

June 29, 2012

Centers for Medicare & Medicaid Services  
Department of Health and Human Services  
Attention: CMS-2249-P2  
Mail Stop: C4-26-05  
7500 Security Boulevard  
Baltimore, MD 21244-1850

**RE: File Code CMS-2249-P2**

To Whom It May Concern:

On behalf of the Association of University Centers of Disabilities (AUCD), we are happy to have the opportunity to comment on the proposed rule regarding the Medicaid Program State Plan Home and Community-Based Services and Setting Requirements for Community First Choice published in the *Federal Register* on May 3, 2012.

AUCD is a national non-profit organization and network of interdisciplinary programs made up of 67 University Centers for Excellence in Developmental Disabilities funded by the Administration on Intellectual and Developmental Disabilities, 43 Leadership Education in Neurodevelopmental Disabilities programs funded by the Maternal and Child Health Bureau, and 15 Intellectual and Developmental Disability Research Centers funded by the National Institute for Child Health and Development. These programs are located in every state and territory and serve as a bridge between the university and community. The AUCD network partners with individuals with disabilities, their families, and communities to promote policy and practice. We thank you for this opportunity to comment on these important regulations.

General Comments:

AUCD applauds the direction that CMS has taken in defining home and community-based services (HCBS) and incorporating the values of person-centered planning into these services. We appreciate the great amount of work CMS has put into previous notices and advance notices to improve these regulations, and we believe that the proposed language will help states meet their obligations under the Americans with Disabilities Act (ADA) and U.S. Supreme Court *Olmstead* decision to serve individuals in the most integrated setting appropriate to their needs. With Convention on the Rights of People with Disabilities (CRPD) currently before the Senate Foreign Relations Committee, it becomes more evident that the strong principles embedded in the ADA and the Convention which around equal treatment and non-discrimination should run through all disability rights laws, including proposed and final regulations (see excerpt of the CRPD below). With this in mind, we offer these comments regarding the characteristics of home and

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community-based settings, person-centered planning, and independent assessments that we hope will help CMS continue to refine HCBS regulations and improve the lives of people with disabilities across the nation.

As a general comment, we think that CMS might find useful some of the language regarding community living in Article 19 of the United National Convention on the Rights of Persons with Disabilities and the definition of Self-Determination included in the Developmental Disabilities Assistance and Bill of Rights Act of 2000. CMS should consider the definitions and values outlined in these documents when finalizing these regulations, writing new documents, and when considering cases that trigger the rebuttable presumption outlined in section 441.530(a)(2)(v) and 441.656(a)(2)(v).

Article 19 of the United Nations Convention on the Rights of Persons with Disabilities protects the right to live independently and be included in the community. It states:

State Parties to this Convention recognize the equal right of all persons with disabilities to live in the community, with choices equal to others, and shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community, including by ensuring that:

- a) Persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement;
- b) Persons with disabilities have access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community;
- c) Community services and facilities for the general population are available on an equal basis to persons with disabilities and are responsive to their needs.

This convention has been signed by 153 states and provides guidance on what it means to live independently in the community. We encourage CMS to keep this article in mind when considering the characteristics of home or community-based settings or those settings that may give rise to a rebuttable presumption.

Section 102(27) of the Developmental Disabilities Assistance and Bill of Rights Act of 2000 defines “Self-Determination Activities” as:

Activities that result in individuals with developmental disabilities, with appropriate assistance having –

- (A) the ability and opportunity to communicate and make personal decisions;
- (B) the ability and opportunity to communicate choices and exercise control over the type and intensity of services, supports, and other assistance the individuals receive;
- (C) the authority to control resources to obtain needed services, supports, and other assistance;
- (D) opportunities to participate in, and contribute to, their communities; and
- (E) support, including financial support, to advocate for themselves and others, to develop leadership skills, through training in self-advocacy, to participate in coalitions, to educate policymakers, and to play a role in the development of public policies that affect individuals with developmental disabilities.

This section of the Act provides a definition for self-determination and the activities that promote it. While home and community-based services do not directly financially support self-determination activities, the principles of self-determination should be shared by the providers of home and community-

based services and should permeate the HCBS system. CMS should keep the importance of self-determination in mind when considering new regulations and definitions of home or community-based settings.

We strongly support CMS's intention to align all regulations pertaining to sections 1915(i), 1915(k), and 1915(c) Medicaid HCBS authorities. This alignment will reduce confusion and improve services for all beneficiaries receiving HCBS, regardless of the regulatory authority that governs their services. Based on the value of this alignment, and the promise shown in these proposed regulations, we encourage CMS to consider extending these rules to all authorities through which individuals may receive HCBS, including 1115 global waivers.

