

Settings Rule: Getting Disability and Aging Input Off Life-support

Overview of Presentation

- Settings Rule Overview
- HCBS Settings Rule and COVID-19
- Engaging the Long-Term Care Ombudsman programs
- Collaborating with the Protection and Advocacy Agencies



Center for Public Representation

HCBS Settings Rule: Updates from Disability and Aging Advocates

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HCBS SETTINGS RULE: OVERVIEW

Engagement of Disability and Aging Advocates

- Since the release of the HCBS Settings Rule in 2014, national disability and aging advocates have been collaborating on implementation of the HCBS Settings Rule
 - Working to educate stakeholders about the Rule and opportunities for input via comments on statewide transition plans
 - Working with CMS and ACL on implementation issues
 - Educating members of Congress about the importance of HCBS and the Settings Rule

Opportunities of the HCBS Settings Rule

- HCBS Settings Rule provides an unprecedented opportunity to:
 - Ensure basic human rights and protections
 - Modernize service models that were designed in the 1980s to better align with 2020 best practices
 - Shift capacity to better align with demand by people with disabilities and older adults
 - Recent study shows nearly 90% of people with IDD want to live in their own home but vast majority of capacity is in congregate settings like group homes
 - 80% of HCBS participants are not receiving employment supports yet almost 60% of these individuals want to
 - Majority of older adults want services to age in place as long as possible

Refresher:

Requirements for all HCBS Settings

The definition focuses on the nature and quality of individuals' experiences and requires that the setting:

- Is **integrated in and supports access to the greater community**;
- Provides **opportunities to seek employment and work in competitive integrated settings**, engage in community life, and control personal resources
- Is selected by the individual from among setting options, **including non-disability specific settings**

Requirements for HCBS Settings (cont'd)

- Ensures the individual receives services in the community to the **same degree of access** as individuals not receiving Medicaid HCBS
- Ensures an individual's rights of **privacy, dignity, respect, and freedom from coercion and restraint**
- Optimizes **individual initiative, autonomy, and independence** in making life choices
- Facilitates **individual choice** regarding services and supports, and who provides them

Important Points to Remember

- The Rule focuses on people's **individual experiences** in any HCBS setting
 - Doesn't prohibit any specific types of HCBS setting
 - It does not set specific size limitations
- The Rule ensures **basic human rights** for people with disabilities and older adults, incl. in provider-owned settings
- There can be **limited modifications** based on health and safety
 - But limitations must be based on individual needs determined through the person-centered planning process

States Must Assess and Categorize All Settings

- Meets **all requirements** of the Rule (or can with changes)
- Can **never meet requirements** of the Rule because it is an institution (nursing home, ICF, hospital, or IMD)
- Is **presumed institutional**
 - Setting is unallowable unless a state can prove through a “heightened scrutiny” process that the setting overcomes the institutional presumption and meets the rule’s requirements

Presumptively Institutional Settings

- Three categories of presumptively institutional settings:
 - Prong 1: Settings in facilities providing inpatient institutional services
 - Prong 2: Settings on the grounds of, or adjacent to, a public institution
 - Prong 3: Settings that **have the effect of isolating HCBS recipients from the broader community**

Heightened Scrutiny

- For **any** presumptively institutional setting identified by a state, the state must closely examine whether the setting overcomes the institutional presumption and **fully complies with the requirements of the Rule**
- If the state believes it does, it must submit a package of evidence to CMS as part of a heightened scrutiny review*
 - The package must go out for public comment first
 - * Settings that are fully remediated prior to July 2021 do not need to be submitted to CMS but a list of those settings must be put out for public comment

HCBS SETTINGS RULE AND COVID-19

COVID-19 and HCBS

- COVID-19 has laid bare the **risks of large congregate settings** and the **importance of individualized community supports**
 - More than 40% of deaths to date have been in institutions
 - Outbreaks have occurred in group homes, assisted living, etc.
- COVID-19 has **stretched the HCBS system**
 - Many providers have had to close programs or drastically change the delivery of services
 - Increased costs for PPE, additional staffing, sick leave, etc.
 - Many people with disabilities, like everyone else, have lost their jobs → needing new or different day services

Impact of COVID-19 on the Rule

- Many states have “waived” the Rule in emergency waivers
 - Waivers relate to issues like limiting visitors and community outings during the COVID-19 pandemic
 - As states are transitioning out of waivers, the Settings Rule must be part of the conversation
- States should see the Settings Rule as a **critical part of their COVID-19 safety strategy**
 - Strengthening HCBS is the best way to keep people with disabilities and older adults safe and out of institutional and other large congregate settings where COVID-19 outbreaks are rampant

