What is HCBS and Why is it important?
HCBS - Background

• Federal Medicaid Regulation that establishes requirements for settings in which individuals receive Medicaid home and community-based services.

• Section 1915(c) of the Social Security Act: to authorize HCBS as an alternative to services in a hospital, nursing facility or intermediary care facility for individuals with intellectual and developmental disabilities.

• State’s HCBS waivers are partially funded by Federal Medicaid, which is administered by the Centers for Medicare & Medicaid Services (“CMS”)

HCBS - Prior to 2014

• States are allowed to provide HCBS funding in a setting that is not a hospital, nursing facility, or ICF.

• This interpretation allowed a broad range of settings from which individuals with disabilities could choose.

• Medicaid programs were NOT permitted to dictate the settings in which an individual lived or received services; individual choice in setting was required.
2014: HCBS Settings Rule

- The HCBS Settings Rule:
  - Set requirements for Home and Community-Based Settings
  - Defined Settings that are NOT Home and Community-Based.
  - Defined Settings Presumed NOT to be Home and Community-Based.
  - Set additional requirements for provider-owned or controlled HCBS residential settings.
Long-term services and supports (LTSS) spending, by payer, 2017.

Total National LTSS Spending = $364.9 billion

Private Insurance, 11%
Out-of-Pocket, 16%
Other Public and Private, 20%
Medicaid, 52%

NOTE: Total LTSS expenditures include spending on residential care facilities, nursing homes, home health services, and home and community-based services. Expenditures also include spending on ambulance services and some postacute care. This chart does not include Medicare spending on postacute care ($81.5 billion in 2017). All home and community-based services are attributed to Medicaid.


Source: Kaiser Family Foundation
Figure 6
Medicaid § 1915 (c) HCBS waiver enrollment and spending by target population, FY 2017.

- Enrollees
  - Total = 1.7 million

- Expenditures
  - Total = $48.6 billion

NOTES: Percentages may not sum to 100% due to rounding. Other populations include children who are medically fragile or technology dependent, people with HIV/AIDS, people with mental health disabilities, and people with traumatic brain or spinal cord injuries.

SOURCE: Kaiser Family Foundation Medicaid FY 2017 HCBS program surveys.

Source: Kaiser Family Foundation
2014: HCBS Settings Rule

The setting:

- Is integrated in, and supports full access of individuals receiving Medicaid HCBS to the greater community to the same degree of access as individuals not receiving Medicaid HCBS.
- Is selected by the individual from among setting options including non-disability-specific settings and an option for a private unit in a residential setting.
- Ensures an individual's rights of privacy, dignity and respect, as well as freedom from coercion and restraint.
- Optimizes, but does not regiment, individual initiative, autonomy, and independence in making life choices, including but not limited to: daily activities, physical environment, and with whom to interact.
- Facilitates individual choice regarding services and supports, and who provides them.
In provider-owned or controlled residential settings:

- The unit or dwelling is a specific physical place that can be owned, rented, or occupied under a legally enforceable agreement by the individual receiving services.

- Each individual has privacy in their sleeping or living unit; including doors lockable by the individual, choice of a roommate if sharing a unit, and the freedom to furnish and decorate their sleeping or living units within the lease or other agreement.

- Individuals have the freedom and support to control their own schedules and activities, and have access to food at any time.

- Individuals are able to have visitors of their choosing at any time.

- The setting is physically accessible to the individual.

- Any modification needs to be supported by a specific assessed need and justified in the person-centered service plan.
It’s not just about Physical Characteristics

• “Outcome oriented”

• “Nature and Quality of individuals’ experiences”

• Maximizing opportunities for integration
Settings that are NOT HCBS

- Hospital
- Nursing Facility
- Intermediary Care Facility for I/DD
- Institution for Mental Disease (IMD)
Settings PRESUMED to be NOT HCBS

- Settings in a publicly or privately-owned facility providing inpatient treatment
- Settings on grounds of, or adjacent to, a public institution
- Settings with the effect of isolating individuals from the broader community of individuals not receiving Medicaid HCBS
What Settings have the effect of isolating individuals from the broader community?