## **Definitions**

Throughout the NPRM, there are terms we felt could use greater clarification. We recommend a definitions section to clarify these terms, including the following definitions.

### *Person-Centered Planning*

Person-centered planning is central to the proposed regulations. We propose that CMS include the definition created by Support Development Associates – noted experts in the person-centered planning field.<sup>1</sup>

Person centered planning refers to a family of approaches designed to guide change in a person's life. This type of planning is carried out in alliance with the person, their family and friends and is grounded in demonstrating respect for the dignity of all involved. Recognized approaches seek to discover, understand and clearly describe the unique characteristics of the person, so that the person:

- Has positive control over the life he/she desires and finds satisfying;
- Is recognized and valued for their contributions (current and potential) to their communities; and
- Is supported in a web of relationships, both natural and paid, within their communities.

### *Informed Choice*

CMS references choice throughout the document, including sections 441.530(a)(1)(ii), 441.530(a)(1)(iv), 441.530(a)(1)(v), 441.530(a)(2), 441.665(a)(1), 441.665(a)(2), 441.665(a)(6), and 441.665(b)(1). Based on the importance of choice in an individual's life and the prevalence of choice throughout the document, AUCD recommends that CMS include a definition for informed choice that should be applied throughout the regulation. For informed choice, we recommend a definition in line with that used in the Rehabilitation Act (Title I, Part A, Sec. 100(a)(3)(c)). We have adapted the definition from that section to include the language of residential setting and services. We propose that informed choice means: "Ensuring individuals with disabilities are active participants in their own [residential setting, services, and supports selection], including making meaningful and educated choices about the selection of their [residential setting, services, and supports]; choices that result from a rational and systematic decision-making process that occurs in a context free from coercion, and are based on an understanding of their options, as conveyed by community providers and/or transition specialists that have sufficient knowledge about community living [ ] to present individuals and their families with specific possibilities for community placements."

### *Shared Authority*

CMS uses this term in Section J of the background (page 26390 of the notice), noting that the intent of the requirements regarding person-centered service planning "is to ensure a process with shared authority

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<sup>1</sup> For more information see [www.sdaus.com](http://www.sdaus.com)

between the individual and the agency and agent”. Shared authority does not have a standard regulatory or legal definition that we are aware of, so we ask that CMS clarify what this means.

### *Substituted Judgment*

In regards to section 441.671 Definition of Individual’s Representative, we recommend a “substituted judgment” standard of decision-making. We propose a definition based on that of the National Guardianship Association: Substituted judgment is a principle of decision-making that promotes the self-determination of the beneficiary and that substitutes, as the guiding force in any surrogate decision made by the guardian, the decision the beneficiary themselves would make based on their own preferences and desires.<sup>2</sup>

### **§ 441.530 Home and Community-Based Setting and § 441.656 State plan home and community-based services under the Act**

The language in section 441.530 is repeated in section 441.656 (except in one noted provision). Our comments refer to section 441.530, but apply to both sections.

### *Qualities of a home and community-based setting*

AUCD strongly supports the general direction that CMS has taken in defining the appropriate settings for HCBS. However, we believe that there are some details of the provisions which should be made stronger to better protect and promote the dignity and self-determination of HCBS beneficiaries. Our comments are detailed below.

#### *441.530(a)(1)*

Part (a)(1) of this section reads “Home and community-based settings shall have all of the following qualities, and such other qualities as the as the Secretary determines to be appropriate, based on the needs of the individual as indicated in their person-centered service plan” AUCD has found that this could be interpreted in two ways. In the first interpretation, it could mean that home and community-based settings must have all of the qualities listed *and* the Secretary can require home and community-based settings to have additional qualities that are based on the needs of individuals documented in their person-centered service plans. In the second interpretation, the provision could mean that home and community-based settings must have the qualities listed, *but* only based on the needs of individuals documented in their person-centered plans, and the Secretary can determine additional qualities. In the first interpretation, the Secretary can require more qualities based on the needs of individuals. In the second, settings need only have certain qualities based on the documented needs of the individuals.

