

June 14, 2011

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-22296-P**

To Whom It May Concern:

On behalf of the Association of University Centers on Disabilities (AUCD), I would like to thank you for this opportunity to comment on the Proposed Rulemaking on the Medicaid Program: Home and Community-Based Services (HCBS) Waivers, published in the *Federal Register* on April 15, 2011.

AUCD is a national non-profit organization that represents a network of interdisciplinary Centers advancing policy and practice for and with individuals with developmental and other disabilities in their communities. Network members consist of:

- 67 University Centers for Excellence in Developmental Disabilities (UCEDD), funded by the Administration on Developmental Disabilities (ADD)
- 39 Leadership Education in Neurodevelopmental Disabilities (LEND) Programs funded by the Maternal and Child Health Bureau (MCHB)
- 18 Intellectual and Developmental Disability Research Centers (IDDRC), most of which are funded by the Eunice Kennedy Shriver National Institute for Child Health and Development (NICHD)

These programs serve and are located in every U.S. state and territory and are all part of universities or medical centers. They serve as a bridge between the university and the community, bringing together the resources of both to achieve meaningful change.

General Comments:

AUCD commends the Centers for Medicare and Medicaid Services for the steps it has taken to clarify values related to community living and person-centered planning in HCBS Waiver rules. These proposed rules will help states meet their obligations under the Americans with Disabilities Act (ADA) and the U.S. Supreme Court *Olmstead* decision to serve individuals in the most integrated setting appropriate to their needs. Throughout the background information, specific program and policy issues related to these values are discussed but appear to be expressed more generally within the regulations. Overall, we concur with the more specific values and expect that the administrative guidance CMS intends to issue to states will incorporate the principles reflected in the background information. It is in this spirit that AUCD offers the following comments and recommendations related to person-centered planning, setting and target groups under §441.30 - Contents of request for a waiver.

*The Person-Centered Plan*

AUCD applauds the inclusion of principles of person-centered planning by CMS in the proposed rules. We suggest strengthening the commitment to the provision of person-centered supports and services by adding the individual and/or his or her legal representative to the list of required signatories to the plan. Additionally, in keeping with the intent of CMS to require a “complete

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and inclusive person-centered planning process”, we believe that it is necessary to include language that requires consideration be given to the values outlined in the background of the proposed rules. These values included: supporting the individual to have a meaningful role in the process, cultural practices and observances, choice and periodic updates as well as meeting times that accommodate the schedule of the individual. AUCD would like to see consideration of these values extended to not only the individual receiving services, but to family members, legal guardians and other participants chosen by the individual as well. In addition, AUCD requests clarification related to the process of obtaining and documenting an individual’s choices and personal preferences during planning as well as inclusion in the resulting document.

Section §441.301(b)(1)(i)(B)(3) requires that the person centered plan “include individually identified goals, which may include, as desired by the individual, items related to relationships, community living, community participation, employment, income and savings, health care and wellness, education, and others.” The use of the term “goals” has long been a source of misunderstanding and appears to be a “holdover” from ICF/MR regulations. A more appropriate and effective approach is to focus the person-centered plan on the accomplishment of specific, identified outcomes that are consistent with the individual’s choices and personal preferences and the intent of the services provided. A sole focus on activities of daily living has a less significant impact on quality of life than outcomes such as getting a job or participating in civic organizations. Establishing outcomes is a way to assess the efficacy of the services being provided and offers a benchmark against which the individual and the service provider(s) can determine whether or not the service or support is appropriate.

### *Setting*

AUCD strongly supports the goal of ensuring that Home and Community-Based Waivers (HCBS) are used to provide services and supports that enable individuals to live in homes of their choosing in the community and not in large congregate facilities that purport to be community based. The proposed rules will de-incentivize the use of HCBS waiver funds to serve individuals in segregated settings or settings with a strong institutional nature.

