

August 18, 2009

Centers for Medicare & Medicaid Services
Department of Health and Human Services
Attention: File Code CMS-2296-ANPRM
P.O. Box 8016
Baltimore, MD 21244-1850

To Whom It May Concern:

File Code: CMS-2296-ANPRM

On behalf of the American Network of Community Options and Resources (ANCOR), we appreciate the opportunity to submit comments on CMS' Advance Notice of Proposed Rulemaking on CMS' in consideration of two changes to the 1915(c) HCBS waiver regulation regarding 1) target groups served per waiver and 2) home and community-based characteristics.

As a national organization, ANCOR has been in existence for more than 40 years and today represents more than 800 private providers of living and employment supports to more than 500,000 individuals with disabilities of all ages who employ more than 400,000 direct support professionals. ANCOR members provide an array of supports and services to individuals with intellectual and developmental disabilities, mental illness, sensory and physical impairments, as well as individuals who are elderly and have developed disabilities. Many of ANCOR's provider agencies were founded by family members of children and/or adults with significant disabilities, are currently directly administered by family members, and include family members and individuals with disabilities on their board of directors.

ANCOR, one of the original members and of the Consortium of Citizens with Disabilities, has supported the Medicaid 1915(c) home and community-based waiver since its inception in 1981 and worked to improve and expand the reach of the HCBS waiver option in all states for the individuals we serve and represent. We believe that that the 1915(c) option is critical in serving hundreds of thousands of individuals with disabilities. The individuals with disabilities and their families for whom ANCOR members support depend upon on state-authorized waiver services so that individuals of all ages can live in their own homes and communities, work and recreate in the community so that they may, like other Americans, lead productive lives and engage in meaningful community integration and participation.

ANCOR supports changes to the waiver program that will improve the implementation and reach of services and supports that assist people in full inclusion in their communities. In fact, ANCOR has advocated for years that these HSBS waiver services should, in fact, be a mandatory Medicaid state plan benefit. We have also worked for years with Congress to expand housing options and supply of available, accessible and affordable housing so that individuals with disabilities have greater choice in housing options in the community and avoid the need for unnecessary institutionalization and large congregate living arrangements.

As Medicaid policy has evolved over time since the 1970s when services were offered in state-operated institutions and nursing homes, ANCOR members have responded to the evolving state and federal Medicaid policy regarding services to individuals with disabilities. ANCOR agencies emerged in response to services in institutions by offering states and individuals with disabilities alternatives to state operated and large congregate living arrangements. Following the inception of the 1915(c) authority, states turned to ANCOR agencies to provide HCBS supports and services. ANCOR members responded to state policy by investing HUD and other private and public resources to secure alternative community housing arrangements. Many ANCOR members serve in seeking and securing Section 8 housing vouchers, help with leasing arrangements, help with home purchases, and secure funding for home modifications so that individuals may live in their own home or apartment. ANCOR members, not only worked to end the institutional bias in Medicaid, but responded to and helped states to expand HCBS services.

ANCOR agrees that these two areas present significant challenges to states designing person-centered, needs-based waiver programs and that the 1915(c) waivers must evolve to meet current realities, address the current unmet needs and growing demand for home and community-based services. ANCOR recognizes the challenges in determining meaningful integration of individuals in the community. ANCOR and its members strongly support person-centered planning, meaningful integration in the community, and the choice of home settings. These challenges present even greater difficulties for states and providers as services and Medicaid payments are cut amidst a recession, housing crisis, and when Congress has temporarily provided additional temporary federal Medicaid funding to states to maintain services and supports.

Therefore, any proposed changes to the waivers are important to ANCOR and its 800 member organizations and to the 500,000 individuals with disabilities of all ages that we support and represent. ANCOR would like to directly work with CMS in support of the direction of modifications to the HCBS waiver programs. We believe that person-centered planning is the keystone to addressing individualized supports and applaud CMS' efforts to make person-centered services the focus in the HCBS waiver. While we recognize the challenge that CMS is facing in moving states in the direction of individualized and person-centered, consumer-controlled home and community-based services, ANCOR has some concerns and cautionary comments regarding the proposals to modify the regulations.

