An Update on the HCBS Settings Rule

Alison Barkoff, J.D.
Director of Advocacy, Center for Public Representation
abarkoff@cpr-ma.org

NACDD Annual Conference
July 14, 2017

Opportunity of the HCBS Settings Rule

- Move forward the vision and mandates of the DD Act: promote self-determination, integration and inclusion of people with IDD
- Engage people with IDD, families, advocates and providers in the vision for your states' service system
- Help expand capacity of best practices that support people in more integrated and individualized settings
- Assist with transformation of outdated models that segregate people with disabilities or are based on low expectations

2

Topics for Presentation

- Brief refresher on the basics
- Recent CMS guidance and potential future topics
- Update on statewide transition plan approvals
- Advocacy strategies

3

A REFRESHER ON THE BASICS OF THE RULE

Context for the HCBS Settings Rule

- Concerns about segregation and isolation in "community" settings
- Changing best practices in services
- ADA and *Olmstead* enforcement challenging settings that segregated people with disabilities yet were funded by HCBS
- Extensive public input
  - Went through multiple rounds of proposed rulemaking, with thousands of public comments
  - Rule morphed from being solely based on size or geographic location to one about individual experiences and community integration in both residential and non-residential services

5

Goal and Scope of HCBS Rule

- To "ensure that individuals receiving services through HCBS programs have full access to the benefits of community living"
- To "further expand the opportunities for meaningful community integration in support of the goals of the ADA and the Supreme Court decision in *Olmstead*"
- Applies to all HCBS authorities

6

Characteristics of Home and Community Based Settings

An outcome oriented definition that focuses on the nature and quality of individuals' experiences, including that the setting:

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

7

HCBS Setting Characteristics (cont'd)

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

Additional requirements for provider-owned residential settings

8

Additional Requirements for Provider-Owned Residential Settings

- A lease or other legally enforceable agreement
- Privacy in his or her unit and lockable doors
- Choice of roommate
- Freedom to furnish or decorate the unit
- Control of his or her schedule, including access to food at any time
- Right to visitors at any time
- Physical accessibility of the setting (not modifiable)

- Any modification of these conditions must be supported by a specific assessed need and justified in the person-centered plan; must first attempt alternative strategies and have periodic reviews

9

States Must Assess and Categorize All Settings

1) Meets <u>all</u> requirements of the rules (or can with modifications)
2) Can <u>never</u> meet requirements of the rules because it is an institution (nursing home, ICF, hospital or IMD)
3) Is <u>presumed institutional</u>
   - Setting is unallowable unless a state can prove through a "heightened scrutiny" process that the setting overcomes the institutional presumption and meets the rules' requirements

10

Presumptively Institutional Settings

- Settings in facilities providing inpatient institutional services
- Settings on the grounds of, or adjacent to, a public institution
- Settings that have the effect of isolating HCBS recipients from the broader community. Characteristics may include:
  - Designed specifically for PWD or with specific disabilities
  - Comprised primarily of PWD and staff providing services
  - PWD are provided multiple types of services onsite
  - PWD have limited interaction with the broader community
  - Use restrictive interventions

11

Settings that Isolate

- CMS has provided specific examples of residential settings that isolate, including:
  - Disability-specific farms
  - Gated disability communities
  - Residential schools
  - Congregate, disability-specific settings that are co-located and operationally related
- CMS has not provided specific examples of non-residential settings that isolate
  - But it has made clear the "settings that isolate" guidance applies to non-residential settings too

12

CMS Guidance: Residential Settings

- Individuals must be given an option of a non-disability specific setting (like own home/apartment) and of a private unit
- Rule does not set a size limit for residential settings but states can set size restrictions/limitations
  - Align with research supporting better quality and more integration in smaller settings
- Settings on grounds of/adjacent to institutions may be "presumptively institutional;" states can completely prohibit
- States shouldn't be building new "presumptively institutional" settings and instead should focus on more integrated models

13

CMS Guidance: Non-Residential Settings

- Individuals must be given an option of a non-disability specific setting (like employment in a mainstream job)
- Facility-based day settings and settings on the grounds of institutions must be closely examined and may be presumptively institutional
  - States can require all day services (including pre-vocational services) to be community-based
- Reverse integration is not alone a sufficient strategy to comply with the community integration requirements of the rule

14

Non-Residential Guidance (cont'd)

- Employment settings
  - Do they "provide individuals with the opportunity to participate in negotiating his/her work schedule, break/lunch times and leave and medical benefits with his/her employer to the same extent as individuals not receiving Medicaid funded HCBS?"
  - Is the individual is receiving the "right service" if competitive, integrated employment is the desired outcome?
- Some day settings will need to be closely examined as potential day "settings that isolate" – sheltered workshops, facility-based day habilitation, adult day health, and day treatment programs