Extension of Implementation Deadline

- State associations sent letters to Congress and CMS leadership requesting at least a one year extension due to COVID-19
- HCBS Advocacy Coalition advocated for **any extension to be targeted, have guardrails and interim deadlines to ensure progress, and that standards are not weakened in any way**
- In July, CMS issued a State Medicaid Director letter announcing a global extension of all deadlines by one year, moving final implementation deadline to March 2023
 - This comes after CMS had previously extended the original March 2019 deadline by three years to March 2022

CMS Extension Guidance

- Extension guidance discusses challenges states are facing, especially doing site assessments during COVID-19 as a justification for giving a one year extension
- Encourages states “to work consistently on their HCBS compliance activities between now and March 17, 2023” and says that CMS “[c]ontinues to expect that states will demonstrate compliance throughout the transition period”
- Reassessment of settings (after the PHE) may be required “if a setting has made significant and permanent changes to the services provided or the location in which those services are provided”

CMS Extension Guidance (cont'd)

- Discusses importance of strengthening HCBS during COVID-19
 - “Availability of **person-centered, individualized supports** will take on an even greater importance” during the PHE and as part of recovery
 - “In light of risks associated with congregate settings and COVID-19, states may wish to give particular priority to those provisions of the rule making available **non-disability specific settings** among the range of options available to individuals with disabilities, including to individuals currently residing in disability-specific congregate settings (for whom transition supports may be necessary to make the option available)
 - States may be interested in further rebalancing efforts, lessening reliance on institutional settings; highlights independent *Olmstead* requirements

Key Deadlines

- **March 31, 2021:** Settings located in the same building as a public or private institution or on the grounds of or adjacent to a public institution must be sent to CMS for heightened scrutiny review
- **July 1, 2021:** Settings that isolate that are remediated by this date do not need be submitted to CMS for heightened scrutiny review
- **October 31, 2021:** Settings that isolate that aren't yet in compliance must be sent to CMS for heightened scrutiny review
- **March 17, 2023:** Deadline for compliance with the Rule

Status of State Implementation

- Approvals of initial statewide transition plans (STPs)
 - All but 4 states have gotten approval of their initial STPs
 - The remaining 4 states are IL, MA, NJ, and TX
- Approvals of final STPs
 - 21 states have received approval for their final STPs
 - This includes the *process* for heightened scrutiny but not all HS settings
- Heightened Scrutiny determinations
 - So far only the pilot on prongs 1 and 2

RESOURCES

General Settings Rule Resources

- CMS HCBS Settings Rule Website
 - www.medicaid.gov/hcbs
- HCBS Advocacy Website
 - Sponsored by national disability groups including CPR
 - www.hcbsadvocacy.org
- ASAN Easy Read Toolkit
 - <https://autisticadvocacy.org/policy/toolkits/hcbsrule>

Heightened Scrutiny Resources

- The Medicaid HCBS Settings Rule: Heightened Scrutiny
 - <https://hcbsadvocacy.files.wordpress.com/2020/03/heightened-scrutiny-explainer-3.18.20-final-2.pdf>
- How to Advocate for Truly Integrated Settings
 - <https://hcbsadvocacy.files.wordpress.com/2020/03/how-to-advocate-for-true-community-settings-3.18.2020-final-2.pdf>
- Identifying, Evaluating and Remediating “Settings That Isolate”
 - <http://materials.ndrn.org/HCBS/HCBS-Settings-Heightened-Scrutiny-CLPC-Document-Feb-2020.pdf>

Implementation Delay Resources

- CMS State Medicaid Director Letter on Delay
 - <https://www.medicaid.gov/Federal-Policy-Guidance/Downloads/smd20003.pdf>
- HCBS Advocacy Coalition Statement
 - <https://hcbsadvocacy.files.wordpress.com/2020/07/hcbs-coalition-statement-on-covid-19-extension.pdf>

QUESTIONS?



