

CMS HCBS Settings Regulation: An Overview and Introduction

Webinar 1 of 5 from:



Introductory Remarks

Ari Ne'eman
President
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History Leading Up To Settings Reg

- June 2009 ANPRM: Acknowledges provider-owned & controlled distinction
- 2010: Nevada Habilitation Center “Gated Community” Proposal
- April 2011: Initial NPRM Proposal
- April 2012: Second NPRM Proposal
- January 2014: Final Rule

Keeping the Promise Summit & Report

- In 2010, ASAN, NYLN & SABE convene Keeping the Promise Summit to identify self-advocate perspectives on HCBS
- 30+ National Self-Advocate Leaders, 72 self-advocates interviewed
- AIDD-funded
- Results released in “Keeping the Promise” report in 2011

Keeping the Promise Summit & Report

- Defined HCBS based on 5 dimensions of quality:
 - Physical Size and Structure
 - Rights and Self-Determination
 - Qualities & Attitudes of Providers
 - Access to Community Life; and
 - Meeting of Support & Access Needs

Medicaid Final Rule: CMS 2249-F and CMS 2296-F

- Published in Federal Register on January 16, 2014
- Designed to ensure that services provide through home and community-based services (HCBS) funding are actually community-based
- Applies to all HCBS provided through the Community First Choice Act, State Plans (Section 1915(i)), or HCBS waivers (Section 1915(c))



The HCBS Settings Regulation: An Opportunity to Change Systems and Further *Olmstead* Compliance

ASAN Webinar Sept. 30, 2014
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What Is Our Vision People with Disabilities?

- Support people with disabilities to have lives like people without disabilities
- Provide opportunities for true integration, independence, choice and self-determination in all aspects of life – where people live, how they spend their days, and real community membership
- Ensure quality services that meet people's needs and help them achieve goals they have identified through real person-centered planning

The HCBS Rule and *Olmstead* can be a path towards this vision!

HCBS SETTINGS RULE

HCBS Settings Rule

- Goal and purpose of the rule:
 - To “ensure that individuals receiving services through HCBS programs have full access to the benefits of community living” (1-14 Informational Bulletin)
 - To “further expand the opportunities for meaningful community integration in support of the goals of the Americans with Disabilities Act and the Supreme Court’s decision in *Olmstead v. L.C.*” (IB)
 - “To be a tool to assist states with adhering to the Olmstead mandate and the requirements of ADA” (rule’s preamble)

HCBS Settings Rule (cont'd)

- Final rule moved away from trying to define what was not community to focusing on what is community
 - Focus on people's actual experiences in settings, not the name or type of setting/service
- Applies to all services provided under any of the HCBS authorities
 - 1915(c) waivers
 - 1915(i) HCBS state plan services
 - 1915(k) Community First Choice option

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Characteristics of Home and Community Based Settings

An outcome oriented definition that focuses on the nature and quality of individuals' experiences, including that the setting:

1. Is **integrated in and supports access to the greater community**;
2. Provides **opportunities to seek employment and work in competitive integrated settings**, engage in community life, and control personal resources
3. Is selected by the individual from among setting options, **including non-disability specific settings**

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HCB Setting Characteristics (cont'd)

4. Ensures the individual receives services in the community to the **same degree of access** as individuals not receiving Medicaid HCBS
5. Ensures an individual's rights of **privacy, dignity, respect, and freedom from coercion and restraint**
6. Optimizes **individual initiative, autonomy, and independence** in making life choices
7. Facilitates **individual choice** regarding services and supports, and who provides them

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Additional Requirements for Provider-Owned Residential Settings

- A lease or other legally enforceable agreement
- Privacy in his or her unit and lockable doors
- Choice of roommate
- Freedom to furnish or decorate the unit
- Control of his or her schedule, including access to food at any time
- Right to visitors at any time
- Physical accessibility of the setting (not modifiable)
- Any modification of these conditions must be supported by a specific assessed need and justified in the person-centered plan; must first attempt alternative strategies and have periodic reviews

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Presumptively Non-HCB Settings

