



Advocacy Checklist and Resources for Impacting State Compliance with Medicaid Home and Community Based Services Settings Rule

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This guide was created for HCBSadvocacy.org, a joint project of the Association of University Centers on Disabilities, National Disability Rights Network, and National Association of Councils on Developmental Disabilities

On March 17, 2014 a final Medicaid rule became effective governing the settings in which home and community-based services (HCBS) may be provided through 1915(c) waivers, the 1915(i) state plan option, and 1915(k) Community First Choice option. This was followed by guidance to states regarding their expectations and interpretations of the new rule. The rule requires states to develop a transition plan identifying how they will change aspects of existing HCBS programs to meet the requirements in the rule. The transition plan must include opportunities for public comment. It is incumbent upon the disability community to help ensure that states conduct accurate assessments of current settings, develop comprehensive transition plans, and submit waivers and state plan options which meet the standards of the HCBS rule. This checklist provides ideas for advocacy and helpful resources.

States have a very short time frame for preparing plans, thus it is advisable to implement recommendations 1-5 simultaneously. This would be more easily accomplished with a group of advocates and agencies who could divide roles.

Checklist and Resources for Advocacy

- 1) Educate yourself, state officials, and the disability community about the new rule.
 - a. See official resources from CMS on Medicaid.gov/hcbs and HCBSadvocacy.org/learn-about-the-new-rules
 - b. Find national advocacy resources on HCBSadvocacy.org/national-resources
 - c. Host town hall meetings, webinars and other trainings to explain the assessment process and transition plan requirements and opportunities for disability community input and involvement. Seek state agency representation at these trainings
 - d. Contact state advocacy organizations and establish a working group in charge of disseminating information and resources about the rule

- e. Prepare materials about the rule in accessible formats for people with disabilities and those with limited English proficiency
 - f. Identify areas where further clarification or guidance would be helpful and seek this information from state agencies
 - g. Watch for future guidance which CMS has indicated is in development, including: Operationalizing person-centered planning in order for states to bring programs into compliance; and How States should apply standards for non-residential settings, such as day programming and pre-vocational training settings. All guidance will be posted at: Medicaid.gov/hcbs
- 2) Educate providers and the disability community on the new requirements for individual choice and person centered service plans.
- a. Contact provider agencies and offer training on person centered requirements and requires for service planning.
 - b. Watch for future CMS guidance on “operationalizing person-centered planning in order for states to bring programs into compliance”;
 - c. Provide information to service providers that explain how to implement individual choice and person centered planning, such as:
 - i. *HCBS Worksheet for Assessing Services and Settings*, prepared by Association of University Centers on Disability, National Association on Developmental Disabilities and the National Disability rights Network, at <http://hcbsadvocacy.org/national-resources/>
 - ii. *Increasing Person-Centered Thinking: Improving the Quality of Person-Centered Planning: A Manual for Person-Centered Planning Facilitators*, by University of Minnesota, Institute on Community Integration at <http://rtc.umn.edu/docs/pcpmanual1.pdf>
- 3) Identify any new applications or requests for renewed or amended 1915(c) waivers and 1915(i) or (k) options expected by March 17, 2015.
- a. Identify 1915(c) waivers that expire before March 17, 2015 at www.hcbsadvocacy.org
 - b. Ask your Medicaid waiver administrator when they plan to file new applications or requests for renewed or amended 1915(c) waivers and 1915(i) or (k) options; remind them that when they file they have to

simultaneously submit a transition plan for services related to the program being renewed, or amended; and within 120 days after submission of the request, the state must submit a transition plan addressing all other Medicaid HCBS in the state

4) Advise the state on the **process** to use for assessing the existing HCBS system.

- a. Request development of, and consumer representation on, an advisory board or planning team to coordinate assessment of current HCBS settings (Be aware, this is not required in the HCBS regulations)
- b. Recommend people or groups the state might consult with to do the assessments
- c. Request transparency during the assessment and plan development process. (Be aware, this is not required in the HCBS regulations) Some possibilities include:
 - i. Posting minutes of assessment team and transition plan meetings
 - ii. Notifying the disability community if CMS is reviewing a setting which is presumptively institutional, but which the state would like to label as HCBS
 - iii. Developing an HCBS stakeholder e-mail notification list that will advise list members in real time of opportunities for public comment

5) Don't wait for the 30 day comment period on the plan. Mobilize while the state is assessing settings and developing the plan to identify settings that will need to be changed in order to qualify for HCBS funding. Make suggestions of changes needed to qualify for HCBS funding.

- a. Develop and advertise a webpage where people can go to report on HCBS programs that do not meet the requirements of the new rule
- b. Train staff, and disability advisory groups how to identify and report settings that do not meet the requirements for HCBS funding
- c. Prepare a template or guidance for advocates to use during the 30 day comment period.
- d. Refer to the CMS document entitled Exploratory Questions to Assist States in Assessment of Residential Settings at

<http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Long-Term-Services-and-Supports/Home-and-Community-Based-Services/Downloads/Exploratory-questions-re-settings-characteristics.pdf>

e. Seek to be involved in the development of conflict of interest standards to ensure the independence of persons or entities who evaluate eligibility for HCBS, assess need for HCBS or develop service plans;

f. Notify CMS of any movements in your state to fundraise for and build segregated planned communities or farmsteads for people with disabilities and request that they not receive HCBS funding.

6) Once transition plans are posted for comment, send in more comments, this time focused on whether the plan is accurate, comprehensive, and realistic.

- a. Check HCBSadvocacy.org and contact your state disabilities agency to identify when transition whether plans have been posted
- b. Request that the state post all public comments received on the proposed transition plan and any revisions made to the plan. (The rules only require is the state to submit a summary of the comments to CMS)
- c. Identify the entities the state proposes to use to evaluate eligibility for HCBS and develop service plans. Check with the P&A and other disability groups to see if there have been complaints about any of these agencies qualifications or independence. If yes, notify the state that this person or entity may not be acceptable to the disability community.
- d. Urge the state to use Affordable Care Act financial incentives and other funding opportunities to design new HCB services and independent housing like the Balancing Incentive Program and. Community-First Choice Option. Information about these funding options and resources can be found at:
 - i. *Long-Term Services and Supports: Opportunities in the Affordable Care Act*, By the Center for Health Care Strategies, Inc. at http://www.chcs.org/usr_doc/LTSS_ACA_Paper_121311.pdf; and
 - ii. *When Opportunity Knocks: How the Affordable Care Act Can Help States Develop Supported Housing for People with Mental Illnesses*, by the Bazelon Center for Mental Health Law at: <http://www.bazelon.org/portals/0/Where%20We%20Stand/Community%20Integration/Olmstead/When%20Opportunity%20Knocks.%20Bazelon%20Center%20for%20Mental%20Health%20Law.pdf>

7) Mobilize public input about settings “presumed to have institutional qualities” but which the state has asked to label HCBS. CMS must use a heightened scrutiny standard when reviewing the evidence the state provides them seeking to prove that a presumptively institutional setting is in fact HCBS. This process includes solicitation of public input, and may involve a visit to the setting by CMS.

- a. Request a conference call with your CMS regional office and organize a group of people with disabilities and disability advocates to join the call and provide input about the setting
- b. Ask individuals who have lived in that setting to share personal stories with CMS in written comments
- c. If CMS decides to visit the setting organize a town hall to meet with CMS and provide input

8) Watch for a second comment period. If a state makes substantive changes to a transition plan, they must allow for a second period of public comment.