CMS should clarify the meaning of this provision. If CMS intended the first interpretation – that the Secretary can require settings to have additional qualities based on the needs of individuals – AUCD supports the provision. If CMS intended the second interpretation – than settings only have certain qualities based on service needs – AUCD does not support it. All home and community-based settings should have the requirements listed in subparts (i-vi), not to be modified through additions to the person-centered plan (except where explicitly listed in subpart (vi)). This provision would allow too easy a modifications process and encourage the modifications for convenience or well-meaning but inappropriately restrictive measures that CMS has sought to discourage.

#### *441.530(a)(1)(i)*

Part(a)(1)(i) of this section provides qualities of a home and community-based setting that include access to the greater community, employment, and control of personal resources. AUCD strongly supports the

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<sup>2</sup> National Guardianship Association “Standards of Practice”. 2007.  
[http://www.guardianship.org/documents/Standards\\_of\\_Practice.pdf](http://www.guardianship.org/documents/Standards_of_Practice.pdf)

language in this section, particularly the note that the setting is integrated in and facilitates access to the community “like individuals without disabilities.” We recommend that these qualities and this standard – comparison to the lives of people without disabilities – be applied to these regulations generally, and particularly in cases where access or freedom is in question. We believe that the qualities listed above – access to community, employment, and personal resources – embody the values of community living and the positive steps CMS has taken in this proposed rule.

#### 441.530(a)(1)(ii)

Subpart (ii) states that the setting must be selected by the individual among all available alternatives. We strongly support that a setting must be selected by an individual, but we believe that too often an individual is not offered a true choice, or that none of the options offered to an individual represented the most integrated setting available to him or her. The current language does not protect either of those concerns. We recommend that CMS strengthen the provision to require that individuals be offered a meaningful choice among all available alternatives, including the most integrated setting.

The subpart also states that the setting must be identified in the person-centered plan. We agree that a high-quality person-centered plan must include the residential setting a person has chosen, and that a high-quality person-centered planning process would include a meaningful choice of residences. However, we disagree that a setting must be identified in an individual’s person-centered plan in order to be considered home or community-based. That requirement refers to the quality of the plan, not the quality of the setting, and an individual should not be denied services in their desired living situation because that setting has not been identified in his or her person-centered plan. The provision that a setting must be included in the person-centered plan should be deleted here and included in the person-centered planning section of the regulations.

Based on these two concerns, we recommend revising the language to read “The setting is selected by the individual [following a meaningful and informed opportunity to choose] among all available alternatives, [including the most integrated setting,] ~~and identified in the person-centered service plan~~”.

#### 441.530(a)(1)(iii)

Subpart (iii) reads “an individual’s essential personal rights of privacy, dignity and respect, and freedom from coercion and restraint are protected”. We support this provision, but we find the terms “essential” and “personal” to be redundant and potentially misleading. This provision could be misread to imply that only the most essential rights must be protected, rather than all rights. Further, we find no difference between personal rights and other rights, so the qualifier “personal” is unnecessary. We recommend that the words essential and personal should be removed to reduce the chance for this confusion, and that the regulation should read “an individual’s ~~essential personal~~ rights of privacy, dignity and respect, and freedom from coercion and restraint are protected”.

#### 441.530(a)(1)(iv)

AUCD supports the language used in subpart (iv) without qualification.

#### 441.530(a)(1)(v)

Subpart (v) reads that “individual choice regarding services and supports, and who provides them, is facilitated.” We strongly support that beneficiaries must have choice regarding the provision of their services and supports. However, the term facilitated means “brought about”. AUCD recommends a stronger phrase. We believe that individual choice must be *ensured*, meaning “made certain or safe”. In a home or community-based setting, personal choice should not only be brought about, but be safe. We recommend revising the language to read “Individual choice regarding services and supports, and who provides them, is ~~facilitated~~ ensured”

Provisions pertaining to provider-owned settings

In regards to provider-owned or -controlled settings, CMS has proposed additional protections in section 441.530(a)(1)(vi)(A-E). CMS asked for comment on these requirements, the modification of these requirements based on service needs, a proposed process for modifying these requirements, and a specific proposed requirement regarding services as a condition for housing. We agree that more protections must be in place in a provider-owned or -controlled setting in order to ensure that the characteristics of home and community-based settings are maintained. We also agree that in rare cases, some of these provisions may be modified to meet the needs of beneficiaries. We agree with the two concerns raised by CMS in the background of the NPRM – 1) that people receiving HCBS must not have their independence or freedoms abridged by providers for convenience or well-meaning but unnecessarily restrictive methods of support, and 2) that some people with cognitive disabilities or other impairments may require modifications to some of the provisions for safety and welfare. However, we have specific concerns and recommendations about the modifications process. Our comments are listed below:

*441.530(a)(1)(iv) – Modification of Additional Protections:*

Section 441.530(a)(1)(iv) provides the conditions on which the additional provisions (A-E) could be modified. AUCD believes that Part (E), which requires that the residence be physically accessible to the beneficiary, should never be modified. While we agree that most other provisions may need to be modified, we cannot imagine an instance where this provision would need modification based on a service need. We recommend that CMS modify section 441.530(a)(1)(iv) to clarify that part (E) should never be modified.