- Settings that are **presumed to be unallowable**, unless a state can prove through a **“heightened scrutiny”** process that it does in fact meet the HCB characteristics and does not have institutional qualities:
 - Facilities providing inpatient institutional services
 - Settings on the grounds of, or adjacent to, a public institution
 - **Settings that have the effect of isolating HCBS recipients from the broader community**

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Settings that Isolate

- Non-exhaustive list of characteristics of “settings that isolate”:
 - Designed specifically for PWD or with specific disabilities
 - Comprised primarily of PWD and staff providing services
 - PWD are provided multiple types of services onsite
 - PWD have limited interaction with the broader community
 - Use restrictive interventions

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Settings that Isolate (cont'd)

- CMS has provided specific examples of residential settings that isolate, including:
 - Disability-specific farms
 - Gated disability communities
 - Residential schools
 - Congregate, disability-specific settings that are co-located and operationally related
- CMS will be providing further guidance giving examples of non-residential settings that isolate
 - But it has made clear the “settings that isolate” guidance applies to non-residential settings too

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Transition Plans

- States must submit transition plans to CMS that outline the changes to the HCBS program to come into compliance with the new regulations
- For existing programs, a plan must be submitted by 3-17-15
- For renewals, plan must be submitted with the renewal application
- Transition plans may be as long as five years
- CMS has issued sub-regulatory guidance, including a “toolkit” and “exploratory questions”

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Transition Plan – Public Input

- A State must provide at least a 30-day public notice and comment period and two statements of public notice and input procedures
- The full plan must be available to the public
- The State must consider and modify the plan to account for public comment
- If a state substantively amends the plan, the new plan must be put out for public comment
- **THIS IS A CRITICAL OPPORTUNITY FOR ADVOCACY!**

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PUBLIC INPUT: The Key to Ensuring Change in Your States' Service System

Key Points for Advocacy:

- Encourage your state to include key stakeholders in the transition planning process, not just to seek public input after the draft plan is complete.
- Provider self-assessment and paper review of regulations are not enough! Push for the state to get input on settings from consumers, family members, and advocates (including the P&A) who are familiar with the setting and to do some of its own on-site visits to verify information from paper review.
- A “work plan” is not a final transition plan. The final transition plan must be subject to public input.

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USING THE HCBS REGULATIONS TO FURTHER *OLMSTEAD COMPLIANCE*

Title II of the ADA

- Prohibits discrimination by public entities in services, programs and activities
- Integration regulation requires administration of services, programs and activities **in the most integrated setting** appropriate
- Most integrated setting is one that enables people with disabilities to **interact with people without disabilities to the fullest extent possible**

***Olmstead v. L.C.:* Unjustified segregation is discrimination**

- S. Ct. held that ADA prohibits unjustified segregation of PWD and that public entities are required to provide community-based services when:
 - Such services are appropriate;
 - Affected persons do not oppose community-based treatment; and
 - Community-based treatment can be reasonably accommodated, taking into account the resources available to the entity and the needs of others receiving disability services
- Applies to all facilities, services, or programs funded/designed by the state, not just those directly operated by the state
- Applies to people in and at-risk of entering segregated settings/programs

What is an Integrated Setting?

- Integrated settings provide people with disabilities the **opportunity to live, work and receive services in the greater community**
 - Located in mainstream society
 - Offer access to community activities when and with whom the person chooses
 - Choice in daily life activities
 - Ability to interact with people without disabilities to the fullest extent possible
- Examples: scattered site supportive housing, supported employment in a mainstream job
- **Note the ADA definition similar to the HCBS settings requirements.**

What is a Segregated Setting?

- Have **institutional qualities**, including:
 - Congregate settings with primarily or exclusively people with disabilities
 - Regimentation in daily activities, lack of privacy/autonomy, limits on ability to freely engage in community activities
 - Settings that provide for daytime activities primarily with other people with disabilities
- Examples: ICFs, nursing homes, adult care homes, sheltered workshops, segregated day programs
- Note that the language is similar to the HCBS regulations about “settings that isolate”.

