Q & A

Home and Community-Based Services Transition Plan Advocacy: Identifying the Issues[1]

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Q: Our state has issued a notice for public comment on an initial plan to transition our Medicaid waiver programs to compliance with the new home and community based standards regulations. The plan seems very general, so is it effective to comment on it? If so, what type of information should we include in our comments?

A: Although states only have to submit a final transition plan, many states will be issuing initial and final transition plans, both of which will be available for public comment. The transition to HCBS is a critical opportunity to push community integration and advocates should be prepared to comment at all opportunities available. By combining information from across an organization, advocates can make effective comments about the specific problems in their state that transition plans must address.

States are beginning to issue initial transition plans to bring existing home and community based (HCBS) waivers and state plan options into compliance with the recent regulations that further defined a community setting.[2] The regulations and subsequent guidance from CMS focus on the nature and quality of participants'

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[2] This Q&A uses the term "HCBS program" to refer to the Medicaid programs affected by the rules on home and community standards published January 16, 2014. *See generally* Home and Community-Based Setting Requirements for Community First Choice and Home and Community-Based Services (HCBS) Waivers, 79 Fed. Reg. 2948, 3011 (Jan. 16, 2014) (to be codified at 42 C.F.R. pts. 430, 431, 435, 436, 440, 441 & 447. [hereinafter HCBS Final Rules] The affected services are those provided under 1915(c) waivers, 1915(i) state plan options, and 1915(k) state plan options.

experiences rather than the setting's location, geography, or physical characteristics.[3] This approach should focus on a person's needs and choices and help individualize what constitutes integration into a community. However, some states may find the transition process challenging as they work to identify the services and settings in their system that meet these requirements or need to change. Advocates have the knowledge and on-the-ground experience in the various issue areas related to HCBS programs to identify the necessary changes to the HCBS programs and to make meaningful comments to CMS.

An Olmstead Opportunity

The implementation of the HCBS regulations is a significant, systemic opportunity for advocates to make a big push on Olmstead generally and influence what it means to be integrated in the community. The pessimistic outlook may be that the states will change as little as they have to, but this a chance to improve community integration because almost every state will have to modify part of their HCBS program. This is a moment where states will be evaluating how their HCBS programs are working and, importantly, CMS will be closely scrutinizing the program and accepting public input. The public comment process, which seems to be occurring in two stages in most states, is a chance to make the HCBS programs as integrated as possible. If advocates miss this opportunity, states may become comfortable that the level of "community" they achieved through the planning process is sufficient and defensible.

States may try to include settings in their HCBS programs that advocates do not see as being community in nature. The regulations require CMS to apply heightened scrutiny if a state wants to use settings that, under the regulations, are presumed to have institutional qualities. For such settings, states will have to submit evidence to CMS explaining how such settings are home and community based and CMS will assess how the settings allow for full integration into the broader community. CMS is not only going to take into account the state's evidence, but will accept information from stakeholders and other third parties regarding whether such settings have the qualities of being home and community-based and do not have the qualities of an institution.[4] The HCBS regulations present a major opportunity for advocates to shift HCBS programs, and the recipients of these services, away from institutional settings.

To achieve the goal of greater community integration in state's Medicaid programs and make it seem feasible to the state, it will likely be necessary to provide concrete issue spotting and possible solutions and explain "what community looks like". Explaining the problems and some possible solutions should help modify waiver programs to embrace integration in all areas and help quell some of the concerns that may arise from family members who are discomfited by some of the changes that may occur.[5] Advocates should be able to provide this information and be leaders on what community should look like moving forward.

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[3] For a review of the settings that are excluded from HCBS or presumed to have institutional qualities, as well as a review of the conditions of a provider-controlled setting, please see the Q&A from January 2014 on the HCBS regulations.
[4] HCBS Final Rules at 2969.
[5] The HCBS requirements limit the types of settings in which HCBS services may be provided. A state may continue to pay for settings that may not meet these requirements, but the state may not use Medicaid-funded HCBS to do so. The answer to requests to keep certain settings may be to identify different funding, which may include non-HCBS Medicaid funding to maintain that setting.

