

Just Like Home: An Advocate's Guide to Consumer Rights in Medicaid HCBS

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Introduction

The National Senior Citizens Law Center (NSCLC) believes that home and community-based services (HCBS) should be provided as an option to every Medicaid beneficiary (consumer) who needs such services, allowing more seniors and persons with disabilities to live with dignity and independence in their homes. Under Medicaid law, HCBS funding exists to give consumers the ability to receive necessary long-term services and supports (LTSS) without moving into a nursing home or other healthcare institution. The value of the HCBS alternative would be destroyed or diluted if HCBS were provided in institution-like settings.

New federal Medicaid rules for the first time set standards to ensure that Medicaid-funded HCBS are provided in settings that are non-institutional in nature. These standards, which took effect in March 2014, apply to residential settings such as houses, apartments, and residential care facilities like assisted living facilities. The standards also apply to non-residential settings such as adult day care programs.

This guide provides consumers, advocates and other stakeholders with information regarding multiple facets of the new standards, including consumer rights in HCBS, and the guidelines for determining which settings are disqualified from HCBS reimbursement. This guide is based on the federal rules and subsequently issued guidance, and will be updated as further information becomes available.

Importantly, many details remain to be determined by individual states, subject to review and approval by the federal government. Stakeholder involvement and advocacy will be critical as state Medicaid programs transition through implementation of the new rules. Throughout the transition process, both the states and the federal Centers for Medicare and Medicaid Services (CMS) must accept and consider recommendations from consumers and other stakeholders.

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Background

What are home and community-based services (HCBS)?

Home and community-based services are services provided to Medicaid consumers who need assistance on a daily or almost-daily basis.¹ One common type of service is assistance with dressing, bathing, walking, and other activities of daily living. Other common services include case management and home health aide services.

Where are HCBS provided?

HCBS often are provided in the consumer's house or apartment. They also may be provided in a facility-based residential setting such as an assisted living facility; in that case, the Medicaid program pays for facility services but not the room and board costs. In addition, HCBS may be provided in a non-residential setting such as an adult day care program.

What is the intent of the new rules?

Within Medicaid, HCBS programs were created to provide an alternative to nursing homes and other types of institutional care. In recent years, however, some HCBS settings have been criticized for being overly institutional in nature. The intent of the new rules is to ensure that HCBS are provided in settings that truly have a non-institutional character.

¹ See, e.g., NSCLC, Medicaid Long-Term Services & Supports 101: Emerging Opportunities and Challenges (Sept. 2012).

What programs are affected by the new rules?

The new rules explicitly apply to three Medicaid programs: HCBS waivers, state-plan HCBS programs, and the Community-First Choice option. These three programs are frequently referred to as Section 1915(c) waivers, Section 1915(i) programs, and Section 1915(k) programs, respectively, based on the relevant sections of the Social Security Act.

In the not-too-distant future, CMS intends to extend these same standards over all types of Medicaid-funded HCBS, including state-plan personal care services. For HCBS provided through Section 1115 demonstration waivers, requirements comparable to the new rules will be set forth in the waivers' special terms and conditions documents.²

Where can the actual language of the new rules be found?

The rules for HCBS settings are found in sections 441.301, 441.530, and 441.710 of Title 42 of the Code of Federal Regulations. These sections govern the HCBS waiver, the Community-First Choice option, and state-plan HCBS, respectively. Sections 441.301 and 441.710 also include standards for the person-centered planning process.

The announcement of the new rules, including the rules and explanatory material,

² 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, at 2.

is found on pages 2,948 through 3,039 of volume 79 of the Federal Register, as published on January 16, 2014.

CMS also has issued guidance regarding the new rules and, as relevant, that guidance is referenced in this guide. Future CMS guidance will address state transition planning, public input requirements, person-centered planning, application of the rules to non-residential settings, changes to the Technical Guide for Section 1915(c) waivers, and other matters.³

The rules, guidance and other relevant material can be found at the CMS website at <http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Long-Term-Services-and-Supports/Home-and-Community-Based-Services/Home-and-Community-Based-Services.html>.

Standards for All HCBS Settings⁴

What standards apply generally to all types of HCBS settings?

- **Integration with community:** The setting must support full access by the consumer to the greater community, “including opportunities to seek employment and work in competitive integrated settings, engage in community life, control personal resources, and receive services

in the community, to the same degree of access as [consumers] not receiving Medicaid HCBS.”

- **Choice:** Consumers must have a choice among setting options, including settings that are not disability-specific.
- **Rights:** The setting must ensure consumer rights to privacy, dignity, and respect, and freedom from coercion and restraint.
- **Independence:** The setting must optimize a consumer’s ability to make life choices, including choices relating to daily activities, the physical environment, and with whom to interact. Similarly, the setting must facilitate choice regarding services and supports and who provides them.

