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For people with intellectual
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Donald M. Berwick, Administrator
Centers for Medicare & Medicaid Services
Department of Health and Human Services
Attention: CMS-2296-P
P.O. Box 8016
Baltimore, MD 21244-8050

June 14, 2011

RE: Comments on CMS Proposed Rule for "Medicaid Program: Home and Community-Based Services (HCBS) Waivers" (42 CFR Part 441, CMS-2296-P, RIN 0938-AP61)

Submitted via: http://www.regulations.gov

Dear Administrator Berwick:

Thank you for this opportunity to comment on the Notice of Proposed Rulemaking (NPRM) for the Medicaid Program: Home and Community-Based Services (HCBS), published in the Federal Register on April 15, 2011. These comments are submitted on behalf of The Arc of the United States.

The Arc has over 140,000 members and more than 700 state and local chapters made up of people with intellectual, developmental, and other disabilities, their families, friends, interested citizens, and professionals. The Arc has represented individuals with disabilities for 60 years.

We support the enhanced flexibility provided in these proposed rules that would give states the option of designing services around individual needs rather than diagnosis. We commend CMS for continuing to push providers and states toward more person-centered and consumer-controlled services for people with intellectual and developmental disabilities. We are encouraged that CMS has continued to heed the input of stakeholders as it grapples with defining characteristics of home and community-based settings. The changes in the proposed rule will enable systems to more easily move toward service delivery that supports person-centered, self-determined lives.

We have comments about certain provisions of the NPRM that could be open to varied interpretations and, we believe, are in need of further clarification. We also offer comments that we believe would strengthen the rule.

Section 441.301 Contents of request for a waiver.

The person-centered planning process and the person-centered plan

The Arc applauds the strong emphasis on person-centered planning in this section. We support placing the individual receiving the services at the center of and in control of the planning process. In order to ensure that the needs, desires, and preferences of individuals with intellectual disabilities are central to the planning process, we feel strongly that in (b)(1)(i)(A) the phrase "or the individual's representative" be added. An individual with an intellectual disability who cannot independently express needs, goals, preferences, and wishes must have a freely chosen representative who can express those things for the individual. CMS should make clear that the representative does not need to be a legally designated representative, but can be a family member, friend, advocate, or other trusted person chosen by the individual or, where appropriate, the individual's family. It also should be clarified that a public guardian may not act as the designated representative due to the inherent unavoidable conflict of interest.

The Arc supports the strong emphasis placed on the individual's preferences in the development of the person-centered plan throughout (b)(1)(i)(B)(1)-(12). The Arc believes that (b)(1)(i)(B)(3) is especially noteworthy. It includes the broad array of goals individuals naturally have and that person-centered planning teams should consider when planning and designing supports for people.

The Arc urges CMS to make clear in (b)(1)(i)(B)(4) that unpaid caregivers should only be included in a plan if they have agreed to provide services and if the recipient agrees to having the unpaid caregivers provide the support.

Following (b)(1)(i)(B)(4), we suggest adding a new (5) that would emphasize to states their responsibility for ensuring compliance with the Americans with Disabilities Act and with the Supreme Court's *Olmstead* decision in the provision of home and community-based services and supports. CMS should require the person-centered plan to reflect the individual's choice of setting in which to receive agreed upon services. The plan should reflect that the individual was given options in order to make an individual decision. The plan should reflect that options in the most integrated community setting appropriate to the person's individual needs enabling that individual to interact with people who do not have disabilities to the fullest extent possible were made available.

The Arc suggests that (b)(1)(i)(B)(9) add a requirement that the person-centered plan include the individual in the quality assurance assessment.

We would ask that the meaning of unnecessary or inappropriate services in (b)(1)(i)(B)(12) be clarified or illustrated through examples. We support the idea that people should be able to decline services they do not need or want; however, without some clarification, exactly what is or is not unnecessary or inappropriate could be open to interpretation.

Home and community-based settings

The Arc supports the characteristics delineated in (b)(1)(iv) that describe home and community-based settings that are integrated into the community, but believes that the list of characteristics should be expanded. Describing characteristics of home and community-based settings that are integrated into the community, rather than listing specific types of settings, would allow the regulation to be flexible and applicable as settings change and evolve in the future. The Arc believes that the following additional characteristics of home and community-based settings that are integrated into the community should be included in the rule:

- An individual's home or apartment is a specific physical space that the recipient has a right to use and occupy with features and amenities that are typically available to people without disabilities in the same type of housing.

- For settings that an individual is occupying under the terms of a contract, the individual may not be dispossessed of the premises without due process of law or other contractually defined process.

- The individual has control over who may enter the living space and how long they may remain in the living space, including spending the night. The individual is free to come and go at any time and for as long as he/she chooses and can lock the premises.

