New Rules for Home and Community-Based Settings and the Person-Centered Planning Process
A Guide For Advocates and Families

Introduction

In January 2014, the federal government announced a new rule explaining which kinds of services can be covered through Medicaid-funded home and community-based services (HCBS) programs.[1] The new rule will help make sure that people who use HCBS are truly integrated into their communities. States will not be allowed to use federal Medicaid dollars to pay for HCBS in settings that isolate people from the community or that do not show respect for people's right to privacy, dignity, and self-determination.

Because states may need some time to make sure that the services that they are providing are actually integrated, the government has told the states to create five-year transition plans explaining how they will follow the new rule. The states must give people with disabilities, their friends and families, and other advocates the opportunity to comment on the transition plans.

This guide is here to help you understand what the new rule means and what they can do to help keep their states on track. States need to hear from you in order to know which kinds of services and supports help people make the most of life in the community.

What is HCBS?

Home and community-based services, or HCBS, are a type of service covered by Medicaid. Many people with disabilities rely on HCBS in order to help them live in their own homes. These services, which are available to many people with disabilities who are covered by Medicaid, can include services like:

- Personal care attendants to help with activities like bathing, dressing, eating, and moving around in the community;
- Help with home-based health care like ventilators, feeding tubes, and diabetes care;
- Help with housekeeping and cooking;
- Help with case management and coordinating of services;
- Transportation services around the community;
- Habilitation, including day habilitation;
- Respite care;
- Supported employment services to help people find an keep a job; and
- "Pre-employment" services to help people develop the skills they need to get a job.

Not everyone on Medicaid gets home and community-based services. They are only available to people with disabilities who need help in order to live safe and healthy lives in the community. In some states, only people with certain kinds of disabilities can get HCBS, and there are often long waiting lists. Home and Community-Based Services programs may

1 The official citation for the new rule is 79 Fed. Reg. 2947 (Jan. 16, 2014). You can read it online at https://www.federalregister.gov/articles/2014/01/16/2014-00487/medicaid-program-state-plan-home-and-community-based-services-5-year-period-for-waivers-provider. You can also read important parts of the new rule at page of this Guide.

ASAN
AUTISTIC SELF ADVOCACY NETWORK

The Autistic Self Advocacy Network (ASAN) is a non-profit organization run by and for autistic people. ASAN provides support and services to individuals on the autism spectrum while working to change public perception and combat misinformation. Our activities include public policy advocacy, community engagement to encourage inclusion and respect for neurodiversity, quality of life oriented research and the development of autistic cultural activities.

be limited to only certain areas or may have limits on the number of people who receive services.

Every state's HCBS program is different. In some states, HCBS is provided through what's called a "waiver." Waivers allow states to give services that aren't usually covered for most people who are on Medicaid to people in certain groups (like people with disabilities). There may be different waivers for different groups – for example, one for people with intellectual and developmental disabilities and one for people who have physical disabilities. Other states may provide HCBS through what's called a "Money Follows the Person demonstration," "state plan option," or "community first choice state plan option." The new rule applies to all of these programs.

What Does the New Rule Say?

The purpose of the new rule was to make sure that states didn't use HCBS funding for programs that are not really integrated into the community, such as group living settings that isolate people from the community. It makes it clear that, in order for a service to be HCBS, it needs to be in a setting that gives people real opportunities to work, live, and socialize in the community.

In General

The new rule includes five standards that all home and community-based services need to meet.

1. Integration into the Community

> "Home and community-based settings must have all of the following qualities, and such other qualities as the Secretary determines to be appropriate, based on the needs of the individual as indicated in their person-centered service plan:
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> (i) The setting is integrated in and supports full access of individuals receiving Medicaid HCBS 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 individuals not receiving Medicaid HCBS."
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> —42 C.F.R. § 441.301(c)(4), (c)(4)(i) (about HCBS waivers); § 441.530(a)(1), (a)(1)(i) (about Community First Choice programs); § 441.710(a)(1), (a)(1)(i) (about State Plan programs).

The rule requires that home and community-based services be provided in a setting that offers full opportunities for integration into the community. This includes making sure that people receiving HCBS are able to:

- Work alongside people without disabilities, and be paid the same amount as people without disabilities;[2]
- "Engage in community life," which can include going to church, volunteering, and/or making and keeping friends outside the service setting;
- Control their own money, possessions, and other resources; and
- Receive services "in the community" and not in isolated settings.

All people who use HCBS need to have these opportunities – not just people who are labeled as "high-functioning" or have fewer support needs. Service providers can't simply assume that a person is too disabled to work or control their own money. Instead, they need to make sure that everyone has the support they need to do these things.

For example, some people may need a lot of help, such as transportation and accompaniment by a support person, to travel around in the community. Without that support, the person won't have full access to the community even if the service provider says that they're "free to go into the community" whenever they want to. People may also need a financial coach or job coach in order to have real access to employment and real opportunities to control their own money.

2 This does not mean that people who receive HCBS have to get a job, it does mean that they have to have the opportunity and support they need to do so. See Eric Carlson, National Senior Citizens Law Center, Just Like Home: An Advocate's Guide for State Transitions under the New Medicaid HCBS Rules page, 15 (2014). You can find this guide online at http://www.nsclc.org/wp-content/uploads/2014/06/Just-Like-Home_-An-Advocates-Guide-for-State-Transitions-Under-the-New-Medicaid-HCBS-Rules.pdf.

The rule requires that people receiving HCBS have access to the greater community "to the same degree" as other people. This means that, for example, an HCBS service provider cannot be "community-based" if it only lets people go on occasional or scheduled trips into the community. Like people without disabilities, people receiving HCBS should be able to choose where they go and when. At the same time, services can still be community-based if they're located in a rural area, as long as people receiving HCBS can travel around and participate in community life in the same way that other people living in that area can.

2. Individual Choice

> "The setting is selected by the individual from among setting options, including non-disability specific settings and an option for a private unit in a residential setting. The setting options are identified and documented in the person-centered service plan and are based on the individual's needs, preferences, and, for residential settings, resources available for room and board."
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> —42 C.F.R. § 441.301(c)(4)(ii) (about HCBS waivers); § 441.530(a)(1)(ii) (about Community First Choice programs); § 441.710(a)(1)(ii) (about State Plan programs).

The new rule also requires that people receiving HCBS have choices about where they get services. They must have the option to get services in places that aren't "disability-specific" – for example, they must have the option of getting in-home services while living in their own apartment instead of having to live in a group home just for people with disabilities. People receiving HCBS also must have the option of choosing a private room instead of having to live with a roommate. The choices have to be based on the person's own needs, preferences, and situation – for example, it is not enough to offer someone a chance to live in their own apartment if the apartment isn't accessible or affordable.

Even if a person has a choice of settings, the setting they do choose needs to meet all the other requirements of the new rule. A setting that is isolated or that does not offer full access to the community cannot be considered "home and community-based" simply because the individual had the option of living in a non-disability specific setting.

3. Individual Rights

> "Ensures an individual's rights of privacy, dignity and respect, and freedom from coercion and restraint."
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> —42 C.F.R. § 441.301(c)(4)(iii) (about HCBS waivers); § 441.530(a)(1)(iii) (about Community First Choice programs); § 441.710(a)(1)(iii) (about State Plan programs).

People who receive HCBS must have a right to "privacy, dignity and respect, and freedom from coercion and restraint."[3] This can include the right to lock one's own bedroom or bathroom door and the right to choose a private room or choose a roommate.[4] It can also include the right to talk privately with friends and family, whether over the phone or the internet. Many self-advocates have said that privacy and dignity are a big part of the difference between an institution and a community-based setting.[5]

3 42 C.F.R. §§ 441.301(c)(4)(iii), 441.530(a)(1)(iii), 441.710(a)(1)(iii).

4 Id.; 42 C.F.R. §§ 441.301(c)(4)(ii), 441.530(a)(1)(ii), 441.710(a)(1)(ii). See also 42 C.F.R. §§ 441.301(c)(4)(vi), 441.530(a)(1)(vi), 441.710(a)(1)(vi) (referring to provider-owned or controlled residential settings).