*441.530(a)(1)(vi)(A-E) – Additional Requirements*

AUCD supports the inclusion of these requirements for provider-owned or -controlled settings, with two recommended revisions regarding Parts (A) and (B)(1).

AUCD supports Part (A), but recommends the addition of language to make clear the requirements of providers under landlord-tenant laws, and the requirements that providers should face in addition to landlord-tenant laws. In particular, we propose that CMS include language regarding situations where a provider is no longer legally allowed to provide care. In the event that an individual develop a medical or other need which the provider is legally prohibited from serving or supporting, it is the responsibility of the provider to assist the individual in finding other housing, services, and supports. We propose that Part A be modified to read “The unit or room is a specific physical place that can be owned, rented, or occupied under a legally enforceable agreement by the individual receiving services, [and the individual has, at a minimum, the same responsibilities and protections from eviction that the tenants have under the landlord/tenant laws of the State, county, city, or other designated entity, and the provider is obligated under the Americans with Disabilities Act to accommodate individual needs. If the provider is legally prohibited from providing the needed level of care, the provider must ensure appropriate housing and continuity of services and supports until an alternate setting is determined appropriate through the person-centered planning process.]”

Section (B)(1) of the provisions regarding provider-owned or -controlled settings notes that individual units must have lockable entrance doors with appropriate staff having keys. AUCD agrees that residents must have privacy in their individual units, which includes the capability to lock doors. AUCD also understands that it is necessary for staff to have keys to individual units for safety and welfare purposes. However, the regulation does not note a process to determine which staff will have keys, or that the individual themselves must have keys. CMS should add language to require that 1) the staff that will have keys are included in the person-centered service plan and chosen by the individual and 2) that the

individual themselves must also have a key to the door. We recommend adding “Staff holding keys will be named in the person-centered service plan and individuals must have keys to their own units” to 441.530(1)(vi)(B)(I), 441.656(1)(vi)(B)(1), and 441.665(b)(3) for clarity across the regulation.

*Proposed Process for Modifying Additional Protections:*

AUCD supports the inclusion of the additional language that CMS proposed in the background material outlining the process for modifications to these provisions. The proposed language states that the plan must “identify a specific and individualized assessed safety need; document less intrusive methods that have been tried but did not work; include a clear description of the condition that is directly proportionate to the specific assessed safety need; include regular collection and review of data to measure the ongoing effectiveness of the modification; and establishing time limits for periodic reviews to determine if the modification can be lifted” (page 26379 of the notice).

We agree that in rare cases some of these provisions must be modified; we also agree with CMS that these modifications should be made in a careful and systematic way that is incorporated into the service plan, rather than in an ad-hoc basis. However, we noticed that while the proposed language states that there must be “time limits for periodic reviews to determine if the modification can be lifted”, they do not state that the person-centered service plan should include documented attempts on the part of the service provider to provide support, services, or training to the individual that would lead to the lifting of modification, where appropriate. We recommend adding this language in order to emphasize that modifications to these provisions are not necessarily meant to be permanent, and providers must seek avenues to remove modifications if possible. We recommend modifying the proposed language to read: “identify a specific and individualized assessed safety need; document less intrusive methods that have been tried but did not work; include a clear description of the condition that is directly proportionate to the specific assessed safety need; include regular collection and review of data to measure the ongoing effectiveness of the modification; [include documentation of attempts to provide services, support, or training to the individual that would lead to the lifting of the modification;] and establishing time limits for periodic reviews to determine if the modification can be lifted.”

AUCD also found that while such a robust modifications process will go far to eradicate unnecessary restrictions, it could also prove unnecessarily cumbersome for some providers and beneficiaries. We would recommend that CMS encourage providers to instead provide a functional-behavioral needs assessment and implement positive behavioral interventions and supports (PBIS) when the cause for modification is behavioral. Functional-behavioral assessments, followed by PBIS, undertake many of the same steps outlined above and employ an evidence-based technique well known in the field. A functional behavioral assessment documents triggers and contexts for behaviors in the home environment to help support staff understand the roots of the behavior. The positive behavior supports and interventions plan based on the assessment and identifies strategies to prevent problem behaviors and to teach positive alternatives such as social-skills and self-regulation and replacement skills. Such a process improves the home environment for everyone and will limit the number of modifications to protections rooted in behavior needs.