Background on HCBS Transition Plans

Some states have invited comments on an initial plan that sets forth their transition process.[6] Before submitting a transition plan to CMS, a State must provide at least a 30-day public notice and comment period, ensure the full plan is available to the public, provide two statements of public notice and input procedures, and "[t]he State must consider and modify the transition plan, as the State deems appropriate, to account for public comment."[7] A transition plan must include all elements detailed by the Secretary, including timelines and deliverables.[8] As states change HCBS programs to become compliant with the regulations governing settings, states also must make changes to waiver quality measures and assurance for applications and renewals submitted after June 1, 2014.[9]

The timing for transition plans for a state will vary, largely depending on whether the state has any existing HCBS programs that are up for renewal before the final due date or transition plans.[10] For existing HCBS programs, a state must submit a transition plan within by March 17, 2015, which is one year after the effective date of the regulation.[11] If a state has a program due for renewal within the first year after the effective date of the regulations, it must submit a transition plan with that application and CMS's approval will be contingent on the inclusion of a CMS approved transition plan.[12] A transition plan for a 1915(c) waiver may be as long as five

[6] CMS has made it clear that States must also provide the opportunity to comment on the final plan, regardless of whether they issue an initial plan and solicit public comment.

[7] 42 C.F.R. § 441.301; HCBS Final Rules at 3031. With the transition plan, the State must submit to CMS evidence of the public notice and a summary of the comments received during the public notice period, reasons why comments were not adopted, and any modifications to the transition plan based upon these comments. HCBS Final Rules at 3031.

[8] 42 C.F.R. § 441.301; HCBS Final Rules at 3031.

[9] CMS, Modifications to Quality Measures and Reporting in § 1915(c) Home and Community-Based Waivers 6 (Mar. 12, 2014). For example, now the subassurance regarding choice focuses on monitoring participants' choice between/among waiver services and providers rather than focusing on evidence on whether choice between institutional and HCBS care was provided. HCBS Programs may also need to Department of Labor rule changes regarding home care workers and the shared living rules. *See* US DOL, Home, We Count on Home Care, http://www.dol.gov/whd/homecare/; US DOL, Medicaid Shared Living Programs, http://www.dol.gov/whd/homecare/shared_living.htm (last visited August 4, 2014).

[10] The website hcbsadvocacy.org is trying to keep up with key dates and deadlines. This website also has other helpful resources on the HCBS transition process, commenting, and what other states are doing.

[11] 42 C.F.R. § 441.301; HCBS Final Rules at 3031.

[12] Within 120 days of the submission of the first waiver renewal or amendment request, the State must submit a transition plan detailing how the State will operate all section 1915(c) HCBS waivers and any section 1915(i) State plan benefits in accordance with the HCBS standards. 42 C.F.R. § 441.301; HCBS Final Rules at 3031. For 1915(k) options, states with approved plans that met the proposed rules published in May 2012 will have a transition period of at least one year to make any needed program changes to come into compliance with the final setting requirements. CMS Questions and Answers – 1915(i) State Plan Home and Community-Based Services, 5-Year Period for Waivers, Provider Payment Reassignment, Setting Requirements for Community First Choice, and 1915(c) Home and Community-Based Services Waivers – CMS 2249-F and 2296-F 4, http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Long-Term-Services-and-Supports/Home-and-Community-Based-Services/Downloads/Final-Q-and-A.pdf [hereinafter CMS Q&A].

years, but "CMS expects states to transition to the new settings requirements in as brief as period as possible and to demonstrate substantial progress towards compliance during any transition period."[13]

Because of the brief comment period, advocates must be proactive about identifying what needs to change in an existing program before the state issues an initial plan. While states are identifying what may need to change, advocates should be doing the same so that have an independently formed vision of what the HCBS program should look like. Identifying issues before the transition plan is open for comment allows advocates to be prepared to agree or refute the plan and have time to formulate comments that are responsive to the plan and portray what integration should look like in the state.

For some states, substantial changes may need to occur for the HCBS programs to come into compliance in a way that truly supports community integration. Advocates may want to press for stronger integration over a longer period of time, such as the five year cycle of the waiver, rather than more immediate but less than ideal compliance. Slower transition may also help the process be more successful and be easier on the individual participants. The changes that states make to the HCBS programs may be the last fundamental change for some time, so advocates should look at this opportunity as one of long-range planning.

