June 14, 2011

Dr. Donald Berwick
Administrator
Centers for Medicare & Medicaid Services
U.S. Department of Health and Human Services
Washington, DC 20201

[Submitted Electronically]

Re: File Code: CMS 22296-P

Dear Dr. Berwick,

The National Association of States United for Aging and Disabilities (NASUAD) and the National Association of Medicaid Directors (NAMD) are pleased to offer joint comments on the Centers for Medicare and Medicaid Services (CMS) proposed rule aimed at amending various provisions of the regulations governing Section 1915(c) Medicaid Home and Community-Based Services (HCBS) waivers, *Medicaid Program; Home and Community Based Services Waivers*, as published in the April 15, 2011 *Federal Register*, volume 76, number 73, pages 21311 to 21317.

Originally founded in 1964 under the name the National Association of State Units on Aging (NASUA), the organization changed its name to NASUAD in 2010 to formally recognize the work that the state agencies were undertaking in the field of disability policy and advocacy. Today, NASUAD represents the nation's 56 state and territorial agencies on aging and disabilities and supports visionary state leadership, the advancement of state systems innovation and the articulation of national policies that support home and community based services for older adults and individuals with disabilities. The Association's mission is "to design, improve, and sustain state systems delivering home and community based services and supports for people who are older or have a disability, and their caregivers."

NAMD is a bipartisan, professional, nonprofit organization representing the nation's 56 state and territorial Medicaid agencies, including the District of Columbia, whose mission is to represent and serve state Medicaid directors. NAMD, formerly National Association of State Medicaid Directors (NASMD), was an affiliate of the American Public Human Services Association (APHSA) beginning in 1979. Medicaid has become the largest public assistance program in every state, the country's foremost program operating as a joint federal-state partnership, and will soon be the source of health insurance coverage for approximately one-sixth of the nation's residents. Federal reforms in 2010 also created explicit links between Medicaid and private health insurance markets. With these fundamental changes, the demands placed on Medicaid Directors have both grown and shifted in focus. NAMD was created to fulfill the need for a new and independent organization representing state Medicaid Directors and the programs they operate.

The members of our respective Associations have the primary authority for developing and operating HCBS waiver programs. Our members are undertaking challenging and important efforts to integrate programs to improve the options and quality of services available to Medicaid consumers, including those who need HCBS services. In general, NASUAD and NAMD support CMS' efforts to improve HCBS options for people and their families, as well

as to provide additional flexibility and guidance to the states. However, due to the potential impact of specific provisions included in the proposed rule, our Associations request a number of clarifications, as well as additional stakeholder dialogue. We offer these coordinated comments as a reflection of the integral working relationships at the state level, and the widespread agreement on the concerns and requests we make herein. Below, please find NASUAD and NAMD's jointly-issued general comments, followed by the two Association's joint comments and recommendations on specific provisions of the proposed rule.

I. NASUAD AND NAMD GENERAL COMMENTS

Combining Waiver Target Populations – Our Associations appreciate CMS' proposal to allow states to combine waiver populations. The notion of supporting whole families in their own homes is a concept that our organizations have long supported. However, we strongly encourage CMS provide more guidance on the Agency's expectations around service delivery and related documentation. Collectively, we also are concerned about quality measurement within a waiver serving populations with significantly different support preferences and needs, such as older adults and persons with intellectual and developmental disabilities (ID/DD). Current CMS quality requirements already are challenging. Additional complexity in quality improvement strategies could prove highly problematic and be a significant barrier to states interested in a combined population waiver.

Person Centered Planning – Again, states have long supported person centered planning and we appreciate CMS' efforts to offer more guidance on such models. However, experience has shown that older adults have very different perspectives on person centered planning and self-direction compared to young adults. Additionally, older persons with dementia may not be appropriate for self-direction. We are concerned about the proposed rule language, which appears to require full participant direction, when such a service arrangement may not be preferable or appropriate for certain populations. Additionally, the proposed language is silent on the role of legal guardians.

HCBS Setting – While our associations understand that CMS' guidance is intended to ensure HCBS settings truly are homes and are not "sign-flips" from small facilities to home-like, the proposed language is highly problematic. We believe that the language, as drafted, would reduce, and not expand, choice. Additionally, the assisted living framework could have serious implications for people who choose to live in assisted living settings. Specifically, the proposed language, which mirrors Money Follows the Person assisted living language, could eliminate most assisted living from Medicaid. A further concern is that assisted living is frequently the long-term services and supports point of entry for older adults who provide pay. If the proposed rule reduces the pool of Medicaid-participating assisted living settings, many older adults who spend-down to Medicaid while in assisted living settings could face eviction. The unintended consequence of the proposed language could be an increase in long-term stay nursing home admissions.

