CONSORTIUM FOR CITIZENS WITH DISABILITIES

[Date]

Cynthia Mann
CMS Deputy Administrator/Director
Centers for Medicare & Medicaid Services
7500 Security Boulevard
Baltimore, MD 21244

Dear Ms. Mann,

We, the undersigned members of the Consortium for Citizens with Disabilities Long-Term Services and Supports Task Force, write regarding the implementation of the new home and community-based settings rule. The Consortium for Citizens with Disabilities is a coalition of more than 100 national consumer, advocacy, provider, and professional organizations advocating on behalf of people of all ages with physical and mental disabilities and their families.

We strongly support the new rule and are eager to support its implementation in a manner consistent with the Americans with Disabilities Act and *Olmstead* decision. However, we have some concerns about trends and questions that remain during this early and important phase in the process. This rule and its implementation will set a foundation for the provision of home and community-based services for years to come and we hope that our recommendations will support an improved implementation and a high-quality HCBS system moving forward.

Ensure Transparency throughout the Process
States, advocates, and other stakeholders are still confused about crucial elements of the rule and compliance process. We urge CMS to increase transparency and consistency throughout the process, including posting online all transition plans, public comment periods, submitted comments, and the current status of waiver applications, renewals, amendments, and transition plan approvals. The transparency requirements for 1115 waivers provide a good example. Increased transparency could reduce confusion and ease anxiety as we undertake this monumental change to our HCBS system.

Ensure Consistency with *Olmstead*
As noted in the January 2014 Notice of Final Rulemaking, it is crucial that the definition of HCBS be consistent with the integration mandate set forth by the Supreme Court in *Olmstead v. L.C.* The *Olmstead* decision requires states to eliminate unnecessary segregation of persons with disabilities and to ensure that persons with disabilities receive services in the most integrated setting appropriate to their needs. Other agencies, including the Department of Justice, have experience interpreting *Olmstead* to apply to services in non-residential settings, including pre-vocational and supported employment services. It is essential that CMS coordinate with the Department of Justice and Department of Labor to ensure that its guidance reflects up-to-date and consistent understandings of how to provide day services and employment services in a manner that is truly the most integrated setting appropriate and provides individuals with maximum opportunities for competitive integrated employment consistent with their strengths, needs, preferences, abilities, and capabilities as identified in their person-centered plans.

Issue Necessary Guidance Promptly
We strongly encourage CMS to issue all necessary guidance as soon as possible, particularly as it relates to non-residential settings. Examples of non-residential settings that comply, do not comply, or would be presumed not to comply – similar to the list provided by CMS on residential settings – would be extremely helpful to stakeholders and states as they begin their planning to come into compliance with the new requirements.

Clarify Rules Regarding Public Comment and Stakeholder Engagement in Transition Plans
To date, many of the transition plans posted for public comment have been brief documents with few details, or claims that the state is already in compliance. Some states, for example, have made "initial determinations" that services in their existing waivers are community-based and comply with the new federal regulations. Stakeholders cannot meaningfully engage or provide comment on plans that provide so few details. CMS should provide guidance to states on the expectations for the contents of transition plans, strategies that they must undertake to demonstrate compliance and the level of stakeholder engagement required. Absent clear expectations, there may be missed opportunities to make meaningful system improvements and/or changes necessary for compliance. Written clarification from CMS that states must accept public comment on the full transition plan would also alleviate concerns among stakeholders that they will not have sufficient opportunity for input.

Clarify Compliance for States with 1115 Waivers
The new rules should apply to all HCBS funded through Medicaid. We have heard that CMS plans for the rules to apply to HCBS in 1115 waivers, which we strongly support. However, both states and stakeholders need formal guidance as to whether this is the case and more information about how services offered through 1115 waivers will come into compliance. This should include deadlines for transition plans, compliance, and expected deliverables. Ideally, states with HCBS in 1115 waivers should be on the same timeline outlined in the rules for other HCBS waivers and state plan amendments.

Clarify Consumer Rights to Autonomy, Dignity and Respect
Clarity is needed in terms of the implementation of consumer rights. Under the current rule, all settings must ensure a consumer's dignity and right of respect. More guidance from CMS on these terms would be useful to states and stakeholders, including guidance beyond the implementation of provider policies simply stating that everyone has a right to dignity and respect.

