

I Want to Choose Where I Live & Who I Live With!

Strengthening Advocacy Around the HCBS Settings Rule

Administration for Community Living

October 13, 2022

Agenda

- Welcome
 - Jill Jacobs, Commissioner of ACL's Administration on Disabilities.
- What is the Home and Community-Based Settings Rule?
 - Kate Brady, PhD ABD, Project Manager for HCBS Stakeholder Engagement, National Center on Advancing Person-Centered Practices and Systems
 - Elliot Kennedy, Director, Office of Policy Analysis and Development
- HCBS Settings Rule Stakeholder Engagement
 - Nancy Thaler, Senior Policy Advisor to ACL
- Why you should care!
 - Erica McFadden, PhD, MSW, Director, Office of Independent Living Programs

The What and Who of HCBS

What are Home and Community- Based Services (HCBS)?

HCBS provide funded support for:

- Employment
- Transportation
- Homecare/home health
 - Medications
 - Housekeeping
 - In-home therapy (PT, OT, Speech, etc.)
- Activities of daily living
 - Bathing, dressing, toileting
 - Cooking
- Finances
- Assistive Technology and Home Modifications

Who receives HCBS?

- In 2018 more than 4.7 million people received Medicaid-funded HCBS
- Each state has its own system and decides to which populations they will offer HCBS waivers

Settings Rule: Why It's Needed

- People living in community-based settings were often living a life that is closer to institutional experience

- The 2014 HCBS final rule attempts to define “community based” for the first time.
- The March 17, 2023 transition period deadline for full state compliance with the HCBS settings regulation, effective March 17, 2014, is fast approaching.
- ACL & CMS remain steadfast in ensuring adherence to the tenets of the rule and the regulatory criteria, which provide the framework for ensuring that HCBS are truly person-centered, and the settings within which they are provided facilitate autonomy and independence.

What Makes a Setting Home and Community-Based?

- It is in the community and supports the person’s full access to the community
- Provides opportunities to
 - seek employment in integrated settings at competitive wages
 - participate in community life
 - control personal resources
- It is selected by the individual from options that include non-disability specific settings
- Ensures the right to privacy, dignity, respect, and freedom from coercion and restraint
- Facilitates individual initiative, autonomy, and independence in making life choices

Core requirements of the CMS HCBS Final Settings Rule (2014)

- Requires every state to ensure that services meet minimum standards for integration, access to community life, choice, autonomy, and other important consumer protections
- Person-centered planning
- States must receive final Statewide Transition Plan approval.
- All states and settings will be fully compliant with the following regulatory settings criteria:
 - Privacy, dignity, respect, and freedom from coercion and restraint; and
 - Control of personal resources.

Additional Conditions: Provider-Owned or Controlled Settings

- Unit is owned, rented or occupied under a legally enforceable agreement
- Privacy, lockable doors Choice of roommates
- Freedom to control one’s own schedule/activities
- Person can have visitors they choose at any time
- Freedom to furnish and decorate
- Access to food at any time

Statewide Transition Plan Status as of August 2, 2022

Corrective Action Plans (State Flexibilities)

- CMS will authorize CAPs to continue federal reimbursement of HCBS beyond the end of the transition period, if states need additional time to ensure full provider compliance with the regulatory criteria NOT mentioned above. These include for example:
 - Access to the broader community;
 - Opportunities for employment;
 - Option for a private unit and/or choice of a roommate; and
 - Choice of non-disability specific settings.
- States must be able to show that their policies and procedures reflect the settings criteria and they have made efforts to implement the criteria to the fullest extent possible and work with CMS on a concrete, time-limited plan to come into full compliance with remaining criteria.
- States should seek stakeholder input when developing CAPs.

Importance of Public Engagement

- ACL works closely with CMS to implement the Settings Rule
- The Rule is a key to engaging community members in the development, provision, and oversight of HCBS programs.
- For the first time, ACL is specifically funding public engagement efforts.

Opportunities for Engagement Now

- Statewide Transition Plans
 - View STPs: <https://www.medicaid.gov/medicaid/home-community-basedservices/statewide-transitionplans/index.html>
- Heightened Scrutiny Packages:
 - CMS Site Visits
 - ACL Stakeholder calls In the future
- Corrective Action Plans
 - States must be able to show that their policies and procedures reflect the settings criteria and they have made efforts to implement the criteria to the fullest extent possible and work with CMS on a concrete, time-limited plan to come into full compliance with remaining criteria.
- Waiver Amendments and Renewals

Who are the stakeholders we need to hear from?

- INDIVIDUAL PEOPLE WITH DISABILITIES THEIR FAMILIES, AND NEIGHBORS
- ADVOCACY GROUPS: Parent Groups Sibling groups Self-advocate groups.
- PROTECTION FROM HARM RESOURCES: State Protection & Advocacy Ombudsman Adult Protective Services
- STATE INDEPENDENT LIVING COUNCILS & CENTERS FOR INDEPENDENT LIVING

Methods for Engagement

- Show up and give in person public comment
- Submit written comments from your organization
- Coordinate templates for others to use in submitting comments
- Consult partners about submitting joint comments
- Call your legislators and other elected officials

Examples of Supporting Stakeholder Engagement

- Vermont
- Pennsylvania
- Alabama

Vermont

- Foundational Value: nothing about us without us
- Practical Reality: Self-advocates and families can see what state agencies cannot.
- Become subject matter experts! Read everything -- Your State's waiver, CMS guidance, state quality strategy; not just the State Transition Plan.
- Use every opportunity for comment, written or oral. Formal public comment vs. other comment. Share comments widely.