Gathering Information Across Issue Areas[14]

The analysis of how an HCBS program needs to change to be compliant with the new rules will involve the knowledge of advocates across issue areas. Although comments to plan changes may usually be seen as a policy issues, the HCBS transition plans also involve the knowledge and experiences of Medicaid, employment, and facility advocates. HCBS programs support an individual's daily life and changes may need to occur in all areas: where they live, what they do with their day such as vocational activities, and the Medicaid services they receive to support them in these endeavors. Understanding existing regulations and policies is important and will form the structure for comments, but the most critical component to making meaningful comments that illustrate what needs to change will come from on the ground knowledge about how these actually services work.

For example, in comparing existing rules about provider owned/controlled setting to the HCBS regulations, a policy advocate may think that the rights of residents in facilities look similar to the HCBS requirements. States often have residents' rights requirements for facilities that include the right to privacy, which seem very similar to the HCBS regulations for a provider-controlled residence. However, an advocate who is familiar with that type of facility and a resident's experience may be able to provide examples of how these rights are not enforced or are not meaningful for the residents. For example, there may be facilities where the right to privacy is construed as the right for a resident to go to her room rather than be in the common room under supervision, as opposed to the lockable door required in the HCBS regulations. Access to food is another right that may be

[13] *Id.* at 5. A transition plan may be approved for a period of up to five years, as supported by individual state's circumstances.

[14] Attached to the end of this Q&A is a bulleted summary of the major changes in the regulations that will likely be addressed in transition plans.

included in current residents' rights protections but that may not meet the HCBS standards. A facility may interpret the existing requirement as allowing a resident to purchase snacks and keep them in their room or storage area. This interpretation assumes the individuals have money to purchase the snacks and does not meet the HCBS requirements about access to food items and choice in items. The examples from the facility advocate would be important to include in comments to show that although on paper the policies seem similar, the individual's experience does not reflect the requirements.

Initial Steps

As discussed above, compliance with the new HCBS regulations could truly change how an HCBS program looks in a state. Questions an organization may ask among its advocates to start the conversation include:

Broad Questions About Community Integration

- What do we think our state's HCBS program should be like?
- How does an individual's experience integration and how can a program foster that?
- What are necessary supports and settings for community integration?
- What does having a meaningful day really mean? How can an HCBS program support how an individual defines a meaningful day?
    - By focusing on the needs of an individual, how does an HCBS program ensure integration but not impose a set idea about what integration means on that individual?
    - How does a program maintain the idea that community integration may look different for everyone?
- How can an HCBS program support community integration, foster friendships and connections, ensure self-determination, and encourage independence?
    - If a person with a disability values the interactions they have with other people with disabilities, how those relationships be fostered in such a way that does not promote segregation?
- In fostering independence and integration, how does an HCBS program maintain the flexibility to meet the desires of an individual?
    - For example, if a person does not enjoy being social every day and would not like to have supported volunteer activities out in the community, but would prefer to quietly feed the ducks with other people in the park, how can a program support that version of community integration?

Questions About Current Programs-Where are HCBS currently provided?

- Are Medicaid-funded HCBS services currently provided in excluded institutional settings? Are they provided in settings presumed to be institutional under the new regulations?
    - For example, are there group homes owned by a provider that also has ICF-I/IDs? Nursing homes? Are these group homes on the same property as the institutional setting?
    - Are there group homes owned/operated by the State on or adjacent to institutions?

- Is HCBS provided in settings that have the effect of isolating individuals?[15]
    - Is the setting designed specifically for people with disabilities, and often even for people with a certain type of disability?
    - Are HCBS services used for farmstead or other disability-specific communities?
    - Is the setting primarily or exclusively people with disabilities and on-site staff provides many services to them?[16]
    - Are multiple types of services and activities on-site, including housing, day services, medical, behavioral and therapeutic services, and/or social and recreational activities?
    - Do people in the setting have limited, if any interaction with the broader community?
    - Do the settings use/authorize interventions/restrictions that are used in institutional settings or are deemed unacceptable in Medicaid institutional settings (e.g., seclusion).[17]

- Are day programs in HCBS settings? States may have changed how day programs operated after CMS issued guidance regarding integration requirements for employment related services in 1915(c) programs in September 2011. However, some programs may need to change to meet the HCBS regulations.[18]
- What needs to change in the current person-centered planning process to be compliant with the regulations and to foster community integration, self-determination, and independence?[19] This would include changes to the role of the individual representative.

