as a model for the HCBS benefit program, CMS provide guidance to the states that encourages the inclusion of the full range of state licensed, certified, or registered assisted living/residential care communities that demonstrate individual choice and respect to their residents under the new HCBS benefit.*

In the background section, CMS provides a list of applicable factors in determining whether a residence is institutional or in the community. One of the factors listed is the "right to assume risk." AHCA/NCAL agrees that this is a valid and important factor, especially in promoting the value of independence. However, CMS also should note that in community living settings, residents and providers need to balance the right of an individual to assume risk with the rights of his/her neighbors not to be placed at unwanted risk (e.g., one individual may want to drive a motorized chair at high speeds in hallways rather than travel at slower, safer speeds that reduce risks to neighbors sharing a hallway).

Promoting the value of "community integration" at times may mean tempering the unfettered exercise of individual freedoms, and is often a balancing act. Another example of balancing individual independence and safety is providing residents with Alzheimer's disease with the maximum opportunity to exercise choice of lifestyle while ensuring their and others' safety, including minimizing potential harm from wandering and injuries resulting from cognitive impairment. Thus we believe that it is important to add an additional factor and we provide the following recommendation:

- *AHCA/NCAL recommends that CMS include as an applicable factor in determining whether a residence is institutional or in the community "the right to assume risk without placing others at risk."*

It also should be noted that assisted living facilities, including larger communities, may actually provide more opportunities for community integration than living in a single-family residence, particularly the ability to eat together with others and to participate in group activities. Many frail elderly living at home are virtually shut in and lack contact with others, especially if they have outlived their friends and family members do not live nearby. While assisted living facilities typically have set periods of time in which most people enjoy their meals, many provide opportunities for residents to obtain snacks and other choices of food upon request. In addition, many residents keep snacks and beverages in their apartments.

Likewise, some larger group homes for people with mental retardation provide more opportunities for community integration than are offered to individuals living in smaller residences.

Finally, CMS would require minimum standards for community living facilities that would be prescribed by the Secretary and would take into account factors such as

opportunities for independence and community integration. Given the serious ramifications of the determination of whether a setting is or is not a community setting, we believe that the minimum standards should be developed with full transparency and with input from the long term care community. Therefore, AHCA/NCAL provides the following recommendation:

- *AHCA/NCAL recommends that the Secretary’s minimum standards for community living facilities be developed with public input and involvement, and released initially as a proposal with a comment period.*

Proposed Rule 42 CFR 441.565(a) – Plan of Care

CMS would require in 441.565(a) a written plan of care that is based on the independent assessment and the plan “must be developed in consultation with the individual’s health care or support professionals, or other appropriate persons, as determined by the state, and **where appropriate**, (emphasis added) with the individual’s family, spouse, caregiver, guardian, or representative.” AHCA/NCAL believes it is usually not only “appropriate,” but also important to involve the individual’s family and guardian or representative. Therefore, we think that the proposed provision should be reworded to acknowledge the inclusion of all these individuals except in rare circumstances. Including family in the care planning is made all the more important given the current provision at 441.565(a) (1) that states the plan must take into account family supports. Therefore, AHCA/NCAL makes the following recommendation:

- *AHCA/NCAL recommends that 441.565(a)(1) be reworded to acknowledge the important role, under normal circumstances, of families, guardians and representatives as follows: “The plan must be developed in consultation with the individual’s health care or support professionals, or other appropriate persons, as determined by the state, and with the individual’s family, spouse, caregiver, guardian, or representative unless the individual has reason to exclude any of these individuals.”*

CMS would require in 441.565(a) (1) that the plan of care take into account “the extent of and need for any family or other supports for the individual.” This does not reflect the language in the background that states: “We conclude that the statute requires that the plan of care should neither duplicate, **nor compel** (emphasis added) natural supports.” Prohibiting a plan of care from compelling natural supports is a vital protection for those family caregivers who cannot continue to provide care due to conditions such as their own poor physical or emotional health, the heavy care needs of their loved ones or their need to work to support themselves. It is also a vital protection for the beneficiary because using non-voluntary, natural support caregivers to support individuals with complex medical and behavioral issues has the potential for abusive or negligent care.

- *AHCANCAL recommends that 441.565(a)(i) be reworded to clarify that only natural support that is voluntary and appropriate is included in the plan of care and that the plan of care considers the potential that natural support may not last.*

Conclusion

According to CMS, “the purpose of section 1915(i) of the Act appears to be to expand access to HCBS to individuals who are not at an institutional level of care, rather than to reduce access to institutional and waiver services.” To meet this intent of the Act and to protect beneficiaries who are elderly and have disabilities from significant reductions in their supports and services, CMS should expand this rule to provide protections, such as those recommended in these comments, from loss of critical services and supports. Furthermore, CMS needs to take care that the full array of community residential options, including assisted living communities, are available to beneficiaries.

Sincerely,

A handwritten signature in cursive script, appearing to read "Bruce Yarwood".

Bruce Yarwood
President and CEO
American Health Care Association

A handwritten signature in cursive script, appearing to read "David Kylo".

David Kylo
Executive Director
National Center for Assisted Living