Before providing specific comments, ANCOR offers the following general comments and recommendations.

A. General Comments Regarding Home and Community Characteristics

- 1. Vital to engage stakeholders in forum(s) on home and community-based characteristics.** ANCOR strongly urges CMS to hold national face-to-face discussions with critical stakeholders first to aid CMS in addressing the need (underlying problems CMS has identified), solutions, potential fiscal and programmatic consequences, state strategies, and development of policy guidelines prior to developing the most thoughtful and considered proposed rule possible. The ANPRM raises more questions and uncertainties than can be addressed in a written response. We believe that CMS should not engage in this kind of policy development without a meaningful dialogue with representatives of all major stakeholders (including individuals with disabilities, family members, providers, and state agencies) in order to correctly assess all implications of CMS' contemplated proposed regulatory changes and to avoid unintended consequences. Other federal agencies have employed this process prior to making significant proposed changes to regulations. ANCOR welcomes participation in the stakeholder meetings and throughout CMS deliberation on the process to develop a proposed regulation.

2. **Variability in State Agency Planning and Specialized Expertise.** States determine the array of services and supports provided under the authority of each state Medicaid plan and waivers. Since the inception of the 1915(c) authority states have sought, albeit not swiftly enough in many states, to rebalance their systems and support increasing numbers of individuals through HCBS waivers. States have called on ANCOR providers to help with this expansion of HCBS services. While CMS has supported state efforts to serve individuals in the “least restrictive setting,” thankfully supported by the U.S. Supreme Court *Olmstead* decision, states—not providers drive the delivery system. In fact, states determine which providers can offer services and under what conditions, number of participants in settings, Medicaid payments and other regulatory requirements. Medicaid programs and available services not only vary between states, but within states.
3. **Recession and State Budget Realities.** There are stark realities that must be included in consideration of characteristics of home and community-based services. ANCOR members are reporting that states, due to budget shortfalls, are proposing increasing the number of participants that must be served in a group setting—for example, from 4 to 6 to 8. We believe that there are fiscal and programmatic implications for states, rural versus urban issues, as well as the capacity and availability of providers that must be considered in consideration of proposed requirements regarding characteristics of home and community-based services.
4. **Medicaid Statutory Definition of Institution.** Eligibility for the 1915(c) waiver is statutorily limited to individuals not residing in “institutions.” Congress has specifically defined institution relative to Medicaid spending as hospitals, ICF/MRs and nursing homes. ANCOR is concerned that CMS efforts to define “home” and “community” based settings bestows a federal definition beyond what Congress has established. Congress did not define home and community in section 1915(c), nor has it more recently provided those definitions when it had the opportunity in enacting the section 1915(i) HCBS benefit option in the Deficit Reduction Act.
5. **CMS Authority Over Medicaid Services Not Housing.** While attempting to define the characteristics of a “home,” it is important to keep in mind that Medicaid prohibits payment for “room and board” under the 1915(c) authority as opposed to statutorily permitting payment for room and in connection with Medicaid-certified NFs, ICFs/MR, and hospitals. The 1915(c) authority provides payment for Medicaid services only. There is a long-standing crisis in affordable and accessible housing in both private and public sectors that operates outside of CMS’ authority. On average across the nation, it takes 112% of an individual’s monthly SSI income to rent a modest one-bedroom apartment as reported in *Priced Out 2008* published by the Technical Assistance Collaborative (TAC) in Boston, Massachusetts, and the Consortium for Citizens with Disabilities (CCD). ANCOR believes that CMS has the authority over the delivery of Medicaid supports and services to an individual under 1915(c), but does not have the authority for regulating nor determining housing settings in private or public housing which are not Medicaid-certified, but are available through the state or chosen by Medicaid beneficiaries eligible to receive 1915(c) HCBS services. The choice of housing/setting in which an HCBS waiver participant receives services and supports should be a choice of the individual participant/family member.
6. **Definitions of Home and Community Raise Concerns.** ANCOR is troubled by prospects of either CMS or the federal government establishing definitions of either home or community. We are deeply concerned that requiring states to develop standards for HCBS beneficiaries who reside in provider owned or leased settings within federal guidelines will result in arbitrary and unintended consequences for individuals in need of HCBS services. ANCOR believes

that the term “provider-controlled” raises questions that require more discussion. Some of these questions are cited in our specific comments below.

