



July 2, 2012

Centers for Medicare and Medicaid Services
U.S. Department of Health and Human Services
7500 Security Blvd., C4-26-05
Baltimore, MD 21244-1850
Attention: CMS-2249-P2

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 Proposed Rule

On behalf of the National Alliance on Mental Illness (NAMI), I am pleased to submit the following comments regarding the implementation of the Medicaid Home and Community-Based Services (HCBS) state plan option 1915(i) and the settings requirements for Community First Choice 1915(k). NAMI is the nation's largest organization representing people living with serious mental illness and their families. Through NAMI's more than 1,100 affiliates in all 50 states we are involved in education, support and advocacy on behalf of people living with serious s mental illnesses such as schizophrenia, bipolar disorder, major depression, schizo-affective disorder, borderline personality disorder and severe anxiety disorders.

NAMI has always placed the highest priority on ensuring that people with mental illness are able to live in the most integrated settings in the community. Access to decent, safe and affordable housing – as well as community-based support services – are central to recovery and a full life in the community for consumers living with mental illness. Overall, NAMI supports this proposed rule and efforts by CMS to ensure that HCBS are available in a broad range of integrated supportive housing settings. This can and should include scattered site housing, set-asides within larger buildings and properties, and single site housing that allow for tenant choice regarding service engagement and where residents have all the rights and responsibilities of tenancy for HCBS.

NAMI is pleased that this proposed rule, and in particular the revised criteria for eligible HCBS settings. In comments that we submitted to CMS in April 2011 for the 1915(c) waiver program, we expressed concern regarding the disallowance of single site congregate settings. We are pleased that this proposed rule broadens the definition of community-based settings to include congregate buildings – as well as scattered site housing. Inclusion of this broader standard is critical to ensuring that this proposed rule honors the principle of consumer choice with respect offering a variety of supportive housing options for people with disabilities – and in many communities, a range of locations near families, peers, employment and education opportunities.

NAMI would like to offer the following specific comments on the proposed rule.

Section 440.182 State Plan Home and Community-Based Services

NAMI strongly supports the opportunities that 1915 creates for states to provide an expanded array of services to individuals with serious mental illness. In furtherance of this objective, we urge CMS to clarify in Section 440.182 that “other services requested by the state as the Secretary may approve” can include those services that have been, or could be, approved as “other services under a 1915(c) waiver and to list specific examples of these services. The statute makes clear that any service within the scope of those permitted under a 1915(c) waiver may be provided through the 1915(i) option; the regulations should make that clear as well.

NAMI would specifically recommend that CMS consider language regarding transition services in the regulation itself. The preamble of the proposed makes clear that “recognizing the 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.”

However, this language does not appear in the regulation itself and we would urge a clarification that transition services can be covered under a 1915(i) option, as a critical link for individuals moving from a hospital or other institution, or from chronic homelessness into a home and community-based setting. The regulation should also list out examples of the types of supports that may be covered as transition services such as those that are now allowed for 1915(c) waivers: security deposits required under a lease, set up fees or deposits for utilities, essential furnishings and moving expenses, and other health and safety assurances needed before occupancy.

NAMI would also recommend that CMS provide additional clarity in the preamble and the rule with respect to how 1915(i) services may not be use for room and board expenses. The regulation lists items that are not to be considered room and board, but does not mention the types of transition services noted above. CMS should clarify the types of transition services in the list of services that are not room and board. For waivers, CMS has defined those transition costs as being outside of the definition of room and board and deemed allowable. The same policy should apply in the context of 1915(i).

It is important to note that the services contained in Section 440.182 align with those traditionally provided in conjunction with supportive housing. Among these are case management, personal care services, adult health services, day treatment and clinic services that are routinely used by tenants in supportive housing. In addition to those listed in the proposed rule, NAMI would like to recommend the addition of following:

- Tenancy Support Services – Specifically, assistance in finding housing, assistance in applying for housing, assistance negotiating and managing conflict with landlords and assistance with understanding and maintaining tenant responsibilities of a lease.

- Medical Respite Services – Specifically services for individuals with illnesses that do not require inpatient care, but that involve extra attention to ensure proper follow-up care – typically as part of a hospital discharge plan. These can include assistance with taking medication, changing bandages, adhering to a dietary plan, etc. – and are critical for preventing hospital readmission. NAMI would recommend that medical respite services for previously homeless populations be an allowable HCBS so long as clients are connected to permanent housing.

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))

NAMI supports the proposed list of qualities that define home and community-based settings in 441.530(a)(1) and 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 Supreme Court’s 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 living with serious mental illness 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.

NAMI 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 removed to avoid confusion.

In Section 441.530(a)(1)(v) and Section 441.656(a)(1)(v), NAMI 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.

