June 29, 2012

Marilyn Tavenner

Acting Administrator

Centers for Medicare & Medicaid Services

Department of Health and Human Services

Attention: CMS-2249-P2

7500 Security Boulevard

Baltimore, MD 21244-1850

Re: Medicaid Program; State Plan Home and Community-Based Services, 5-Year Period for Waivers, Provider Payment Reassignment, and Setting Requirements for Community First Choice (2249-P2)

Dear Administrator Tavenner:

The Arc is the nation’s oldest and largest nonprofit organization for people with intellectual and developmental disabilities (I/DD), promoting and protecting their human rights and actively supporting their full inclusion in the community throughout their lifetimes. The Arc’s 705 state and local chapters, in 49 states and the District of Columbia, serve more than 1.5 million people with I/DD and immediate family members with a diverse range of services in the area of education, health care, employment, housing and community living, financial planning and more.

**Section 441.530 Home and Community-Based Setting**

**Section 441.656 State plan home and community-based services**

1. Qualities of home and community-based settings (Sections 441.530(a)(1) and 441.656(a)(1))

The Arc supports the proposed list of qualities that define home and community-based settings in **Section 441.530(a)(1) and Section 441.656(a)(1)**. The listed qualities promote integration of people with disabilities into typical neighborhoods and communities “like individuals without disabilities.”

We suggest that additional language be added to **Section 441.530(a)(1)(ii) and Section 441.656(a)(1)(ii)** that we believe would strengthen the proposed rule. The proposed rule should include language that reflects the tenets of the ADA and the Olmstead decision, and include language that reflects that the individual’s choice of setting must be an informed choice. We suggest that Section 441.530(a)(1)(ii) and Section 441.656(a)(1)(ii) be modified as follows:

*The setting is selected by the individual following a meaningful opportunity to choose from all available alternatives, including the setting that is the most integrated setting appropriate for the individual.*

Individuals with intellectual and developmental disabilities (I/DD) may need more than verbal descriptions or pictures of alternatives in order to make meaningful choices. They may need to visit alternative settings, perhaps more than one time, in order to make an informed choice. The setting that is the most integrated setting appropriate for the individual is more specific than the proposed “all available alternatives” and conveys clearly that states must ensure compliance with the ADA.

The Arc suggests that **Section 441.530(a)(1)(iii) and Section 441.656(a)(1)(iii)** state clearly that individuals’ human rights (privacy, dignity and respect, and freedom from coercion and restraint) must be protected. We suggest that “essential personal” be omitted to avoid confusion.

In **Section 441.530(a)(1)(v) and Section 441.656(a)(1)(v),** The Arc suggests that the word “facilitated” be omitted and that “ensured” be substituted. Individual choice of services and supports and who provides them is one of the key elements of home and community-based services and must be ensured.

1. Qualities of provider-owned or controlled home and community-based settings (Sections 441.530(a)(1)(vi) and 441.656(a)(1)(vi))

The Arc believes that in provider-owned or controlled residential settings modifications of the conditions (qualities) in **Section 441.530(a)(1)(vi)(A)-(E) and Section 441.656(a)(1)(vi)(A)-(E)** may be necessary in order to safeguard the health and safety of some individuals. Such modifications should be rare. Ensuring individual autonomy and independence should be balanced against perceived safety or health risks. The standard for instituting conditions should be a high standard. The Arc suggests that additional requirements be added to Section 441.530 (a)(1)(vi) and Section 441.656(a)(1)(vi):

*The person-centered plan must document the specific and individualized assessed health or safety needs that require a modification, that less restrictive alternatives have been tried but were not successful, and attempts to provide services, supports, or training to the individual that will lead to lessening or discontinuing the modification. The person-centered plan must include a schedule, at least every six months, for reviewing the modifications to determine their effectiveness and continued need.*

Consideration should be given to giving human rights review committees the additional responsibility of reviewing modifications of the conditions to ensure the protection of individuals whose basic human rights must be restricted. There should be a clear appeal process available for any individual who does not agree to the conditions.

The Arc supports giving individuals who receive home and community-based services in provider-owned or operated settings **Section 441.530(a)(1)(vi)(A) and Section 441.656(a)(1)(vi)(A)** protections regarding transfer and discharge. The Arc suggests the following:

*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 that defines the individual’s due process rights prior to any transfer or discharge.*

CMS asked for comments about including as a criterion for provider-owned or controlled residential settings a requirement that receipt of any particular service or support cannot be a condition for living in the unit. The Arc supports inclusion of the criterion and believes that individuals should have the right to choose their living environment as well as their supports and services. Settings that require a type of treatment in order to participate in the program and live in the setting are not home and community-based settings.

The Arc supports the delineation of settings that would not be considered home and community-based settings in **Section 441.530 (a)(2) and Section 441.656(a)(2)** but believes there should be additions to the list and one modification. We suggest that any setting that is located in a building or on the grounds of or adjacent to a public or private facility that provides institutional treatment be included in the list of settings that would not be considered home and community-based settings. We believe that Section 441.530(a)(2)(iv) should mirror Section 441.656(a)(2)(iv) and include any hospital, not just hospitals that provide long term care.