Administrative Proposals – We understand CMS' desire to improve federal-state communication and offer clear guidance on public comment. However, the changes in "substantive amendment" could prove problematic. Specifically, changing the effective date to the date of approval from the date of submission, and precluding retroactive application of the change(s), could present serious challenges to states in today's budgetary environment, as well as for state agencies under legislative mandates to implement changes or budget initiatives. Additionally, clear guidance on public notice expectations is needed. While public input is an important part of any waiver development or modification effort, requirements for extensive public input periods could prove challenging for analogous reasons.

II. NASUAD AND NAMD SPECIFIC COMMENTS AND RECOMMENDATIONS

Section 441.301(b)(1)(i) - The rule should clarify that the operating agency should have authority to approve the written services and supports plan when the Medicaid agency has delegated the operations of the Medicaid waiver. <u>NASUAD and NAMD request that CMS add language stipulating that the operating agency should have</u>

such authority when expressly delegated by the Medicaid agency. We recognize that the Medicaid agency would retain ultimate accountability for, and authority over, the 1915(c) waiver.

Section 441.301(b)(1)(i) - The requirement for person-centered services and supports planning is a welcome policy direction. Individuals utilizing waiver services will be assured that their personal preferences and goals will be valued and utilized as part of the assessment and planning process. However, the requirements of the person-centered services and supports plan would require additional resources for states that serve large targeted groups under separate waivers. These requirements would result in states redesigning their current assessment and planning tools to comply with the additional requirements proposed at (b) (1) (A) and (B). Such requirements, coupled with the changes in 441.301(b)(6), would be an administrative burden for states that currently have well-developed systems in place to serve targeted populations. Our organizations request that CMS clarify that certain principles for person-centered planning must be addressed but that states may meet the requirements of such principles in a variety of ways as negotiated between the states and the federal government.

Section 441.301(b)(1)(i) - While self-direction should be a goal for any individual receiving long-term supports, cognitive impairments; dementia; and criminal history must also be addressed in the planning process for services and community supports, while maintaining a focus on self-direction and quality of life. We request that CMS clarify the role of legal guardians or representatives in self-direction, as well as scenarios under which self-direction may not be appropriate, and how CMS will accommodate such individual preferences or needs.

Section 441.301(b)(1)(i)(A)(3) - In the person-centered planning process section of the proposed regulation, assessing and planning for an individual's needs in their own home and community is essential to gaining an accurate picture of the persons support needs. NASUAD and NAMD request that CMS specify that the plan development process be face-to-face, and that, whenever possible, the plan development process occurs in the individual's home and community at a time convenient to the individual.

Section 441.301(B)(1)(i)(B)(4) - In (B)(4), CMS indicates that the plan "reflect … the providers of those services and supports." The current language implies that a plan would have to be updated whenever providers change; such a requirement would be burdensome on people, providers, and state systems. Our organizations request that CMS clarify that the plan need not be updated each time a provider changes.

Section 441.301(B)(5) - In regard to (B)(5), in addition to the services and supports provided and risk factors and measures to minimize risk, the services and supports plan should also address any identified service needs that are not being met, and allow the state to identify and plan for mitigating risks when an individual poses a danger to self or others due to serious cognitive impairments, severe dementia, or previous criminal involvement. Individuals may have certain needs unmet for a number of reasons. A risk plan that identifies risk factors may not always allow for a plan to minimize the risk or provide a back-up strategy if the individual is unwilling or unable to address specific needs. Individuals may be unable or unwilling to comply with all aspects of care planning. A services and supports plan should include areas where agreement cannot be reached between all parties where unmet needs and risks are identified, or where there are documented risks when the individual poses a danger to self or others. Our organizations request that CMS clarify the process for development and core elements of a risk plan.

Section 441.301(B)(6), and (B)(10) - In regard to (B)(6) and B(10), we believe involvement in all parties is problematic. In (B)(6), requiring "all individuals and providers" sign the plan could present a timeliness of service start date issue. Additionally, not all parties need to see the entire plan; stated another way, such a sign-off and distribution process, as noted in (B)(10) could raise privacy issues. NASUAD and NAMD recommend rephrasing (B)(6) and (10) to stipulate that only those selected by the participant and integral to implementation of the plan be required to sign and/or receive a copy of the plan.