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

NAMI 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. NAMI 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 granting an additional level of review and oversight of the conditions to ensure the protection of individuals whose basic rights must be restricted. There should be a clear appeal process available for any individual who does not agree to the conditions.

NAMI 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 under landlord tenant law. We suggest adding protections afforded by the ADA to this section. Individuals living in provider owned or operated settings whose needs for services and supports change must be afforded accommodations in order to continue living in the setting. For example, if an individual experiences a sudden increase in challenging behaviors (for example, as a result of an acute episode of psychosis, mania or depression), the provider must provide appropriate accommodations, such as increased staff, development of a behavior intervention plan, change in activities, etc. If the need for additional service exceeds what the provider may legally provide, a transition process that ensures continuation of services until the person-centered planning team can locate an appropriate alternative setting must occur. NAMI suggests the following:

The unit or room is a specific physical place that can be owned, rented or occupied under another legally enforceable agreement by the individual receiving services, and the individual has, at a minimum, the same protections from eviction that tenants have under the landlord tenant law 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.

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. NAMI 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. Housing should not be made contingent on acceptance of services. Settings that require a type of treatment in order to participate in the program and live in the setting are inconsistent with the principles of home and community-based settings.

In general, NAMI supports the delineation of settings that would not be considered home and community-based settings but believe there should be a modification and additions to the list. 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. NAMI suggests the following additions:

- (2) Home and community-based settings do not include the following:*
- (i) A nursing facility;*
- (ii) An institution for mental diseases;*
- (iii) An intermediate care facility for the mentally retarded;*
- (iv) A hospital or*
- (v) Any setting that is located in a building that is also a publicly or privately operated facility that provides inpatient institutional treatment; or*

NAMI believes that the rebuttable presumption that certain settings are not home and community-based described in Section 441.530(a)(2)(v) and Section 441.656(a)(2)(v) may result in unnecessary confusion and uncertainty and should not be utilized. In particular, “disability-specific housing complex” in Section 441.530(a)(2)(v) and Section 441.656(a)(2)(v) be more clearly defined. In many states, individuals living with serious mental illness live in group homes, many of which received capital financing and ongoing project-based operating assistance from the HUD Section 811 program. Likewise, many formerly homeless individuals living with serious mental illness live in congregate permanent supportive housing developments financed through the McKinney-Vento Homeless Assistance Act. These include programs such as Shelter Plus Care, SHP and Section 8 SRO. NAMI recommends that congregate developments financed through all of the programs – Section 811 and McKinney-Vento permanent supportive housing – be excluded from the definition of disability-specific housing complexes. They would, of course, be subject to the qualities of home and community-based setting enumerated in Section 441.530(a)(1) and Section 441.656(a)(1).

NAMI believes that this change is needed 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 Project-Based Assistance (PRA) program

authorized in the Melville Act, we expect that Section 811 funds will be directed toward scattered site housing. CMS should consider working with HUD to formulate federal policy to help transition facilities constructed with pre-Melville Act funds into integrated settings. The rule should include a “grandfathering” provision for congregate housing developed through 811 and McKinney-Vento permanent supportive housing. 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.

(3) State Plan Home and Community-Based Services for Elderly and Disabled Individuals

NAMI 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), NAMI reiterates its suggestions made above concerning meaningful choice. Extra efforts may be required to enable individuals living with serious mental illness 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 serious mental illness 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. NAMI 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.

NAMI 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. NAMI 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.

NAMI suggests that Section 441.668(c) be strengthened. Agents performing independent assessments and plans of care will play critically important roles in individuals’ lives. NAMI 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), NAMI 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. NAMI 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.

Section 441.656 State Plan Home and Community-Based Services Under the Act

Several important statements that can guide states as they develop their Section 1915(i) state plan amendment appear only in the preamble (pg. 26376). NAMI would urge CMS to consider moving the following statements into the regulation. The regulation should explicitly state that a “a state may propose more than one set of section 1915(i) benefits, with each benefit package targeted toward a specific population” and that the state may also target multiple populations under one set of benefits or offer different services to each of the defined target groups within the benefit.

The regulation should also explicitly state in §441.656(e) that states may propose a section 1915(i) benefit that “does not choose non-application of comparability and instead uses only the needs-based criteria to establish eligibility for the benefit.”

Section 441.659 Needs-based Criteria and Evaluation

Clear evaluation standards are critical to ensuring that individuals who need home and community-based services are accurately identified. The preamble (pg. 26369) of the proposed rule makes clear that a state may consider a person's need for assistance with

instrumental activities of daily living (IADLs) as a basis for eligibility for 1915(i) services. This is not clear, however, in the proposed regulation. The need for assistance with instrumental activities of daily living, such as the ability to manage finances and managing psychiatric medications, is often more relevant to and a more important measure of the unique requirements of individuals with serious mental illnesses who may have difficulty carrying out cognitive tasks. It will be important for CMS to clarify in the final regulation that the need for assistance with IADLs may be a basis for eligibility for services under a 1915(i) option.

