Medicaid’s New Rule to Promote Independence and Choice for Persons Receiving Home and Community-Based Services: What Older Persons and their Advocates Need to Know

Why was a new rule needed?

Many older adults want to age in place – to receive necessary services without moving into a nursing facility or other health care institution. The Medicaid program provides this type of assistance through home and community-based services (HCBS) programs. These programs are designed to help people remain in their communities.

HCBS programs are meant to create alternatives to nursing facility care, but recently there have been concerns that HCBS recipients are living and receiving services in overly institutional settings. Assisted living services can be funded through HCBS programs, but while some assisted living is fully integrated into the community, other assisted living facilities are virtually as restrictive as nursing facilities. Day services/programs also can be funded through HCBS programs, but while some day programs are community-focused, many day programs have restricted participants to the program center, with little opportunity to experience the community outside those walls.

To address this problem, the federal government in March 2014 issued a new rule to increase integration and better align with best practices for Medicaid HCBS programs. As described in more detail below, the rule sets standards that are meant to reduce isolation while encouraging choice and independence.

Although the rule was issued in March 2014, states have until March 2019 to bring their Medicaid HCBS programs into compliance.

Which settings are affected by the new rule?

The new rule applies to all settings in which a HCBS recipient lives or receives the HCBS services. For older persons, the most common settings affected by the rule are:

- Assisted living facilities approved to accept Medicaid coverage of assisted living services. Most states now offer some level of Medicaid coverage for assisted living services.
- Adult day centers approved to accept Medicaid coverage for day services.

Private homes are generally considered automatically to be a non-institutional setting. An institution-like setting cannot be converted into a “private home” by having each person “own” his or her particular living unit.
What standards does the rule set for HCBS settings?

The rule sets out broad requirements. All HCBS settings must:

- Be integrated with the community, so that persons have full access to the community and are not segregated only with other persons who require HCBS.
- Provide each person with choice among settings.
- Provide each person with choice of services and supports, including who provides them.
- Honor each person’s right to privacy, dignity, respect, and freedom from coercion and restraint.
- Maximize each person’s independence and autonomy.

Additional requirements apply to assisted living facilities and other settings where the individual’s residence is owned and/or controlled by the HCBS service provider. These requirements include:

- A lease or similar agreement that identifies the particular room(s) where the person lives.
- Protections from eviction in that lease or agreement that are at least as strong as the state’s eviction protections for tenants.
- Lockable entrance doors for the person’s living unit.
- Freedom for the person to control his/her daily schedule and activities.
- Freedom for the person to furnish and decorate his/her living unit.
- Access to food at all times.
- Right to accept visitors at any time, i.e., no visiting hours.
- Choice of roommate, if a person lives in a double-occupancy unit.
- Physical accessibility of the setting to persons with disabilities.

These requirements can be modified (except for the physical accessibility requirement) in limited circumstances. The need for the modification must be set forth and supported in the person’s assessment and service plan.

For Long-Term Care Ombudsmen: The new federal rule promotes goals/values that are fundamental to ombudsman work, such as person-centered care, individual empowerment, dignity, respect, rights, choice, and independence. Also, implementation of the new rule is an opportunity for ombudsman programs to strengthen and enhance a state’s assisted living regulations. Each state must review its regulations to make sure they comply with the HCBS rule. Any time a regulation is opened up for revision, it’s a chance to make improvements!

Will the new rule require some current HCBS providers to change their practices to continue serving as Medicaid-certified providers?

Yes, some HCBS providers will need to make changes. They will have an opportunity to improve their practices and come into compliance. A provider cannot receive Medicaid reimbursement as a HCBS setting if the setting does not meet the standards of the new rule.
Some settings will be presumed to be institutional, and therefore not qualify. A setting is presumed institutional if:

1. The setting shares a building with an institutional setting such as a nursing facility;
2. The setting shares property with a “public institution” such as a state hospital.
3. The setting isolates people from the broader community of persons who are not receiving HCBS.

This presumption can be overcome if the state Medicaid program convinces the federal government that the provider actually operates in a way that is not institutional and does not isolate the persons receiving services.

How will states ensure that individuals can live in settings that are integrated?

- Individuals will be provided information to make choices about the range of services and supports that they can access. States will be expanding capacity in their systems to create new programming that does not isolate individuals.
- Most facilities and centers will modify their procedures to come into compliance with the new rules. If they do not, individuals will receive assistance so they can make a meaningful choice of a new service provider and transition safely. States must develop procedures to help the persons receiving services when a facility or center does not come into compliance.
- Advocates can help shape the process to develop new capacity and procedures for transitioning individuals to different settings if needed.

States are making important decisions now

States will have different strategies to comply with the new federal rule. Most states will need to amend their state regulations. Changing regulations could have two advantages:

1. The regulation could apply the HCBS requirements to all facilities and centers, whether or not they currently accept Medicaid reimbursement, and
2. The requirements could be enforced through the state’s existing mechanism for inspecting facilities and centers and responding to complaints.

The state must establish workable mechanisms to conduct inspections, accept complaints, and ensure facilities and centers comply with the requirements. For the new HCBS rules to be meaningful, the state must be able to enforce those rules in the years to come. States must come into compliance by March 2019, but initial compliance is not enough — compliance must be ongoing.

Why do I need to pay attention to this rule?

You can shape how the rule will be implemented and enforced in your state. Each state is in the process of developing a transition plan to guide the transition to new state policies. This transition plan will set the standards that must be followed by the state’s HCBS service providers (such as assisted living facilities and adult day services programs). Each state must make many decisions regarding its HCBS programs, such as how assisted living and day programs are structured. These decisions will be subject to review and approval by the federal government. Older persons and their advocates can make a significant impact on what ultimately will be decided.
What are the most important steps I can take as an advocate right now?

- Educate yourself about the rule. See below for resources.
- Get involved. Create recommendations to protect the rights of older adults, such as assisted living residents and day center participants. Justice in Aging and Consumer Voice have sample recommendations you can use.
- Submit comments in response to a request for public input. You can also provide input at any time.
- Send your comments to the state and the federal Medicaid agencies. You can find your state Medicaid office by going to https://www.medicaid.gov/about-us/contact-us/contact-us.html and entering your state where it says, “Contact your State Medicaid Agency.” To contact the federal government, you can email the Center for Medicaid and Medicare Services at hcbs@cms.hhs.gov.
- Join with other advocates in the aging community and work together.

Where can I find more information?

Both Justice in Aging and the National Consumer Voice for Quality Long-Term Care have more information for advocates who want to be involved as states make policy changes. We are creating a series of Advocacy Guides on different parts of the rule. Justice in Aging has published a guide to the rule and a guide to transition plans. Also, you can learn more from HCBSAdvocacy.org, a website designed specifically for advocates for persons with disabilities and older adults. This site has a toolkit for advocates who want to work on the rule. The federal government has posted information on the rule—including state-specific information on states’ current processes—on the HCBS page of Medicaid.gov.