These standards are relatively broad. Has CMS issued any guidance on how they should be interpreted and applied?

A few days after the rules’ effective date, CMS released a six-page document entitled “Exploratory Questions to Assist States in Assessment of Residential Settings.” It is presented by CMS as an “optional tool” for states, and gives insight into factors that CMS is likely to consider significant.

The tool contains dozens of questions; a selection of those questions that may be of particular interest to consumers and their advocates are reproduced in this guide’s appendix. Note that the questions are applicable in all residential settings, and not just those that (like an assisted living facility) are controlled by the provider of services.

³ 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, at 5.

⁴ 42 C.F.R. §§ 441.301 (HCBS waivers), 441.530 (Community First Choice option), 441.710 (state-plan HCBS services).

Can a rural setting provide adequate access to the community?

Yes. Under the rules, consumers must have the same degree of access to the community as persons who are not receiving Medicaid HCBS.⁵ The relevant comparison is with persons who are in the same geographic area but do not receive Medicaid HCBS. Thus, in rural settings, adequate access is based on the access that is typical locally, and not to greater access that may be more prevalent in (for example) urban settings.

Standards Specific to Residential Care Facilities⁶

Can HCBS payment be made for services provided in a provider-controlled residential setting such as an assisted living facility?

Yes, provided that additional standards are met.

The rules allow a housing provider also to be a service provider. States must ensure that a consumer has made an informed choice to reside in a setting that provides both housing and services.⁷

Because of the increased risk that a residential facility such as an assisted living facility may be overly institutional, such facilities must meet additional standards. These standards, which are discussed in more detail below, include protections

⁵ 79 Fed. Reg. at 2,975.

⁶ 42 C.F.R. §§ 441.301 (HCBS waivers), 441.530 (Community First Choice option), 441.710 (state-plan HCBS services).

⁷ 79 Fed. Reg. at 2,958.

against eviction, privacy rights, freedom of choice, a right to receive visitors, and physical accessibility. The standards apply when the setting “is a specific physical place that is owned, co-owned, and/or operated by a provider of HCBS.”⁸

As discussed later in this guide, some of these standards can be modified based on the consumer’s needs as documented in the service plan.

If a residential care facility provides Medicaid-reimbursed HCBS, do the standards apply to all facility residents, or only to those whose services are reimbursed through Medicaid?

The standards should apply to all facility residents. The relevant regulatory language in most instances refers to the rights of an “individual” without regard to whether or not the individual’s services are reimbursed through Medicaid. In a few instances, the regulatory language refers specifically to an “HCBS participant” or to “individuals receiving Medicaid HCBS,” indicating that the term “individual” by itself should not be limited to persons receiving Medicaid-reimbursed services.

In addition, it would make little sense for a facility to provide and honor the specified rights for Medicaid-eligible consumers, while denying those same rights to other consumers living in the facility. An intent of the regulations is to foster a non-institutional environment, and creating and maintaining such an environment requires fair treatment of all consumers, regardless of the consumer’s reimbursement source.

⁸ 79 Fed. Reg. at 2,979.

What eviction protections must be provided in residential facilities?

Consumers must have a right to reside in a specific living unit within the facility. The right must be established by a legally enforceable agreement, such as a lease.

Also, consumers must have protections against eviction that are at least as strong as those that apply under the state’s landlord-tenant law. If, under relevant state or local law, landlord-tenant law does not apply, the State must ensure that a lease or other written agreement will be in place for each HCBS participant,⁹ and that the document provides eviction protections comparable to those provided under the relevant landlord-tenant law. To do so, the State can use existing laws or establish new laws, as long as federal requirements are met.¹⁰ The adequacy of such laws, and of the leases or agreements referenced in those laws, is determined by CMS review of waivers and state plan amendments.¹¹

⁹ This requirement applies to an “HCBS participant” in the rules for HCBS waivers and HCBS state-plan services, and to a “participant” in the rules for the Community First Choice option. See 42 C.F.R. §§ 441.301(c)(4)(vi)(A) (HCBS waivers), 441.530(a)(1)(vi)(A) (Community First Choice option), 441.710(a)(1)(vi)(A) (state-plan HCBS services).

¹⁰ 79 Fed. Reg. at 2,960.

¹¹ 79 Fed. Reg. at 2,961-62.

If a facility initiates an eviction or involuntary discharge, “the [S]tate must ensure that proper procedures for such actions are followed and [consumers] are fully informed of their rights.”¹²

What privacy rights apply in a residential facility?