- If the setting is other than the individual's own home or apartment, such as a group home, any limitation on the person's activity must be described in the person-centered plan of care, must be related to risks to the person's health and safety, and must be agreed to in writing by the individual or the individual's representative.

- The individual has meaningful access to the community.

- The individual has a choice of providers of services and supports.

- The individual has choice and control about daily activities and routines in the home and community based setting (mealtime, bedtime, etc.)

- The individual may remain in the setting even if the person's needs change. The need for additional qualified services and supports is not justification for asking a person to leave the setting. Should the person's needs exceed what legally can be provided in the setting (due to state certification requirements, for instance), appropriate transfer processes must be in place.

Section (b)(1)(iv)(A) describes three types of settings that would not be home and community-based settings integrated into the community. The Arc offers the following comments about this portion of the NPRM:

NPRM Language: A setting is not integrated in the community 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 Arc's Comment: Inpatient institutional treatment and custodial care are not defined and are not clear. The Arc believes that it would be clearer to state that nursing facilities (NF), hospitals, and intermediate care facilities for the mentally retarded (ICF/MR) are not home and community based settings. The Arc believes that states' past and current attempts to change the funding mechanism and call a setting "integrated into the community" have been inappropriate and contrary to the spirit of the ADA and *Olmstead* decision. An ICF/MR that suddenly flips into an HCBS waiver setting and retains all of the qualities that it had as an ICF/MR is still an institutional setting. The setting simply has dodged the regulatory requirements of an ICF/MR. When measured against the characteristics we are suggesting be used to determine whether settings are home and community-based settings that are integrated into the community, these flipped settings would not pass the test. Such practices should be clearly prohibited.

NPRM Language: A setting is not integrated in the community if it is: . . . "in a building that is on the grounds of, or immediately adjacent to, a public institution."

The Arc's Comment: Some institutions where individuals with disabilities receive inpatient habilitative services or treatment are private facilities or "schools." The Arc agrees that states must be prohibited from turning buildings on public *or private* institutional campuses into home and community-based settings and from building clusters of group homes or other types of living units on public *or private* institutional grounds. CMS should make clear in its definition of institution that it does not include institutions of higher education.

NPRM Language: A setting is not integrated in the community if it is: . . . "a housing complex designed expressly around an individual's diagnosis or disability."

The Arc's Comment: This language calls into question Section 811 housing for persons with disabilities, Section 202 housing for the elderly that includes a certain number of units or a separate floor(s) for persons with disabilities, and privately-financed accessible, independent living apartment complexes designed for persons with a specific disability. This is a very complicated issue. The Frank Melville Act will begin to transform the way we provide housing for individuals who are poor. New 811 housing will be integrated into mainstream public housing enabling individuals with disabilities to be integrated with people who do not have disabilities. The Melville Act will enable providers of low income housing to provide more integrated types of housing and move away from building settings for groups of individuals with disabilities. Initiatives such as the Money Follows the Person grant program that enable individuals to transition out of institutions and into settings with no more than three other individuals with disabilities is also reshaping the residential landscape for people with disabilities. However, as these positive changes are evolving, The Arc believes that individuals living in HUD-funded

affordable housing should be eligible to receive home and community-based services and supports.

NPRM Language: A setting is not integrated in the community if it . . . "Has qualities of an institutional setting, as determined by the Secretary."

The Arc's Comment: The phrase "as determined by the Secretary" used in (b)(1)(iv)(B) is troublesome. Developers of service settings and providers of services need some degree of specificity as to what the acceptable standards are in order to plan and move ahead.

Rather than trying to articulate in the regulations an all inclusive list of what is NOT a home and community based setting, The Arc believes it would be more productive to focus this regulation on defining the characteristics of home and community based settings and mandating that a state incorporate the defining characteristics in its waiver plan. The regulations should also require that in the administration of the waiver plan a State may only fund services that are provided in home and community based settings as determined consistent with the characteristics listed in the regulation.

Based on this approach, the existing 42 C.F.R. 441.301(b) could be restructured as follows: (**Bold Font** is current regulation; Underlined Font is our suggested new language.)

(b) If the agency furnishes home and community-based services, as defined in §440.180 of this subchapter, under a waiver granted under this subpart, the waiver request must—

(1) Provide that the services are furnished—

(i) . . .