Section 441.301(b)(1)(iv) - CMS' proposal to clarify community-based settings' characteristics is a positive step and should minimize the efforts to simply convert institutional settings into community-based care settings, while maintaining an institutional environment. However, NASUAD and NAMD believe that the proposed rule will have

far-reaching and unintended consequences, including reducing, rather than expanding, consumer choice. Additionally, the proposed language fails to recognize the array of needs across the continuum of long-term services and supports. Specifically, as drafted, the rule appears to imply that services may only be delivered in a home or in a small residential setting. Such options may not be desirable to or appropriate for many individuals participating in a waiver program. Additionally, such arrangements may not be feasible in rural, frontier or wilderness regions of states. NASUAD and NAMD recommend that CMS take these potential consequences into consideration and incorporate language in the final regulation that addresses these concerns.

Section 441.301(b)(1)(iv)(A) – The proposed section (b)(1)(iv)(A) states that a setting is not an integrated community setting if it is "located in a building that is also a publicly or privately operated facility that provides inpatient institutional treatment or custodial care." The term "custodial care" is not defined in the proposed regulation, and the definition could have a significant impact on the settings where individuals may receive HCBS services. CMS should clarify if the term custodial care in this section refers to inpatient institutional custodial care. Custodial care, as defined in the Medicare Manual, Chapter 16, section 110, states "Custodial care serves to assist an individual in the activities of daily living, such as assistance in walking, getting in and out of bed, bathing, dressing, feeding, and using the toilet, preparation of special diets, and supervision of medication that usually can be self-administered. Custodial care essentially is personal care that does not require the continuing attention of trained medical or paramedical personnel"…"Institutional care that is below the level of care covered in a SNF is custodial care." If the language above is the working definition, it should be clarified in the proposed regulations. NASUAD and NAMD recommend that CMS define and clarify the term "custodial care" for the purposes of this proposed regulation.

Section 441.301(b)(1)(iv)(A) - The term "disability-specific housing complex" is not defined. Memory care residences specifically designed for individuals with Alzheimer's or dementia do not appear to be permissible under the proposed regulations. Such residences offer specific services to support a population that can be served in the community, but also require staff that are trained specifically in memory and dementia care. Prohibiting any disability-specific housing complex could result in the relocation of individuals with memory care needs back into institutional settings. The term may also preclude the provision of HCBS in any building immediately adjacent to or on the grounds of Section 202 (Supportive Housing for the Elderly) or Section 811 (Supportive Housing for Persons with Disabilities) housing. The phrases "on the grounds of or immediately adjacent to," "designed expressly around an individual's diagnosis," or "geographically segregated from the larger community" also require clarification. CMS appears to indicate that HCBS could not be delivered near Section 202 or 811 housing which are critical housing programs. NASUAD and NAMD request that CMS define and clarify "disability-specific housing complex," "on the grounds of or immediately adjacent to," as well as "designed expressly around an individual's diagnosis," and "geographically segregated from the larger community."

Section 441.301(b)(1)(iv)(A) - The assisted living setting clarification also could result in the involuntary relocation of a large population of individuals currently residing in Assisted Living Facilities (ALFs). ALFs may be reluctant to accept higher acuity individuals without the ability to discharge residents when the facility cannot meet the individual's needs or that may be a danger to self or others as their care needs progress. Individuals may also be reluctant to sign long-term ALF leases. The unintended consequences of these new regulations may be more instability in the affordable assisted living marketplace and that developers will be reluctant to build new facilities at a time when affordable assisted living and/or housing with services are more important than ever due to the economic downturn. NASUAD and NAMD recommend that CMS address these potential consequences of the proposed regulation to promote stability in the assisted living marketplace.

Section 441.301(b)(1)(iv)(A) - As noted earlier, ALFs and Continuing Care Retirement Communities (CCRCs) are the preferred entry points into waiver services for many individuals that spend down to Medicaid levels. CCRCs are an entry point because of the full continuum of care offered and an option that many individuals choose. If such settings are not permissible because of certain characteristics of the setting, providers may be unwilling to accept potential Medicaid eligible individuals that would otherwise spend down to Medicaid income and resource limits, or would evict these individuals for non-payment once their resources have been spent down. Individuals facing eviction as they become eligible for Medicaid could be subject to unnecessary institutionalization, or forced into a

long-term care setting that is not of their choosing. Our Associations believe that both the home and community based setting definition and the assisted living language present serious challenges that could negatively impact people. NASUAD and NAMD strongly urge CMS to use the definition of HCBS currently in effect, strike these provisions, and convene a stakeholder working group to arrive at language that will ensure the development of, and access to, integrated homes that offer people opportunities for meaningful community connection. Furthermore, NASUAD and NAMD recommend that the dialogue begin with choice and characteristics of community connection based on personal preference rather than the building location and features.