AUCD is concerned, however, about the unintended consequences if people living in other situations become ineligible for HCBS services should the provider no longer meet the criteria for community-based under the proposed rules. The exclusion of housing designed around an individual’s diagnosis or disability, while again a positive step, is somewhat ambiguous and open to interpretation. While we are supportive of this provision, we are unsure as to the types of settings that are allowable or prohibited. We are aware that there are proposals in several states to develop “clusters” of homes on large campus-based settings intended to serve a specific disability group. We assume that such segregated programs would not qualify as community-based settings, but recommend that additional language be added to this provision to clearly explain its intent. People should be eligible for HCBS services wherever they live, so long as it is not in a nursing home, ICF/MR (intermediate care facility for people with intellectual disability or related conditions), hospital, or IMD (Institute for Mental Disease).

A question has also come up regarding apartment complexes within which are scattered “supported” apartments. In other words, within a larger building serving the general community, several apartments may serve individuals who need support, provided by staff who may or may not live in the complex. In these settings individuals rent their own apartments, have full access to the community and do seem to meet the other criteria for what constitutes community. AUCD welcomes further clarification of the distinction between “a housing complex designed expressly around an individual’s diagnosis or disability” [§441.30(b)(1)(iv)(B)(12)(iv)(A)] and a residence in which one or more individuals are receiving waiver services.

### *Target Groups*

AUCD commends the Centers for Medicare and Medicaid Services for including an option to combine waiver programs for the elderly and disabled, those with intellectual and/or developmental disabilities and mental illness in § 441.301(b) (6). This option supports on-going efforts by advocates to shift the emphasis of long-term supports from diagnosis to functional needs. Additionally, it adds flexibility for states in designing waivers and offers promise regarding the provision of services to specific groups or individuals in particular situations, such as an adult with intellectual disabilities living with an aging parent or sibling, both of whom need support services that meet the needs of the entire family. As such, AUCD considers it necessary to specifically state that waiver programs for the three target groups may be combined and suggests that §441.30(b)(1)(iv)(B)(6) read “Be limited to *one or a combination* of the following target groups...” instead of the current “Be limited to *one or more* of the following target groups...”.

While we see advantages to combining target groups, we are concerned about the potential loss of the specialized expertise and capacity that is needed to adequately and appropriately support persons with intellectual and developmental disabilities and related needs as well as the danger that individuals will be underserved or receive services that are inappropriate to their needs. AUCD recommends the inclusion of clarification to ensure that each group included in such a combined waiver program continues to receive supports and services in a manner consistent with not only individual needs and preferences, but also with the dominant underpinning philosophies and best practices of services and supports for that target group.

In a comprehensive waiver serving multiple target groups we believe that it is important to assure that the specialized supports and services remain available to individuals who need highly tailored supports and services such as those with brain injury, autism spectrum disorders, co-occurring developmental disabilities and mental illnesses, seniors with dementia or Alzheimer's disease or persons with other conditions. Additionally, these supports and services must be delivered by trained professionals in community settings.

The vast majority of paid community supports received by persons with developmental disabilities and their families are provided by direct support professionals who offer a wide range of supportive services, including the educational, social, physical, health and therapeutic supports. Currently, there are not nearly enough trained providers of services and supports. The physical and emotional demands of direct support work, the need for adequate and individualized preparation of direct support professionals for it, and the relatively low compensation for those who perform it, have contributed to turnover rates that nationally average 40 to 70% as well as vacancy rates that nationally average more than 10%. Direct support for persons with disabilities has been projected by the Department of Labor to be seventh among the fastest growing occupations in the next decade, with the number of direct support professionals needed by persons with developmental disabilities projected to grow by 40% by 2020. Tens of thousands of families face the future with fear that there will be no one to take care of their sons and daughters with developmental disabilities in the community when they are no longer able to do so themselves.

*Duration, extension, and amendment of a waiver*

AUCD strongly supports the use of a public input period for proposed waiver modifications. In particular, AUCD endorses the participation of waiver program beneficiaries and/or their representatives in the waiver review and planning process.

AUCD appreciates the opportunity to provide input and again thanks CMS for its initiative in proposing these regulations to improve the quality and availability of Medicaid home and community-based services.

Again, thank you for the opportunity to comment on this proposal. Please feel free to contact me or Kim Musheno at AUCD at 301-588-8252; [kmusheno@aucd.org](mailto:kmusheno@aucd.org).

Sincerely,



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