Each consumer must have privacy in his or her living unit, including a lockable entrance door, a choice of roommates (in shared occupancy situations), and the freedom to furnish or decorate the living unit.

Can a facility’s staff members have a key to the consumer’s living unit?

Yes, a key can be held by “appropriate staff.” The consumer should have a say in which staff members have a key, and agree on the staff member or members who have a key.¹³

In guidance, CMS has released a list of questions that states may use, at their option, in evaluating whether provider-controlled facilities have met the HCBS settings standards. Regarding locks and keys, the questions address whether the consumer can lock bedroom and bathroom doors, whether staff and other residents knock and ask permission before entering a bedroom or bathroom, and whether staff enters a

¹² 79 Fed. Reg. at 2,961.

¹³ 79 Fed. Reg. at 2,964.

**CONSUMER RIGHTS
IN RESIDENTIAL CARE
FACILITIES**

- Landlord-tenant protections
- Lockable doors
- Choice of roommates
- Freedom to furnish and decorate
- Control over schedule
- Access to food anytime
- Visitors anytime
- Physical accessibility

living area or “privacy space” only under limited circumstances agreed upon with the consumer.¹⁴

Is private occupancy required in a residential facility?

No, the federal rules do not require a private living unit or even a private bedroom. States are responsible for “ensur[ing] that there are private room options available within a state’s HCBS program,”¹⁵ and a consumer has the right to choose between private occupancy or shared occupancy. The considerations in making that choice include the consumer’s financial resources and the relatively higher cost of private occupancy.

To a certain extent, it is misleading to talk about “choosing” shared occupancy as if it were the preferable outcome. In many cases, consumers “choose” shared occupancy because they have no practical alternative — their available income is insufficient, under Medicaid rules, to afford private occupancy.

If a consumer chooses to share a room, he or she must have a choice of roommate.

Of course, it should always be kept in mind that the federal rules set minimum standards, and individual states are free to establish higher standards. Ohio, for example, allows shared occupancy only when the consumers have an “existing relationship.”¹⁶

¹⁴ CMS, Exploratory Questions to Assist States in Assessment of Residential Settings (March 2014), at 6.
¹⁵ 79 Fed. Reg. at 2,964.
¹⁶ Ohio Assisted Living Waiver Application, Appendices C-1 (definition of “assisted living services) & C-2(c).

In a residential facility, is the consumer’s right to decorate or furnish an unlimited right?

No. A consumer has the right to furnish or decorate the living unit within the scope of the lease or other residency agreement.

What rights are included in freedom of choice in a residential facility?

A consumer must have freedom and support to control his or her schedule and activities, and access to food at any time.

What specifically is required in a consumer’s right to have access to food at any time?

A consumer must have 24-hour-a-day access to food. This requirement can be met in a variety of ways, including by giving consumers control in selecting the foods they eat, storing food in their rooms, eating in their rooms, and deciding when to eat. Minimal options, such as the choice of a snack bar or crackers, will not meet the requirement: a consumer “should not be presented with narrow options, decided by someone else, without input from the [consumer].”¹⁷

According to CMS, the relevant rule supports a requirement that “living units ... have access to food storage and preparation space.”¹⁸

What are a consumer’s rights to accept visitors in a residential facility?

A consumer has the right to have visitors of his or her choosing at any time. Visitation should be done in a way that respects the

¹⁷ 79 Fed. Reg. at 2,966.
¹⁸ 79 Fed. Reg. at 2,965.

preferences of other consumers living in the facility.

Overnight visitation is possible, although a lease or other residency agreement could limit the extent to which a visitor can stay overnight, in order to avoid situations where a “visitor” essentially moves into the facility.¹⁹

What physical accessibility standards apply in residential facilities?

Residential facilities must be physically accessible to consumers. CMS guidance mentions obstructions such as steps, lips in a doorway, and narrow hallways, and adaptations such as a stair lift or elevator.²⁰

Can the standards for residential facilities be modified?

Yes, based on specific facts relating to a particular consumer. Modification is allowed only for the following standards:

- Protections against eviction;
- Privacy (including lockable doors, choice of roommates, and freedom to decorate or furnish a living unit);
- Freedom to control schedules and activities;
- Access to food at any time; and
- Visits at any time.

On the other hand, the right to a physically accessible living unit cannot be modified.

¹⁹ 79 Fed. Reg. at 2,966.

²⁰ CMS, Exploratory Questions to Assist States in Assessment of Residential Settings (March 2014), at 4.

Under what circumstances can standards for residential facilities be modified?

Modification is allowed if it is supported by a specific assessed need and justified in the consumer’s service plan. CMS rejected suggestions to allow modification based on a consumer’s overall condition.²¹ The modified standard must be described clearly, and must be proportional to the resident’s assessed need.