5 See Autistic Self Advocacy Network, Keeping the Promise: Self Advocates Defining the Meaning of Community Living pp. 6-7 (2012). You can find this report available at http://autisticadvocacy.org/wp-content/uploads/2012/02/KeepingthePromise-SelfAdvocatesDefiningtheMeaningof-Community.pdf.

4. Autonomy

> "Optimizes, but does not regiment, individual initiative, autonomy, and independence in making life choices, including but not limited to, daily activities, physical environment, and with whom to interact."
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> —42 C.F.R. § 441.301(c)(4)(iv) (about HCBS waivers); § 441.530(a)(1)(iv) (about Community First Choice programs); § 441.710(a)(1)(iv) (about State Plan programs).

People who receive HCBS must be able to make day-to-day choices for themselves, including choices about what they do every day, who they talk to, what kinds of relationships to be part of, and where they spend their time. The HCBS provider can't "regiment" these choices, such as by offering only a few options or by requiring people to keep to a rigid schedule.

People need the same kinds of choices and freedoms that non-disabled people usually have. This doesn't necessarily mean that people who receive HCBS should never have to do certain things at certain times: for example, a person receiving HCBS who works at a restaurant will still have to show up at the restaurant at their scheduled times, just as anyone else who works at that restaurant. But people who get HCBS should have the ability and the support they need to make last-minute plans or decisions about how to spend their free time, just like everyone else.

This same idea applies to the rules that people receiving HCBS have to follow. For example, if a person receives in-home HCBS while living in an apartment, they may have to follow normal rules of apartment living like paying rent on time and avoiding loud activities late at night. But they should not have to follow rules that other people living in apartments don't have to follow, like a night-time curfew or rules against having guests, choosing furniture or putting pictures on walls.

Sometimes people might need support to make these choices. For example, they might need help remembering appointments, choosing meals, and deciding what to do during the day. People might need communication technology or other forms of support in order to communicate and have relationships with other people. Someone's need for support cannot be used as a reason to take away options, or to only provide supports when the person makes the choices that the provider wants them to make.

5. Choice Regarding Services and Providers

> "Facilitates individual choice regarding services and supports, and who provides them."
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> —42 C.F.R. § 441.301(c)(4)(v) (about HCBS waivers); § 441.530(a)(1)(v) (about Community First Choice programs); § 441.710(a)(1)(v) (about State Plan programs).

People need to have the ability to choose what services they get and who provides those services. Whenever possible, people should be encouraged to "self-direct" their own services by choosing their own support workers and deciding which days and times of day they need their support workers. Nobody should have to accept services that they don't want. People also need a meaningful choice of services and providers. If a person is offered a choice of many providers, and only one of them actually offers the services that the person needs or is actually available, that would not be considered a meaningful choice.

The new rule requires that services be chosen through a "person-centered service planning process." This process, which has to happen at least once a year, is supposed to help make sure that people are getting the services that they want from the providers they want. People need to be given meaningful choices during this process, including the ability to get services in non-disability-specific settings. There must be safeguards in place to make sure that the process isn't driven by the same service providers who are going to be providing HCBS to the person, unless there is nobody else who can help with the process. This helps prevent service providers from letting their own interests influence the planning process.

Special Rules

The rules listed above apply in general to all HCBS settings. The new rule also includes some detailed rules about certain kinds of settings.

Provider-Owned Residential Settings

The new rule also includes many rules that apply to residential settings (that is, places where people live) that are owned by the HCBS provider. These settings are usually group homes or other housing arrangements where many people with disabilities are living together and getting in-home services from the same provider. In this sort of setting there is an extra risk that people will be isolated from the community or that their day-to-day choices will be limited for the convenience of the provider. For example, the provider might want to set meal times and curfews because these are easier than accommodating multiple people's schedules.

The new rule makes clear that HCBS programs can't pay for placements in provider-owned settings that restrict people's choices and daily activities. People living in provider-owned settings must:

- Have the same rights and responsibilities as regular tenants under state law, including protections against being kicked out of their homes without notice;
- Have the right to privacy in their bedrooms and living rooms, including the ability to lock their own doors. Only "appropriate staff" should have extra keys to these rooms. People also need to have the right to choose their own roommates and choose their own furniture and decorations;
- Have the "freedom and support" to control their own daily schedules;
- Have access to food "at any time"; and
- Have the right to have visitors at any time.

The provider can make changes to these rights if the changes are based on people's individual needs and documented in their service plans. For example, staff may need to remind a person with diabetes who needs help regulating blood sugar not to eat at specific times. But the group home cannot force all of its residents to eat only at certain times simply because one of the residents needs to keep a schedule or because it's more convenient to have a schedule. The rule also includes specific rules about how people's service plans can be written. See "Person-Centered Service Plans" later on in this Guide.

"In a provider-owned or controlled residential setting, in addition to the above qualities [defining home and community-based settings], the following additional conditions must be met."

—42 C.F.R. § 441.301(c)(4)(vi) (about HCBS waivers); § 441.530(a)(1)(vi) (about Community First Choice programs); § 441.710(a)(1)(vi) (about State Plan programs).

"The unit or dwelling is a specific physical place that can be owned, rented or occupied under a legally enforceable agreement by the individual receiving services, and the individual has, at a minimum, the same responsibilities and protections from eviction that tenants have under the landlord tenant law of the State, county, city or other designated entity.

For settings in which landlord tenant laws do not apply, the State must ensure that a lease, residency agreement or other form of written agreement will be in place for each participant and that the document provides protections that address eviction processes and appeals comparable to those provided under the jurisdiction's landlord tenant law."

—42 C.F.R. § 441.301(c)(4)(vi)(A) (about HCBS waivers); § 441.530(a)(1)(vi)(A) (about Community First Choice programs); § 441.710(a)(1)(vi)(A) (about State Plan programs).

"Each individual has privacy in their sleeping or living unit:

1. Units have entrance doors lockable by the individual, with only appropriate staff having keys to doors as needed.
2. Individuals sharing units have a choice of roommates in that setting.
3. Individuals have the freedom to furnish and decorate their sleeping or living units within the lease or other agreement."

—42 C.F.R. § 441.301(c)(4)(vi)(B) (about HCBS waivers); § 441.530(a)(1)(vi)(B) (about Community First Choice programs); § 441.710(a)(1)(vi)(B) (about State Plan programs).

"Individuals have the freedom and support to control their own schedules and activities, and have access to food at any time."

—42 C.F.R. § 441.301(c)(4)(vi)(C) (about HCBS waivers); § 441.530(a)(1)(vi)(C) (about Community First Choice programs); § 441.710(a)(1)(vi)(C) (about State Plan programs).

The provider-owned setting also needs to be physically accessible to the people living in it. Unlike the privacy and autonomy-related requirements, this requirement can't be changed under any circumstances. This is because, while some people may need to follow a food schedule, nobody specifically needs a housing arrangement that doesn't meet their accessibility needs.

"Individuals are able to have visitors of their choosing at any time."

—42 C.F.R. § 441.301(c)(4)(vi)(D) (about HCBS waivers); § 441.530(a)(1)(vi)(D) (about Community First Choice programs); § 441.710(a)(1)(vi)(D) (about State Plan programs).

Settings that are Presumed to be Institutions

The new rule lists certain kinds of settings that, usually, will automatically be considered "institutional" and not home and community-based:

- Institutions—like state developmental centers, nursing homes, hospitals, or intermediate care facilities (ICFs)
- Places right next to an institution, or that share space with an institution
- Any other place that has the "effect of isolating" people from the community, such as:
    - gated communities,
    - disability-specific "villages,"
    - places that are located far away from the rest of the community,
    - residential or boarding schools for people with disabilities, or
    - other places that are designed to provide many different kinds of services just to people with disabilities.

"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 individuals with intellectual disabilities;

(iv) A hospital; or

(v) Any other locations that have qualities of an institutional setting, as determined by the Secretary. Any setting that is located in a building that is also a publicly or privately operated facility that provides inpatient institutional treatment, or in a building on the grounds of, or immediately adjacent to, a public institution, or any other setting that has the effect of isolating individuals receiving Medicaid HCBS from the broader community of individuals not receiving Medicaid HCBS will be presumed to be a setting that has the qualities of an institution unless the Secretary determines through heightened scrutiny, based on information presented by the State or other parties, that the setting does not have the qualities of an institution and that the setting does have the qualities of home and community-based settings."