Types of Settings that Have Been Successfully Challenged Under the ADA

- Residential settings
 - Publicly and privately-operated ICFs
 - Publicly and privately-operated psychiatric hospitals
 - Privately-operated nursing homes
 - Privately-operated adult homes/board and care homes
- Remedies have included expansion of integrated housing (e.g., scattered site supportive housing, supported apartments) and services need to support people in those community settings (e.g., HCBS waivers, crisis services, supported employment)

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Types of Settings that Have Been Successfully Challenged Under the ADA (cont'd)

- Non-residential settings
 - Sheltered workshops
 - Segregated day programs
- Remedies have included expansion of individual, integrated supported employment and integrated day services (e.g., individualized recreational, social, and educational activities of the individual's choosing)

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ADVOCACY TO ALIGN STATES' TRANSITION PROCESS WITH OLMSTEAD GOALS

- Transition plans can be an opportunity to move your state's system towards real integration and community membership and further *Olmstead* compliance.
- HOWEVER, if CMS approves transition plans that include the very settings that advocates and DOJ have been challenging under *Olmstead*, this could undermine *Olmstead* efforts in your state and nationally (even though the ADA and Medicaid create independent obligations).
 - It is critical that advocates provide concrete evidence about people's experiences in these settings vis-à-vis the rule's requirements.

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Advocacy Around the HCBS Settings Regulation

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Avenues for Advocacy

- States need to develop clear criteria for residential, non-residential settings
 - Will states continue to rely heavily on group homes and other congregate arrangements?
 - Will states continue to fund congregate day services, like sheltered workshops and center-based day habilitation?

Major Concerns

- States have mostly submitted “plans to plan” – don’t yet have detailed information on what they will consider HCBS
- Transition plans not cognitively accessible
- Many transition plans have focused on residential services and not on non-residential services, in part because states are waiting on further guidance from CMS on non-residential settings

Residential Settings

- States may focus on details of residential settings requirements, to the exclusion of substantive requirements like integration. For example:
 - A group home that nominally obeys the regulation’s requirements for residents’ choices, privacy, and autonomy, but is understaffed and therefore can’t actually accommodate flexibility and choice in residents’ schedules; residents have to choose from limited menu of options. This is difficult to avoid in congregate settings.
 - State will take position that congregate settings are part of “continuum of choices,” without providing meaningful access to non-disability-specific settings.
 - Advocates should push states instead toward expanding scattered-site options with self-directed residential supports

Employment Services

- We may see similar focus on “maintaining continuum of settings,” without addressing substantive issues with congregate settings.
 - E.g., state claims that sheltered workshops are “integrated” because service recipients theoretically have access to supported employment services – despite the fact that segregated settings don’t meet basic integration requirements.
 - Advocates need to push for meaningful system reform, transition toward supported employment models

Non-Employment Day Services

- State may take the position that services are “integrated” if it allows people to make group excursions “into the community,” with choices limited to a “menu” of options for each day
- Advocates need to push for self-directed, non-group-based, non-center-based day services.

Size Matters

- Strong research basis showing that smaller size equates to more choice & control - across every level of ID
- Research clearly in favor of scattered site housing over congregate
- Clustering individuals with complex support needs increases, not reduces, difficulty of service-provision with choice & control
- Congregate employment services (e.g., sheltered workshops) have only 5% rate of helping people gain competitive employment. Supported employment services are proven more effective.

But So Do Other Things...

- Provider owned or not?
- Choice of Roommates or not?
- Access to Phone/Internet or not?
- Access to Visitors or Not?
- Choice of Location/Activities/Timing?
- Privacy?
- Much, much more...

Tools for change

- Explaining how congregate service models are inconsistent with text of regulations
 - E.g., requirement that individuals have maximum opportunities for competitive integrated employment, controlling personal resources
- Presenting regulations as opportunity to develop comprehensive plans for reform
- Using other sources of law, such as *Olmstead*

Tracking State Transition Plans

- States must make transition plans available for public comment
- ASAN's toolkit for Advocates, available at autisticadvocacy.org/hcbs, explains how to use HCBSAdvocacy.org to find transition plans for each state, and how to contact state administrators with comments or questions.