Prior to modification, the facility first must attempt alternative strategies — “positive interventions and supports” and “less intrusive methods of meeting the need that [were] tried but did not work.” Importantly, modification is allowed only with the informed consent of the consumer (or, as appropriate, the consumer’s representative). As a result, the consumer has control over modifications, since he or she can simply deny consent for any unwanted service plan modification.

In the case of a modification, the service plan must include an assurance that interventions and supports will not harm the consumer. Also, the service plan must include “regular collection and review of data to measure the ongoing effectiveness of the modification,” and “time limits for periodic reviews to determine if the modification is still necessary or can be terminated.”

How can a consumer force a residential care facility to comply with these rules?

Enforcement procedures will be determined state by state, with CMS approval required. Consumer advocates should be forceful in

²¹ 79 Fed. Reg. at 2,978.

asking for effective enforcement procedures. This guide recommends that CMS and the states create effective mechanisms to monitor facility compliance and investigate any allegations that a facility has violated a standard.

Qualification as an HCBS Setting²²

Can a nursing home or hospital qualify as an HCBS setting?

No, nursing homes and hospitals are classified as institutions. The same disqualification applies to an institution for mental diseases and to an intermediate care facility for persons with intellectual disabilities.

Nonetheless, HCBS can continue to be provided to a consumer who is temporarily hospitalized, provided that the services do not duplicate the services that the hospital must provide. Also, HCBS can be provided as transition services to assist a consumer in moving from an institution to an HCBS setting.²³

What other settings are disqualified as HCBS settings?

The rules also disqualify any other location that has the “qualities of an institutional setting” as determined by CMS. Under this standard, a setting is presumed to have such institutional qualities if the setting has the effect of isolating individuals receiving Medicaid HCBS from the broader community. More specifically, a setting is presumed

²² 42 C.F.R. §§ 441.301 (HCBS waivers), 441.530 (Community First Choice option), 441.710 (state-plan HCBS services).

²³ 79 Fed. Reg. at 2,951, 2,954-55, 2,967, 2,971.

to have these institutional qualities if the setting’s building:

- Includes also a facility providing inpatient institutional treatment; or
- Is on the grounds of, or immediately adjacent to, a public institution.

A “public institution” is defined as an institution under the responsibility or control of a governmental unit, and includes facilities like state psychiatric hospitals. The term “public institution” does not apply to medical institutions, intermediate care facilities, child care institutions, publicly operated community residences, universities, public libraries, and other similar settings.²⁴

What does it mean to say that a setting is “presumed” to have institutional qualities?

For those settings presumed to have institutional qualities, CMS will review information submitted by the State or other parties to determine, with “heightened scrutiny,” whether the setting can qualify as an HCBS setting. CMS will be looking for “strong evidence” that a setting is home and community-based in order to overcome the presumption.²⁵ Otherwise, the setting cannot be considered an HCBS setting.

If a setting is presumed to have institutional qualities, but the State seeks to have the setting treated as an HCBS setting, the State must provide evidence supporting its request. Such evidence is submitted as part of the State’s transition plan (discussed in more detail below) or as part of the State’s request for a new waiver, a waiver amendment, or a state plan amendment.

²⁴ 42 C.F.R. § 435.1010; 79 Fed. Reg. at 2,972.

²⁵ 79 Fed. Reg. at 2,969.

Prior to any submission to CMS, the state must make its proposed submission available to the public for comment. At its discretion, the state will modify its submission based on public comment; in any case, the submission to CMS must summarize the public input and explain if and how the input was incorporated into the submission.²⁶ CMS states that, during these review processes, CMS will accept and consider information from stakeholders and other third parties, in addition to the information provided by the state.²⁷

Can HCBS payment be made for a consumer living in a Continuing Care Retirement Community (CCRC)?

Probably, depending on the situation.

A CCRC generally includes independent living units, an assisted living facility, and a nursing home. As discussed above, HCBS funding never is available in a nursing home, but may be available in an assisted living facility, provided that the facility meets the HCBS standards for residential facilities. Also as discussed above, a setting will be presumed to have institutional qualities if the setting shares a building with a facility (such as a nursing home) providing inpatient treatment, or otherwise has the effect of isolating Medicaid HCBS consumers from the broader community.

If a CCRC resident lives in an independent living unit or assisted living facility that does not share a building with a nursing home, it is likely that setting will be eligible for HCBS funding. CMS has stated that the isolation

risk is relatively limited in CCRCs, “particularly since CCRCs typically include residents who live independently in addition to those who receive HCBS.”²⁸

For the purposes of these federal rules, the term “Continuing Care Retirement Community” or “CCRC” refers to a setting that includes independent living units, an assisted living facility, and a nursing home, without regard to whether the CCRC requires a large entrance fee.