Vermont: How do we work with our partners?

- Conduit for information.
- Convenor of stakeholder meetings & town halls.
- Composer of public comment for sign-on.

Vermont: Act as a Trusted Messenger on HCBS Rule

- Build partnerships with other disability groups or HCBS programs – for example, Independent Living
- Explain the settings rule in plain language. Ensure that self-advocates and family members know about their new rights in provider-owned settings.
- Gather Stakeholders and invite State Decision-Makers – for example, host a “Town Meeting.”
 - Put information in Plain Language
 - Look for stories about services in advance
 - Coach speakers in advance
 - Follow-up with a written summary of key points

Vermont: Tips for Stakeholder Engagement

- Set your terms and insist upon them – recording, time, location, etc.

- Ensure a safe space – consider confidentiality & conflicts of interest.
- Insist meeting materials are accessible.
 - Send materials in advance
 - Need to know vs nice to know
 - Use plain language
- Ask open-ended questions.

Pennsylvania

- PADDCC and Temple Partnership
- DDC Issued HCBS Final Rule Grant (2017-2021)
 - Advocacy, education and monitoring
 - Authentic and meaningful implementation of the Final Rule
- Institute on Disabilities at Temple awarded the Grant
 - The Institute partnered with several organizations including Disability Rights PA, PA Health Law Project and Self Advocates United as One (SAU1) to carry out the grant.
 - <https://disabilities.temple.edu/programs-services/policy/home-andcommunity-based-services/hcbs-living-my-life-my-way-mark>

Pennsylvania: Created the Coalition for Inclusive Community

- Came together to support State Institution Closures • Included the DD Council, UCEDD and P&A
- Included Advocacy leaders
 - Self Advocate Organizations
 - Statewide Family Advocacy Groups
 - Centers for Independent Living
 - Arc of PA Pennsylvania
- Active Participants on the State Information Sharing and Advisory Committee
 - Led by the Office of Developmental Programs
 - Broad Stakeholder Group
 - DD Act Network § Self Advocates
 - Families
 - Providers

Pennsylvania: Additional Support

- Providing Model Comments for Others to Use
- Convening small groups of families and self-advocates
- Explaining HCBS Final Rule to Others
- Providing Plain Language Resources
- Social Media Engagement Alabama

Alabama

- Conduct vigorous monitoring of HCBS settings
- Incorporated monitoring results into two public comments in Fall 2022 and Spring 2022
- Conducted multiple listening sessions with stakeholders to support public comments
 - In state
 - With Federal Partners

Resources and Toolkits

- Designed for state programs to strengthen their infrastructure and develop stronger HCBS for beneficiaries
- Toolkit contains four modules
 - State strategies to help increase the share of long-term services and supports (LTSS) provided in community-based settings (history/context of LTSS reform and rebalancing)
 - Tools designed to assist states with policy and programmatic strategies (describes key elements of HCBS systems that are economically sustainable and equitable for all individuals with LTSS needs)
 - Cases studies of innovative programs and creative ways states are leveraging available federal authorities to transform LTSS systems (describes the various Medicaid authorities that states can choose from to cover their HCBS programs)
 - Links to resources (provides examples of state models of care and strategies to reform LTSS systems and expand HCBS)
- Go to <https://www.medicaid.gov/medicaid/homecommunity-based-services/guidance/homecommunity-based-services-final-regulation/index.html>
- Published a toolkit for advocates, families, and administrators on how to ensure that people with disabilities receive Medicaid-funded HCBS in integrated settings that offer full access to the community
- Includes four different resources
 - A resource for advocates and their families that explains what the new HCBS rule means and how to make their voices heard as their states make their transition plans. It also includes scripts for writing to their state's Medicaid agencies on how they think their state's HCBS program needs to change
 - A resource for state administrators and professionals on how to come into compliance with the new rule. It includes detailed guidance on the implications of the new rule, suggestions for elements to be included in the transition plan, and examples of useful tools and questionnaires for accessing provider compliance.
 - A research brief explaining how scattered-site supported housing can help states meet the integration and choice standards in the new rule.
 - A fact sheet on integrated housing for people with disabilities.
- Go to <https://autisticadvocacy.org/policy/toolkits/hcbsrule/>

Additional Resources

VIDEOS

- HCBS Video: Overview (7:26 minutes) at <https://www.youtube.com/watch?v=xnbtb5Jpz7c> •
- HCBS Video: What does the Rule Guarantee? (5:17) at <https://www.youtube.com/watch?v=8sJl-LF5ufg>
- HCBS Video: Provider Requirements for Residential Settings (6:32) at <https://www.youtube.com/watch?v=sjy334aMXXk&feature=youtu.be>
- HCBS Video: Rights Restrictions & Modifications (3:44) https://www.youtube.com/watch?v=Vg5DA_ouOwY
- HCBS Video: Your Services Should Be All About You – for people receiving HCBS that discusses rights and choice. <https://www.youtube.com/watch?v=-xqttlDcAkM>

INTERACTIVE GUIDES

- HCBS Guide: Your Right To A Community Life (for people receiving HCBS) <https://www.c-ql.org/resources/guides/hcbs-guide-your-right-to-a-community-life/>
- HCBS Guide: Supporting The Right To A Community Life (for staff who support people receiving HCBS – focuses on community) <https://www.c-q-l.org/resources/guides/hcbs-guide-supporting-the-right-to-a-community-life/>

Thank you