(ii) Only to recipients who are not inpatients of a hospital, NF, or ICF/MR; and

(iii) Only to recipients who the agency determines would, in the absence of these services, require the Medicaid covered level of care provided in—

(A) A hospital (as defined in §440.10 of this chapter);

(B) A NF (as defined in section 1919(a) of the Act); or

(C) An ICF/MR (as defined in §440.150 of this chapter);

(iv) Only in home and community-based settings that are integrated into the community as defined by the following qualities and characteristics.
(A) The setting is integrated in the community, including that it:
(1) provides meaningful access to the community and community activities, and
(2) is not located in a facility that is an entity described in (b)(1)(ii), above, or that is on the grounds of or immediately adjacent to such a facility.
(B) For home based services:
(1) The setting is a home, apartment, condominium, or other specific physical space that the individual has the right to use and occupy, with features and amenities that are typically available for people without disabilities in the same type of housing.

(2) For settings that an individual is occupying under the terms of an oral or written contract, the contract provides that an individual may not be dispossessed of the premises because of a change in the person's needs, or other reasons, without due process of law or other appropriate, contractually defined process.

(3) Except as may otherwise be provided in the person-centered plan, as a condition of receiving services the terms of occupancy do not limit the freedom of the occupant to:

(a) come and go as s/he chooses,

(b) control who may enter the living space and how long they may remain in the living space, including spending the night,

(c) control his/her daily activities and routines, such as mealtime and bedtime,

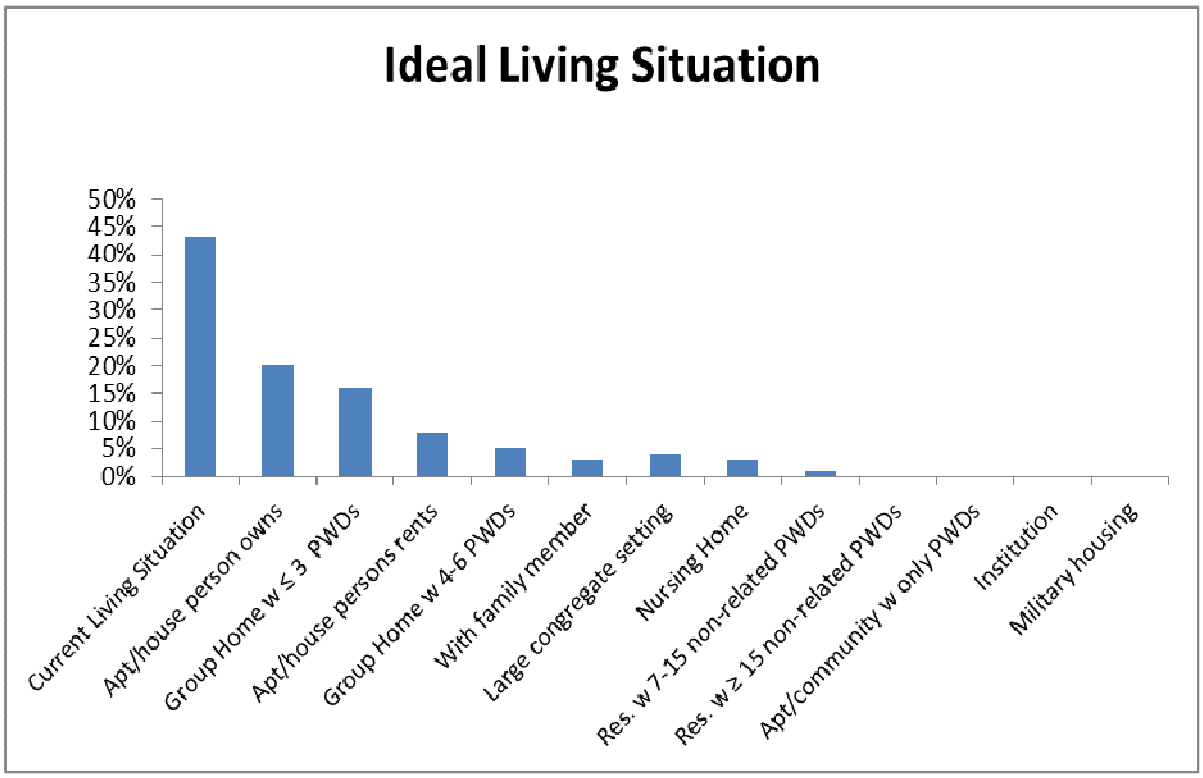
(d) choose the individuals with whom to interact, and

(e) choose the providers from whom to receive services and supports.

For purposes of these proposed rules and for this particular section especially, information from a report released by The Arc on June 14, 2011 entitled, "2010 FINDS National Survey," contains data that are very informative. The Arc conducted a national internet survey of more than 5,000 parents/caregivers of people with intellectual and developmental disabilities (I/DD) in 2010. Ninety-five percent (95%) of respondents were parents of a person with I/DD. The survey yielded data about numerous issues of critical importance to people with I/DD and their families and caregivers, including employment, housing, education, health, family support, and more.