B. Removing Regulatory Barrier to Designing 1915(c) Waivers Based on Needs Rather Than Diagnosis or Condition

ANCOR supports providing states either with the option of removing the barrier of targeted waivers based on diagnosis or condition. ANCOR provided that support in comments October 8, 2008 to *CMS Draft White Paper: Removing Barriers: Allowing 1915(c) Home and Community Based Waivers to Serve More than One Target Population*.

ANCOR represents providers of supports to **individuals with disabilities of all ages, with multiple disabilities, including individuals who are elderly and developed disabilities as they became elderly**. The rules and practices of existing waiver programs issued in the early 1990s have not caught up with current realities. The result of this targeted policy has led to exclusion of many individuals with significant disabilities from receiving the services and supports that they need.

Rather than targeting waivers based on specific diagnosis or conditions, it makes more sense to provide similar services and supports based on individuals’ actual need for supports and functional abilities/disabilities based upon a person-centered plan. ANCOR believes that allowing states to combine one or more of the target populations would reduce duplication, operational costs, and managing multiple waivers, while still providing eligibility for 1915(c) waiver services based on level of care associated with specific institutional setting.

As an example of state flexibility that this change could provide is that of “transportation services.” Currently, different targeted waivers offer similar transportation services, although at different reimbursement rates. States could leverage their Medicaid aging and ID/DD transportation services under one waiver—thereby reducing duplication in equipment and operational costs by taking advantage of multiple funding sources to strengthen and expand Medicaid-eligible transportation services.

However, ANCOR is not aware of any state where each individual in any of the targeted populations receives all of the services and supports that they need. We do wish to see that this policy change result in individuals who are currently served to lose services. We do not believe that the federal government should promote competition between populations in need. Many states have mature and long-standing service systems for some populations. Those states must not be pressed into reducing or eliminating the number of participants or services in order to meet the demand for services from others. Instead, states should be encouraged and even incentivized to expand their state plans to meet the needs of all eligible people with disabilities.

ANCOR provides the additional comments regarding combining waivers:

- ANCOR strongly recommends that the **savings states derive from these flexibilities must be directed at addressing state waiting lists, increasing the number of participants served, and the actual costs of rising costs of services—including the recruitment and retention of direct support professionals**.
- The ability to combine any of the three target populations must be an **option** left up to each state and not mandatory requirement placed on states.

- All eligible HCBS waiver participants who currently receive 1915(c) services and would continue to be eligible under a target waiver must continue to receive waiver services. That is, no one should be terminated as a result of combining target populations under a single waiver. Existing eligible participants should be grandfathered into any new combined waiver.
- Significant state diagnostic- and condition-related expertise has developed as the HCBS system has matured. While there may be similar needs of individuals across diagnosis and conditions (e.g. Alzheimer’s and intellectual disabilities/developmental disabilities), the services with the same name do not necessarily carry the same skills or expertise. ANCOR is concerned that specialized expertise may be lost and we urge the protection of the specialized expertise throughout the waiver delivery system.
- CMS states differences in waiver services are due to “more mature delivery systems” or who “have more successful advocacy techniques.” While this proposed change may help states better address the needs of a wider range of individuals with disabilities of all ages, it is worth noting that no existing targeted population has all of their needs met. There are currently long waiting lists for targeted populations that have traditionally received more funding due to these mature delivery systems and advocacy efforts. And, just because an individual from that target group is not on a waiting list is not an indication that an individual is receiving the comprehensive supports needed.
- CMS must adopt in any regulation its stated intent that the additional targeting will not affect cost-neutrality, especially since the existing Section 1915(c) waiver application accommodates multiple levels of care and the corresponding institutional costs. If states were forced to use the same institutional and waiver costs across a mixed population, it could result in fewer services to people or could discourage states from choosing to mix target populations in one waiver.
- ANCOR supports the proposal to require that the service planning process be person-centered, and that the services specified in the plan of care be based upon the needs of the individual, not on average need among one target group.
- ANCOR supports updating the language to more contemporary, people-first language
- ANCOR urges CMS to also consider the term “aging” in a broader sense. Individuals with disabilities—whether acquired in their developmental years or currently labeled as non-elderly individuals with disabilities—age but are also considered as “disabled” and never “elderly.” We hope that the change CMS seeks will in fact allow states when and where appropriate to so take that into consideration when developing waivers that include one or more targeted groups.