Section 441.301(b)(6) - We commend the notion of supporting whole families and appreciate CMS' efforts to reduce administrative burden. However, the Associations have a number of concerns that, if not addressed, could impact state adoption of the new Section 1915(c) flexibility. If States choose the option of serving multiple target groups or subgroups under a single waiver, it appears that there would be a requirement to use separate assessment tools to establish levels of care, but the same service and supports planning tools for person-centered planning. While it appears the revision would create administrative efficiencies, the initial resource requirements to change the current assessment and planning tools to create a single, consistent tool, would be an obstacle for States. States that currently serve large populations under separate waivers would be at a disadvantage due to the scale and costs associated with such changes. Additionally, in the preamble, CMS notes that "through this proposed rule, we include expectations that each individual within the waiver, regardless of target group, has equal access to the services necessary to meet their unique needs." Our organizations, and other state government associations, have previously expressed concerns about CMS' quality improvement expectations. The language above, alone, presents significant challenges with designing a quality measure system and collecting related data; when coupled with CMS' current quality requirements, implementation and operation of a quality measurement system that includes elements such as 100 percent remediation becomes a significant barrier. NASUAD and NAMD request that CMS clarify quality measurement expectations in mixed population waivers.

Section 441.301(b)(6) - Program integrity is a priority for states and CMS, as federal and state partners work to be effective stewards of Medicaid funds. Medicaid requires that services link to individual Medicaid beneficiaries, not family units. In scenarios where an older parent and a child, or an older parent and an adult child with a disability, are receiving supports in the same location, such as a home, we request that CMS clarify the supports structure, service delivery expectations, and documentation expectations that demonstrate delivery of services to individual Medicaid waiver participants.

Section 441.301(b)(6) - Waivers that combine populations would require a new approach to calculating cost neutrality, for example, mixing ICF/MR with NH. The Associations request that CMS clarify how cost neutrality would be calculated for waivers that mix populations.

Section 441.304(d)(1) and (2) - Clarification of substantive changes will allow states to be more efficient in the submission of waiver amendment requests. However, limiting substantive changes to the date of CMS approval rather than the date of submission presents significant challenges when a state is under a legislative mandate to make a change and/or implement a budget initiative. While our Associations recognize the importance of providing information on any transitions that might be required when making substantive changes, we recommend that substantive changes be retroactive to the date of the waiver amendment submission date, at a minimum, for changes that have minimal impact on current participants.

Section 441.304 (e), (f)(1) and (2) - We recognize and embrace the importance of public notice. However, CMS' expectations for public notice are unclear. For example, CMS' intent appears to have different expectations for rate change public notice as opposed to public notice standards for operations and service changes. Furthermore, as with substantive changes, timeliness of proposed changes is critical. NASUAD and NAMD request that CMS clarify what is meant by public notice "be sufficient in light of the scope of the proposed changes" as well as "meaningful opportunities for input."

Section 441.304(g) - We applaud CMS' interest in creating additional options for corrective action. The Associations recommend that CMS consider formalizing current options, such as one-year renewals with external

monitoring or evaluation; conditional renewals, requiring the state to hire a monitor; and intensive CMS monitoring. However, CMS should ensure that consistent strategies are used and that timeframes and expectations are reasonable given the circumstances of the deficiency. NASUAD and NAMD request that CMS consider formalizing current options for corrective options in such a way as to ensure consistency and reasonableness.

On behalf of NASUAD and NAMD, we thank you for the opportunity to comment on this proposed rule. We look forward to continuing to work with CMS on these issues throughout this rulemaking process and beyond. If you have any questions or concerns about these submitted comments, please do not hesitate to contact Mike Cheek, NAUSAD's Senior Director for State Services at mcheek@nasuad.org and Andrea Maresca, NAMD's Director of Federal Policy and Strategy at andrea.maresca@namd.us.org.

Sincerely,

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