The preamble of the proposed rule also states on page 26370 that the inability to perform 2 or more ADLs is a required element of the independent assessment that is to be completed after an individual is evaluated as eligible to receive 1915(i) services. Inability to perform 2 or more ADLs is, however, only suggested as possible criteria for the eligibility evaluation. NAMI recommends that CMS clarify in the regulation that the inability to perform 2 or more ADLs or IADLs is required for individuals to be eligible for 1915(i).

Finally, it is important, as is mentioned in preamble page 26374, that FFP be available for evaluations (including both for medical services and administrative costs incurred for evaluation and assessment activities), even when an individual is subsequently found ineligible for 1915(i) services. Without this provision, individuals may not be able to access an evaluation in some circumstances.

Section 441.662 Independent Assessment

Clear assessment standards are necessary to ensure that individuals deemed eligible for 1915(i) services receive the services that are most appropriate and effective. The following improvements and clarifications are needed in the regulation in order to make it as robust as possible:

1. The preamble indicates in the Independent Evaluation section on pg. 26369 that an assessment of “needs and strengths” is more appropriate than needs and capabilities, as the words capability and ability are historically connected with a deficit oriented approach to assessment. We believe it is important to continue to refer to both needs and strengths throughout the regulation. The language in 441.662(a) only mentions an independent assessment of “needs” without including the word “strengths” – although strengths appears later in the section, it should also be included in opening paragraph (a).
2. Paragraph (a) should also specifically state, as does the preamble (pg. 26370), that the State must provide for an independent assessment of both physical and mental needs and strengths. Paragraph (a) (4) eventually refers to both physical and behavioral needs and strengths, but it must also be made clear in the opening paragraph (a) that physical and mental needs and strengths must be assessed in order to establish a service plan.

3. The preamble states on page 26371 that the “role of the assessor is to facilitate free communication from persons relevant to the support needs of the individual.” This language should also be included in the regulation itself.

4. The regulation should also include the language in the preamble (pg. 26372) that indicates that services must be furnished to individuals with an assessed need, and must not be based on available funds. The subsequent language that concludes that individuals who qualify for home and community-based services must not be compelled to receive them.

Section 441.665 Person-Centered Service Plan

As is stated in the preamble, a complete and inclusive person-centered planning process that addresses health and long-term services and support needs in a manner that reflects individual preferences is critical in order to fully meet the needs of individuals and facilitate meaningful access to and participation in their homes and communities. It is important that the regulation include the statement in the preamble (pg. 26372) that indicates that the service plan “should be constructed in a manner that promotes service delivery and independent living in the most integrated setting possible.”

Additionally, the regulation should clarify that providers of home and community-based services may participate in the service planning. In many instances, it will not be feasible for service planning for individuals with serious mental illness to be furnished by any other individual or entity.

Section 441.668 Provider Qualifications

This provision explains the exception to the conflict of interest requirement that the agent performing the independent assessment cannot be the same as the HCBS provider, unless the State can demonstrate that they are the only willing and qualified agent to perform the task. This allowance requires that the state create conflict of interest protections including separation of agent and provider functions within the provider agency.

Within supportive housing, it could often be the case that the agent performing the independent assessment will be employed by the HCBS agency. In most cases, it is the service providers within supportive housing that have built the trust and relationships necessary to complete an accurate assessment. In many cases, these service providers are part of the same entity that will access the HCBS, presenting the potential for a conflict. To mitigate this potential, supportive housing providers have developed roles clear lines of authority within organizations, and protocols for working across an organization. Supportive housing providers have a strong, successful history of navigating these dual roles; often as a property manager and a service provider, to best meet the needs of their tenants. CSH fully agrees that safeguards should be in place, but if the requirements the state must meet are too cumbersome or the separation of the agent and provider functions too restrictive, this provision could unintentionally limit the availability of supportive housing for HCBS beneficiaries.

Section 441.677 State Plan HCBS Administration: State Responsibilities and Quality Improvement

All Medicaid services furnished in the three months prior to a determination of eligibility can be billed and FFP is available for those services. In addition to the presumptive payment options described in the rule, CMS should clarify that home and community-based services furnished to individuals in the 3 months prior to a final determination of eligibility are also eligible for FFP once eligibility has been confirmed.

Conclusion

NAMI appreciates the opportunity to submit comments on this important proposed rule. We look forward to working with CMS to ensure that the final rule for 1915 meets our shared goal of community integration and genuine recovery for people living with severe mental illness.

Sincerely,

A handwritten signature in black ink that reads "Michael J. Fitzpatrick". The signature is written in a cursive, flowing style.

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