The National
CONSUMER VOICE
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formerly NCCNHR

ENGAGING THE LONG-TERM CARE OMBUDSMAN PROGRAM

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Long-Term Care Ombudsman Program

- Each state must have a State Long-Term Care Ombudsman program (SLTCOP)
 - Federal Older Americans Act
- Federally required to serve residents of long-term care facilities
 - Medicaid funded assisted living facilities (residential care, board and care, personal care homes)
- Some states have expanded LTCOP authority to HCBS clients

Engaging the LTCOP: Now - March 17, 2023

In General

- Invite the State LTC Ombudsman (SLTCO) to participate in any transition stakeholder groups
- Ask LTCOP to comment as part of any public comment period
- Request the LTCOP inform their network about comment periods, encourage submission of comments, assist consumers/their families if possible

Engaging the LTCOP: Now - March 17, 2023

Heightened Scrutiny

- Discuss with SLTCO the program's ability/capacity to comment on HS evidentiary packages
- If yes:
 - Notify the LTCOP of the state's:
 - Determination that a setting has overcome the presumption of being an institutional setting 7
 - Justification for that determination

LTCOP has access to evidence package with or without Public Health Information (PHI)

Engaging the LTCOP: Now - March 17, 2023

Heightened Scrutiny

Involving consumers

- Partner with LTCOP to:
 - Develop training for consumers and families on heightened scrutiny process
 - Create questionnaire/survey for consumers and their families to provide feedback on their setting
- LTCOP might be able to assist residents in providing feedback

Engaging the LTCOP: Now - March 17, 2023

Relocation of Beneficiaries

- Consult and/or work with LTCOP to develop:
 - A relocation plan
 - Written information for consumers about the process and their rights

Engaging the LTCOP: After March 17, 2023

Ongoing Monitoring

- Obtain input from or include LTCOP in:
 - Establishing a strong survey process
 - Designing a robust complaint process
 - Creating individual experience survey
- Ask the LTCOP about complaints, concerns, observations in a setting



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Collaborating with Protection and Advocacy Agencies (P&As) On HCBS Settings Rule

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Protection and Advocacy (P&A) Authority from the Developmental Disabilities Act

“Pursue legal, administrative & other appropriate remedies”

- Range of Issues and all disabilities
- Range of Remedies (I&R to class actions, and policy advocacy)
- Ability to Respond (monitoring, investigations, individual and systemic representation)
- Unique Access to Persons, Records, Facilities

P&A Experience Relevant to HCBS Planning

- **Discharge planning, on-going monitoring, and person-centered services** requirements and common problems/limitations
- **Identifying residential and non-residential settings with institutional qualities** and less obvious limitations on community integration resulting from unwritten rules and policies
- **Latest Olmstead and Medicaid requirements and;**
- **Gathering input from people with full range of disabilities**

State and P&A Joint Activities

- **Educate** stakeholders prior to comment period
 - P&As can distribute State Informational materials and encourage detailed, personal comments to state
 - Stakeholder advisory roles – assist interviews/surveys
- **Testify** at public forums and **Comment** on plans
 - using knowledge from Monitoring visits and client complaints
- **Conduct site visits:** of settings state is likely to seek H.S.
- Consult P&A as part of heightened scrutiny review.
(HIPAA and P&A role)
- **Train on Medicaid, Olmstead, supported decision making, person-centered planning, and more.**

Joint Efforts with P&As can help answer

- Does the systemic assessment appropriately identify conditions at setting
- Does this meet H.S. requirements (consult P&A as part of review)?
- What are effective remediation strategies
 - How can remediation be coordinated with housing, employment, IDEA, MLTSS transition, and Olmstead compliance efforts?
- What are effective long-range monitoring options?

Best Practices: Remediation Phase

***Comprehensive Survey** of HCBS gaps, housing, transportation, employment, individuals in the community at risk

***Continuous Stakeholder Engagement**

***Improve/expand HCBS** (phase out sheltered work, develop non-disability specific settings)

***Coordinate Planning with other state efforts**

- HUD Housing
- DOL - employment first, WIOA compliance;
- Dept. of ED - IDEA compliance and Voc. Rehab.
- DOT (planning bus lines, pedestrian access)
- Olmstead planning and enforcement

DOJ States: “A state’s obligations under the ADA are independent from the requirements of the Medicaid program.”

Continuous Monitoring

- Providers set a process for **periodic reviews of PCP** to determine whether or not a modification could be less restrictive;
- Use the state's quality assurance process (e.g. licensing reviews, case management visits, etc.) and **expand licensing staff** to sample PCP and rule adherence;
- Create means for **continuous resident training** and establish resident compliant process
- Create a **statewide training for case managers and providers** writing PC plans and for licensing professionals;
- Establish **data collection protocols**, update technology;
- **Report non-compliant settings** to state and P&A