Can a state convert an existing institution into an HCBS-appropriate setting?

Maybe, but such conversions are disfavored. Conversion of institutions should not be a state’s first option to develop community-based residential settings, since institutional structures often have been built in a way that inherently hinders the integration of consumers with the broader community. Nonetheless, a state may submit evidence to CMS to support a request that a converted institution be accepted as an HCBS setting.²⁹

Has CMS issued any additional guidance on the type of residential settings that are likely to lead to isolation, and that thus require heightened-scrutiny review?

Yes. In guidance issued only a few days after the rules became effective, CMS lists the following residential settings as typically isolating HCBS consumers from the broader community: a gated or secured “community” for persons with disabilities, a residential school, or a disability-specific farm

²⁶ CMS, Incorporation of Heightened Scrutiny in the Standard Waiver Process (March 2014).

²⁷ 79 Fed. Reg. at 2,968-69.

²⁸ CMS, Guidance on Settings that Have the Effect of Isolating Individuals receiving HCBS from the Broader Community (March 2014), at 3.

²⁹ 79 Fed. Reg. at 2,971.

community (“farmstead”).

Also, CMS states that isolation is likely when multiple settings are located together and operated by the same provider, because such settings tend to congregate large numbers of people with disabilities, limiting their ability to interact with the broader community. This category includes, according to CMS, group homes on the grounds of an intermediate care facility, or numerous group homes located on a single site or in close proximity to each other. This category does not include continuing care retirement communities (CCRCs), as discussed in a question-and-answer above.³⁰

Can a non-residential setting be disqualified from being an HCBS setting, due to its participants being excessively isolated from the broader community?

Yes, potentially. CMS intends to provide further guidance on the application of the rules to non-residential settings such as adult day care programs. Notably, a non-residential HCBS provider may be disqualified due to the consumer’s residence being out of compliance with the HCBS setting regulations, even though HCBS are not provided at the residence.³¹

³⁰ CMS, Guidance on Settings that Have the Effect of Isolating Individuals Receiving HCBS from the Broader Community (March 2014), at 2-3.

³¹ 79 Fed. Reg. at 2,960; 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, at 3.

State Transition Process and Stakeholder Involvement³²

When do standards for HCBS settings become effective?

The rules formally became effective on March 17, 2014, but the implementation process may take several years, depending on the state.

Do the HCBS setting standards apply to a state’s application for a new program?

Yes. When a state requests approval for the first time for a particular HCBS waiver, a HCBS state-plan amendment under Section 1915(i), or the Community First Choice option, CMS will require that the new program meet the HCBS setting standards.

When will the standards for HCBS settings be applied to a state’s pre-existing HCBS programs?

The standards will be phased in. Each state will submit transition plans that, subject to CMS approval, will set forth how and when the standards will be applied. In general, transition plans must be submitted to CMS by March 17, 2015. A different timeline, however, applies if prior to March 17, 2015, a state submits a new application or a request for renewal or amendment of an existing program. In that case, the application or request must address transition issues related to the program being proposed, renewed, or amended. Furthermore, within 120

³² 42 C.F.R. §§ 441.301 (HCBS waivers), 441.530 (Community First Choice option), 441.710 (state-plan HCBS services).

days after submission of the application or request, the state must submit a transition plan addressing all other Medicaid HCBS in the state.

How can the public express opinions regarding a state’s implementation of the standards?

A state must provide a 30-day notice-and-comment period for each transition plan. The state’s notice must explain public input procedures, with the public being provided with a complete copy of the proposed transition plan.

Following the notice-and-comment period, the state must consider the comments and, as the state deems appropriate, modify the transition plan in response. When the state submits the transition plan to CMS, the submission must include 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 those comments.”³³

Consumers, advocates and other stakeholders also may submit comments directly to CMS, for consideration by CMS during its review of a state’s proposed transition plan.

Will public opinion be influential in determining which settings are deemed to be eligible for HCBS reimbursement?

Yes, in many cases, although of course states vary in how and to what extent they respond to public opinion. For its part, CMS has stated that it intends to rely heavily on stakeholder input, since CMS does not have enough staff

³³ 79 Fed. Reg. at 3,031.

to conduct independent investigations of a state’s LTSS system and options.

How much time is a state allowed to transition its programs to compliance?