*Modifications Should be Approved by Human Rights Committee*

AUCD also recommends that, in addition to the modifications process listed above, with the additional step recommended by AUCD, modifications to conditions A-E (excluding condition E) should also be approved by a human rights committee, made up of experts in human, civil, and disability rights. A committee of this nature will prevent cases where modifications are made for the convenience of providers or for well-intentioned but unnecessarily restrictive reasons.

### *Services as a Condition of Residence*

AUCD supports the inclusion of the requirement proposed by CMS in the background document that “receipt of any particular service or support cannot be a condition for living in the unit” (page 28379 of the notice). CMS listed two possible interpretations of the provision: first, that those residing in a provider-owned or -controlled setting do not need to accept services from that provider, but can instead seek another qualified provider for their services; second, that providers cannot evict an individual because the individual refused to accept a particular service. With regards to people with developmental disabilities, acceptance of services should never be a prerequisite for choosing a particular residence or service provider. Too often in the disability service system providers of residential services have required that residents also participate in employment or other services which may be inappropriate, unnecessary, or overly restrictive for the individual. People with disabilities should never be evicted for refusing to accept a service.

### *441.530(a)(2) Settings that are Not Considered Home or Community-Based*

With regard to section 441.530(2), AUCD supports the reiteration that nursing facilities, institutions for mental diseases, and ICFs/MR are never to be considered home or community-based. With regards to section (2)(iv), AUCD agrees that a hospital providing long-term care services is not a home or community-based setting. However, we recommend striking “providing long-term care services” from the definition for two reasons: 1) This leaves open the question whether a hospital providing acute (not-long-term) care services may be considered a home or community based setting, and a hospital providing acute care services is no more a home or community-based setting than a hospital providing long-term care services, and 2) removing this language would align the language used in 441.530(a)(2)(iv) which reads “a hospital providing long-term care services” and the language used in 441.626(a)(2)(iv) which reads “a hospital”. We also wish to reiterate and support what CMS noted in the background on page 26380 of the notice, that while HCBS are not available in an institution or hospital they should be available to assist an individual to leave an institution or hospital. Admission to a hospital should not disqualify a beneficiary for HCBS; instead HCBS should be available to help the individual transition back home.

Furthermore, we strongly encourage CMS to include certain transition services in the list of “other services” to be offered to individuals to assist them in their return to the community.” The preamble of the proposed rule (Background section (E)(2.)) states that “recognizing that individuals leaving institutions require assistance to establish themselves in the community, we would allow States to include in a section 1915(i) benefit, as an “other” service, certain transition services to be offered to individuals to assist them in their return to the community.” This language does not appear in the regulation, however, and we urge that the clearly state that transition services can be covered under a 1915(i) option, and that they can be provided to individuals moving from a hospital or other institution, or from homelessness, into a home and community based setting. The regulation should also specify examples of the types of supports that may be covered as transition services, and these should include, at a minimum, the same as those now allowed for 1915(c) waivers, such as security deposits required to obtain a lease; set-up fees or deposits for utility or service access (e.g. telephone, electricity, heating); essential furnishings and moving expenses, and health and safety assurances (such as pest eradication, allergen control or one-time cleaning prior to occupancy).

### *441.530(a)(2)(v) – The Rebuttable Presumption*

AUCD supports the rebuttable presumption that CMS will apply to the settings listed in section (v). However, we are concerned about the capacity of some communities to comply with this requirement with regards to disability-specific housing complexes. For many years, the Department of Housing and Urban Development (HUD) constructed complexes of disability-specific housing that remains among the only accessible and affordable housing available in some areas. We commend the work that HHS, CMS, HUD, and the Department of Transportation have done in this area in the Year of Community Living

initiatives to expand community access and capacity, and we support the current efforts of CMS and HUD to align programs, including the expansion of tenant-based, rather than project-based, affordable housing programs. We agree that a disability-specific housing complex is not an ideal home or community-based setting, and we must work as a nation to expand our supply of affordable and accessible housing. However, we do not wish to disqualify beneficiaries from home or community-based services based on lack of capacity and past federal action in their communities. With this in mind, we recommend a phase-in period of 3-5 years for this particular provision before enforcement takes effect. This period would allow recent HUD voucher programs to take effect and give a sufficient warning period to providers and tenants regarding the rule.