CMS’s Guidance on “Settings that have the effect of isolating individuals receiving HCBS from the Broader Community” (Click to read)

• The setting is designed and built specifically and exclusively for people with disabilities.

• Multiple settings located together and operated by the same provider. The setting provides multiple types of services and activities on-site including “housing, day services, medical, behavioral and therapeutic services, and/or social recreational activities”

• Farmstead or disability-specific farm community, Gated or secured community and other disability-specific communities.
If a setting is presumed to be NOT HCBS but does have the qualities of a HCBS

• The state can submit evidence (including public input) demonstrating that the setting DOES have the qualities of a home and community-based setting and NOT the qualities of an institution (Heightened Scrutiny).

• CMS has to review the evidence and agree.
HCBS Settings Rule: Unintended Consequences

• **Misinterpretation** of the Settings Rule and the 2015 guidance (Read *Myths vs. Facts* by Jill Escher, President of Autism Society of SF Bay Area).

• **UNFAIR, UNWARRANTED and UNFOUNDED** characterization of farmstead communities, “intentional communities” and other disability-specific communities as being isolating and segregating (Read Covington & Burling’s Legal Memo on CMS’s *Settings Rule*).

• The Heightened Scrutiny process placed a heavy administrative burden on the states, motivating many to prohibit funding for disability-specific settings.

• Discouraged and threatened new housing developments for people with I/DD.
2017: Formation of Together for Choice
TFC in Washington
March 2019
19
TFC’s Criticisms of the Settings Rule

Highlights from TFC’s Chairman Scott Mendel’s Letter to CMS on 11/3 2017 (Click to Read)

• Individuals with I/DD should have the same right as non-disabled individuals to choose the communities they wish to access.

• Communities are often not geographically based. Rather, they are based on common interests.

• The rule’s heightened scrutiny provision for campus settings, farmsteads and other intentional communities is a discrimination.

• The rule is highly prescriptive and impose a significant burden on individuals, their families, their providers and the states.
Our Ask

• Members of Congress to write a letter urging CMS to amend its regulations to return choice to individuals and their families

• Support legislation that would restore the individual’s right to choose the setting which best meets his or her needs.

• The proposed regulatory amendments and the proposed legislation would not change the prohibition on individuals receiving home- and community-based services in an institution.

• The proposed regulatory amendments and the proposed legislation would not limit CMS’s ability or a State’s ability to regulate and monitor the quality of services provided or to crack down on neglect or abuse of individuals with disabilities.
TFC’s Proposed Changes

Highlights from TFC Chairman Scott Mendel’s Letter to CMS on 11/3 2017 (Click to Read)

(xiii) Document that any modification of the additional conditions, under paragraph (c)(4)(vi)(A) through (D) of this section, must be supported by a specific assessed need and justified in the person-centered service plan.

(3) Review of the Person-Centered Service Plan. The person-centered service plan must be reviewed, and revised upon reassessment of functional need as required by § 441.365(e), at least every 12 months, when the individual’s circumstances or needs change significantly, or at the request of the individual.

(4) Home and Community-Based Settings. Home and community-based settings must have all of the following qualities, and such other qualities as the Secretary determines to be appropriate, based on the needs of the individual as indicated in their person-centered service plan:

(i) The setting supports full access of individuals receiving Medicaid HCBS to the communities

chosen by the individual, including opportunities to seek employment and work in competitive integrated settings, engage in community life, control personal resources, and receive services in the community, to the same degree of access as individuals not receiving Medicaid HCBS, if that is the choice of the individual.

(ii) The setting is selected by the individual from among setting options including non-disability
TFC’s Proposed Changes

Highlights from TFC Chairman Scott Mendel’s Letter to CMS on 11/3 2017 (Click to Read)

(B) Each individual has privacy in their sleeping or living unit.

(C) Individuals have the freedom and support to control their own schedules and activities.

(E) The setting is physically accessible to the individual.