CMS will approve transition plans of up to five years.³⁴ The length of the transition period will vary from state to state, depending on the circumstances. CMS guidance states that “CMS expects states to transition to the new settings requirements in as brief a period as possible and to demonstrate substantial progress towards compliance during any transition period.”³⁵ If a state has an existing program under the Community First Choice option, and that program was designed to be in compliance with the proposed rules published in May 2012, the state will be given a transition period of at least one year.³⁶

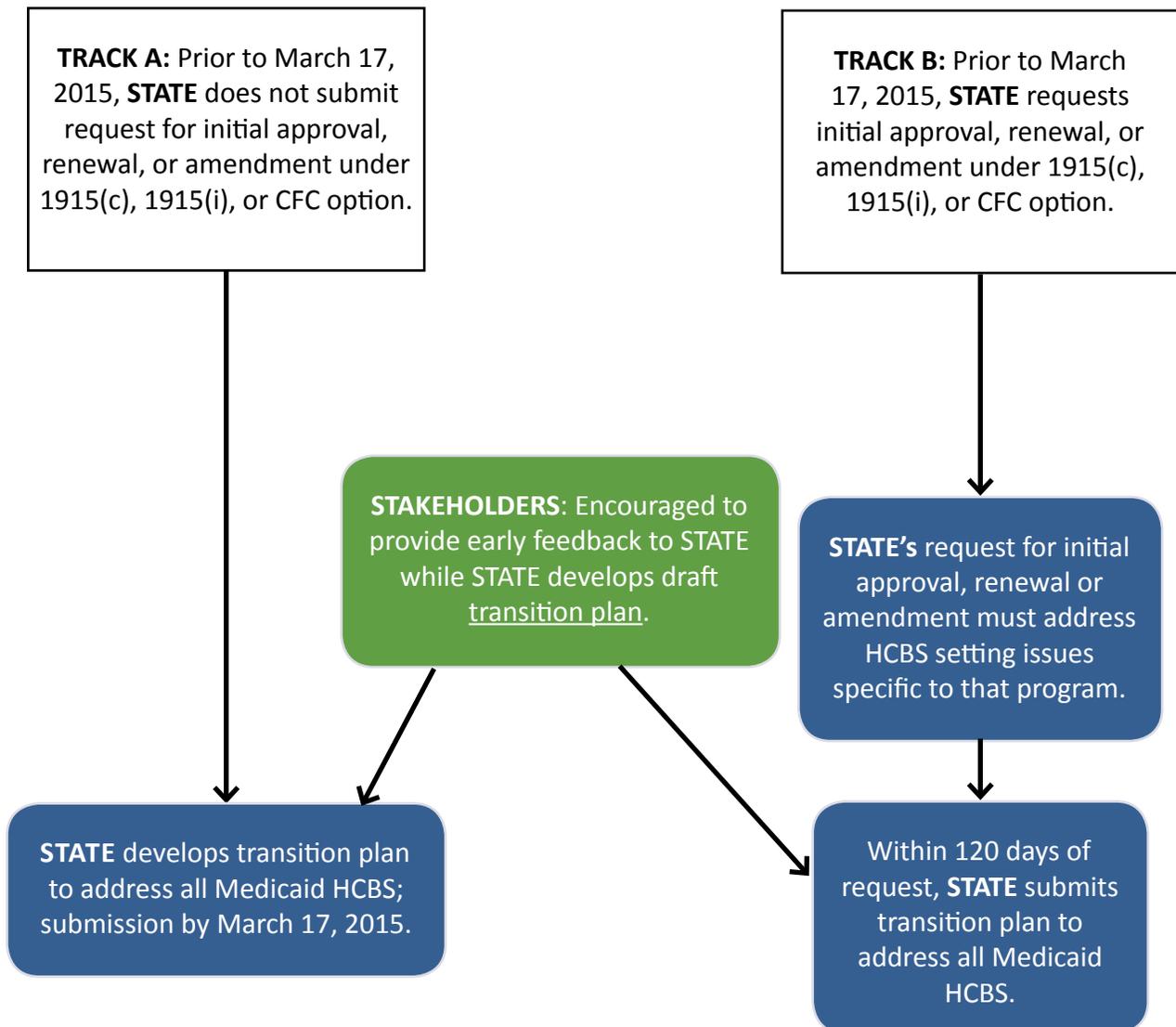
³⁴ 79 Fed. Reg. at 2,979; CMS, Fact Sheet: Summary of Key Provisions of the Home and Community-Based Services (HCBS) Settings Final Rule (Jan. 20, 2014), at 2.

³⁵ 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, at 5.

³⁶ 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, at 5.

How Can Stakeholders and State Advocates Impact the Transition Process?

In general, a STATE must submit a transition plan to CMS by March 17, 2015. If prior to that date, however, a STATE requests initial approval, renewal or amendment of a 1915(c) waiver, a 1915(i) state-plan program, or the Community First Choice (CFC) option, the submission deadline for the statewide transition plan is set at 120 days after the request for the approval, renewal, or amendment. On either timeline, STAKEHOLDER involvement is encouraged throughout the process.