—42 C.F.R. § 441.301(c)(5) (about HCBS waivers); § 441.530(a)(2) (about Community First Choice programs); § 441.710(a)(2) (about State Plan programs).

Unless the state proves that they actually don't isolate people and are really community-based, people can't provide HCBS in these settings unless the HCBS is helping them move from that setting to another, more community-based setting. Any other services in these settings would have to be funded through some other program.

The state shouldn't be able to prove that settings like these are "really" community-based just because people can take trips outside the setting. Instead, exceptions should be only for situations when people without disabilities often use the same setting for the same service. For example:

- Sometimes, hospitals will offer fitness courses to the whole community. A person with a disability could use their home and community-based services to help them get to a fitness class at the hospital.
- A person could use home and community-based services to visit a parent living in a nursing home.

- A person could use home and community-based supported employment services to take a job at a hospital, as long as the job is integrated and she is paid the same salary that she would receive if she didn't have a disability.
- A person could use home and community-based services while they are temporarily staying at a hospital, as long as the hospital doesn't offer the same type of service.
- A person could use home and community-based services while living in the dormitory at a boarding school that isn't mainly for students with disabilities.

On the other hand, settings that *aren't* also used by people without disabilities to get the same service should not count as exceptions. For example:

- A nursing home builds a bunch of houses for people with disabilities right next door to the nursing home. The houses are built like houses that people without disabilities might live in, but the main people who live in these houses are people with disabilities and their staff. These houses would be considered institutional, not community-based.
- A residential school for people with developmental disabilities also offers life skills classes for adults with disabilities. These classes are on the school grounds. The main people at these classes are people with disabilities, school staff, family members, and other care workers. Because they are on the grounds of a residential school, home and community-based services programs could not pay for these classes.

Person-Centered Service Plans

Under the new rule, everyone who gets home and community-based services should have a "person-centered service plan." The person-centered service plan must be in writing and must be created through a process that "includes people chosen by the individual." You can read the full requirements of this planning process online by going to the new rule and scrolling down to "Part 441—Services: Requirements and Limits Applicable to Specific Services."[6] Here are a few important points:

- "Where possible," the person with a disability is supposed to lead the process of making a person-centered service plan. People should get the information and support they need to lead the process. The process should include people "chosen by the individual."[7]
- Unless absolutely necessary, the same providers who are going to be providing HCBS to the individual shouldn't be creating the service plan or directing the process.[8]
- The service plan needs to include assurances that the person will get services in integrated community settings, as required by the new rule.[9]
- The service plan needs to include information about where the person will live and receive services, as well as what services the person will receive. It should also include information about the person's strengths and preferences, support needs, goals, and any existing safety risks.[10]
- The service plan needs to be accessible and in plain language so that the person with a disability can understand it.

6 https://www.federalregister.gov/articles/2014/01/16/2014-00487/medicaid-program-state-plan-home-and-community-based-services-5-year-period-for-waivers-provider#h-87. The Person-Centered Service Planning rules for HCBS programs that only serve people with disabilities are at 42 C.F.R § 441.301(c)(1)-(3). The rules for HCBS State Plan programs are at 42 C.F.R. § 441.725. The wording of both rules is almost exactly the same.

7 42 C.F.R. § 441.301(c)(1) (for waivers); 42 C.F.R. § 441.725(a) (for State Plan programs).

8 42 C.F.R. § 441.301(c)(1) (for waivers). The same language isn't there in the part about State Plan programs, but it still requires "conflict of interest" rules to prevent service providers from controlling the planning process in ways that encourage people to use their services. 42 C.F.R. § 441.725(a)(5).

9 42 C.F.R. § 441.301(c)(1) (for waivers); 42 C.F.R. § 441.725(a) (for State Plan programs).

10 42 C.F.R. § 441.301(c)(2) (for waivers); 42 C.F.R. § 441.725(b) (for State Plan programs).

The plan must "be understandable to the individual receiving services and supports, and the individuals important in supporting him or her. At a minimum, for the written plan to be understandable, it must be written in plain language and in a manner that is accessible to individuals with disabilities and persons who are limited English proficient, consistent with § 435.905(b) of this chapter."

—42 C.F.R. § 441.301(c)(2)(vii) (about HCBS waivers); § 441.725(b)(7) (about State Plan programs).

How Can I Make Sure States Follow the New Rule?

The new rule includes lots of opportunities for self-advocates, their friends, and families to help make sure states follow the new rule. The new rule requires states to create a *transition plan* describing the changes they will make to their programs in order to follow the new rule. People with disabilities and their families have to have the chance to read the transition plan and comment on it.

By sending in your comments on your state's transition plan, you can tell states which types of services are really integrated into the community and which aren't. You can also tell them what kinds of policies they need to put in place in order to make sure that service providers follow the rule.

Find Out What Is Going on in Your State

The first step is to find out when your state needs to send in a transition plan, what it says in its transition plan, and what advocacy groups in your state are saying.

You can find this information by going to HCBSAdvocacy.org. This is a web site created by a group of advocacy organizations: the Association of University Centers on Disabilities (AUCD), National Association of Councils on Developmental Disabilities (NACDD), and the National Disability Rights Network (NDRN).

Once you go to HCBSAdvocacy.org, you can find the page for your state either by clicking on the map in the middle of the screen, or by scrolling down and finding the name of your state on the list:

Clicking on your state will bring you to a page that contains the following information:

- "Dates and Deadlines." These are the deadlines by which the state must submit a transition plan.
- "State Documents." These are announcements and transition plans that the state has already published. If your state has not yet created a transition plan, this section might be blank.
- "Resources." These include letters or other things that advocates have written about the state's need to follow the new rule on home and community-based services.
- "News." These include any other bits of news about the state's compliance with the new rule.
- "State Partners." These include any organizations that may help make sure the state is following the new rule.

Dates and Deadlines

When you look at your state's page on HCBSAdvocacy.org, the first thing you should do is look at the "Dates and Deadlines" section. This gives you information on when your state is going to publish its transition plan.

States have to publish a transition plan either (1) whenever it has to ask the government to renew or change one of its HCBS programs, or (2) by March 17, 2015, *whichever is earlier*. HCBSAdvocacy.org will tell you whether the state has to ask the government to renew or change one of its HCBS programs before March 17, 2015. For example, if you look at the Virginia page, you will see this:

> All states must submit to CMS a plan for transitioning their current HCBS system into compliance with the new rule by March 17, 2015. States submitting a 1915(c) waiver renewal or amendment before March 17, 2015 must include a transition plan in that submission. States then have 120 days from that submission date to submit a transition plan for the remainder of their HCBS system.
>
> Virginia has one waiver expiring before March 17, 2015. The Intellectual Disability 1915(c) waiver provides personal assistance, prevocational services, residential support, respite, supported employment, and other services for individuals with intellectual disabilities of any age. It expires June 30, 2014.
>
> For more information visit Medicaid.gov.

This means that Virginia had to submit a transition plan by June 30, 2014.

If your state has already submitted a transition plan, go to the "State Documents" section on the same page, and check out what your state has already said in its transition plan. Check to see if there is a deadline for comments on the plan. If the deadline has already passed, don't worry! Most transition plans will have to be updated before they are accepted, so there may be another opportunity for comments later.[11] You can also send in comments at any time, or send comments to your "state partners." This guide will talk about this in more detail later.

If your state has not yet submitted a transition plan, you can still write to your state Medicaid agency or to your state partners to tell them what you think. Or you can make a note of the deadline for the transition plan, and check HCBSAdvocacy.org again on that date. If the transition plan isn't yet published, you might need to wait a few days and check again.

State Documents

If your state has already posted a transition plan, it should show up under "State Documents." For example, if you go to Virginia's page on HCBSAdvocacy.org, you will see this:

> Draft Transition Plan for ID Waiver open for public comment until September 5, 2014.
>
> Integrated Day Activity Plan open for public comment until August 21, 2014.
>
> - Accompanying Service Definition
> - Responses
>
> For more information visit Medicaid.gov.

Here you can see that there are deadlines for public comments: September 5, 2014, for the ID Waiver transition plan and August 21, 2014, for the Integrated Day Activity Plan.