Sample State Response: TN

- Tennessee submitted “[concept paper](#)” for transition on May 30, 2014.
- Will create a new program, *Employment and Community First CHOICES*, that will be “geared toward promoting and supporting integrated, competitive employment and independent living as the first and preferred option” for all people with ID/DD
- Will be operated as a managed long-term services and supports program.

Sample State Response: TN

- Consumers can choose from 3 models of service delivery:
 - Consumer direction: person manages own support budget
 - Health home agency with choice: person selects a provider who will help direct services
 - Basic managed long-term services and supports

Sample State Response: TN

- Tennessee program will provide preparation and transition services to youth with disabilities under age 21
- Adults will receive employment supports regardless of whether they are at the “nursing facility” level of care.
- Will first target “new” HCBS recipients, then be expanded to existing recipients
 - (existing recipients have already been receiving “employment first” services through pre-existing program)

Sample State Response: WI

- Wisconsin recently submitted a letter to CMS asking for permission to allow “sheltered workshop”, “facility based day habilitation”, under the regulation
- Significant opposition from disability rights organizations
- CMS has not yet responded to the letter

Transition Plan Politics

- Many states may be evaluating compliance by interviewing facilities, not service recipients – so people need to actively make their voices heard
- Advocates should reference specific settings, not just broad principles
 - Is there a disconnect between “brochure” descriptions of a provider, and actual experience of service recipients?
 - Which service models work the best?
- Consider key stakeholder groups in your state:
 - Self-Advocates
 - Families
 - Providers – including self-directed service workers and referral networks

Bringing up *Olmstead*

Olmstead

- States that provide services must provide them in most integrated setting appropriate to individual needs
- Applies to *all* state-funded services, not just HCBS

HCBS Final Rule

- All HCBS services must be “integrated in and supports full access of individuals . . . to the greater community.”
- Compliance with *Olmstead* is explicit goal, but applies only to HCBS-funded services

***Olmstead* and HCBS**

- New CMS rules interact with *Olmstead* requirements to provide services in most integrated setting
- Terms of *Olmstead* settlements – especially those reflecting the Department of Justice’s interpretation of the ADA – can give concrete examples of compliant vs. non-compliant settings

***Olmstead* vs. HCBS**

- Requirements of *Olmstead* and Final Rule are *not co-extensive!* For example:
 - State provides Final Rule-compliant services to small population, with long waiting list. Individuals on the waiting list are at risk of institutionalization. State may be violating *Olmstead*.
 - State complies with terms of *Olmstead* settlement with narrow target population. Waiver participants outside target population get congregate or institutional services. State is violating Final Rule *and Olmstead* with respect to people outside “target population.”

Recent *Olmstead* Litigation: Residential

- *United States v. O’Toole et al.*, (2013)
(DAI’s “adult homes” case)
- *United States v. Virginia*, (2012)
(developmental centers)
- *United States v. North Carolina*, (2012)
 - All three settlement agreements included requirements to develop scattered-site supportive housing.

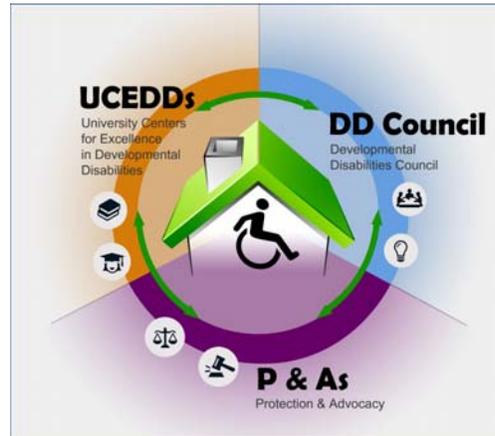
Recent *Olmstead* Litigation: Non- residential

- *United States v. Rhode Island* (settled 2014):
consent decree requires phase-outs of sheltered workshops and increase in supported employment services
- *United States v. Virginia* (2012): requires states to provide supported employment to people with ID/DD
- *Lane v. Kitzhaber* (Oregon, pending):
Department of Justice issued findings letter stating that segregated employment services violate the ADA

