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
HCBS Settings Rule:
Updates from Disability and Aging Advocates

Alison Barkoff
Center for Public Representation
abarkoff@cpr-us.org

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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 thought 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”
• 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

• How to Advocate for Truly Integrated Settings

• Identifying, Evaluating and Remediating “Settings That Isolate”
Implementation Delay Resources

• CMS State Medicaid Director Letter on Delay

• HCBS Advocacy Coalition Statement
QUESTIONS?
ENGAGING THE LONG-TERM CARE OMBUDSMAN PROGRAM

Robyn Grant
National Consumer Voice for Quality Long-Term Care
rgrant@theconsumervoice.org
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
The National Consumer Voice for Quality Long-Term Care

www.theconsumervoice.org

Connect with us:

National Consumer Voice for Quality Long-Term Care

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

Elizabeth Priaulx
Senior Disability Legal Specialist
National Disability Rights Network
820 1st Street, N.E.
Washington, D.C. 20002
202-408-9514 x 113
Elizabeth.Priaulx@ndrn.org
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