The State of the Nation:
Accessing and Tackling the Data to Help Support Choice

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Part 1: HCBS Final Rule

- History of Policy Changes That Support Expanding Choices
- Where to find resources about Final Rule

At the end of presentation if time allows:
- What’s in the Final Rule
- Guidance from CMS
- Implementation Timeline
- Next Steps
1980: Home and Community Based Service waivers introduced.
   • Gives another choice to accessing support services
1990/2008: Americans with Disabilities Act
“The purposes of this Act are-
(1) to carry out the ADA's objectives of providing "a clear and comprehensive national mandate for the elimination of discrimination" and "clear, strong, consistent, enforceable standards addressing discrimination" by reinstating a broad scope of protection to be available under the ADA...”
1999: The Supreme Court *Olmstead Decision*

“recognition and unjustified institutional isolation of person with disabilities is a form of discrimination...” -119 S.Ct. 2176, 2179, 2187

“We emphasize that nothing in the ADA or its implementing regulations condones termination of institutional settings for persons unable to handle or benefit from community settings...Nor is there any federal requirement that community-based treatment be imposed on patients who do not desire it.” -119 S. Ct. 2176, 2187
History of Policy Changes Supporting Choice

How will the Supreme Court *Olmstead Decision* continue to influence housing and support choices in the future?

- The continuation of endless waiting lists, particularly for individuals who are at risk of forced institutionalization for lack of housing / waiver supports may violate Olmstead.
- State prohibition to access of waiver funding in a person’s chosen residence and/or least restrictive setting that would otherwise put them at risk of institutionalization may violate Olmstead.
- Lack of affordable, accessible housing resulting in the risk of or forced institutionalization may violate Olmstead.
2000: **Developmental Disabilities Assistance and Bill of Rights Act:**
- “assure that individuals with developmental disabilities and their families participate in the design of and have access to needed community services, individualized supports, and other forms of assistance that promote self-determination, independence, productivity, and integration and inclusion in all facets of community life ...” - 42 U.S.C. 15001 (b) (2006)

2014: **CMS HCBS Final Rule** based on outcome-oriented criteria with an emphasis on person-centered planning and community access.
- “In this Final Rule, CMS is moving away from defining home and community settings by “what they are not” and toward defining them by the nature and quality of individuals experiences. The home and community-based setting provisions in this final rule establish a more outcome-oriented definition of home and community-based settings, rather than one based solely on a setting’s location, geography, or physical characteristics.” —CMS Final Rule Q&A
Medicaid website gives links to Final Rule, CMS guidance documents, State Transition Plans, and any official correspondence between states and CMS regarding the State Transition Plans:

Where to Find Resources on HCBS Final Rule

Home & Community Based Services

Home and community-based services (HCBS) provide opportunities for Medicaid beneficiaries to receive services in their own home or community. These programs serve a variety of targeted populations groups, such as people with mental illnesses, intellectual or developmental disabilities, and/or physical disabilities.

- Final Regulation: 1915(i): State Plan HCBS, 5-Year Period for Waivers, Provider Payment Requirement, Setting Requirements for Community First Choice, and 1915(c) HCBS Waivers - CMS-2249-F/FCMS-2296-F
- Informational Bulletin - Final regulations for HCBS provided under
Where to Find Resources on HCBS Final Rule

**Medicaid website**:

Complete Final Rule. First ~70 pages is CMS responses to public comment of NPRM’s.

CMS webinar that gives overview of Final Rule.

Q&A about the Final Rule in general.

- **Settings Requirements Compliance Toolkit**
- **Additional Resources**

**CMS email for questions and concerns**

- Self Direction
- Integrating Care
- Money Follows the Person
- Real Choice System Change
- Health Homes
- PACE
- Community Living
- Workforce

Information provided by the Disabled and Elderly Health Programs Group. To request clarifications please contact hcbs@cms.hhs.gov
Where to Find Resources on HCBS Final Rule

Examples of comments section in Final Rule offers guidance and evidence that CMS supports choice:

Pg 2961:

and individuals are fully informed of their rights.

Comment: One commenter wanted to know if it is the responsibility of the provider to assist the individual in finding other housing, services, and supports.

Response: The state is responsible for addressing this assistance through the person-centered planning process.