15

CMS Guidance: Heightened Scrutiny

- CMS review the heightened scrutiny request to determine:
  - Every one of HCBS characteristics is met for every resident;
  - People in the setting are not isolated from the greater community
    - Proximity to resources, activities and transportation
    - Varied schedules based on interests; not all activities provider organized
    - Activities that foster relationships with community members
    - Choice of setting (including non-disability specific setting)
    - People without disabilities consider it part of their community
  - Strong evidence that the setting does not have institutional qualities
    - Different practices, provider qualifications, no interconnectedness

16

CMS Guidance: Tiered Standards

- States have flexibility to set different standards for existing and new settings through their statewide transition plan
  - Existing settings must meet the minimum standards set forth in the HCBS rules but the state "may suspend admission to the setting or suspend new provider approval/authorizations for those settings"
  - State may set standards for "models of service that more fully meet the state's standards" for HCBS and require all new service development to meeting the higher standards
  - The tiered standard can extend beyond the transition plan timeframe
  - This allows states to "close the front door" to settings/services

17

CMS Guidance: Planned Construction

- CMS will not give "pre-approval" through heightened scrutiny to planned construction for a setting presumed to be institutional (such as a gated community or farmstead)
  - A setting must be operational and occupied by beneficiaries for a state, and then CMS, to do a heightened scrutiny review
- CMS expects "that after publication of the final regulation, stakeholders would not invest in the construction of setting that are presumed to have institutional qualities, but would instead create options that promote full community integration"

18

CMS Guidance: Person Centered Planning & Modifications to HCBS Settings Criteria

- General person centered planning requirements (including conflict of interest rules) went into effect in March 2014
  - BUT states have 5 years to fully implement the provisions re modifications to the rules for provider-owned resid. settings thru PCP
- PCP modifications process balances safety and rights of people with complex needs served in integrated settings
  - Must be individualized, less intrusive means tried first, modifications proportional to the assessed need, regular data collection & periodic reviews, and informed consent
  - Cannot limit freedoms on a class or group of individuals or implement as "house rules"

19

CMS Guidance: Wandering

- Guidance addresses questions raised by aging community and providers about how to serve people with dementia and comply with the rule
  - Relevant to people with IDD (esp autism) with exit-seeking behaviors
- Focus on PCP, training, and best/promising practices
- For settings with controlled-egress:
  - Individual must be given a choice of settings
  - Must be individualized determinations of unsafe exit-seeking behaviors and accommodations for people in setting not at risk
  - Must include strategies for community integration (requires sufficient staffing and transportation)

20

Recent CMS Guidance and Potential Future Topics

21

Medicaid Flexibilities Letter from Secretary Price

- March 15, 2017 letter from Sec. Price and Administrator Verma to states regarding Medicaid flexibility:
  - "In recognition of the significance of the reform effort underway, CM will work toward providing additional time for states to comply" with the HCBS Settings Rule
  - "We will be examining ways in which we can improve our engagement with states on implementation of the HCBS settings rule, including greater state involvement in the process of assessing compliance of specific settings"
  - Likely in part in response to Republican Governor's Association request to suspend several regs, including the HCBS settings rule

22

Recent Updates from CMS: Extended Implementation Timeline

May 9, 2017 CMCS Informational Bulletin

- "Promoting Community integration remains a high priority for CMS" and "acknowledge the important work underway at the state level in implementing" the HCBS Settings Rule
- STPs for settings operating before March 17, 2014; meaning all new settings must comply with the rule (consistent with prior guidance)
- Final STP approval by original deadline of March 17, 2019
- Three extra years for implementation of STP to be "helpful to states to ensure compliance activities are collaborative, transparent & timely"
- CMS committed to ongoing TA to states & other stakeholders

23

Potential Areas Being Considered by CMS

- Level of validation required by CMS for state assessments, particularly for "heightened scrutiny" submissions
- Pressure to revisit sub-regulatory guidance on "settings that isolate," including intentional communities and sheltered workshops
- Pressure to reconsider some kind of "grandfathering" of settings or people (had been rejected in the preamble to the rule)
- Potential use of 1115s to exclude certain settings from compliance with the rule

24

Statewide Transition Plan Approval Process

25

State Plan Approval Steps

- States must submit a statewide transition plan (STP) to CMS describing how will bring system into compliance
  - Recent communication from HHS says date will be extended
- **Step 1: Initial STP approval**
  - Approval of the state's systemic assessment of all relevant rules, regulations, licensing, etc. for compliance with & support of the rule.
  - Systemic assessment must include any necessary remediation steps to modify any rules, regulations, licensing requirements, etc.
  - Description of the process for site assessment, validation and identifying presumptively institutional settings

26

State Plan Approval Steps (cont'd)

- **Step 2: Final STP approval**
  - Approval of the state's site-specific assessments, including the process used for assessments and validation and determinations made about compliance of specific sites
  - Approval of the process for identifying presumptively institutional settings and determining whether the presumption is overcome.
  - Approval of remediation steps, including relocation process
- **Step 3: Heightened scrutiny review process**
  - CMS determination of any presumptively institutional settings submitted by the state for HS review if overcome the presumption
  - Can occur at any point in the process

27

Transition Plan – Public Input

- A State must provide at least a 30-day public notice and comment period
- The State must consider and modify the plan to account for public comment
- Whenever a state substantively amends the plan, the new plan must be put out for public comment.
- States are encouraged to have a process for ongoing transparency and input from stakeholder on implementation of the plan
- THIS IS A CRITICAL OPPORTUNITY FOR ADVOCACY!