C. Home and Community-Based Characteristics

ANCOR appreciates the challenges that CMS is wrestling with in its consideration of home and community and does not support Medicaid HCBS waiver services provided in any setting—whether it be an individual’s own home or apartment, foster care, or in alternative living arrangements—being “institution-like.” We support CMS’s efforts to ensure that states focus person-centered HCBS services in any home, apartment or small setting that supports increased independence for the individual.

ANCOR commends CMS in not limiting number of participants in a setting as a means of defining a home.

States have developed their own unique service systems with most of them relying predominantly on a provider-based system. Each of these systems varies in terms of services and characteristics. It should not be assumed, however, that provider-based services are inherently bad. States have the authority to qualify providers as eligible Medicaid providers and the responsibility for assuring that providers meet their programmatic and fiscal responsibilities.

ANCOR is troubled by prospects of either CMS or the federal government establishing definitions of either. We are deeply concerned that requiring states to develop standards for provider-controlled settings within federal guidelines will result in arbitrary and unintended consequences for individuals in need of HCBS services.

- *Definitions and Choice Should Remain with the Medicaid Beneficiary.* ANCOR believes that these definitions should remain ultimately the decision of the beneficiary or, where appropriate, his or her representative. There is certainly “no one size fits all” approach when it comes to each individual’s view of what constitutes a home or a community. ANCOR believes that definitions for both vary widely and are influenced by subjective, cultural, geographic, socio-economic, and other factors.
- *Person-Centered Plan Is the Keystone.* ANCOR supports CMS’ intent to propose (1) that the service planning process be person-centered and (2) that the services specified in the plan of care be based upon the needs of the individual. We believe that the process is where the case manager and individual with disability should discuss all the alternative living arrangements, including definition of home and community, in order to reach person-centered decision about where and how services and supports will be determined. Those decisions and the plan of care can then reflect any changing needs or desires. The plan of care should be addressing the rights of individuals to privacy, personal preferences, consumer-controlled activities, independence, and meaningful integration and participation in the community. In addition to consumer satisfaction, states have the authority and responsibility to ensure that these goals are addressed in meaningful ways.
- *Lack of Housing Alternatives.* We also wish to point out that the lack of affordable and accessible housing is a major determinant regarding “settings” for states—with providers scrambling to locate and in some cases, actually provide housing in order for people to leave institutions, get off of long waiting lists, exit aging parent or inappropriate homes in order to live in the community. ANCOR providers offer Medicaid supports and are involved in housing arrangements (seek grants and loans, conduct fundraising, go into debt) as the only way to ensure that community supports are available to people with disabilities. There is a particular challenge in rural communities to locate housing. Urban areas present another challenge in terms of cost of housing. On average across the nation, it takes 112% of an individual’s monthly SSI income to rent a modest one-bedroom apartment as reported in *Priced Out 2008* published by the Technical Assistance Collaborative (TAC) in Boston, Massachusetts and the Consortium for Citizens with Disabilities (CCD). Recently, two ANCOR providers reported that with a *Money Follows the Person* grant and working with a consultant, they have not yet been able in nearly a year to locate appropriate housing. Urged by states to develop community group homes, providers have made financial investments in housing with both federal and state grants. ANCOR has for years urged HUD to help providers reduce occupancy size in older Section 202 and Section 811 and still provide the housing subsidy associated with the original occupancy size. ANCOR urges CMS to work with HUD, the Department of Agriculture, and state authorities in addressing the crisis in housing available to individuals with disabilities.