Comment: One commenter recommends the regulation require that

person-centered plan, personal outcomes and satisfaction.
Response: We very much appreciate hearing personal stories as they help us better understand how our proposed actions will affect individuals receiving services under the HCBS waiver program. We believe that individual choice is important and have worked to promote choice in the final rule. In addition, it is important to note that HCBS waiver funding is only one way in which federal Medicaid finances long term services and supports; a setting that may not meet the HCB definition may still qualify for Medicaid financing, but not as a home and community based service.

We agree that the definition we included in the proposed rule for HCBS settings may have had the result of restricting the settings in which HCBS waiver services can be provided in a way that we did not intend and in narrowing choices for participants. The final rule is more flexible and less prescriptive in that it does not preclude certain settings per se but rather establishes affirmative, outcome-based criteria for defining whether a setting is or is not home and community-based. The language in the final rule specifies that any setting that is located in a

Comment: A number of commenters

that we will continue to be discerning about what types of settings qualify for waiver funds. We are including language in the final rule that focuses on the critical role of person-centered planning and addresses fundamental protections regarding freedom, dignity, control, daily routines, privacy and community integration.

Comment: A number of individual commenters shared personal stories expressing satisfaction with their current living arrangements and displeasure that new regulations might force them to move or dictate where they should live. One person wrote, “Please allow Medicaid waivers to continue to pay for services in planned communities similar to retirement communities. I want to live in a community with my friends.” Another noted, “I believe this proposed rule would . . . deny access to residential care and assisted living for those who need it most.” Many commenters talked about the importance of retaining freedom of choice. One commenter stated, “. . . what I am advocating is CHOICE. We should be expanding options rather than narrowing possibilities and options, and we should ask those with disabilities and their families what they want, not what others think they want.” Finally, quite a few commenters echoed a warning to stay away from a “one size fits all”
Where to Find Resources on HCBS Final Rule

**Medicaid website:** Summary of fully compliant setting regulations

CMS guidance, NOT part of the Final Rule!

Q&A for HCBS settings and public comment requirements

Helps clarify the higher scrutiny process

CMS questions to consider in determining if settings have HCB characteristics
Where to Find Resources on HCBS Final Rule

‘Summary of regulatory requirements on fully compliant HCBS settings’:

**Regulatory Requirements for Home and Community-Based Settings:**

For 1915(c) home and community-based waivers and, for 1915(i) State plan home and community-based services, home and community-based settings must have all of the following qualities defined at §441.301(c)(4) and §441.710 respectively, 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:

- The setting is integrated in and supports full access of individuals receiving Medicaid HCBS to the greater community, 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.
- The setting 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. The setting options are identified and documented in the person-centered service plan and are based on the individual's needs, preferences, and, for residential settings, resources available for room and board.
- Ensures an individual's rights of privacy, dignity and respect, and 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 a provider-owned or controlled residential setting, in addition to the qualities specified above, the following additional conditions must be met:

1. 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, and the individual has, at a minimum, the same responsibilities and protections from eviction that tenants have under the landlord-tenant law of the State or locality where the individual resides.

6. Any modification of the additional conditions specified in items 1 through 4 above, must be supported by a specific assessed need and justified in the person-centered service plan. The following requirements must be documented in the person-centered service plan:

- Identify a specific and individualized assessed need.
- Document the positive interventions and supports used prior to any modifications to the person-centered service plan.
- Document less intrusive methods of meeting the need that have been tried but did not work.
- Include a clear description of the condition that is directly proportionate to the specific assessed need.
- Include regular collection and review of data to measure the ongoing effectiveness of the modification.
- Include established time limits for periodic reviews to determine if the modification is still necessary or can be terminated.
- Include the informed consent of the individual.
- Include an assurance that interventions and supports will cause no harm to the individual.
Where to Find Resources on HCBS Final Rule

Settings That are Not Home and Community-Based:

For 1915(c) home and community-based waivers, settings that are not home and community-based are defined at §441.301(c)(5) as follows:

- A nursing facility;
- An institution for mental diseases;
- An intermediate care facility for individuals with intellectual disabilities;
- A hospital; or
- Any other locations that have qualities of an institutional setting, as determined by the Secretary.