#### *Additional characteristics of home and community-based settings*

CMS specifically asked for comments on whether there are settings in addition to those currently enumerated that are, by their nature, location, or administration inherently non-community based. In the background document (page 26384) CMS noted that other characteristic that CMS might consider to render a setting institutional include but are not limited to “settings which are isolated from the broader community, do not allow individuals to choose whether or with whom they share a room, limit individuals’ freedom of choice on daily living experiences such as meals, visitors, and activities, or limit individuals’ opportunities to pursue community activities”. Some, but not all, of these characteristics are included in the regulatory language. We recommend that CMS include this description of non-community based settings in section 441.530(a)(2)(v) and note that these characteristics would give rise to the rebuttable presumption that the setting is institutional in nature.

#### **§ 441.662 Independent Assessments**

Regarding sections 441.662(b), 441.65(a)(7), and 441.665(c) AUCD agrees that reassessments and revisions to the person-centered plan should occur frequently, when an individual’s support needs or circumstances change significantly, or when requested by the individual as stated in section 441.665 (a)(7) and 441.664(c). However, we have three concerns: 1) that assistive technology or other alternative or augmentative communication should be made available for those who would benefit from it, 2) for individuals unable to communicate via spoken, signed, written, or alternative/augmentative communication, the regulations should include language that significant changes in behavior and/or temperament indicate a need for reassessment of services and an individual’s request to modify the plan, and 3) CMS should clarify that the requirement for reassessment should not be interpreted to mean that each individual requires a full-scale medical re-evaluation (in the traditional medical model of services), but instead re-evaluation of services currently being used by the individual and assessment for new services requested by the individual or those important to him or her. The assessment and re-assessment process should be based primarily on individual need, and not place burdensome processes on the individual.

#### **§ 441.665 Person-centered service plan**

AUCD strongly supports the inclusion of person-centered planning in these regulations. We also agree with CMS in their decision to change the language from “care plan” to “service plan”, as noted in the background document on page 26371 of the notice, in alignment of language across sections 1915(c), 1915(i), and 1915 (k) and consistent with a person-centered approach. Additionally, the “service plan” should be constructed in a manner that promotes service delivery and independent living in the most integrated setting possible. We encourage CMS to consider using the term “service and support plan” in the future, to even better capture a person-centered and empowered approach to service and support delivery.

#### 441.665(a)(1)

AUCD agrees with CMS in provision 441.665 (a)(1) that the person-centered planning process should include people chosen by the individual. We would like to emphasize that individuals should be allowed to express preferences for the individuals involved via their own method of communication – be it speaking (in their native language), signing, or alternative or augmentative communication. Also, in cases where the beneficiary has difficulty articulating or cannot name specific preferences, the process should include people who know and care about the individual. We recommend revising the regulation to read “Includes people chosen by the individual [and who know and care about the individual].”

#### 441.665(a)(2)

Subpart 441.665(a)(2) requires that the person-centered planning process “provides necessary information and support to ensure that the individual directs the process to the maximum extent possible, and is enabled to make informed choices and decisions.” AUCD is concerned that some people with intellectual and developmental disabilities will require exposure to a variety of options before they can make informed choices. The planning process may require multiple meetings and/or visits to residential sites to ensure that the individual is participating and directing the process to the maximum extent and making his or her own decisions. We recommend that CMS modify the provision to read: “provides necessary information,[experiences,] and support to ensure that the individual directs the process to the maximum extent possible, and is [provided meaningful opportunity] ~~enabled~~ to make informed choices and decisions.”

#### 441.665(a)(3)

AUCD supports the provision in section, 441.665(a)(3) that the person-centered planning process must be timely and at the convenience of the individual. However, we recommend adding “and flexible” to the provision listed in section in order to emphasize that person-centered planning is process that should be responsive to the changing needs, preferences, and circumstances of the individual, rather than a simple event. We recommend that CMS revise the provision to say, “Is timely[, flexible,] and occurs at times and locations of convenience to the individual.”

#### 441.665(a)(8)

Section 441.665(a)(8) requires that the plan record the alternative home and community-based settings that were considered by the individual. AUCD agrees that individuals should have as many options as possible in their residential settings, and that including the other options considered by the individual will help ensure that other options are, in fact, provided. However, this provision could create unnecessary burdens on beneficiaries who choose to live in their *own* homes. If a beneficiary lives in his or her own home, he or she should not be required to consider other environments that are most likely more restrictive. AUCD recommends that CMS amend the regulation to read “Records the alternative home and community-based settings that were considered by the individual [if the individual is not residing in his or her own home].”