The above questions are merely a starting point for the broader discussion within an organization. Once there is an understanding about what an HCBS program should look like, with some understanding of what is possible, the next step is identifying which aspects of the current program need to change. Some of this information will

[15] CMS, Guidance on Settings that have the Effect of Isolating Individuals Receiving HCBS from the Broader Community (May 2014), http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Long-Term-Services-and-Supports/Home-and-Community-Based-Services/Downloads/Settings-that-isolate.pdf. CMS has provided a non-exhaustive list of examples of residential setting that typically have the effect of isolating people receiving HCBS from the broader community. These settings are (1) farmstead or disability-specific farm communities; (2) gated/secured "communities" for people with disabilities; (3) residential schools; and (4) multiple settings co-located and operational related (i.e., operated and controlled by the same provider). *Id.*

[16] *Id.*

[17] *Id.*

[18] In trainings on the new regulations, CMS has referred to this memo as initial guidance on this issue. Even if a state changed these programs in response to this bulletin, the changes may not be sufficient to meet the new regulations. CMCS Informational Bulletin (Sept. 16, 2011), http://downloads.cms.gov/cmsgov/archived-downloads/CMCSBulletins/downloads/CIB-9-16-11.pdf (providing guidance on integration requirements for employment related services under 1915(c) waivers).

[19] US DHHS, Guidance for Implementing Standards for Person-Centered Planning and Self-Direction in Home and Community-Based Services Programs (June 6, 2014), http://www.acl.gov/Programs/CDAP/OIP/docs/2402-a-Guidance.pdf.

come from knowledge of how the program is actually functioning, but the approved documents for the waiver or state plan option can also act as a guide.[20] For example, in a 1915(c) waiver:

- Appendix B-7 sets forth the freedom of choice policy.[21]
- Appendix C identifies the services available in the waiver and part of each service identification is the section on provider qualifications. This information provides initial direction as to settings in which the services are currently provided, allowing advocates to evaluate each type of setting. 441.301(c)(4) and 3010-3017 of the Federal Register.
- Appendix D explains the policies on person-centered planning, which can be compared to § 441.301(b)(1)(i)(A)-(B) and pages 3004-10 of the Federal Register.
- Appendix E is about self-directed services, which should have the same changes on regarding person-centered planning, HCBS settings, etc.
- Appendix F describes the Participant Rights, including appeal rights and grievances. This section ideally would include specific language about how a person may complain about their person-centered plan and/or the process. The same would be true for a complaint about a provider not meeting the expected standards or standing in the way of implementation of the person-centered plan.
- Appendix G may include information about restrictions on residents' rights that may not comply with the new regulations. Appendix G also includes quality improvement strategies, which should change to reflect the CMS memo on 1915(c) quality measures from March 2014.[22]

Other HCBS programs, such as 1915(i) state plan options, do not have a standardized application, but the approved document should have similar information that can guide a review of providers, program requirements, etc.

[20] Most states post the waiver documents or state plan option, but the CMS website should also have the recent approved waiver or state plan option, http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Waivers/Waivers_faceted.html.

[21] This section of the waiver may continue to just be the choice between waiver or institutional services while the choice from a range of options is elsewhere in the waiver, but the quality assurances indicate this section will likely change because the focus is supposed to be less on the institutional v. waiver choice.

[22] CMS has also issued a directive requiring States to focus performance measures on various factors, including compliance with HCBS setting requirements and other new regulatory components. CMS, Modifications to Quality Measures and Reporting in 1915(c) Home and Community-Based Waivers 12 (Mar. 12, 2014), http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Waivers/Downloads/3-CMCS-quality-memo-narrative-.pdf.

Who Knows What?

The changes to HCBS programs are across various areas, but many organizations have the knowledge in-house or within existing coalitions. While gathering additional information may be helpful, most of the information needed to make comments can be compiled by getting the right people together to discuss the issues.