For 1915(i) State plan home and community-based services, settings that are not home and community-based are defined at §441.710(a)(2) as follows:

- A nursing facility;
- An institution for mental diseases;
- An intermediate care facility for individuals with intellectual disabilities;
- A hospital; or
- Any other locations that have qualities of an institutional setting, as determined by the Secretary.
Settings that are Presumed to have the Qualities of an Institution:

For 1915(c) home and community-based waivers, section 441.301(c)(5)(v) specifies that the following settings are presumed to have the qualities of an institution:

- any setting that is located in a building that is also a publicly or privately operated facility that provides inpatient institutional treatment,
- any setting that is located in a building on the grounds of, or immediately adjacent to, a public institution, or
- any other setting that has the effect of isolating individuals receiving Medicaid HCBS from the broader community of individuals not receiving Medicaid HCBS.

For 1915(i) State plan home and community-based services, section 441.710(a)(2)(v) specifies that the following settings are presumed to have the qualities of an institution:

- any setting that is located in a building that is also a publicly or privately operated facility that provides inpatient institutional treatment,
- any setting that is located in a building on the grounds of, or immediately adjacent to, a public institution, or
- any other setting that has the effect of isolating individuals receiving Medicaid HCBS from the broader community of individuals not receiving Medicaid HCBS.
Where to Find Resources on HCBS Final Rule

CMS Guidance (NOT Final Rule): “List of examples of residential settings that typically have the effect of isolating individuals receiving HCBS from the broader community:”

- Farmsteads or disability-specific farm community
- Gated/secured “community” for people with disabilities
- Residential schools
- Multiple setting co-located and operationally related
Medicaid website:

Home & Community Based Services

Home and community-based services (HCBS) provide opportunities for Medicaid beneficiaries to receive services in their own home or community. These programs serve a variety of targeted populations groups, such as people with mental illnesses, intellectual or developmental disabilities, and/or physical disabilities.

The final HCBS regulation published January 26, 2014, requires states operating a section 1915(c) waiver or a section 1915(i) state plan benefit (that was in effect on or before March 17, 2014) to submit a statewide transition plan addressing compliance with the regulation. More information about this plan is available in the Statewide Transition Plan Toolkit for Alignment with HCBS Settings Regulation Requirements.

In an effort to keep stakeholders apprised of the status of HCBS Statewide Transition Plans (STP), the following documents will be posted on the Statewide Transition Plans page, as they become available or are sent to states:

1. Proposed Plan URL: The URL link to the STP the state submitted to CMS.
2. CMIA: Clarifications and/or Modifications required for Initial Approval: The communication CMS sends to the state notifying the state that public

1) CLICK THIS TAB to change the information displayed

2) CLICK THIS LINK to get to page with STP and CMIA
State Transition Plan submitted by your state including summary of public comments, **not yet approved.**

Clarifications and/or Modifications required for Initial Approval (CMIA), look for deadlines!
Important Next Steps:

1. Read the **HCBS Final Rule setting requirements**

2. Read the **CCC Mini-Toolkit** for tips on what to look for in STP

3. **Read your STP and CMIA** and use the CCC Mini-Toolkit to get involved

4. **LIKE the CCC Facebook Page**

5. **Join the CCC!**
Additional resources for members only:

- Monthly newsletters
- Conference Calls
- Toolkits and Calls to Action
- Technical Assistance from National Coordinator

www.CoalitionForCommunityChoice.org
Part 2: Finding Statistics to Support Choice

- Demonstrate the real growth gap of LTSS in your state
- Demonstrate inaccess to affordable housing for those with I/DD in your state
- Explore quality of life assessments for those with I/DD in your state
- Demonstrate abuse is occurring “in community” and offer reports of victims with I/DD in your state
Dr. David Braddock has been publishing this report for decades, tracks over 35 years of data on residential supports and settings.

- Full 2015 Report available in print only, not digital.
- State Profiles
Click on your state to see its profile.

Jump to Page 6 first!
Page 6, using IL profile as an example:

• Identify how many individuals with I/DD are living with family caregivers = 70% / 142,194

• Identify how many individuals with I/DD are living with family caregivers over the age of 60 = 32,732
IMPORTANT QUESTION: If the growth rate of residential supports is approximately 575 individuals a year, how does the state plan to meet the demand of 33,000 who will soon lose their primary caregiver, their elder parents?
Page 1 using IL profile, $2.70 of every $1000 of taxpayer money is going to support those with I/DD in IL.