11 See National Senior Citizens Law Center, State Transition Plans for New Medicaid HCBS Regulations: Four Tips for Consumer Advocates (2014), available at http://www.nsclc.org/wp-content/uploads/2014/07/State-Transition-Plans-for-New-Medicaid-HCBS-Regulations_Four-Tips-for-Consumer-Advocates.pdf.

Many "transition plans" that have already been published will have to be updated later. This means that if the public comment period for your state has already passed, you will still have a chance to comment when the transition plan is updated. Sometimes, if you read the transition plan carefully, you will also see that there are other periods for public comment built into the transition plan. And even outside of special "public comment" periods, you can still send in your comments to the state or to your State Partners.

Resources and News

Sometimes, but not always, a state page on HCBSAdvocacy.org will have other resources for advocates, and news articles. Reading these resources on HCBSAdvocacy.org might help give you some more information about what other advocacy groups think. For example, on Wisconsin's page under "Resources," you will find a link to a letter from disability organizations explaining how Wisconsin should follow the new rule, and another link to a web site for advocates. And on Wisconsin's page under "News," you will see many news articles on how advocates in Wisconsin are responding to Wisconsin's transition plan.

State Partners

The "State Partners" section includes a list of groups in your state that are helping advocate for people with disabilities who use HCBS. These may include your state's Protection and Advocacy (P&A) organization, its council on developmental disabilities, and any other disability-related advocacy organizations. You may want to send comments to these organizations explaining your thoughts and asking if they know of any other opportunities for advocacy.

Think About What You Need to Say.

Once you've seen your state's transition plan, it is time to decide what you want to say in your comments. Your comments don't just have to be about what's *in* the transition plan. They can also be about your own experiences with HCBS so far, or about things that aren't in the transition plan or aren't clearly explained. It is okay if you don't feel that you understand everything about the transition plan before writing your comments.

If you already use HCBS, you should say so in your comments. Explain, in one or two sentences, what kinds of home and community-based services you use, who provides them, and where you receive them. Then, talk for one or two paragraphs about whether you think these services are meeting the standards of the new rule: do you have the chance to find a job in the community, talk with friends, and set your own schedule? Do you feel included in your community? What would you like to see changed?

Whether or not you use HCBS, you can also talk about the transition plan. Here are some questions to think about:

- Is it understandable or is it confusing?
- Do you think it will actually help people get services in the community, or will it still allow some providers to segregate or isolate people?
- Does it have enough detail already, or does it say that it will come up with a more detailed plan later? What details do you think it needs to include?
- Does it include a plan to make sure that people have real, meaningful access to services in non-disability-specific settings like their own apartment, or does it continue to assume that most people will be in group homes and center-based day programs?
- Does it include a plan to make sure that people get day services in integrated settings, or does it only talk about residential services? Does it assume that day services are "integrated" simply because people can take part in organized community activities, like group trips to the movies?
- Many transition plans say that they will follow a process to decide which providers already follow the rule. Does the process include asking people who use the provider about their experiences, or will it take the provider's word on whether it follows the rule?
- Does the plan talk about how it will make sure providers continue to follow the rule even after they've been approved? Does it explain what people can do if they have a complaint?
- Does it acknowledge that people have the right to the supports they need in order to participate in the community, like transportation, supported employment, and personal assistants?
- Does it explain how it will manage "conflicts of interest" when the same service provider plays a part in someone's person-centered planning process and provides services to the person?
- Does it make lots of "exceptions" to the rule that it shouldn't be making, like allowing people to live in gated communities or allowing group homes to limit people's activities and privacy?

It can help to take a few notes about what you want to say, or to talk through the comments you want to send with someone you trust.

Find Out Where to Send Comments.

State Agencies

Check your state's transition plan on HCBSAdvocacy.org to see where to send your comments. This information will usually be on the first or last page of the transition plan. In some states this information is in one of the other documents under "State Resources" on HCBSAdvocacy.org, often named something like "Public Notice Regarding Transition Plan," or "Fact Sheet for Transition Plan."

If you still can't figure out where to send your comments, check out the contact information for your state Medicaid director at http://medicaiddirectors.org/about/state-directors, and your state ID/DD Services director at http://www.nasddds.org/state-agencies/. Some states want commenters to send their comments to the Medicaid director, and others want commenters to send comments to the ID/DD Services director. This means that, if you can't tell where to send in your comments, it's a good idea to send them to both.

Local Partners

You may also want to send comments to one of the "local partner" organizations listed on HCBSAdvocacy.org. These organizations will probably be sending in comments to the state agencies, and it can help to let them know what people with disabilities in your state are experiencing and how they feel about the HCBS they are receiving. You can also ask them if they know of other opportunities to get involved.

Centers for Medicare and Medicaid Services

The Centers for Medicare and Medicaid Services (CMS) is the part of the United States government that sets rules for states on how to run their Medicaid programs. It's CMS that wrote the new rules for home and community-based services. If you write comments to your state Medicaid director, you can also send those comments to CMS by emailing them to Hcbs@cms.hhs.gov. That way they will know what people in your state think about your state's transition plan. If you have things you want to say about the rule in general, you can e-mail your thoughts to Hcbs@cms.hhs.gov too.

Write Your Comments.

Once you've decided where to send your comments, it's time to write them down!

There's no single format that you need to follow when writing down your comments. That said, it is usually a good idea to type them up in the form of a letter. The letter should probably be 2-3 pages, and no more than five. If your letter is much longer than that, pick the parts that are *most* important to you, and cut out less important parts. Keep the focus on specific things that you'd like to change – you don't need to spend a lot of space explaining the purpose of the rule or what it says, or explaining why it's important that people live in the community. That's something you can assume the person reading the comments already knows.

On the next page is an example of a letter that you could send. Most likely, you will want to change some details and add other details so that it matches your experiences and describes the actual transition plan for your state. This guide will also include a fill-in-the-blank document that you can type into in order to write your own letter.

Your Address Goes Here	Jane Doe 1457 Imaginary Dr. Springfield, State, 00000
The date that you sent the letter	September 2, 2014
The address of the agency where you are sending the comments	Division of Long Term Care 1 West Imaginary Street Capitol, State 00001
If you know the name of the person reading the comments, replace this with "Dear [Name]"	To Whom It May Concern, I am writing to share my comments on the transition plan for compliance with the new home and community-based services regulations.
Introduce yourself and explain any experience you have with HCBS	I am a 25-year-old autistic person living in Springfield. I use home and community-based services, including a personal care attendant to help me stay in my home. My personal care attendant comes to my apartment for two hours a day to help me dress myself, cook, and keep the apartment clean.

Most state transition plans are not very detailed right now. If that is the case for your state, include a paragraph like this first.	The new regulations require that states let people who use HCBS comment on the transition plans. I have read the transition plan, but it is not detailed enough for me to tell which kinds of services people will be getting. It only says that you will be forming a detailed plan based on our comments and then you will submit the plan to CMS for approval. It is important that you also let us comment on the full plan before you send it to CMS. In the meantime, here are some thoughts on what needs to be in the full plan.
Using headings can help you organize your letter. **This is just an example of one of the issues you might want to comment on.**	***Enforcement*** The full plan needs to explain how you will make sure that providers are really following the rule. It is not enough to simply make sure that providers have written policies saying that they will do things like respecting people's privacy, helping people find competitive employment, and so on. People I know who live in group homes especially have told me that what is in the written policy is very often very different from how staff actually act. For example, some group homes will say that residents can leave at any time, but they won't have enough staff to accompany people when they want to leave. This means that people often have to wait a long time until someone can help them go somewhere, or are even forced to just stay at home instead. There needs to be a way for HCBS users and their advocates to complain about providers that aren't actually following the rules. Because some people might not know how to send in a complaint, the state should also interview service users on a regular basis to make sure that providers are following the rule.
Here is another example. It may help to include specific information about what day services in your state are like right now, if you know.	***Day Services*** The plan needs to make sure that people are included in the community not just in terms of where they live, but also how they spend their day. Right now many people are getting group-based day services that are not really integrated. People will spend most of the day at a center that only serves people with disabilities. When they go out on trips "into the community," they are in big groups and don't get to interact with people outside of the group. Instead of funding center-based day services, we should be giving people individual day services that let them participate in the community on their own terms. For example, a person might need transportation support and a personal attendant to help them find their way around the community. People should be able to choose activities that they want to do, not just options on a list. We should have the support that we need to visit our friends and relatives, join clubs, volunteer, or find a job. Sheltered workshops and "work crews" are also an example of day services that aren't integrated. In sheltered workshops, people with disabilities all work together – the only people without disabilities are supervisors and service workers. In work crew arrangements, people might be working in the same building as nondisabled people but they are still isolated because everyone on the work crew has a disability. Sheltered workshops and work crews also usually pay less than the minimum wage. Instead of funding these kinds of job placements, we should be funding supported employment services that help people find and keep real jobs that pay real wages. People should be working either independently or alongside coworkers who don't have disabilities. Many states, like Rhode Island, are already moving people out of sheltered workshops and into integrated employment.