Service Planning³⁷

Are service planning rules identical for all Medicaid HCBS programs?

No, but they are very similar. CMS explains that it has tried to bring the service planning rules into harmony, but various statutory differences prevent the rules from being absolutely identical.³⁸

The service planning rules for HCBS waivers, the Community First Choice option, and HCBS state-plan services are located at sections 441.301 (HCBS waivers), 441.540 (Community First Choice), 441.725 and 441.730 (HCBS state-plan services) of Title 42 of the Code of Federal Regulations.

This guide discusses the service planning rules for HCBS waivers and HCBS state-plan services. These rules were released simultaneously and became effective on March 17, 2014. Unless otherwise specified, this guide’s service planning discussion applies to both HCBS waivers and HCBS state-plan services.

Who leads the service planning process?

In HCBS waivers, the consumer leads the planning process “where possible.” If, due to incapacity, the consumer cannot lead, the consumer’s representative steps into the leadership role. If the consumer is capable of leading, however, the consumer’s representative should participate “as needed and defined by the [consumer].”

³⁷ 42 C.F.R. §§ 441.301 (HCBS waivers), 441.725 (HCBS state-plan services).

³⁸ 79 Fed. Reg. at 3,004.

In HCBS state-plan services, the service plan is developed or approved by the State. The plan’s development is done jointly with the consumer or (if applicable) the consumer’s representative, with the planning process being “driven by” the consumer.

What assistance does the consumer receive in the planning process?

The planning process must provide “necessary information and support to ensure that the [consumer] directs the process to the maximum extent possible, and is enabled to make informed choices and decisions.”³⁹

Can a consumer choose who does (and does not) participate in the planning process?

Yes. The rules state that the planning process includes persons chosen by the consumer. CMS has emphasized that consumers can “choose who does or does not attend the [planning] meeting.”⁴⁰

Can an HCBS service provider develop the service plan?

The answer in general is “no.” In order to limit conflicts of interest, service planning (or case management) cannot be performed by an HCBS service provider for the consumer, or any person who has an interest in or is employed by an HCBS service provider for the consumer.

An exception can be made only if the State demonstrates that, within a particular geographic area, an HCBS service provider is

³⁹ 42 C.F.R §§ 441.301 (c) (1) (ii), 441.725 (a) (2).

⁴⁰ 79 Fed. Reg. at 3,005.

the only entity that is “willing and qualified” to develop service plans or provide case management. In these cases, the entity must establish internal separation between its planning and service-providing functions, under conflict of interest protections developed by the State and approved by CMS. In addition, consumers must have access to “a clear and accessible alternative dispute resolution process.”

These rules, however, do not prevent a service provider from being in attendance during service planning. The consumer chooses whether a service provider should or should not be present during service planning. Also, these rules should not apply to the provisional service plans used to initiate HCBS as soon as possible.⁴¹

In addition, the rules for HCBS state-plan services require that each state define conflict of interest standards that ensure the independence of the persons or entities who evaluate eligibility for HCBS, assess need for HCBS or develop service plans. At a minimum, such persons or entities must not be any of the following:

- Related by blood or marriage to the consumer or to any paid service provider for the consumer.
- Financially responsible for the consumer.
- Empowered to make the consumer’s financial or health-related decisions.
- Holding a financial interest in any entity paid to provide “care” for the consumer.⁴²

⁴¹ CMS, Olmstead Update No. 3, Atch. 3-a (July 25, 2000).

⁴² 42 C.F.R. § 441.730(b).

When and where should service planning meetings be held?

Any meetings should be held “at times and locations of convenience to the [consumer].”

How should the service planning process be made accessible?

The process must reflect the consumer’s “cultural considerations.” Information should be provided in “plain language” and in an accessible manner. For persons with disabilities, auxiliary aids and services must be made available at no cost to the consumer. For persons with limited English proficiency, similarly, language services must be made available at no cost.⁴³

What information must the consumer receive regarding possible services?

The consumer must be offered “informed choices” regarding services and supports, and who will provide those services and supports. CMS expects that “all services and support options will be articulated and discussed with the [consumer].”⁴⁴

What items must be included in the service plan?

- **Setting:** The plan must indicate that the consumer selected the setting in which he or she resides. The State must ensure that the setting supports full integration of Medicaid-eligible consumers into the greater community.
- **Goals and strengths:** The plan must reflect the consumer’s strengths and preferences, and identify individual goals

⁴³ 42 C.F.R. § 435.905(b).

⁴⁴ 79 Fed. Reg. at 2,989.

and desired outcomes.