28

Status of State Plan Approvals: Initial Approvals

- 30 states have received initial approval for their systemic assessment,
  - Many included letters describing additional steps needed to be taken for final approval; the letters are not being published on the CMS website any longer but you can request them from your state
  - As of June 23, states with initial approval AL, AK, AR, CT, DE, HI, ID, IN, IA, KY, LA, MN, MO, MS, MT, NE, NM, ND, OH, OK, OR, PA, RI, SC, SD, TN, UT, VA, WA, WV, and WY.

29

Status of State Plan Approvals: Final Approvals

- Steps required for final approval:
  - Comprehensive site-specific assessment of <u>every</u> HCBS setting, including strategies for validating results
  - Site specific remediation strategies with a timeline for completion of modifications
  - Heightened scrutiny process for settings presumed to be institutional
  - A process for communicating with beneficiaries who may be impacted by provider changes, including closures
  - Ongoing monitoring and quality assurance processes
  - Plans to ensure adequate capacity in the state for non-disability specific settings

30

Status of State Plan Approvals: Final Approvals (cont'd)

- Three states have also received final approval – Tennessee, Arkansas, and Kentucky
- Best practices from the STPs:
  - Ongoing stakeholder input and engagement (TN)
  - External stakeholder committee with self-advocates, families, advocates, and providers to review and decide on HS packages (KY)
  - Internal interagency HS review before deciding whether to submit to CMS (TN, AR)
  - Using tiered standards to transform to community-based day services (TN)
  - Developed ongoing monitoring tools (KY)

31

Themes from CMS Approvals

- Public Comment
  - STPs must include a summary of comments; must give specific response to comments (not just "considering it")
  - Public comment required for completed assessment and HS evidence
- Setting descriptions
  - STPs must include a complete list of settings used in each individual waiver with the # of settings and # of participants in those settings
- Systemic settings assessments
  - STP must crosswalk state standards to each HCBS requirement and note if in compliance, in conflict, or silent; must include plan to remediate when in conflict or silent

32

Themes from CMS Approvals (cont'd)

- Individual setting assessments
  - All settings must be adequately assessed; provider self-assessments not enough and must validated; participant surveys must be able to be tied to specific settings; must have criteria for on-site visits
  - All congregate settings must be assessed
  - Reverse integration is not alone sufficient to comply with the community integration requirements
- Heightened scrutiny process
  - Using location alone not sufficient to identify all "presumptively institutional" settings; must have a process for identifying "settings that isolate;" "private residence" presumption in not allowed for congregate settings
  - That someone "chose" a setting does not make it HCBS

33

Themes from CMS Approvals (cont'd)

- Capacity building
  - Must have a plan for expanding capacity of non-disability specific settings (to ensure a real choice)
  - Must ensure that service definitions and provider reimbursement rates ensure capacity of, and incentivize, integrated settings
- Remediation
  - Must have specific timelines and cannot backload
  - Must have a clear process for transition out of non-compliant settings, including notice, informed choice of other settings, and a good transition process
- Ongoing monitoring
  - Must describe how licensure or other QM programs will include ongoing monitoring of compliance

34

Best Practices and Advocacy Strategies

35

Positive State Examples

- Some states are moving towards more individualized and integrated services through the HCBS transition process:
  - Moving from facility-based to all community-based day services
  - Transforming models for facility-based day habilitation
  - Phasing out sheltered workshops
  - Setting size limits on residential settings
  - Requiring housing subsidies to be used in scattered site apartments
  - Expanding the capacity of competitive, integrated employment
  - Funding help bring providers into compliance through model changes
  - Aligning with *Olmstead* activities

36

Strategies Being Used by DD Councils

- Ongoing education of stakeholders, especially self-advocates and families, about the importance of the Rules (including through direct work and funding of projects)
- Participating in or helping lead stakeholder implementation councils or groups
- Helping stakeholders – especially self-advocates and families – engage in the public comment process (e.g., model comments)
- Working with state leadership on the vision and strategies

37

Discussion

- How is your DD Council engaging around the Rule? What strategies have been most successful?
- What are you most concerned about with the Rule? What are you most optimistic about?
- What kind of information and support from NACDD would be helpful to your advocacy?

38

HCBS Settings Rule Resources

- CMS HCBS Settings Rule Website
  - www.Medicaid.gov/hcbs
- HCBS Advocacy Website
  - Sponsored by national disability groups including NACDD
  - www.hcbsadvocacy.org

39

QUESTIONS?

40