Since 1977, the burden of costs for taxpayers as increased only .59 cents for every $1000 of taxable income, and has declined significantly since 2009.

IMPORTANT QUESTION: Do you think Illinois citizens would vote to allocate $5 of every $1000 taxed for their neighbors with I/DD to have access to the supports they need?
• **Priced Out in 2014** shows that individuals with disabilities can not afford housing without assistance.

• Housing Choice Vouchers and Section 8/811 projects can not meet the demand.

• Report broken down into counties.
Even if an individual can access waiver supports, they can not afford to pay for housing without housing assistance in any part of the state.

IMPORTANT QUESTION: How does the state plan to increase the affordable housing supply of 33,000 individuals with I/DD who otherwise will be forcefully institutionalized or left homeless for lack of affordable, accessible housing?
Fact sheet offers good suggestions, but additionally, policy barriers cannot get in the way of local public-private solutions nor should the state prohibit access to essential life supports for an individual to live in a home of their choosing.
Access to Housing: *Out of Reach 2015*

*National Low Income Housing Coalition* is NOT disability-specific, but shows the necessary income to afford housing across the country.

In order to afford housing, individuals with I/DD must work full-time for over double the minimum wage.
Out of Reach State Profile offers lots of information about housing affordability at the county level as well as the opportunity to connect with others in your state.

$220 monthly rent would be considered ‘affordable’ for someone whose income is solely SSI in Illinois.
Access to Housing: *Out of Reach 2015*

<table>
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<tr>
<th>Housing Wage</th>
<th>Illinois</th>
<th>Chicago-Naperville-Joliet HMFA *</th>
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<tr>
<td>ZERO-BEDROOM</td>
<td>$13.52</td>
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<td>ONE-BEDROOM</td>
<td>$15.51</td>
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<td>TWO-BEDROOM</td>
<td>$18.78</td>
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<td>THREE-BEDROOM</td>
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<td>$26.79</td>
</tr>
<tr>
<td>FOUR-BEDROOM</td>
<td>$28.17</td>
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<td>$812</td>
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<td>ONE-BEDROOM</td>
<td>$807</td>
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<td>FOUR-BEDROOM</td>
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<tr>
<th>Annual Income Needed to Afford</th>
<th>Illinois</th>
<th>Chicago-Naperville-Joliet HMFA *</th>
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<tbody>
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<td>ZERO-BEDROOM</td>
<td><strong>$28,131</strong></td>
<td>$32,480</td>
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<td>ONE-BEDROOM</td>
<td><strong>$32,260</strong></td>
<td>$36,880</td>
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<td>TWO-BEDROOM</td>
<td><strong>$39,067</strong></td>
<td>$43,720</td>
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<tr>
<td>THREE-BEDROOM</td>
<td><strong>$50,391</strong></td>
<td>$55,720</td>
</tr>
</tbody>
</table>

**IMPORTANT QUESTION:** How can the state remove barriers and support local public-private initiatives that increase the affordable housing supply for those who never will earn an annual wage of $30,000?
National Core Indicators data is available in most states. It is being used in some states as part of their evaluation and assessment of quality of life of waiver participants during the period of State Transition.
National Core Indicators data for most states can be downloaded as a PDF.
National Core Indicators can generate state-specific charts of data giving a snapshot of different aspects of quality of life.

For example: How much money are individuals making in community settings?
Quality of Life: National Core Indicators

1) Select measure
2) Select State
3) Click gold generate chart button
Quality of Life: National Core Indicators

Person in Community Paid Job

The proportion of people who have a job in the community.

Amount of Community Gross Wages Earned During Two-Week Period

The average bi-weekly earnings of people who have jobs in the community.

Less than 2% are making at least $7,200 annually in paid community jobs in IL. Combined with SSI, this gives an annual income of less than $16,000. Economic self-sustainability is not a realistic solution for most individuals with I/DD!
INDV. WITH I/DD WHO ‘SOMETIMES’ OR ‘OFTEN’ FEEL LONELY BY SETTING (2012-2013)

<table>
<thead>
<tr>
<th>Setting</th>
<th>Percentage</th>
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<tbody>
<tr>
<td>IDD Specific Institution</td>
<td>37%</td>
</tr>
<tr>
<td>Group Home</td>
<td>41%</td>
</tr>
<tr>
<td>Independent Home/Apt</td>
<td>43%</td>
</tr>
<tr>
<td>Foster Home</td>
<td>51%</td>
</tr>
<tr>
<td>Family Home</td>
<td>40%</td>
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</tbody>
</table>

