HCBS Settings Rule: What It Means for Consumers

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Why Is the Rule Important?
Consumer Perspective

• Once consumers transitioned they were completely isolated, or their only companionship was their workers or pets.
  o One consumer said his feelings of isolation caused him to begin hallucinating and he ended up in the hospital for a short period of time.

• They needed to be able to get out on their own, “otherwise they might as well stay in the nursing home.”
  BUT
  o Getting out into the community was difficult - transportation was problematic
Basic Standards

• Integration with Community
• Choice
  o Services and supports, and who provides them
  o Optimizes individual initiative and autonomy, without regimentation
• Rights - privacy, dignity, and respect
“Provider-Controlled Settings”

• Protection from eviction
  o Dwelling is specific physical space

• At least the protection provided by state landlord-tenant law
Privacy Rights

- Lockable entrance doors
- Choice of roommates in shared units
- Furnishing and decorating living unit
More Facility Standards

• Control of schedule and activities
  o Including access to food at any time

• Right to receive visitors

• Physical accessibility
Some Facility Protections
Subject to Modification

• Modification under service plan possible for
  o Privacy (e.g., lockable doors, choice of roommate, right to decorate)
  o Control of schedule & activities
  o Access to food at any time
  o Visitors at any time
Process for Modifications

- Modification process must include
  - Consideration of alternatives
  - Periodic review
  - Participant’s informed consent
Presumed Institutional Settings

- State can submit evidence to overcome presumption, but CMS will evaluate with heightened scrutiny
  - Sharing grounds with public institution
  - Sharing building with nursing facility or other institution
  - Has effect of isolating Medicaid HCBS consumers from broader community
Tending to Isolate Medicaid HCBS Consumers

• Setting is designed specifically for people with disabilities, or with a certain disability

• Persons in setting are primarily, or exclusively, persons with disabilities and the service providers
HCBS Settings Rule: Supporting and Enhancing Consumers’ Lives

Our Recommendations
Integration with the Community

• Individual should not be limited to day center/facility
• Reverse integration is not sufficient
• Provider should facilitate individual’s ability to access the community
  o Facilitation includes all necessary supports
Privacy, Dignity, Respect

- Private information should be private
- Services must be delivered in a culturally competent way
- Recognition of individual needs and preferences
  - What’s important to the person
Freedom from Coercion and Restraint

- Physical and chemical restraints should be prohibited!
Choice: Activities

- Group (large and small) and individual activities
- Activities both at and outside the day center/facility
- Activities consistent with individual’s interests and preferences
- Meaningful choice of activities
- Necessary supports
Choice: Services, Supports, Service Providers

- Choice exercised through service planning process
- Service plan should be led by consumer
- Important to educate and equip consumer
- Plan should be updated, modified
Choice: Options

• Must be range of options
  o Include non-disability specific settings
• Sufficient number of providers in each region of the state
• Mix of service options for individuals
Staffing

- Increased staffing levels
  - Adequate provider rates

- Staff training
  - Person-centered care; dementia
HCBS Settings Rule and Dementia

Our Recommendations
Guiding Principle

• It is dispiriting to be limited to the same enclosed space, day after day, week after week
  o This is true for persons with dementia, as well as other persons
Integration and Dementia

• Access to community should be real, not just theoretical
  o Not enough to inform program participants about activities and public transportation
  o Service provider must provide necessary assistance
    ▪ By definition, participants need help with ADLs
Visits to the Setting Are Insufficient

- Visits by others are good, but cannot substitute for access to community
But Going into Community Is Not Mandatory for Participants

- Regulations speak about a participant’s “opportunity” to engage in community activities
  - Personal preference will determine what type of community access a participant might want
Choice

• Persons with dementia can make choices
  o Choices made in service plans
  o Routine day-to-day choices
Freedom from Coercion and Restraint

• No physical restraints
• Ability to move within a residential center or day center
Freedom to Leave the Facility?

- First option always should be good dementia care
  - Adequate staffing levels
  - Individualized care
Limitations OK Under Some Circumstances

• Authority is tightly defined, and not justified solely by dementia diagnosis
• Authority determined through service planning process, and
• Limitations implemented in non-institutional manner
Discussion

• Any thoughts?
• What do you see happening in your state?
Let Us Know If We Can Help

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