

# 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.
  - 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
  - Getting out into the community was difficult - transportation was problematic

# Basic Standards

- Integration with Community
- Choice
  - Services and supports, and who provides them
  - Optimizes individual initiative and autonomy, without regimentation
- Rights - privacy, dignity, and respect

# “Provider-Controlled Settings”

- Protection from eviction
  - 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
  - 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
  - Privacy (e.g., lockable doors, choice of roommate, right to decorate)
  - Control of schedule & activities
  - Access to food at any time
  - 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
  - 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
  - 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
  - This is true for persons with dementia, as well as other persons

# Integration and Dementia

- Access to community should be real, not just theoretical
  - Not enough to inform program participants about activities and public transportation
  - 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
  - Choices made in service plans
  - 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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