IMPORTANT QUESTION: If individuals with I/DD feel the most lonely in a “home-like” foster setting or their own apartment - why are these settings given greater “home” value than IDD specific settings? Why are states using physical characteristic as HCB values instead of how many unpaid friendships people have?
The Disability & Abuse Project conducted a national survey in 2012 to learn more about the victims and rate of abuse of those with disabilities.
Abuse: Disability Abuse Project, 2012 National Survey

“The bottom line is that abuse is prevalent and pervasive, it happens in many ways, and it happens repeatedly to victims with all types of disabilities.”

63% of adults with I/DD have been victims of abuse

- 34% sexually abused
- 40% more than 10x
- Only 54% reported the abuse

Reasons for not reporting:

- 58% believed nothing would happen
- 38% had been threatened or were afraid
- 33% did not know how or where to report
Abuse: Disability Abuse Project, 2012 National Survey

The Project ‘newsfeed’ archives compiled lists of abuse cases that have been in the media since 2011. Look for your state in CAPS.
Working together, we CAN make a difference!

The CCC is a new alliance of organizations, businesses, and housing professionals that strive to meet the housing and employment demand for an array of life options for those with intellectual/developmental disabilities (I/DD).
For More Information:

www.MadisonHouseAutism.org
www.CoalitionForCommunityChoice.org
www.AutismHousingNetwork.org

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In response to Affordable Care Act, federal HCBS regulations needed to be revised:

2008: NPRM for 1915(i) - not finalized
2009: NPRM for 1915(c)
2011: NPRM for 1915(c)
2011: NPRM for 1915(k)
2012: NPRM for 1915(i) and 1915(k)
2013: NPRM for 1915(c), (i), and (k)
2014: CMS-2249-F/CMS-2296-F published

“The Rule, as part of the Affordable Care Act, supports the Dept. of HHS Community Living Initiative. The initiative launched in 2009 to develop and implement innovative strategies to increase opportunities for Americans with disabilities and older adults to enjoy meaningful community living.”

–CMS website
What’s in the Final Rule?

• New regulations and criteria for residential and non-residential settings that use HCBS funding
• Settings eligibility based on individual outcomes and experiences
• Emphasis on integration in, and full access to, community same as those who are not receiving waiver services
• No setting size, physical characteristics, prohibition of disability-specific person limits
• Emphasized authority of and mandates Person Centered Plans to be created and reviewed in order to access funds
• Ensuring transparency and accountability via public comment periods
• Set a baseline, but gave states the flexibility to implement more restrictive regulations
Final Rule and All HCBS Settings

• The setting is integrated in and supports full access of individuals receiving Medicaid HCBS to the greater community, 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.

• The setting 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. The setting options are identified and documented in the person-centered service plan and are based on the individual's needs, preferences, and, for residential settings, resources available for room and board.
• Ensures an individual's rights of privacy, dignity and respect, and 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.
ADDITIONAL criteria for provider owned or controlled 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, and the individual has, at a minimum, the same responsibilities and protections from eviction that tenants have under the landlord/tenant law of the State, county, city, or other designated entity. For settings in which landlord tenant laws do not apply, the State must ensure that a lease, residency agreement or other form of written agreement will be in place for each HCBS participant, and that the document provides protections that address eviction processes and appeals comparable to those provided under the jurisdiction's landlord tenant law.
Each individual has privacy in their sleeping or living unit:

- Units have entrance doors lockable by the individual, with only appropriate staff having keys to doors.
- Individuals sharing units have a choice of roommates in that setting.
- Individuals have 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 must be supported by a specific assessed need and justified in the person-centered service plan:
  • Identify a specific and individualized assessed need.
  • Document the positive interventions and supports used prior to any modifications to the person-centered service plan.
  • Document less intrusive methods of meeting the need that have been tried but did not work.
  • Include a clear description of the condition that is directly proportionate to the specific assessed need.
  • Include regular collection and review of data to measure the ongoing effectiveness of the modification.
  • Include established time limits for periodic reviews to determine if the modification is still necessary or can be terminated.
  • Include the informed consent of the individual.
  • Include an assurance that interventions and supports will cause no harm to the individual.
Settings NOT Eligible for HCBS Funding

- Settings that are not home and community-based are defined at §441.301(c)(5) as follows:
  - A nursing facility;
  - An institution for mental diseases;
  - An intermediate care facility for individuals with intellectual disabilities;
  - A hospital; or
  - Any other locations that have qualities of an institutional setting, as determined by the Secretary.