(F) Any modification of the additional conditions, under § 441.301(c)(4)(vi)(A) through (D), must be supported by a specific assessed need and justified in the person-centered service plan.

(5) Settings that are not Home and Community-Based. Home and community-based settings do not include the following:

(i) A nursing facility,

(ii) An institution for mental diseases;

(iii) An intermediate care facility for individuals with intellectual disabilities;

(iv) A hospital

(6) Home and Community-Based Settings: Compliance and Transition:

Deleted: Individuals are able to have visitors of their choosing at any time.
TFC’s Proposed Changes

Highlights from TFC Chairman Scott Mendel’s Letter to CMS on 11/3 2017 (Click to Read)

Proposed Changes to the HCBS Settings Rule

42 C.F.R. § 441.301(c)

(c) A waiver request under this subpart must include the following—

(1) Person-Centered Planning Process . . .

(2) The Person-Centered Service Plan. The person-centered service plan must reflect the services and supports that are important for the individual to meet the needs identified through an assessment of functional need, as well as what is important to the individual with regard to preferences for the delivery of such services and supports. Commensurate with the level of need of the individual, and the scope of services and supports available under the State's 1915(c) HCBS waiver, the written plan must:

(i) Reflect that the setting in which the individual resides is chosen by the individual. The State must ensure that the setting chosen by the individual supports full access of individuals receiving Medicaid HCBS to the communities chosen by the individual, including opportunities to seek employment and work in competitive integrated settings, engage in community life, control personal resources, and receive services in the community to the same degree of access as individuals not receiving Medicaid HCBS, if that is the choice of the individual.

(ii) Reflect the individual's strengths and preferences.
HCBS Updates

• On May 9, 2017, CMS extended the HCBS implementation period by 3 years. The extended deadline is March 17, 2022.

• On March 22, 2019, CMS issued a new guidance that superseded and replaced prior guidance on the criteria of an isolating setting (“Settings that Isolate”). Click HERE to read the new guidance. Thank YOU, advocates, for showing up and speaking up!

• Together for Choice issued a press release (Click HERE) in response to the new guidance, applauding the new guidance, but urging CMS to take further actions to maximize individual’s choice.

• Together for Choice met with CMS on March 26, 2019 to discuss the new guidance and to advocate for choice in all settings.
The New Guidance

Frequently Asked Questions: HCBS Settings Regulation Implementation

Heightened Scrutiny Reviews of Presumptively Institutional Settings

(Click HERE)
Q2. “What are the characteristics of a setting that isolates HCBS beneficiaries from the broader community?”

- CMS intends to take the following factors into account in determining whether a setting may have the effect of isolating individuals receiving Medicaid HCBS from the broader community of individuals not receiving HCBS:
  - Due to the design or model of service provision in the setting, individuals have limited, if any, opportunities* for interaction in and with the broader community, including with individuals not receiving Medicaid-funded HCBS;
  - The setting restricts beneficiary choice to receive services or to engage in activities outside of the setting; or
  - The setting is physically located separate and apart from the broader community and does not facilitate beneficiary opportunity to access the broader community and participate in community services, consistent with a beneficiary’s person-centered service plan.
“Due to the design or model of service provision in the setting, individuals have limited, if any, opportunities* for interaction in and with the broader community, including with individuals not receiving Medicaid-funded HCBS”

• Intended to address provider policies, procedures and practices

• Examples: How do you organize community engagement activities, individual schedules, transportation, etc.?
“The setting is physically located separate and apart from the broader community and does not facilitate beneficiary opportunity to access the broader community and participate in community services, consistent with a beneficiary’s person-centered service plan.”

**CMS’s Explanation**

- Isolation can be twofold: both Physical and Programmatic.

- For campus settings that are significantly isolated from a broader community AND if people never have to leave, this will raise a flag for further exploration.

- At the same time, there is NO prohibition of on-site services, but people should have real choices and know them.
Q3. “Does CMS expect states to submit information specific to settings located in rural areas for a heightened scrutiny review?”