Here's another topic that you might want to raise. Again, if you've gotten HCBS services before – either in a group home or while living in your own home, or both at different times – it can help to add that in.	***Supported Housing*** The plan should make sure that everyone, even people who need a lot of support, has the chance to live in their own home instead of a group home. Even if a group home has policies saying that they will respect people's freedom, privacy, and unique needs, in practice they are very restrictive. Whenever service providers group people with disabilities together in the same place, they are isolating us from the rest of the community. Grouping people together also makes it much harder for people to decide exactly which services they need, because people are limited by the needs of the staff. For example, staff might not be able to leave the group home to help one resident go to the store, because they need to stay and provide services to someone else in the group home. Instead, people with disabilities should be able to live in their own apartment or with family and friends. Instead of paying staff at a group home, the HCBS program would pay someone to come to people's homes and provide the services that they need. People would be able to choose who provides their services and when. They would also be able to decide which services they needed at which times. By choosing their own staff, people with disabilities would be able to make sure that the person who helps them on a daily basis is someone works well with them and understands their needs. As someone who has a personal care attendant who comes to my house, I know that this system works very well.
Include references to other resources.	I also encourage you to review the Autistic Self Advocacy Network's toolkit for administrators, which is available at http://autisticadvocacy.org/hcbs/. This toolkit explains in more detail the types of services that do and do not comply with the new rule.
Include a "thank you" at the end and an explanation of how best to contact you (for example, by phone or by email).	Thank you for taking the time to read my comments. Please feel free to contact me with any questions you may have. I do not use the phone, but I can be reached via email at janedoe@email.com.
Type your name at the bottom. If you plan on printing the letter and mailing it, you should leave a space for your signature, and sign it before mailing.	Sincerely, Jane Doe

You may also want to write a letter to your state partners. Here is an example of a quick letter or email that you can send.

Your Address Goes Here	Jane Doe 1457 Imaginary Dr. Springfield, State, 00000
The date that you sent the letter	September 2, 2014

The address of the state partner	John Roe Health Policy Director State Disability Rights Project 8203 Imaginary Lane Springfield, State, 00001
Introduce yourself and explain your personal experience (if any) with HCBS.	Dear Mr. Roe, I am a 25-year-old autistic person living in Springfield. I am writing because I am interested in helping to speak out about the new home and community-based services regulation and the state transition plan. I am a 25-year-old autistic person living in Springfield. I use home and community-based services, including a personal care attendant to help me stay in my home. My personal care attendant comes to my apartment for two hours a day to help me dress myself, cook, and keep the apartment clean. I have many friends who also use HCBS. Some of them live in group homes. It is very important to make sure that the state transition plan gives everyone the chance to live and spend their days in integrated settings. As someone who uses HCBS, I want to make sure that my voice is heard.
Mention if you are interested in joining any advocacy efforts. **If you've written comments on the transition plan, print them out and include them in the letter.**	Please let me know if you know of any volunteer opportunities or upcoming events where I can share my thoughts. I also plan on sending in comments on the transition plan. I'm attaching a copy of my comments to this letter.
Let your state partner know about other resources they might find helpful.	I'd also like to make sure that you know about a resource that the Autistic Self Advocacy Network has written for administrators and advocates on how to make sure that HCBS services are fully integrated into the community. You can find it at http://autisticadvocacy.org/hcbs/.
Include a "thank you" at the end and an explanation of how best to contact you (for example, by phone or by email).	Thank you for your time. Please feel free to contact me with any questions you may have. I do not use the phone, but I can be reached via email at janedoe@email.com.
Type your name at the bottom. If you plan on printing the letter and mailing it, you should leave a space for your signature, and sign it before mailing.	Sincerely, Jane Doe

Other Resources

You might find these other resources helpful in understanding the new rule.

State Transition Plans for New Medicaid HCBS Regulations: For Tips for Consumer Advocates, by the National Senior Citizens Law Center and National Disability Rights Network, available at http://www.nsclc.org/wp-content/uploads/2014/07/State-Transition-Plans-for-New-Medicaid-HCBS-Regulations_Four-Tips-for-Consumer-Advocates.pdf

HCBS Advocates Worksheet for Assessing Services and Settings, by the National Association of Councils on Developmental Disabilities, Association of University Centers on Disabilities, and National Disability Rights Network, can help you decide whether specific services you've seen are following the new rule. It is available at http://hcbsadvocacy.files.wordpress.com/2014/04/hcbs-advocates-worksheet.pdf

Just Like Home: An Advocate's Guide for State Transitions Under the New Medicaid HCBS Rules, by the National Senior Citizens Law Center, available at http://www.nsclc.org/wp-content/uploads/2014/06/Just-Like-Home_-An-Advocates-Guide-for-State-Transitions-Under-the-New-Medicaid-HCBS-Rules.pdf

Keeping the Promise: Self Advocates Defining the Meaning of Community Living, by the Autistic Self Advocacy Network, available at http://autisticadvocacy.org/wp-content/uploads/2012/02/KeepingthePromise-SelfAdvocatesDefiningtheMeaningofCommunity.pdf

Separate and Unequal: States Fail to Fulfill the Community Living Promise of the Americans with Disabilities Act, by the United States Senate Health, Education, Labor, and Pensions Committee, available at http://www.harkin.senate.gov/documents/pdf/OlmsteadReport.pdf

If you have any questions about this toolkit, please let us know by contacting Samantha Crane, Director of Public Policy, at scrane@autisticadvocacy.org.

Appendix: Quick Reference: New Rules for Home and Community-Based Settings and the Person-Centered Planning Process

The new rule can be found online at https://www.federalregister.gov/articles/2014/01/16/2014-00487/medicaid-program-state-plan-home-and-community-based-services-5-year-period-for-waivers-provider. This web site, however, can be confusing to read. It includes a long discussion of how they decided on the rule and responses to comments that people sent in about the new rule. Here is a copy of the rule itself.

You can use this to talk about specific parts of the new rule. If you want to talk about a specific part of the rule, there's a specific way to write out the place in the rule you're talking about. First you write out the title and section, then you write the subsections.

The title and section are the letters and numbers at the top of each part of the rule typed out here. For example, the title and section of the part about HCBS programs is "42 C.F.R. § 441.301." "42" is the title, and "441.301" is the section. "C.F.R." means "Code of Federal Regulations," which is a set of books where this rule will eventually be published. The "§" is called a "section symbol." The subsections are the letters and numbers in parentheses (like "(a)" and "(1)").

So, for example, if you want to talk about the part of the rule where it says the person-centered planning process has to include people "chosen by the individual," you would write "42 C.F.R. § 441.301(c)(1)(i).

How to write in the subsections can be confusing. If you're having trouble, the Guide for Advocates has taken a lot of the most important parts of the rule and written out the citation right below, like this:

"The setting is physically accessible to the individual."

—42 C.F.R. § 441.301(c)(4)(vi)(E) (about HCBS waivers); § 441.530(a)(1)(vi)(E) (about Community First Choice programs); § 441.710(a)(1)(vi)(E) (about combined programs for the elderly and people with disabilities).

Regulations for HCBS waiver programs.

42 C.F.R. § 441.301. Contents of request for a waiver.

Note: Section § 441.301 itself is not new. The old § 441.301 only had a subsection (a) and a subsection (b). The new rule added a new subsection, (c). Subsection (a) and (b) include other rules about HCBS waivers that aren't very important to this Guide.