Assessment of Current Settings Should Not Rely Solely on Provider-Reported Information
States must gather information to ascertain how current HCBS settings comply, or fail to comply, with the new regulations. CMS representatives have frequently stated that the rule is about the experience of consumers who receive Medicaid HCBS. No one knows a consumer's experience better than the consumer him/herself; accurate assessments of settings must include the voices and experiences of those who receive services. We have heard of at least two states that are surveying providers that own, operate or control settings as the sole or primary basis for identifying settings out of compliance with the rule. Input from service providers is necessary but not sufficient to properly assess a state's current service system. To gather a complete picture, states must include input from consumers, families, advocacy organizations, and other stakeholders. Clarification from CMS should specify that a state should not rely inordinately on provider reports to obtain data both in evaluating settings now and in evaluating compliance in the future.

Ensure States Properly Identify and Categorize Settings
CMS should ensure that state policies, including assessment and transition plans, include a process for properly identifying and categorizing settings, including those that have the effect of isolating HCBS consumers from the broader community of persons not receiving Medicaid HCBS. Under the new rule, there are three categories of settings that are presumed not to be home and community-based. It is

relatively easy for states to identify settings in two of the categories: 1) shares a building with a facility providing inpatient institutional treatment, and 2) on the grounds of, or adjacent to, a public institution. The third category – a setting that isolates Medicaid HCBS consumers from the broader community of consumers not receiving Medicaid HCBS – is harder to identify.

We are concerned that some transition plans released so far have not included sufficient analysis of the third category. Without this analysis, states may skip over settings that have the effect of isolating consumers as well as settings that are presumed to be isolating but could, with changes, meet the characteristics of HCBS described in the rule. When reviewing plans, we request that CMS ensure that states have sufficient assessment of settings and have properly identified and categorized settings.

Prohibit Payment-Source Discrimination in Provider-Owned or -Controlled Settings
The standards for provider-owned or -controlled settings should be applied broadly, as operational requirements for all settings providing residential Medicaid HCBS. Providers who wish to offer Medicaid HCBS services must meet these requirements for all of the individuals they serve. A setting that has the characteristics of an institution for some of its residents should be considered to have the characteristics of an institution for all residents. If the protections of the HCBS settings rule were applied to Medicaid beneficiaries, but denied to other residents receiving the same services, the result would be an institutional environment. Imagine, for example, a facility that generally barred visitors and imposed strict curfews and meal times, but allowed visitors and made scheduling exceptions for the one resident for whom it received HCBS funding. This type of payment-source discrimination clearly would be contrary to the goal of a home-like environment and thus harmful to Medicaid beneficiaries.

Convene Working Group of Stakeholders to Enhance the Understanding of the Setting Requirement
We recommend that CMS establish a stakeholder advisory group to inform implementation through assisting in the development of materials and tools, providing input issues, and coordinating with other federal agencies to build consistency in regulatory interpretation. The workgroup must move quickly enough to be helpful to states that are already taking steps to comply.

Place Emphasis on the Need for On-Going Monitoring
Compliance should not be a one-time event. In some states, transition plans focus heavily on settings coming into compliance, with the implicit assumption that once a setting comes into compliance, it always will be compliant. Compliance depends on a number of factors, including the actions of service providers and functioning of the person-centered plan. As a result, a setting might be compliant in one month and become noncompliant in a subsequent month. Also, a setting may violate regulatory standards in various ways on an on-going basis. In order to properly protect consumers, a state's HCBS system should have the capacity to evaluate compliance on an on-going basis — for example, to investigate complaints and require remedies for individual consumers. Transition plans must provide for meaningful ongoing enforcement and include descriptions of how compliance monitoring will continue past the end of the period covered by the transition plan, including changes to licensure and other laws and regulations.

Reiterate to States the New HHS Guidance on Implementing Section 2402 (a) of the Affordable Care Act
Finally, we would like to express our appreciation for the efforts of the Secretary of Health and Human Services (HHS) to implement Section 2402(a) of the Affordable Care Act and support for the guidance on person-centered planning and self-direction. We are disseminating the guidance to our members and request that CMS redistribute this important guidance to help ensure that states, agencies, providers, people with disabilities, families, and other stakeholders are aware of this important guidance to assist them in the development of systems and services that are person-centered and maximize self-direction.

We support and appreciate the work CMS has done over the past years to finalize and implement this rule and hope that we can continue to work together to improve the lives of people with disabilities.

Sincerely,

ACCSES
American Association on Health and Disability
Association of University Centers on Disabilities
Easter Seals
Lutheran Services in America Disability Network
National Association of State Directors of Developmental Disabilities Services
National Down Syndrome Congress
National Multiple Sclerosis Society
National Senior Citizens Law Center
The Arc
United Spinal Association