In addition, we believe that CMS needs to add clarifications to prevent some unintended consequences.  Many state institutions across the country are located in or near neighborhoods within cities; while in other areas, suburbia has surrounded once rural institutions.  CMS needs to clarify that individuals living in their own typical homes, either by themselves, with roommates, or in the family home, even if adjacent to an “institution” (ICFs, nursing facilities, or hospitals) are not disqualified from HCBS services.  CMS should also address the situation where individuals live in a group home of typical size for the neighborhood, in close proximity to an ICF, nursing facility, or hospital with which it is **not associated in any way**.  This latter situation is becoming more common as living situations are becoming more dispersed.  Residents of the group home should not be penalized.

The Arc believes that CMS did not intend to include group homes located in and fully integrated into typical neighborhoods within the meaning of “disability-specific housing complex” in **Section 441.530(a)(2)(v) and Section 441.656(a)(2)(v)**. The Arc suggests that CMS clarify that our interpretation is correct.

The Arc believes that there is a need to accommodate settings that resulted from past federal policy, for example the HUD Section 811 supportive housing for persons with disabilities program complexes which carry long-term leases (typically a 30-year use restriction). Beginning in 2012, under the Melville Act program, we expect that Section 811 funds will be directed toward integrated settings. CMS should consider working with HUD to formulate federal policy to help transition facilities constructed with pre-Melville Act funds into integrated settings, and any transition should be accomplished in a manner that increases access to and availability of affordable, integrated housing for individuals with disabilities. The rule should include a “grandfathering” provision. Consideration should be given to establishing a reasonable target date for completion of a CMS-HUD transition process. We believe that clarity about what is not a home and community-based setting together with a grandfather provision will move the provision of services forward without penalizing providers nor jeopardizing individuals who live in settings we no longer view as fully integrated in the community.

1. State Plan Home and Community-Based Services for Elderly and Disabled Individuals

The Arc suggests that **Section 441.665(a)(1)** address those individuals who are not able to indicate a choice of whom they would like to participate in the person-centered planning process. For those individuals, the process should allow inclusion of people who know and care about the individual.

In **Section 441.665(a)(2),** The Arc reiterates its suggestions made above concerning meaningful choice. Extra efforts may be required to enable individuals with intellectual and developmental disabilities (I/DD) to direct the person-centered planning process to the maximum extent possible and to make informed choices and decisions. Individuals leaving institutional settings, for example, may never have had the opportunity to direct planning about their lives or to make their own decisions. Some individuals with I/DD will require exposure to a variety of options before they can make informed choices. The planning process may take longer and require multiple meetings to ensure that the individual is participating and directing the process to the maximum extent and making his or her own decisions. The Arc suggests the following:

*The process: (2) Provides necessary information, support and experiences, if needed, to ensure that the individual directs the process to the maximum extent possible, and is provided meaningful opportunity to make informed choices and decisions.*

The Arc supports **Section 441.665(b),** The person-centered service plan. We would suggest that equal emphasis be placed on what is important for the individual and what is *important to* the individual. The Arc suggests:

*The person-centered service plan must reflect the services and supports that are important for the individual to meet the needs identified through an assessment of functional need, and what is important to the individual with regard to preferences for the delivery of such services and supports, including, but not limited to, living arrangement, neighborhood, leisure activities, and relationships.*

The Arc suggests that **Section 441.668(c)** be strengthened. Agents performing independent assessments and plans of care will play critically important roles in individuals’ lives. The Arc suggests the following:

*Qualifications for agents performing independent assessments and plans of care must include training in evidence-based best practices in assessment of individuals whose physical or mental conditions trigger a potential need for home and community-based services and supports, current knowledge of best practices to improve health and quality of life outcomes, person-centered planning, informed decision-making, and improving the health and quality of life outcomes for people receiving home and community-based services.*

In **Section 441.671(c),** The Arc has concerns about the term “best interest.” The representative should use substituted judgment rather than best interest when acting as the individual’s chosen representative. Exceptions to using substituted judgment are warranted if following the individual’s wishes would cause substantial harm to the individual or if the representative cannot ascertain the individual’s wishes. In those situations, the best interest standard must be used. The Arc suggests that the section read as follows:

*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 uses substituted judgment on behalf of the individual. State policies must address exceptions to using substituted judgment when the individual’s wishes cannot be ascertained or when the individual’s wishes would result in substantial harm to the individual. 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 accordance with these policies or cannot perform the required functions.*

CMS may wish to refer to the National Guardianship Associations Standards of Practice, 7- Standards for Decision-Making[[1]](#footnote-1)

The Arc believes that these rules would not preclude receipt of certain home and community-based services, employment supports for example, simply because an individual, who did not request or receive residential services, were residing in a setting that did not meet the qualities of a home and community-based setting, a board and care setting, for example. The Arc believes that individuals should be able to receive employment and other supports that would enable them to participate in integrated activities even if they reside in settings that are not home and community-based. The Arc requests that CMS clarify this position.

The Arc appreciates the opportunity to comment on the proposed regulations.

Sincerely,

Maureen Fitzgerald

Director, Disability Rights

1. National Guardianship Association *Standards of Practice Third Edition 2007.* <http://www.guardianship.org/documents/Standards_of_Practice.pdf>. Accessed 6/26/12.

   II. SUBSTITUTED JUDGMENT

   A. Substituted Judgment is the principle of decision-making that substitutes,

   as the guiding force in any surrogate decision made by the guardian, the

   decision the ward would have made when competent.

   B. Substituted Judgment promotes the underlying values of self-determination

   and well-being of the ward.

   C. Substituted Judgment is not used when following the ward’s wishes would

   cause substantial harm to the ward or when the guardian cannot establish

   the ward’s prior wishes. [↑](#footnote-ref-1)