- With respect to determining whether a rural setting may be isolating to HCBS beneficiaries, states should compare the access that individuals living in the same geographical area (but who are not receiving Medicaid HCBS) have to engage in the community.

**CMS’s Explanation**

- CMS believes this access comparison should be applicable to all settings, not just rural.
- Person-Centered Planning is the biggest part of the evaluation.
Q5. “What are some promising practices to remediate settings that have been identified as being isolating to ensure compliance with the home and community-based settings criteria?”

“Promote skills development and facilitate training and educational opportunities among HCBS beneficiaries designed to attain and expand opportunities for community-based integration (including volunteering, social and recreational activities, and competitive, integrated employment”

**CMS’s Explanation**

**TFC**: How about individuals with severe behavior or complex medical challenges that require high-level of support?

**CMS**: This should be established by the person-centered plan. However, some with severe behavior or complex medical challenges shouldn’t be totally excluded from the greater community – the greater community should have to deal with them, too. There should be further conversation about severe behaviors.
Q5. “What are some promising practices to remediate settings that have been identified as being isolating to ensure compliance with the home and community-based settings criteria?”

4th primary bullet, 2nd secondary bullet answer:

“Decentralize staff structures to promote greater flexibility and encourage staffing focused on individuals’ access to and participation in the broader community rather than centralized insular staff models focused around a specific facility/site.”
CMS's Explanation

**TFC:** Is there a bias against “centralized insular staff models focused around a specific facility/site”?

**CMS:**

- This response should be regarded as a best practice suggestion, not a requirement.
- Intended to address static staffing models that do not address individual’s needs and requests.
- Does not prohibit fixed staffing.
- Focus on being flexible and person-centered.
- People living different lives (One size does not fit all).
Q9. “How will CMS review state requests for heightened scrutiny of settings that the state believes overcome the presumption of having the qualities of institutional settings?”

- CMS will use the list provided by a state to compile a random sample of settings to review. The review sample will also include any setting the state requests CMS to review and any setting that generated significant public comment in opposition of the state’s assessment.

- Based on the process described in the state’s STP on how CMS feedback on a particular setting will be applied to similarly situated settings, the state will use the CMS feedback to remediate settings that have the qualities of an institution not included in the CMS review sample.

- CMS may also request information on any setting for which the state received public comments that the setting was presumptively institutional but was not included on the state’s heightened scrutiny list because the state determined it to meet the HCBS settings criteria.
Notes from TFC’s Meetings with CMS on March 26, 2019

CMS’s Explanation

• CMS will pull the samples from the state’s list of settings that are under Heightened Scrutiny and “any setting that generated significant public comment in opposition of the state’s assessment (Size will depend on the state).

• CMS believes that under the new guidance, some settings may no longer be on the Heightened Scrutiny list.

• CMS will make assessments by reviewing the sample settings and the remediation that ensued.

• The States will then apply CMS’s assessment to the rest of the settings on the H.S. list.

• Emphasis on settings that been most troubling to the particular state.
Regarding TFC’s Concerns about Public Comments:

- CMS reserve the right to review any setting.

- Those making public comments and calling out a provider need to make a legitimate case that the provider is not in compliance.

- The stakeholder needs to be well informed and their comment has to be well founded for CMS to take the comment seriously.

- CMS would take notice of who was making the comments and the specificity of those comments.
Additional Info on the New Guidance

Assumptions on Private Residences

• Private residences are presumed to be in compliance.

• Examples: Non-licensed homes where individuals own or rent including market-rate or affordable apartment units, single family homes or accessory dwelling units.
What Now?

• State Advocacy (i.e. State Transition Plan, Public comment on Heightened Scrutiny, etc.)

• Hold DDS and Regional Centers accountable and make sure they follow the rules, not their own ideology.

• Establish Quality Measures

• Legislative path

• Our focus should go beyond HCBS Settings. We need to advocate for continuum of care and coordinated care models.

• We are stronger together. Help spread the word! Invite your friends and fellow advocates to join Together for Choice!
Questions?

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