- **Services and supports:** The plan must indicate the services and supports (paid and unpaid) that will assist the consumer in achieving identified goals, along with the providers of those services and supports.
- **Risks:** The plan must include risk factors along with measures in place to minimize risk, such as individualized backup plans and strategies.⁴⁵
- **Monitoring:** The plan must identify the person and/or entity responsible for monitoring the plan.

What protections exist to ensure that the plan reflects the consumer's choices?

- **Understandable Style and Format:** The plan must be understandable to the consumer and the persons supporting him or her. At a minimum, the plan must be written in plain language and in a manner accessible to persons with disabilities and persons with limited English proficiency. "Accessibility" includes auxiliary aids and services at no cost for persons with disabilities, and language services at no cost for persons with limited English

⁴⁵ 79 Fed. Reg. at 3,030.

proficiency.⁴⁶

- **Consent:** The consumer must demonstrate informed consent to the plan in writing, and anyone responsible for implementing the plan must sign it.
- **Appeal Rights:** The service planning rule itself does not provide for additional appeal protections. However, in response to concerns about appeal rights, CMS stated that all fair hearing requirements at part 431, subpart E, of the Code of Federal Regulations, apply to all Medicaid services.⁴⁷

How frequently must service plans be reviewed?

A service plan must be reviewed (and revised, as necessary) every 12 months, when the consumer's circumstances or needs change significantly, or when the consumer requests review. In comments to the final rules, CMS stated that a review also should be conducted at the request of a healthcare provider for the consumer.⁴⁸

⁴⁶ 42 C.F.R. § 435.905(b).

⁴⁷ 79 Fed. Reg. at 2,982.

⁴⁸ 79 Fed. Reg. at 2,991.

Appendix: CMS's Exploratory Questions

In March 2014, CMS released a six-page document entitled Exploratory Questions to Assist States in Assessment of Residential Settings. The document describes itself as an “optional tool ... to assist states in assessing whether the characteristics of Medicaid Home and Community-[B]ased Services, as required by regulation, are present.” This Appendix below reproduces some of the questions that may be of particular interest:

- **Participation in Activities; Access to Community**
 - Is the individual aware of or does/he have access to materials to become aware of activities occurring outside of the setting?
 - Does the individual shop, attend religious services, schedule appointments, have lunch with family and friends, etc., in the community, as the individual chooses?
 - Are individuals moving about inside and outside the setting as opposed to sitting by the front door?
 - Do individuals in the setting have access to public transportation?
 - Are there bus stops nearby or are taxis available in the area?
- **Controlling a Personal Schedule**
 - Does the individual have access to such things as a television, radio, and leisure activities that interest him/her and can s/he schedule such activities at his/her convenience?
- **Dignity**
 - Does staff talk to other staff about an individual(s) as if the individual was not present or within earshot of other persons living in the setting?
 - Does staff address individuals in the manner in which the person would like to be addressed as opposed to routinely addressing individuals as “hon” or “sweetie”?
- **Clothing**
 - Are individuals dressed in clothes that fit, are clean, and are appropriate to the time of day and individual preferences?
- **Controlling Resources**
 - Does the individual have a checking or savings account or other means to control his/her funds?
- **Food and Meals**
 - Can the individual request an alternative meal if desired?
 - Does the dining area afford dignity to the diners and are individuals not required to wear bibs or use disposable cutlery, plates and cups?
 - Is the individual required to sit at an assigned seat in a dining area?
- **Choice of Service Provider**
 - Can the individual identify other providers who render the services

s/he receives?

- **Communication Devices**

- Does the individual have a private cell phone, computer or other personal communication device or have access to a telephone or other technology device to use for personal communication in private at any time?
- Do individuals' rooms have a telephone jack, Wi-Fi, or Ethernet jack?

- **Choice; Freedom from Coercion**

- Do the individuals in the setting have different haircut/hairstyle and hair color?
- Are individuals prohibited from engaging in legal activities?

- **Physical Location**

- Is the setting in the community among other private residences [or] retail businesses?
- Is the community traffic pattern consistent around the setting (e.g., individuals do not cross the street when passing to avoid the setting)?

- **Physical Access within Setting**

- Do individuals have full access to typical facilities in a home such as a kitchen with cooking facilities, dining area, laundry, and comfortable seating in the shared areas?
- Are appliances accessible to individuals (e.g. the washer/dryer are front loading for individuals in wheelchairs)?
- Are tables and chairs at a convenient height so that individuals can access and use the furniture comfortably?

- **Language Access**

- Is informal (written and oral) communication conducted in a language that the individual understands?

- **Privacy**

- Is health information about individuals kept private?
- Are schedules of individuals for PT, OT, medications, restricted diet, etc., posted in a general open area for all to view?



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