(c) A waiver request under this subpart must include the following—

(1) Person-Centered Planning Process. The individual will lead the person-centered planning process where possible. The individual's representative should have a participatory role, as needed and as defined by the individual, unless State law confers decision-making authority to the legal representative. All references to individuals include the role of the individual's representative. In addition to being led by the individual receiving services and supports, the person-centered planning process:

(i) Includes people chosen by the individual.

(ii) Provides necessary information and support to ensure that the individual directs the process to the maximum extent possible, and is enabled to make informed choices and decisions.

(iii) Is timely and occurs at times and locations of convenience to the individual.

(iv) Reflects cultural considerations of the individual and is conducted by providing information in plain language and in a manner that is accessible to individuals with disabilities and persons who are limited English proficient, consistent with § 435.905(b) of this chapter.

(v) Includes strategies for solving conflict or disagreement within the process, including clear conflict-of-interest guidelines for all planning participants.

(vi) Providers of HCBS for the individual, or those who have an interest in or are employed by a provider of HCBS for the individual must not provide case management or develop the person-centered service plan, except when the State demonstrates that the only willing and qualified entity to provide case management and/or develop person-centered service plans in a geographic area also provides HCBS. In these cases, the State must devise conflict of interest protections including separation of entity and provider functions within provider entities, which must be approved by CMS. Individuals must be provided with a clear and accessible alternative dispute resolution process.

(vii) Offers informed choices to the individual regarding the services and supports they receive and from whom.

(viii) Includes a method for the individual to request updates to the plan as needed.

(ix) Records the alternative home and community-based settings that were considered by the individual.

(2) The Person-Centered Service Plan. 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, as well as what is important to the individual with regard to preferences for the delivery of such services and supports. Commensurate with the level of need of the individual, and the scope of services and supports available under the State's 1915(c) HCBS waiver, the written plan must:

(i) Reflect that the setting in which the individual resides is chosen by the individual. The State must ensure that the setting chosen by the individual is integrated in, and supports full access of individuals receiving Medicaid HCBS 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 individuals not receiving Medicaid HCBS.

(ii) Reflect the individual's strengths and preferences.

(iii) Reflect clinical and support needs as identified through an assessment of functional need.

(iv) Include individually identified goals and desired outcomes.

(v) Reflect the services and supports (paid and unpaid) that will assist the individual to achieve identified goals, and the providers of those services and supports, including natural supports. Natural supports are unpaid supports that are provided voluntarily to the individual in lieu of 1915(c) HCBS waiver services and supports.

(vi) Reflect risk factors and measures in place to minimize them, including individualized back-up plans and strategies when needed.

(vii) Be understandable to the individual receiving services and supports, and the individuals important in supporting him or her. At a minimum, for the written plan to be understandable, it must be written in plain language and in a manner that is accessible to individuals with disabilities and persons who are limited English proficient, consistent with § 435.905(b) of this chapter.

(viii) Identify the individual and/or entity responsible for monitoring the plan.

(ix) Be finalized and agreed to, with the informed consent of the individual in writing, and signed by all individuals and providers responsible for its implementation.

(x) Be distributed to the individual and other people involved in the plan.

(xi) Include those services, the purpose or control of which the individual elects to self-direct.

(xii) Prevent the provision of unnecessary or inappropriate services and supports.

(xiii) Document that any modification of the additional conditions, under paragraph (c)(4)(vi)(A) through (D) of this section, must be supported by a specific assessed need and justified in the person-centered service plan. The following requirements must be documented in the person-centered service plan:

(A) Identify a specific and individualized assessed need.

(B) Document the positive interventions and supports used prior to any modifications to the person-centered service plan.

(C) Document less intrusive methods of meeting the need that have been tried but did not work.

(D) Include a clear description of the condition that is directly proportionate to the specific assessed need.

(E) Include a regular collection and review of data to measure the ongoing effectiveness of the modification.

(F) Include established time limits for periodic reviews to determine if the modification is still necessary or can be terminated.

(G) Include informed consent of the individual.

(H) Include an assurance that interventions and supports will cause no harm to the individual.

(3) Review of the Person-Centered Service Plan. The person-centered service plan must be reviewed, and revised upon reassessment of functional need as required by § 441.365(e), at least every 12 months, when the individual's circumstances or needs change significantly, or at the request of the individual.

(4) Home and Community-Based Settings. Home and community-based settings must have all of the following qualities, and such other qualities as the Secretary determines to be appropriate, based on the needs of the individual as indicated in their person-centered service plan:

(i) The setting is integrated in and supports full access of individuals receiving Medicaid HCBS 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 individuals not receiving Medicaid HCBS.

(ii) The setting is selected by the individual from among setting options including non-disability specific settings and an option for a private unit in a residential setting. The setting options are identified and documented in the person-centered service plan and are based on the individual's needs, preferences, and, for residential settings, resources available for room and board.

(iii) Ensures an individual's rights of privacy, dignity and respect, and freedom from coercion and restraint.

(iv) Optimizes, but does not regiment, individual initiative, autonomy, and independence in making life choices, including but not limited to, daily activities, physical environment, and with whom to interact.

(v) Facilitates individual choice regarding services and supports, and who provides them.

(vi) In a provider-owned or controlled residential setting, in addition to the qualities at § 441.301(c)(4)(i) through (v), the following additional conditions must be met:

(A) The unit or dwelling is a specific physical place that can be owned, rented, or occupied under a legally enforceable agreement by the individual receiving services, and the individual has, at a minimum, the same responsibilities and protections from eviction that tenants have under the landlord/tenant law of the State, county, city, or other designated entity. For settings in which landlord tenant laws do not apply, the State must ensure that a lease, residency agreement or other form of written agreement will be in place for each HCBS participant, and that the document provides protections that address eviction processes and appeals comparable to those provided under the jurisdiction's landlord tenant law.

(B) Each individual has privacy in their sleeping or living unit:

(1) Units have entrance doors lockable by the individual, with only appropriate staff having keys to doors.

(2) Individuals sharing units have a choice of roommates in that setting.

(3) Individuals have the freedom to furnish and decorate their sleeping or living units within the lease or other agreement.

(C) Individuals have the freedom and support to control their own schedules and activities, and have access to food at any time.

(D) Individuals are able to have visitors of their choosing at any time.

(E) The setting is physically accessible to the individual.

(F) Any modification of the additional conditions, under § 441.301(c)(4)(vi)(A) through (D), must be supported by a specific assessed need and justified in the person-centered service plan. The following requirements must be documented in the person-centered service plan:

(1) Identify a specific and individualized assessed need.

(2) Document the positive interventions and supports used prior to any modifications to the person-centered service plan.

(3) Document less intrusive methods of meeting the need that have been tried but did not work.

(4) Include a clear description of the condition that is directly proportionate to the specific assessed need.

(5) Include regular collection and review of data to measure the ongoing effectiveness of the modification.

(6) Include established time limits for periodic reviews to determine if the modification is still necessary or can be terminated.

(7) Include the informed consent of the individual.

(8) Include an assurance that interventions and supports will cause no harm to the individual.

(5) Settings that are not Home and Community-Based. 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 individuals with intellectual disabilities;

(iv) A hospital; or

(v) Any other locations that have qualities of an institutional setting, as determined by the Secretary. Any setting that is located in a building that is also a publicly or privately operated facility that provides inpatient institutional treatment, or in a building on the grounds of, or immediately adjacent to, a public institution, or any other setting that has the effect of isolating individuals receiving Medicaid HCBS from the broader community of individuals not receiving Medicaid HCBS will be presumed to be a setting that has the qualities of an institution unless the Secretary determines through heightened scrutiny, based on information presented by the State or other parties, that the setting does not have the qualities of an institution and that the setting does have the qualities of home and community-based settings.

(6) Home and Community-Based Settings: Compliance and Transition:

(i) States submitting new and initial waiver requests must provide assurances of compliance with the requirements of this section for home and community-based settings as of the effective date of the waiver.