DD Network – Who We Are

National organizations:

- **UCEDDs:** Association of University Centers on Disabilities (AUCD)
- **DD Councils:** National Association of Councils on Developmental Disabilities (NACDD)
- **P&As:** National Disability Rights Network (NDRN)



- DD Councils are part of the Developmental Disabilities Network outlined by the Developmental Disabilities Assistance and Bill of Rights Act Amendments of 2000 (the DD Act) originally enacted 50 years ago
- There is a DD Council in every state and territory (56 in total)
- DD Councils have a full-time staff *and* a Council made up of Governor-appointed citizens who volunteer to serve
- **Our Mission:** NACDD serves as the National Voice of State and Territorial Councils on Developmental Disabilities. We support Councils in implementing the Developmental Disabilities Assistance and Bill of Rights Act promoting the interest and rights of people with developmental disabilities and their families.

P&As and Community Monitoring

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Overview of the Protection and Advocacy Systems

- In every state and territory
- Cross-Disability
- Special access and records review authority
- Full range of legal advocacy options (from I&R to systemic litigation)
- Investigations of abuse and neglect in facilities is a standing priority –P&As must set other issue priorities at least every 2 years.

Jurisdiction to investigate and monitor

- Psychiatric hospitals & residential treatment centers
- ICF/ID
- Nursing facilities
- Assisted living facilities and other Residential Care
- Group homes
- Homeless shelters
- Jails/prisons
- Adult day care and sheltered workshops

Community related monitoring

- Discharge planning and transition monitoring
- Alternatives to guardianship (e.g. promoting SDM)
- Monitoring representative payee's
- Olmstead enforcement including, application to adult day & sheltered workshops, & settlement oversight
- HCBS rule comments (providing P&A case examples to show settings with institution qualities or policies that limit PCP)
- Campaign to stop HCBS funding for disability communities and re-builds on institution grounds
- Promoting more and better trained state investigators

Mission

To advance **policy** & practice **for** and **with** people living with developmental and other disabilities, their families, and communities by supporting our members as they engage in research, education, and service that further independence, productivity and a satisfying quality of life.



Three National Networks of Centers

- 67 University Centers for Excellence in Developmental Disabilities (UCEDDs)
- 43 Leadership Education in Neurodevelopmental and Related Disabilities (LEND) Programs
- 15 Intellectual and Developmental Disabilities Research Centers (IDDRCs)



DD Network Work on the HCBS Rule

- **December 2010:** Submitted Formal Comments to CMS from National Associations
 - Key Themes:
 - Aligning definitions of inclusion and integration with the Developmental Disabilities & Bill of Rights Act definitions
 - Ensuring CMS standards meet expectations of the Americans with Disabilities Act & *Olmstead* decision
 - Recognition of research demonstrating the benefit of community living
 - Recommendations for defining home and community based living arrangements for individuals with developmental disabilities
- **May 2014:** Created hcsadvocacy.org site to provide tracking, tools, and information on the new rule for all stakeholders

HCBS Advocacy

Information for advocates about the new home and community-based services rules

State Resources

HCBSadvocacy.org is a platform for the aging and disability communities to post information and resources regarding the new HCBS settings rule and steps each state is making to comply with the new rule. Click on a state or choose from the list below to see resources, dates and deadlines, state documents, news, and other information from that state. This site is a work in progress that relies on state and national partners to find information and share resources. Have news or resources to post? Send them to hcsadvocacy@gmail.com.

Please click on the state you are interested in to view that state's information:



Search

Search

Key Dates & Deadlines

Comment Deadlines:

Tennessee: Comments on the concept paper are due June 30, 2014

Kansas: Comments on the transition plan are due July 15, 2014

Oregon: Comments on the second transition plan are due July 23, 2014

Florida: Comments on the preliminary transition plan are due July 25, 2014

Expected Waiver Renewal Submission Dates:
1915(c) Waiver Renewal Dates Through April 2015

States with waivers expected to be submitted June 30, 2014: These states must include a transition plan with this waiver submission if they have not yet already submitted a plan.