- It is also worth noting that due to the severe financial problems facing states, that some ANCOR providers are reporting that their states are considering or have already notified providers that they must increase the size (beyond 4 to 6 or 8 individuals) of home settings linked with Medicaid funding.
- *Medicaid HCBS Waiver Pays for Services, Not for Room and Board.* While we appreciate CMS goal to ensure that states do not condone institutional-like living arrangements under their HCBS waivers, Medicaid does not pay for the costs of room and board for individuals enrolled in the HCBS waiver program. Individuals might live in a wide variety of settings and we fear that the proposed guidelines/regulations of provider-controlled settings may result in needy individuals being found ineligible solely due to where they live.
- *Congress Has Defined Institutions, But Not Home or Community.* ANCOR is concerned that CMS efforts to draw lines between institution and home and community based settings bestows a federal definition beyond what Congress has established. Congress has specifically defined institution relative to Medicaid spending as hospital, ICF/MR and nursing home. It did not define home and community in section 1915(c), nor has it more recently provided those definitions when it had the opportunity more recently when enacting section 1915(i). Nor have the courts provided specific definitions. ANCOR wholeheartedly supported and continues to support the U.S. Supreme Court's Olmstead decision which affirmed the right of individuals with disabilities to be free from unnecessary institutionalization. However, the Court did not define "home" and "community" beyond "unnecessary institutionalization."
- *Two Criteria for Residing in the Home or Community.* The ANPRM notes CMS's intention to require that "individuals receiving HCBS waiver services must reside in the home or community, in accordance with either of two criteria enumerated below:
 1. "Resides in a home or apartment not owned, leased or controlled by a provider of any health-related treatment or support services; or
 2. "Resides in a home or apartment that is owned, leased or controlled by a provider of one or more health-related treatment or support services, and that meets standards for community living, as defined by the State and approved by the Secretary."

ANCOR wishes to comment on the second criteria. It is not uncommon, and is necessary in some circumstances, for providers to either "own" or "lease" the housing arrangement for individuals with disabilities. As stated above, providers in response to state deinstitutionalization and expansion of HCBS services have encouraged providers to build, purchase, or rehabilitate housing in order to provide community living arrangements. Providers have had to seek alternative resources than Medicaid to also modify homes to make accessible or accommodate individual disabilities. These represent considerable provider investments and services which Medicaid does not cover under the HCBS waiver.

In many cases, it is the individual's own needs and choices which bring a "provider" into the housing arrangement. It is not uncommon for private housing sector to refuse to lease an apartment to an individual without a co-signature of a known provider on the lease. Many landlords look to providers to co-sign leases. The owner may be unwilling to lease to the individual due to a lack of credit history, poor rent history, inability to pay up-front costs, prior problems in other housing, doubt that the individual is capable of signing legal documents, or other factors related to the owner's judgment of the prospective tenant's capabilities for meeting the leasing requirements. In some cases, individuals with mental illness who require hospitalization, not only lose their SSI income that would pay for their rent, but would lose the housing unit, if not for the provider leasing the housing. Without a family member, representative payee in another location, or other responsible representative but the

provider, these housing options would not be available to the individual. Nor is it appropriate to force individuals to seek guardianship and give up other rights to decision-making in order to obtain housing. Guardianship is far more restrictive than who owns or leases the housing. This issue is not as cut and dry as the proposal sets forth. In fact, this second criteria could easily discriminate against some individuals with the most severe disabilities.