(ii) CMS will require transition plans for existing section 1915(c) waivers and approved state plans providing home and community-based services under section 1915(i) to achieve compliance with this section, as follows:

(A) For each approved section 1915(c) HCBS waiver subject to renewal or submitted for amendment within one year after the effective date of this regulation, the State must submit a transition plan at the time of the waiver renewal or amendment request that sets forth the actions the State will take to bring the specific waiver into compliance with this section. The waiver approval will be contingent on the inclusion of the transition plan approved by CMS. The transition plan must include all elements required by the Secretary; and within one hundred and twenty 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 benefit in accordance with this section. The transition plan must include all elements including timelines and deliverables as approved by the Secretary.

(B) For States that do not have a section 1915(c) HCBS waiver or a section 1915(i) State plan benefit due for renewal or proposed for amendments within one year of the effective date of this regulation, 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 benefit in accordance with this section. This plan must be submitted no later than one year after the effective date of this regulation. The transition plan must include all elements including timelines and deliverables as approved by the Secretary.

(iii) A State must provide at least a 30-day public notice and comment period regarding the transition plan(s) that the State intends to submit to CMS for review and consideration, as follows:

(A) The State must at a minimum provide two (2) statements of public notice and public input procedures.

(B) The State must ensure the full transition plan(s) is available to the public for public comment.

(C) The State must consider and modify the transition plan, as the State deems appropriate, to account for public comment.

(iv) A State must submit to CMS, with the proposed transition plan:

(A) Evidence of the public notice required.

(B) 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.

(v) Upon approval by CMS, the State will begin implementation of the transition plans. The State's failure to submit an approvable transition plan as required by this section and/or to comply with the terms of the approved transition plan may result in compliance actions, including but not limited to deferral/disallowance of Federal Financial Participation.

The regulations for HCBS Community First Choice services are available at 42 C.F.R. § 441.530.

§ 441.530 Home and Community-Based Setting.

(a) States must make available attendant services and supports in a home and community-based setting consistent with both paragraphs (a)(1) and (a)(2) of this section.

(1) Home and community-based settings must have all of the following qualities, and such other qualities as the Secretary determines to be appropriate, based on the needs of the individual as indicated in their person-centered service plan:

(i) The setting is integrated in and supports full access of individuals receiving Medicaid HCBS 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 individuals not receiving Medicaid HCBS.

(ii) The setting is selected by the individual from among setting options, including non-disability specific settings and an option for a private unit in a residential setting. The setting options are identified and documented in the person-centered service plan and are based on the individual's needs, preferences, and, for residential settings, resources available for room and board.

(iii) Ensures an individual's rights of privacy, dignity and respect, and freedom from coercion and restraint.

(iv) Optimizes but does not regiment individual initiative, autonomy, and independence in making life choices, including but not limited to, daily activities, physical environment, and with whom to interact.

(v) Facilitates individual choice regarding services and supports, and who provides them.

(vi) In a provider-owned or controlled residential setting, in addition to the above qualities at paragraphs (a)(1)(i) through (v) of this section, the following additional conditions must be met:

(A) The unit or dwelling is a specific physical place that can be owned, rented or occupied under a legally enforceable agreement by the individual receiving services, and the individual has, at a minimum, the same responsibilities and protections from eviction that tenants have under the landlord tenant law of the State, county, city or other designated entity. For settings in which landlord tenant laws do not apply, the State must ensure that a lease, residency agreement or other form of written agreement will be in place for each participant and that the document provides protections that address eviction processes and appeals comparable to those provided under the jurisdiction's landlord tenant law.

(B) Each individual has privacy in their sleeping or living unit:

(1) Units have entrance doors lockable by the individual, with only appropriate staff having keys to doors as needed.

(2) Individuals sharing units have a choice of roommates in that setting.

(3) Individuals have the freedom to furnish and decorate their sleeping or living units within the lease or other agreement.

(C) Individuals have the freedom and support to control their own schedules and activities, and have access to food at any time.

(D) Individuals are able to have visitors of their choosing at any time.

(E) The setting is physically accessible to the individual.

(F) Any modification of the additional conditions, under paragraphs (a)(1)(vi)(A) through (D) of this section, must be supported by a specific assessed need and justified in the person-centered service plan. The following requirements must be documented in the person-centered service plan:

(1) Identify a specific and individualized assessed need.

(2) Document the positive interventions and supports used prior to any modifications to the person-centered service plan.

(3) Document less intrusive methods of meeting the need that have been tried but did not work.

(4) Include a clear description of the condition that is directly proportionate to the specific assessed need.

(5) Include regulation collection and review of data to measure the ongoing effectiveness of the modification.

(6) Include established time limits for periodic reviews to determine if the modification is still necessary or can be terminated.

(7) Include the informed consent of the individual.

(8) Include an assurance that interventions and supports will cause no harm to the individual.

(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 individuals with intellectual disabilities;

(iv) A hospital providing long-term care services; or

(v) Any other locations that have qualities of an institutional setting, as determined by the Secretary. Any setting that is located in a building that is also a publicly or privately operated facility that provides inpatient institutional treatment, or in a building on the grounds of, or immediately adjacent to, a public institution, or any other setting that has the effect of isolating individuals receiving Medicaid HCBS from the broader community of individuals not receiving Medicaid HCBS will be presumed to be a setting that has the qualities of an institution unless the Secretary determines through heightened scrutiny, based on information presented by the State or other parties, that the setting does not have the qualities of an institution and that the setting does have the qualities of home and community-based settings.

(b) [Reserved]

The regulations for HCBS State Plan services at 42 C.F.R. § 441.710 and § 441.725.

§ 441.710 State plan home and community-based services under section 1915(i)(1) of the Act.

(a) Home and Community-Based Setting. States must make State plan HCBS available in a home and community-based setting consistent with both paragraphs (a)(1) and (a)(2) of this section.

(1) Home and community-based settings must have all of the following qualities, and such other qualities as the Secretary determines to be appropriate, based on the needs of the individual as indicated in their person-centered service plan:

(i) The setting is integrated in and supports full access of individuals receiving Medicaid HCBS 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 individuals not receiving Medicaid HCBS.

(ii) The setting is selected by the individual from among setting options, including non-disability specific settings and an option for a private unit in a residential setting. The setting options are identified and documented in the person-centered service plan and are based on the individual's needs, preferences, and, for residential settings, resources available for room and board.

(iii) Ensures an individual's rights of privacy, dignity and respect, and freedom from coercion and restraint.

(iv) Optimizes, but does not regiment, individual initiative, autonomy, and independence in making life choices, including but not limited to, daily activities, physical environment, and with whom to interact.

(v) Facilitates individual choice regarding services and supports, and who provides them.

(vi) In a provider-owned or controlled residential setting, in addition to the above qualities at paragraphs (a)(1)(i) through (v) of this section, the following additional conditions must be met:

(A) The unit or dwelling is a specific physical place that can be owned, rented, or occupied under a legally enforceable agreement by the individual receiving services, and the individual has, at a minimum, the same responsibilities and protections from eviction that tenants have under the landlord/tenant law of the state, county, city, or other designated entity. For settings in which landlord tenant laws do not apply, the State must ensure thata lease, residency agreement or other form of written agreement will be in place for each HCBS participant and that the document provides protections that address eviction processes and appeals comparable to those provided under the jurisdiction's landlord tenant law;

(B) Each individual has privacy in their sleeping or living unit:

(1) Units have entrance doors lockable by the individual, with only appropriate staff having keys to doors;

(2) Individuals sharing units have a choice of roommates in that setting; and

(3) Individuals have the freedom to furnish and decorate their sleeping or living units within the lease or other agreement.

(C) Individuals have the freedom and support to control their own schedules and activities, and have access to food at any time;

(D) Individuals are able to have visitors of their choosing at any time;

(E) The setting is physically accessible to the individual; and

(F) Any modification of the additional conditions, under paragraphs (a)(1)(vi)(A) through (D) of this section, must be supported by a specific assessed need and justified in the person-centered service plan. The following requirements must be documented in the person-centered service plan:

(1) Identify a specific and individualized assessed need.

(2) Document the positive interventions and supports used prior to any modifications to the person-centered service plan.

(3) Document less intrusive methods of meeting the need that have been tried but did not work.

(4) Include a clear description of the condition that is directly proportionate to the specific assessed need.

(5) Include regular collection and review of data to measure the ongoing effectiveness of the modification.