#### 441.665(b)

AUCD strongly supports the inclusion of a person-centered plan as a requirement for HCBS, and we generally support the provisions of person-centered planning outlined in section 441.665(b). We especially support the inclusion of language differentiating what is “important for” a beneficiary from what is “important to” a beneficiary. According to best practices and research in person-centered planning, what is *important for* a person includes the help or support that they need to be healthy and safe, while what is *important to* a person is what really matters to them, from their perspective.<sup>3</sup> However, the language proposed by CMS requires that the service plan must reflect the services and supports important

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<sup>3</sup> See The Learning Community at: <http://learningcommunity.us>

*for* the individual, and what is important *to* him or her only in the delivery of those services and supports. This reads as if what is important *to* the individual is a subset of what is important *for* him or her, only including what is important *to* the individual with regard to the delivery of service and supports that are important *for* him or her. In a true person-centered process, the plan would also include what is important *to* the individual in matters other than the delivery of services, such as preferences for living arrangements, neighborhoods, leisure activities, etc. We recommend adding “and other preferences of daily living important to the individual” in order to capture this aspect of person-centered planning and emphasize the importance of choices in what is important to an individual, beyond the delivery of services and supports. We recommend that it read, “The person-centered service plan...delivery of services and supports [and other preferences of daily living important to the individual]. Commensurate...”

#### *441.665(b)(5)*

In section 441.665(b)(5), CMS uses the term natural supports. Most people in the field use the term “natural supports” interchangeably with “informal supports”. In order to reduce confusion, CMS should provide a definition of natural supports that makes clear that natural supports are the same as informal supports.

#### *441.665(b)(7)*

Subsection 441.665(b)(7) reads that the service plan must be understandable to the individual. Understandability refers to an individual’s ability to comprehend the material provided. This means that the material must be both in a language that the individual knows (and/or prefers to communicate in) and be of sufficient readability. Accessibility means that the material is provided in a format reasonable to the individual. Given that these are different and both important, AUCD recommends adding language that includes accessibility and native language in provisions 441.665(b)(7) and 441.664(b)(10), in order to emphasize that plans must be both understandable and accessible to the beneficiary and others important to him or her.

#### *Access to Allocated Budgets*

Finally, we recommend that CMS consider expanding some of the benefits available to those self-directing their supports to those who choose not to self-direct. Specifically, individuals who self-direct services have access to an individualized budget of services available to them. While beneficiaries not self-directing services may not control a personal budget of expenditures, they should have access to the allocation of funds used by their service provider. Experts in our network have found that the inclusion of dollar figures and individual allocation in person-centered service plans helps to promote autonomy among individuals and understanding between providers and beneficiaries. We recommend that each person-centered service plan include the dollar figures of the budget allocations provided to each beneficiary.

### **§ 441.668 Provider Qualifications**

Our comments in this section refer to the definition and qualifications of the agents who perform assessments, as referenced in sections 441.668 and 441.662.

Agents performing assessments serve a crucial role in the HCBS system proposed under this rule. These agents perform the assessments that shape the person-centered planning process, determine which services and supports an individual will receive, how those services and supports may change, and when they may be eliminated, as reference in sections 441.662, 441.665(a), and 441.665(b). They also perform the assessments to determine if modifications can be made to the protections listed in section 441.530(a)(1)(vi)(A-E), which are designed to protect the rights and freedoms of beneficiaries.

Despite this crucial role, relatively little is said about the training or qualifications of these agents. Section 441.668(c) states that agents must have “training in assessment of individuals whose physical or mental conditions trigger a potential need for home and community-based services and supports, and current knowledge of best practices to improve health and quality of life outcomes”. Section 441.662(a)(1)(i)(A) also refers to the qualifications of the assessor, specifying that the assessor is “health care professional” and meets qualifications defined by the State, including in the operation of required information technology.

AUCD has a number of concerns regarding the paucity of requirements listed here. Despite the critical role played by these agents in ensuring proper services and supports are supplied, the proposed rules regarding the training, qualifications and necessary competencies are not clearly stated and defined. It is unclear if one agent performs an assessment, or different agents with different expertise. It is unclear what qualifications agents must possess, apart from the reference in section 441.662(a)(1)(i)(A) that they must meet the qualifications as determined by the State. This is of concern because many states do not have training requirements in place for people who provide services to beneficiaries of HCBS. Minimally these agents must have skills and competencies in person centered planning and assessment techniques. We are also concerned by the reference in section 441.662(a)(1)(i)(A) to “health care professionals,” given that often assessments of support needs – such as the Supports Intensity Scale and functional-behavioral needs assessments – are made by case managers or social workers, rather than health care professionals.