For example:

- Advocates familiar with HCBS programs through their work assisting with Medicaid appeals or transitioning people to the community can help identify the areas that need to be changed to meet the regulations, especially in the areas of person-centered planning process, assessments, risk analysis, budgets, and conflicts of interests.
- Advocates who are often in facilities, including community facilities, can help identify settings with institutional qualities.
- Facility advocates can help predict how the provider-controlled setting rules may be interpreted by facilities if a state is not specific or the issues are not addressed in the transition plan. For example, what does privacy look like? Is choice currently the choice between sitting in the living room or sitting in the living room doing a puzzle? What are current policies and practices on visitors and how will that change, or not?
- Facility advocates can also use their experience to identify the rules and issues that facilities may bring up as limitations to their ability to have truly integrated settings. For example, if a person is supposed to have more choice and independence, what factors may exist that limit that choice, such as availability of staffing levels or transportation restrictions.
- Facility advocates are also familiar with how treatment plans may be overly general in how they justify restrictions on rights. This knowledge would translate into how community facilities will likely try to justify modifications of the conditions of a provider controlled setting.
- Employment advocates can identify the problems in day programs since many of them are operated as "pre-vocational programming."
- Employment advocates can also help brainstorm about what integrated day activities could look like and what changes would need to occur.
- Housing advocates can identify how the requirement of a lease or residential agreement that provides the same protections as a lease may work in practice. For example, will the facilities try to use very short-term agreements that automatically renew so that the eviction protections that apply are as minimal as possible.

Conclusions and Recommendations

The transition plans to change HCBS programs so that they comply with the new regulations governing community-based services is a significant opportunity to optimize how these programs support community integration. Most advocacy programs have the information they need to make meaningful comments, they just need to mine that information from people who work on different issue areas and bring these people together to determine what needs to change. There are a few key things to remember:

- The changes to the HCBS are specific to 1915(c) waiver programs and 1915(i) and 1915(k) state plan options. Regular state plan services are not affected by these regulations.
- The HCBS requirements apply to all settings in which HCBS is provided and applies to the setting where an individual receiving those services lives.
- Many states are doing transition plans in two stages for public comment, one an initial plan to plan and then a later formal transition plan that will be submitted to CMS. It is critical that advocates fully and specifically comment on the initial plans as this is the opportunity to highlight what needs to change. The final plan will be the opportunity to say why the specifics of the transition plan is not sufficient. Not all states will do two stage transition planning and advocates should not wait until the final transition plan to communicate concerns.
- A transition plan that occurs over an extended period of time may be achieve more community integration, and be more successful than a transition that is more immediate.
- Advocates should identify what needs to change in an HCBS program in advance of initial transition plans, including identifying examples of how a current policy works in practice or the institutional nature of certain settings.
- If a state wants to use settings that are presumed institutional in nature, CMS is looking for direct commentary about why those facilities should not be used for HCBS or what needs to change to meet the regulations.

Attachment – Summary of the Major Areas of Change

The HCBS regulations change more than just the characteristics of settings in which individuals may receive HCBS. The following are the areas that advocates will likely focus comments for transition plans:[23]

- Needs-based criteria and Evaluation (1915(i))
- Independent assessment (1915(i))
- Person-centered Service plan[24]
- Home and Community Based Settings
    - Settings specifically excluded
        - Nursing facilities, institutes for mental disease, intermediate care facilities for individuals with intellectual disabilities, and hospitals
    - Settings presumed to have institutional qualities[25]
        - Publicly or privately owned facilities that provide inpatient treatment;
        - On the ground of, or immediately adjacent to, a public institution;
        - Settings that have the effect of isolating individuals receiving Medicaid-funded HCBS from the broader community of individuals not receiving Medicaid-funded HCBS[26]
    - HCBS setting qualities:
        - Is integrated in and supports full access to the greater community;
        - Is selected by the individual from among setting options;
        - Ensures individual rights of privacy, dignity and respect, and freedom from coercion and restraint;
        - Optimizes autonomy and independence in making life choices; and

[23] Other areas of changes are important, such as how states may combine waivers, what actions CMS make take to enforce compliance, when a State has to provide for public comment in response to a substantive change, administrative changes, etc. However, these changes are not likely to be included in a transition plan and thus are not the focus of this Q&A.