Alabama

HCBSadvocacy.org

HCBS Advocacy

Information for advocates about the new home and community-based services rules

Key Dates & Deadlines

Comment Deadlines:

Indiana: Comments on the assessment plan are due August 7, 2014

Texas: Comments on the transition plan and assessment plan are due August 18, 2014

West Virginia: Comments on the transition plan are due August 24, 2014

States with waivers expected to be submitted September 30, 2014: These states must include a transition plan with this waiver submission if they have not yet already submitted a plan.

- California
- Florida
- Illinois
- Iowa
- Kansas
- Maine
- New Hampshire
- Nevada
- Pennsylvania
- South Carolina
- Utah
- Tennessee
- Wisconsin

Expected Waiver Renewal Submission Dates:
1915(c) Waiver Renewal Dates Through April 2015

HCBS Advocacy

Information for advocates about the new home and community-based services rules

National Resources

Use this page to find national-level advocacy resources on home and community-based services (HCBS) and the Centers for Medicare and Medicaid Services final rule regarding HCBS in the Medicaid program.

Implement and Advocate

Just Like Home: An Advocate's Guide for State Transitions Under the New Medicaid HC National Senior Citizen's Law Center

This guide provides government officials and stakeholders with multiple aspects of the determining which settings are disqualified for HCBS, and enforcing consumer protection.

Advocacy Checklist and Resources for Impacting State Compliance with Medicaid HC Rule [HCBS_Advocates_Checklist](#)

DD Network

Don't know where to start? Use this list to gain ideas and resources on how to get involved and advocate for high-quality home and community-based services in your state.

Assessment Worksheet for Advocates [HCBS Advocate's Worksheet](#)

DD Network

This worksheet includes the regulatory language and CMS guidance in an easy-to-use format about the HCBS settings in their state and help their state make accurate and comprehensive.

Learn About the New Rules

Use this page to find official resources and information from the federal government regarding the rule.

Centers for Medicare and Medicaid Services

The Centers for Medicare and Medicaid Services have provided fact sheets, webinar slides, informational bulletins, and toolkits on [Medicaid.gov/hcbs](#). These resources are copied below. Visit [Medicaid.gov/hcbs](#) for the most up-to-date information from CMS on the HCBS settings rule.

Recent Guidance

The final Home and Community-Based Services regulations set forth new requirements for several Medicaid authorities under which states may provide home and community-based long-term services and supports. The regulations enhance the quality of HCBS and provide additional protections to individuals that receive services under these Medicaid authorities.

- Final Regulation: 1915(i) State Plan HCBS, 5-year Period for Waivers, Provider Payment Reassignment, Settlement Requirements for Community First Choice, and 1915(C) HCBS Waivers
- Informational Bulletin - Final regulations for HCBS provided under Medicaid's 1915(c), 1915(i) and 1915(k) authorities
- Press Release - Final regulations for HCBS provided under Medicaid's 1915(c), 1915(i) and 1915(k) authorities
- Fact Sheets Regarding Final Regulation CMS-2249-F/CMS-2256-F
- Overview of Regulation
- 1915(c): Changes to HCBS Waiver Program
- 1915(i): Key Provisions for HCBS State Plan Option

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HCBS Advocacy

Information for advocates about the new home and community-based services rules

Have Resources to Share?

Send them to hcbsadvocacy@gmail.com

Questions?



Next Webinar: October 7th, 1-2:30 PM

October 7 1-2:30 PM EST

Topic: The New HCBS Rule – How Does it Affect Housing for People with Disabilities

The new HCBS rule establishes specific qualities that a home must exhibit in order for a state to qualify for federal HCBS funding including being integrated in the community, supporting independence, involving individual choice, and protecting individuals from coercion and restraint. This webinar will walk through these specific requirements, the federal guidance, and a step by step analysis of changes that may need to occur in your state. Speakers will also discuss how the rule aligns with and moves forward the mandate from Congress and the U.S. Supreme Court that states must design and deliver federally funded services in a manner that does not unduly isolate or segregate individuals with disabilities.