(6) Include established time limits for periodic reviews to determine if the modification is still necessary or can be terminated.

(7) Include the informed consent of the individual.

(8) Include an assurance that interventions and supports will cause no harm to the individual.

(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 individuals with intellectual disabilities.

(iv) A hospital.

(v) Any other locations that have qualities of an institutional setting, as determined by the Secretary. Any setting that is located in a building that is also a publicly or privately operated facility that provides inpatient institutional treatment, or in a building on the grounds of, or immediately adjacent to, a public institution, or any other setting that has the effect of isolating individuals receiving Medicaid HCBS from the broader community of individuals not receiving Medicaid HCBS will be presumed to be a setting that has the qualities of an institution unless the Secretary determines through heightened scrutiny, based on information presented by the State or other parties, that the setting does not have the qualities of an institution and that the setting does have the qualities of home and community-based settings.

(3) Compliance and transition:

(i) States submitting state plan amendments for new section 1915(i) of the Act benefits must provide assurances of compliance with the requirements of this section for home and community-based settings as of the effective date of the state plan amendment;

(ii) CMS will require transition plans for existing section 1915(c) waivers and approved state plans providing home and community-based services under section 1915(i) to achieve compliance with this section, as follows:

(A) For each approved section 1915(i) of the Act benefit subject to renewal or submitted for amendment within one year after the effective date of this regulation, the State must submit a transition plan at the time of the renewal or amendment request that sets forth the actions the State will take to bring the specific 1915(i) State plan benefit into compliance with this section. The approval will be contingent on the inclusion of the transition plan approved by CMS. The transition plan must include all elements required by the Secretary; and within one hundred and twenty days of the submission of the first 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 benefit in accordance with this section. The transition plan must include all elements including timelines and deliverables as approved by the Secretary.

(B) For States that do not have a section 1915(c) waiver or a section 1915(i) State plan benefit due for renewal or proposed for amendments within one year of the effective date of this regulation, the State must submit a transition plan detailing how the State will operate all section 1915(c) waivers and any section 1915(i) State plan benefit in accordance with this section. This plan must be submitted no later than one year after the effective date of this regulation. The transition plan must include all elements including timelines and deliverables as approved by the Secretary.

(iii) A State must provide at least a 30-day public notice and comment period regarding the transition plan(s) that the State intends to submit to CMS for review and consideration, as follows:

(A) The State must at a minimum provide two (2) statements of public notice and public input procedures.

(B) The State must ensure the full transition plan(s) is available to the public for public comment.

(C) The State must consider and modify the transition plan, as the State deems appropriate, to account for public comment.

(iv) A State must submit to CMS, with the proposed transition plan:

(A) Evidence of the public notice required.

(B) 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.

(v) Upon approval by CMS, the State will begin implementation of the transition plans. The State's failure to submit an approvable transition plan as required by this section and/or to comply with the terms of the approved transition plan may result in compliance actions, including but not limited to deferral/disallowance of Federal Financial Participation.

(b) Needs-Based Eligibility Requirement. Meet needs-based criteria for eligibility for the State plan HCBS benefit, as required in § 441.715(a).

(c) Minimum State plan HCBS Requirement. Be assessed to require at least one section 1915(i) home and community-based service at a frequency determined by the State, as required in § 441.720(a)(5).

(d) Target Population. Meet any applicable targeting criteria defined by the State under the authority of paragraph (e)(2) of this section.

(e) Nonapplication. The State may elect in the State plan amendment approved under this subpart not to apply the following requirements when determining eligibility:

(1) Section 1902(a)(10)(C)(i)(III) of the Act, pertaining to income and resource eligibility rules for the medically needy living in the community, but only for the purposes of providing State plan HCBS.

(2) Section 1902(a)(10)(B) of the Act, pertaining to comparability of Medicaid services, but only for the purposes of providing section 1915(i) State plan HCBS. In the event that a State elects not to apply comparability requirements:

(i) The State must describe the group(s) receiving State plan HCBS, subject to the Secretary's approval. Targeting criteria cannot have the impact of limiting the pool of qualified providers from which an individual would receive services, or have the impact of requiring an individual to receive services from the same entity from which they purchase their housing. These groups must be defined on the basis of any combination of the following:

(A) Age.

(B) Diagnosis.

(C) Disability.

(D) Medicaid Eligibility Group.

(ii) The State may elect in the State plan amendment to limit the availability of specific services defined under the authority of § 440.182(c) of this chapter or to vary the amount, duration, or scope of those services, to one or more of the group(s) described in this paragraph.

§ 441.725 Person-centered service plan

(a) Person-centered planning process. Based on the independent assessment required in § 441.720, the State must develop (or approve, if the plan is developed by others) a written service plan jointly with the individual (including, for purposes of this paragraph, the individual and the individual's authorized representative if applicable). The person-centered planning process is driven by the individual. The process:

(1) Includes people chosen by the individual.

(2) Provides necessary information and support to ensure that the individual directs the process to the maximum extent possible, and is enabled to make informed choices and decisions.

(3) Is timely and occurs at times and locations of convenience to the individual.

(4) Reflects cultural considerations of the individual and is conducted by providing information in plain language and in a manner that is accessible to individuals with disabilities and persons who are limited English proficient, consistent with § 435.905(b) of this chapter.

(5) Includes strategies for solving conflict or disagreement within the process, including clear conflict of interest guidelines for all planning participants.

(6) Offers choices to the individual regarding the services and supports the individual receives and from whom.

(7) Includes a method for the individual to request updates to the plan, as needed.

(8) Records the alternative home and community-based settings that were considered by the individual.

(b) The person-centered service plan. 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, as well as what is important to the individual with regard to preferences for the delivery of such services and supports. Commensurate with the level of need of the individual, and the scope of services and supports available under the State plan HCBS benefit, the written plan must:

(1) Reflect that the setting in which the individual resides is chosen by the individual. The State must ensure that the setting chosen by the individual is integrated in, and supports full access of individuals receiving Medicaid HCBS 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 individuals not receiving Medicaid HCBS.

(2) Reflect the individual's strengths and preferences.

(3) Reflect clinical and support needs as identified through an assessment of functional need.

(4) Include individually identified goals and desired outcomes.

(5) Reflect the services and supports (paid and unpaid) that will assist the individual to achieve identified goals, and the providers of those services and supports, including natural supports. Natural supports are unpaid supports that are provided voluntarily to the individual in lieu of State plan HCBS.

(6) Reflect risk factors and measures in place to minimize them, including individualized backup plans and strategies when needed.

(7) Be understandable to the individual receiving services and supports, and the individuals important in supporting him or her. At a minimum, for the written plan to be understandable, it must be written in plain language and in a manner that is accessible to individuals with disabilities and persons who are limited English proficient, consistent with § 435.905(b) of this chapter.

(8) Identify the individual and/or entity responsible for monitoring the plan.

(9) Be finalized and agreed to, with the informed consent of the individual in writing, and signed by all individuals and providers responsible for its implementation.

(10) Be distributed to the individual and other people involved in the plan.

(11) Include those services, the purchase or control of which the individual elects to self-direct, meeting the requirements of § 441.740.

(12) Prevent the provision of unnecessary or inappropriate services and supports.

(13) Document that any modification of the additional conditions, under § 441.710(a)(1)(vi)(A) through (D) of this chapter, must be supported by a specific assessed need and justified in the person-centered service plan. The following requirements must be documented in the person-centered service plan:

(i) Identify a specific and individualized assessed need.

(ii) Document the positive interventions and supports used prior to any modifications to the person-centered service plan.

(iii) Document less intrusive methods of meeting the need that have been tried but did not work.

(iv) Include a clear description of the condition that is directly proportionate to the specific assessed need.

(v) Include a regular collection and review of data to measure the ongoing effectiveness of the modification.

(vi) Include established time limits for periodic reviews to determine if the modification is still necessary or can be terminated.

(vii) Include informed consent of the individual; and

(viii) Include an assurance that the interventions and supports will cause no harm to the individual.

(c) Reviewing the person-centered service plan. The person-centered service plan must be reviewed, and revised upon reassessment of functional need as required in § 441.720, at least every 12 months, when the individual's circumstances or needs change significantly, and at the request of the individual.