Some individuals may desire to live in proximity to friends that rent from the same provider, may find the providers residences to be in a convenient location, or may appreciate the availability of ancillary services such as transportation. Living in a provider-owned apartment may afford the greatest amount of personal independence. If that provider were not qualified under the states' standards, would the individual then be ineligible for needed HCBS services?

Whether a living arrangement is a home or is in the community is not dependent on who signs a lease or rent agreement or pays the mortgage. Again, Medicaid does not pay for room and board under the HCBS waiver. This second criteria could well lead to harsh and arbitrary results for the individual due to circumstances which s/he may be unable to control. It also seems to negate the concept that people should be eligible for HCBS services wherever they live, so long as it is not in a Medicaid funded nursing home, ICF/MR, hospital or IMD.

It appears that the goal of CMS centers on the on the issue of "provider-controlled." ANCOR believes that the issue of provider-control requires more discussion through national stakeholder forums. At this time, ANCOR has more questions to pose than comments with the answers determining who may or may not be eligible for HCBS services.

1. What is the term "provider of any health-related treatment or support services" intended to cover?
2. Does that mean only those providers which provide Medicaid health-related treatment or support services under the state plan?
3. Additionally, is this restriction limited only to those providers that provide (Medicaid) services to that particular individual?
4. Would a board and care facility or an assisted living facility which does not provide HCBS services to that individual qualify as a provider for purposes of the enumerated criteria? And if so, would the individual be ineligible for the HCBS services if the provider failed to meet the state standard even though the individual would not receive HCBS services from that provider?
5. Would the individual's services in other settings, such as supported employment services, be in jeopardy due to his/her living arrangement?
6. Is the real issue those *situations* where the provider has more than one relationship with the individual – providing both housing/residential support as well as Medicaid funded health-related treatment or support services?

- *Development of State Criteria and CMS Guidelines and Proposed Regulation.* ANCOR believes that the issue of "provider-controlled" is the more appropriate focus for discussions on modifications to the HCBS waiver regulation. With this as the central issue, then discussion regarding the control that individuals have over their own lives should be the criteria for the individual to determine "home" and "community" as well as the extent to which any provider interferes with the rights of the individual that is supported. Their right to personal space and privacy, when visitors are permitted, who may enter and exit their home or space, when and what they choose to eat, when to go to bed, and other rhythms of the day are examples of what could constitute consumer-controlled, non-institutional home and community.
- *National Stakeholder Input and Forums.* These uncertainties raise more questions about how to best improve the HCBS policy to more positively affect living arrangements. The issues

ANCOR has raised add to our concern about unintended consequences of the living arrangements listed in the ANPRM. ANCOR believes that these issues and concerns require further stakeholder input with major organizations representing people with various disabilities and organizations representing providers should be at the table. ANCOR welcomes participation in the stakeholder meetings and throughout CMS deliberation on the process to develop a proposed regulation.

- *State Stakeholder Input.* If states are to develop home and community-based criteria as proposed in the ANPRM, ANCOR believes that states must fully engage in gathering input from the development stages through to final stages from a wide range of stakeholders. We believe that the state's process must ensure *meaningful* stakeholder and public participation when considering such changes to its state HCBS waiver program. The state should ensure involvement to include geographic diversity, cross-disability representatives, including individuals with disabilities, family members, providers, and state agencies. It is important to collect information on fiscal impact of changes, illicit unintended consequences and any service disruptions, as well as what is required of the state to make regulatory changes through its administrative procedures requirements, and timeframes for implementation. ANCOR also strongly recommends public announcement of opportunities for input; maintain a record of stakeholder and public input; respond to the stakeholder and public comments; and provide review and comment on final decisions. ANCOR recommends that CMS include such requirements in its NPRM.

ANCOR appreciates the opportunity to comment and looks forward to working with CMS throughout the process in developing the NPRM. If there are any questions, please contact me at 703-535-7850 or at sgalbraith@ancor.org.

Sincerely,
Suellen R. Galbraith
Director for Government Relations