One of the survey questions asked respondents to describe the current living situation of their family member with I/DD. The respondents reported that the current living situation for 94% of the individuals with I/DD was their own home or apartment, the home of a family member, or a setting with no more than six other non-related persons with disabilities. Another survey question asked respondents to describe the ideal living situation for their family member with I/DD. Forty-three percent (43%) of the respondents indicated that they would choose their current living situation. Fifty-two percent (52%) of respondents indicated that the ideal living situation would be in settings their family member with I/DD owned or rented, the home of a family member, or in settings with no more than six other persons with disabilities. Just 1% of respondents identified as ideal a setting with 7 to 15 other residents with disabilities. No respondents identified a residence with more than 15 unrelated people, or an apartment or community that included only persons with disabilities, as an ideal living situation.

Below is a graphical representation of how respondents described the ideal living situation for their family member with I/DD.



These data, the tenets of the ADA, and the *Olmstead* decision should guide CMS in describing the characteristics about what is a home and community-based setting that is integrated into the community. The Arc believes that the determination should be based on the characteristics we have suggested above that define living in natural communities in settings that reflect the kinds of settings the vast majority of citizens in this country call home.

Given the well-documented lack of accessible, affordable housing in this country and in order to avoid the unintended consequence of disrupting the lives of current recipients of home and community-based services, people who are living in settings that have been considered to be home and community-based settings that would no longer qualify under revised standards should be given a reasonable amount of time and technical assistance to transition to settings that would meet the revised standards and should continue to receive services until they succeed in doing so.

Target Groups

We commend CMS for providing more flexibility to states in (b)(6) by allowing them to target more than one group in waivers. However, CMS must require states to provide assurances that the expertise needed in developing services and supports for individuals with intellectual and developmental disabilities remains in place and is a part of any service delivery model that serves multiple groups through one waiver. CMS must require service providers to demonstrate that they have staff with appropriate expertise to meet the needs of individuals with intellectual and developmental disabilities. CMS must provide oversight to ensure that states and providers who serve individuals with diverse needs within a single waiver do not overlook the needs of individuals with I/DD, especially service providers who typically serve only individuals who are elderly or have physical disabilities. The Arc is concerned that expertise developed over decades

of providing services to individuals with I/DD could be lost if states decide to combine populations within one waiver and consolidate oversight and monitoring functions.

CMS should employ the lessons learned through the aging and disability resource center model. One of the defining characteristic of ADRCs is that all populations and income levels receive services. When the ADRC model was initiated in 2003, little thought was given to preparing the aging network to incorporate the needs, preferences, and wishes of people with intellectual and developmental disabilities. As a result, in 2008 and 2010--five and seven years after inception of the ADRC model, only 3.2% of the clients served nationally by ADRCs were individuals with intellectual and developmental disabilities. In order to provide services to people with varying disabilities and myriad functional needs across the age span, the service delivery system must include concomitant levels of expertise.

Section 441.302 State Assurances.

The Arc suggests the addition of assurances in this section that would require states to ensure that those currently receiving home and community-based services will not lose services when waiver populations are combined and that eligible recipients will have equal access to home and community-based services.

Section 441.304 Duration, extension, and amendment of a waiver.

Substantive changes

The Arc commends CMS for providing a definition of substantive change to a waiver. We also support the public notice provisions in this section, and we have several suggestions for enhancing the provision to ensure opportunities for meaningful public input. All of the public notice provisions should apply to new waivers and waiver renewals as well as to waiver amendments. We suggest that states be required to involve stakeholders as waivers are being developed.

The public input process should be expanded in the proposed regulation. CMS should require states to provide a public input process that is accessible to all who want to participate. CMS should include timelines and requirements for electronic posting of information on websites and to listservs of interested parties. We suggest that CMS require individual states to post proposed waivers, waiver renewals, and waiver amendments with substantive changes on dedicated pages of their websites. States should be required to give the public at least a 30-day time period to review and comment on proposed waivers and waiver amendments. Public comments should be published as well as a summary of key issues and the state's responses to those issues. We also suggest that CMS post waiver submissions and waiver amendments including all relevant materials submitted by the state on a dedicated page on its website and give the public a comment period of at least 15 days.

Strategies to ensure compliance

The Arc believes that these interim steps will enable CMS to work with states to bring their waiver programs into compliance and give CMS the leverage to compel needed changes. The current all or nothing process is unrealistic and is a barrier to realizing real systems change.

CMS is to be commended for its on-going attempts to push the service delivery system toward greater consumer control and direction. The Arc commends CMS for making the provision of services more transparent and for fostering greater stakeholder input and participation. We also support CMS's efforts to make home and community-based service settings look like actual communities where people want to live, work, and play.

Respectfully submitted,

Marty Ford
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