*These are the only settings explicitly stated in the Final Rule as NOT Home and Community-Based!
The following settings are presumed to have the qualities of an institution:

- any setting that is located in a building that is also a publicly or privately operated facility that provides inpatient institutional treatment,
- any setting that is located in a building on the grounds of, or immediately adjacent to, a public institution, or
- any other setting that has the effect of isolating individuals receiving Medicaid HCBS from the broader community of individuals not receiving Medicaid HCBS.

*These are presumed to be institutional thus MAY need to undergo the heightened scrutiny process as determined by the State.
• First case of a setting presumed to be institutional: Life Skills & Training Center, Grafton, ND
• CMS contractor NORC conducted review
• Information provided by State and other parties
• Determine that is does not have qualities of an institution and
• Does have the qualities of HCBS

CMS determined LSTC meets HCBS setting criteria based on access to and integration of residents in community.
• CMS Guidance expanded on the Final Rule and identified settings that are presumed to be institutional

• Settings that have these two characteristics alone might, but will not necessarily, meet the criteria for having the effect of isolating individuals:

  • #1 – The setting is designed specifically for people with disabilities, and often even for people with a certain type of disability
  • #2 – The individuals in the setting are primarily or exclusively people with disabilities and on-site staff provides many services to them.
Settings that isolate people receiving HCBS from the broader community may have any of the following characteristics:

- The setting is designed to provide people with disabilities multiple types of services and activities on-site, including housing, day services, medical, behavioral and therapeutic services, and/or social and recreational activities.
- People in the setting have limited, if any, interaction with the broader community.
- Settings that use/authorize interventions/restrictions that are used in institutional settings or are deemed unacceptable in Medicaid institutional settings (e.g. seclusion).

Non-exhaustive list of examples of residential settings that typically have the effect of isolating people receiving HCBS from the broader community:

- Farmstead or disability-specific farm community
- Gated/secured “community” for people with disabilities
- Residential schools
- Multiple settings co-located and operationally related (i.e. operated and controlled by the same provider)
  - Excluded CCRCs (Continuing Care Retirement Communities)
Jan. 10, 2014 - Final Rule published

March 17, 2014 - Transition Clock Starts

March 17, 2015 - State Transition Plans Due

March 17, 2019 - Transition Complete, All Settings Must be in Compliance
CCC STP Concerns

CCC letter to CMS cited concerns:
• States were reverting back to physical characteristics instead of outcome oriented criteria
• States were telling advocates and providers that campus settings, farmsteads, and intentional communities would not be funded by CMS
• States were creating restrictive criteria that would automatically exclude settings from being evaluated or put through the higher scrutiny process
Use the [CCC STP Mini-Toolkit](#) to learn more about the Final Rule and how to access and become part of your State Transition Plan process!

It is IMPERATIVE your voice is present, and the Final Rule requires that the state documents that they have heard your concerns and suggestions.
Next Steps

• State will seek input for assessment tool for setting assessments.
  • Read and give feedback.
  • Remove questions that are based on physical characteristics.
  • Add questions that will identify and document barriers to access

*Example:*
• How many times a month does Maria go out to dinner?
• How many times does she want to go out to dinner?
• What prevents her from going out to dinner as often as she would like?
Next Steps

• See if your state has created a transition advisory committee / workgroup and ask to join!

Stakeholders should include:
- HCBS recipients who reside in different settings
- Parents of HCBS recipients
- Service Providers
- Direct Support Professionals
- Affordable Housing Developers

• If none exist, request to create one.
Next Steps

• Build relationships with your legislatures!

• They MUST become more aware of the statistics and stories of their constituents with I/DD who are struggling to be supported in their community and find appropriate affordable housing options.
Next Steps

Start the Person Centered Planning Process!
• Look at the Final Rule Requirements for PCP’s
• Increase self-advocacy skills of HCBS recipients so they can lead the process as much as possible