[24] There is some question as to when a person-centered plan must comply with the new HCBS regulations. CMS has stated that it expects states will implement the changes to plans of care and the person centered planning process on an individual basis as plans are developed or updated with each participant. The effective date of the rules is March 17, 2014. If a standard plan of care is a one-year plan, a state could require that the any plan that will last through March 17, 2014 should comply. However, this may not be feasible as many states will not have implemented their transition plans by this point. The reality will likely be that plans will continue to be developed as they have been until next year because the planning process changes will likely be with next year's plan. Plans that need to be updated, which may not be many, will likely be update next year. For many, the plan may not need to be updated because what will likely change the most will probably be how the services in a person's plan are delivered, e.g., changes to the policies in a person's residence including any restrictions. However, it is unclear how much a transition plan may delay full implementation of all pieces of the regulations. CMS Q&A, *supra* note 10, at 4.

[25] If a state wishes to present evidence that such settings are home and community-based, CMS will engage in heightened scrutiny of the transition plan and/or SPA and supporting documentation to make a determination. This review will include assessment of how the settings allow for full integration into the broader community.

[26] The emphasis is on access to an individual's chosen activities and whether the individual has the same degree of access to such activities as individuals not receiving Medicaid-funded HCBS. HCBS Final Rules at 2975.

        - Facilitates choice regarding services and who provides them.[27]
    - Conditions for provider owned or controlled settings
        - Lease or agreements that require similar protections[28]
        - Freedom to decorate one's own sleeping or living unit[29]
        - Units have lockable doors and privacy[30]
        - Choice of roommate[31]
        - Control of one's own schedule, including access to food at any time[32]
        - The right to visitors at any time[33]
        - Physical accessibility of the setting[34]
- Provider Qualifications
- Conflict of Interest[35]
- Definition of Individual's Representative
- Self-directed services
- State Plan HCBS Administration: State Responsibilities and Quality Improvement

[27] *See, e.g., id.* at 3030-31 (to be codified at 42 C.F.R. § 441.301(c)(4)).
[28] Lease or residency agreements are supposed to provide, at a minimum, eviction processes and appeals. CMS states that it expects the person-centered planning process to address what happens after a person has a crisis, the level of care changes, or if the individual engages in risky behavior that endangers themselves or those around them. *Id.* at 2960-64.
[29] Landlord tenant laws may allow landlords to set reasonable limits as long as the limits are not discriminatory or otherwise deny rights granted to tenants under the state law. *Id.* at 2963. The rules also do not require that everyone have a private room, just that private rooms are among the options provided by the state's array of services. *Id.* at 2964.
[30] Although the requirement for a lockable entrance may be modified if supported by a specific assessed need and justified and agreed to in a PCP, only appropriate individuals should have access to an individual's room. If more than the minimum number of individuals necessary has the key to achieve the purpose of the limitation, then the limitation is too broad and that condition is not met. In addition, even if the person's needs do not support a locked door, alternative means for assuring meaningful individual privacy should be required, such as knocking and waiting for a reply. *Id.* at 2963-4.
[31] HCBS Final Rules at 2963-64.
[32] In response to a comment about how most provider controlled facilities have scheduled meals and may maintain institutional like qualities, CMS responded that a residential facility should be able to reasonably accommodate an individual's preferences on a 24-hour a day basis. "The opportunity for individuals to select the foods they eat, store food in their room, eat in their room, and decide when to eat are all ways in which the access to food requirement can be met." *Id.* at 2965-66.
[33] *Id.* at 2966
[34] This condition cannot be modified as physical accessibility could be a safety hazard. HCBS Final Rules at 2967, 3033, 3034 (to be codified at 42 C.F.R. §§ 441.530(a)(1)(vi)(F), 441.710(a)(1)(vi)(F)).
[34] *Id.* at 3030, 3032, 3033, 3034, (to be codified at 42 C.F.R. §§ 441.301(c)(2)(xiii), 441.301(c)(4)(vi)(F), 441.530(a)(1)(vi)(F), 441.710(a)(1)(vi)(F), 441.725(b)(13)).
[35] *E.g.*, 42 C.F.R. § 441.301(c)(1)(v) for 1915(c); HCBS Final Rules at 3006-07.