

HCBS Settings Rules: How to Advocate for Truly Community Based Settings (Abridged)

A companion resource to:

HCBS Settings Rules: How to Advocate for Truly Integrated Community Settings (Unabridged)

Created by the HCBS Advocacy Coalition

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Background – New Rules for HCBS

Home and community based services (HCBS) provide opportunities for Medicaid participants to receive services in their own home and in the broader community. These programs provide services to a variety of populations, including people with mental illnesses, intellectual or developmental disabilities, and physical disabilities, as well as older adults.

The [final HCBS settings rule](#) created new requirements for all HCBS settings, including that they provide opportunities for participants to engage in community life, have access the community, control their personal resources, and seek employment and work in competitive settings. These new rules will enhance the quality and definition of HCBS and provide additional protections to individuals that receive services.

Starting March 2014, each state had 15 months to [draft](#) a Statewide Transition Plan; these need to be finalized and implemented by March 2019. The Centers for Medicaid and Medicare Services have reviewed these plans and given states feedback on needed areas for improvement and next steps. **This is an extremely important time for advocates to become involved in providing input into state transition plan development and refinement.**

Advocacy – Why is it important?

Input from advocates and HCBS participants is critical to states implementing the settings rules in ways that ensure HCBS participants receive the benefits of, and are fully included, in the broader community.

CMS has stressed the importance of the public comments process and are looking closely at state outreach and response to public comments. Advocates and HCBS participants have important information about the settings in the system, including settings that do not comply with the rules or are institutional in nature. Advocates can have an impact on ensuring that state plans actually lead to the system change envisioned by the new rules.

Get Involved – 9 Action Steps

Step 1. Start Evaluating Settings Early

- Assessment of states' HCBS settings should be an ongoing process.
- Give yourself time to gather information so you are prepared for the comment period.
- Comparing your assessment with that of the state's should be an ongoing process.

Step 2. Create a List of Settings where HCBS Participants Receive Services

- Identify all settings (even if you are unsure of the funding source).
 - Categorize into settings that meet the new rule, those that do not, and those that are institutional in nature (including settings that isolate).
- Resources to help you find these settings:
 - State HCBS documents; provider listings and websites; managed care organizations; licensure listings, reviews, surveys and/or inspections; list of [14\(c\) certificate](#) holders; and [Housing & Urban Development \(HUD\)](#) website.

Step 3. Gather & Analyze Information about the Settings on Your List

- Look for evidence that the settings do not comply with the rules or are institutional in nature—meaning they have characteristics that isolate individuals from the community—as well as settings that are in or on the grounds of institutional settings.
- Use the CMS “Exploratory questions for settings” (both [residential](#) and [non-residential](#)).
- Evidence should include: How an individual experiences the setting (gather this information from the individual, families, and anyone one else with direct knowledge) and the specifics of the setting (e.g., range of services on-site, visitation policy, transportation, types of participation in community events and activities). See [unabridged document](#) for an extended list of examples starting on page 9.

Step 4. Identify Institution-like Settings & those that Require Heightened Scrutiny

- Individual experience, policies, community opportunities all help to identify whether a setting is institution-like or would require [heightened scrutiny](#).
 - Review CMS guidance on [heightened scrutiny](#).
 - Brainstorm about settings that could be isolating based on location, size, or relationship to other institutional settings.

Step 5. Share your Setting Specific Information with the State

- Share your findings in advance; this can help influence the state's process and highlight potential issue areas with settings and with the process itself.
- If your state has already made public some of its preliminary results, be sure to highlight where your findings differ from the states findings.

Step 6. Analyze Your State's Setting Assessment Results

- Evaluate your state's amended plan using the information you have gathered as well as CMS guidance.
- Look closely at the amount and specificity of the state's reasons for why each setting is not institutional or meets the characteristics of an HCBS setting.
 - Identify in your comments any settings that are incorrectly categorized as compliant or settings that were not identified.
- See unabridged version for some questions you may want to ask as you go through the state's assessment results starting on page 15.

Step 7. Prepare & Submit Comments on the State's Revised STP

- Comments on settings should have a level of specificity.
- Use evidence gathered about the individual setting and the individual's experience (omitting identifiable information about the person).
- Review updated plans for its responsiveness to the issues raised by CMS.

Step 8. Encourage Others to Share their Opinions Too

- The more the better! Number of comments submitted is significant.
 - Encourage other groups, family members, and individuals to submit individual comments rather than having a sign-on.
 - Use and distribute to other advocates a sample template.

Step 9. Submit to CMS Your List of Settings & Critique of State Setting Assessments

- Review how the state responded to your comments.
- If you think sufficient changes were not made and did not offer reasonable explanations as to why, you may consider sending your comments to CMS with the full list of specific settings identified along with a cover letter highlighting areas the state failed to respond to and the settings that most concern you.

Stay Involved – We Need You

Strong implementation of the HCBS rules will require advocacy throughout the process. However, this does not mean that advocacy must always be resource intensive; much of the work is monitoring the state process. Advocacy is especially important in the statewide transition plans and assessments in order to ensure states have strong plans to follow.

HCBS Advocacy Coalition & Contact Information

These national organizations are all working on HCBS implementation and are working collaboratively to assist state advocates in understanding the process, evaluating state plans and assessment processes, crafting effective comments, and advocacy planning.

State advocates may contact these organizations by emailing hcbsadvocacy@gmail.com. You can also visit the coalition website: hcbsadvocacy.org

The HCBS Advocacy Coalition is a voluntary association of the following organizations working together to advance state compliance with HCBS setting requirements:

- [American Network of Community Options and Resources](#)
- [Association of People Supporting Employment First](#)
- [Association of University Centers on Disabilities](#)
- [Autistic Self Advocacy Network](#)
- [Bazelon Center for Mental Health Law](#)
- [Coalition to Promote Self-Determination](#)
- [Justice in Aging \(formerly National Senior Citizens Law Center\)](#)

- [Human Services Research Institute](#)
- [National Association of Councils on Developmental Disabilities](#)
- [National Consumer Voice for Quality Long Term Care](#)
- [National Council on Independent Living](#)
- [National Disability Rights Network](#)
- [National Down Syndrome Congress](#)
- [National Health Law Program](#)
- [TASH](#)
- [The Arc of the United States](#)