AUCD recommends much more detailed clarification on the training, qualifications, and necessary skills and competencies required of agents who perform assessments. At a minimum, we recommend that agents must have current knowledge in evidence-based practices for assessment and evidence-based best practices to improve health and quality of life outcomes for beneficiaries with various types of disabilities and related support needs. We recommend that CMS identify broad competency areas and then identify the specific skills associated with each of these competency areas. As an illustrative example:

1. Assessment:
  - a. knowledgeable about formal and informal assessment practices in order to respond to the needs, desires and interests of the participants,
  - b. completes an assessment process by gathering information (e.g., participant's self-assessment and history, prior records, test results, additional evaluation) and informing the participant about what to expect throughout the assessment process,
  - c. discusses findings and recommendations with the participant in a clear and understandable manner, following up on results and reevaluating the findings as necessary,
  - d. Select and use a comprehensive assessment process that is sensitive to age, gender, racial and ethnic culture, and disabilities,
  - e. Document assessment findings and treatment recommendations;
2. Person Centered Planning and Thinking,
  - a. enhances the ability of the participant to lead a self-determining life by providing the support and information necessary to build self-esteem, assertiveness, and to make decisions
  - b. provides assistance to persons in ways that focus on his/her dreams, hopes, strengths, challenges, and needs
  - c. implements an individualized plan based on the individual’s preferences, needs, and interests

A competency framework of this kind would ensure that agents performing assessments. AUCD would be happy to provide more information on competency frameworks.

#### 441.671 Definition of Individual's Representative

Section 441.671 defines an individual's representative. AUCD supports the provisions that an individual's representative may not necessarily be the individual's guardian, but some other representative freely chosen by the individual and important to him or her. Part C of this section refers to the authorization of representatives and the assurance that representatives act in the best interest of the participant. The National Guardianship Association (NGA) has established clear guidelines regarding best interest and decision-making that we believe apply here. According to the NGA, the best course of action for a guardian or substitute decision-maker to take is to first consider the *substituted judgment* of the individual in question. Substituted judgment is a decision-making process in which the substitute decision-maker considers the preferences, wishes, opinions, and desires of the individual to try to determine what choice the individual would make for themselves. This process involves consultation with the individual and those important to him/her. The NGA also says that if a substituted judgment is not available, guardians can implement a "best interest" principle, which considers all options and alternatives and bases the decision on what a reasonable person would do in the given situation. However, the NGA is clear that a best interest principle is a less-desirable option and is only implemented when substituted judgment is not available. For more information see the NGA's Standards of Practice<sup>4</sup> and information on surrogate decision making.<sup>5</sup> AUCD recommends that CMS revise the language to include a substituted judgment standard of decision-making by an individual's representative in line with the standards of practice for guardians, and provides a definition of "substituted judgment" in the definitions section.

We recommend that CMS revise the regulation to read: When the State authorizes representatives in accordance with paragraph (b) of this section, the State must have policies describing the process for authorization; the extent of decision-making authorized; and safeguards to ensure that the representative functions in the ~~best interests~~ [substituted judgment] of the participant. States may not refuse the authorized representative that the individual chooses, unless in the process of applying the requirements for authorization, the State discovers and can document evidence that the representative is not acting in the ~~best interest~~ [substituted judgment] of the individual or cannot perform the required functions.

Thank you again for this opportunity to comment on these regulations important to so many people with disabilities and their families. If you have any questions about our comments, please feel free to contact Kim Musheno at kmusheno@aucd.org or 301-588-8252 or Dawn Rudolph at drudolph@aucd.org or 301-588-8252.

Sincerely,



George Jesien, PhD  
Executive Director

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<sup>4</sup> National Guardianship Association. "Standards of Practice." 2007.  
[http://www.guardianship.org/documents/Standards\\_of\\_Practice.pdf](http://www.guardianship.org/documents/Standards_of_Practice.pdf)

<sup>5</sup> National Guardianship Association. "The Guardian as Surrogate Decision-Maker."  
[http://www.guardianship.org/pdf/Surrogate\\_Decision\\_Maker.pdf](http://www.guardianship.org/pdf/Surrogate_Decision_Maker.pdf)