National Disability Policy: Opportunities to Strengthen Full Inclusion and Integration of People with Disabilities

November 6, 2015
Doubletree Suites by Hilton, Mt. Laurel, NJ

The attached handouts are provided as part of The Boggs Center’s continuing education and dissemination activities. Please note that these items are reprinted by permission from the author. If you desire to reproduce them, please obtain permission from the originator.
National Disability Policy: Opportunities to Strengthen Full Inclusion and Integration of People with Disabilities
Alison Barkoff, J.D.
Director of Advocacy, Bazelon Center for Mental Health Law
alisonb@bazelon.org

The Boggs Center on Developmental Disabilities
Developmental Disabilities Lecture Series
November 6, 2015

What Is the Vision of a System For 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

Federal Law and Policies Leading Towards These Goals
• Historical background leading to modern disability policies
• Civil rights laws: the ADA and Olmstead enforcement
• CMS’ Home and Community Based Services Settings Rule
• Workforce Innovation and Opportunity Act

Historical Background

Harms of Segregation
• Segregation of people with disabilities:
  ➢ perpetuates “unwarranted assumptions” that they are “incapable or unworthy of participating in community life.”
  ➢ “severely diminishes the everyday life activities of such individuals,” including family, work, education and social contacts.

U.S. Supreme Court decision

Segregation As the Norm
• From the late 19th century through the late 1970s, institutionalization of people with disabilities was the norm
  – “Asylums for the lunatics and feeble minded”
  – Parents were told this was the best option for their children. Children did not have a right to a public education.
• Institutions focused on custodial care. Very little treatment, teaching new skills or working towards independence or recovery.
Segregation As the Norm (cont’d)

• Children with disabilities did not have a right to a public education. If got any education, typically in special schools only for children with disabilities.
• People with disabilities were not empowered in any way to make decisions about their own lives.

The Start of Evan’s Story

• Born with Down syndrome in the late 1970s
• My parents were told institutionalization was the best option for Evan and our family
  – When children entered institutions, they generally stayed for life.
• No “rival image” about what a life in the community could look like
  – Children with disabilities had just won the right to a public education a few years before; no idea yet about what educational opportunities would be available
  – No developed community service system; no idea yet about opportunities for independent living, work, etc.

Changing Societal Views and Expectations

• Over the last 25 years, significant changes in the expectations for and by people with disabilities due to:
  – Emergence of the disability rights movement
    • Self-advocates — “nothing about us without us”
    • Families who demanded other options
      – Development of community based service system as an alternative to institutionalization
      – Creation of civil rights laws, giving basic rights and protections to people with disabilities

Emergence of the Disability Rights Movement

• Starting in the 1970s, public attention on the inhumane conditions, lack of “treatment” and abuse and neglect of people with disabilities in institutions
  – This led to a push for deinstitutionalization and for families to fight for alternatives to placing their children in institutions
• In 1975, the Education of All Handicapped Children’s Act (precursor to the Individuals with Disabilities Education Act) gave students with disabilities a right to a public education
  – Families for the first time had an option in the community for their young children

Emergence of the Disability Rights Movement (cont’d)

• At the same time, the Independent Living movement pushed for access to the broader community (including transportation, physical accessibility, etc.) and for more control over their own lives.
  – “Nothing about us without us.”
• Strong emphasis on self-advocacy/consumer voice, peer-to-peer, and family-to-family supports.

Emergence of the Disability Rights Movement (cont’d)

• Set out a vision for people with disabilities:
  – Full inclusion in all aspects of society, from school to community living to work
  – High expectations
  – Self-determination, dignity of risk, and choice, driven by the individual’s own preferences and goals
Advocacy For Community Services

• Until the 1980s, public disability funding could only pay for care in institutions
• One little girl, Katie Beckett, and her family successfully challenged this policy
• Beginning in 1982, Medicaid created an optional “waiver” program that allowed states to provide community services as an alternative to institutional care
• Now every state provides Home and Community Based Services (HCBS) through a range of funding streams, including 1915c waivers, 1915k Community First Choice, and 1915i State Plan HCBS, as well as state plan services and managed care authorities

Shift Towards Community Services (cont’d)

• Dramatic shift away from institutional care towards community services
  – In FY 2012, nearly 50% of spending on long term services and supports nationally on community services
  – But differences by disability population (70% of IDD services, 39% of aging and PD services, and 35% of MI services)
  – Differences by states (a low of 27% in NJ to a high of 78% in OR)
  – 200,000 people in DD institutions at their peak, now down to about 53,000. Today 13 states have no publicly operated DD institutions, numerous more with only one; 15 states have no private ICFs
  – Most people with DD (77%) are now living in their own home, family home or in a small setting. 9% of people live in large congregate settings (7-15 people) and 14% in 16+ person institutions

Institutional vs Community Spending

HCBS as a Percentage of LTSS by State

I/DD Institutions
### Shift Towards Community Services (cont’d)

- But Medicaid’s “institutional biases” still lead to many people being unnecessarily institutionalized or segregated
  - Institutional services are an entitlement while community services are optional (thousands of people are on waitlists for community services)
  - Medicaid pays for room and board in an institution but is prohibited from paying for rent in the community. Many people are “stuck” in institutions due to a lack of affordable housing.

### Evolving Models of Disability Services

- Early “community” models – disability specific, congregate care settings, where people with disabilities live/spend the day together in settings where services were provided
  - Group homes
  - “Step down” models
  - Board and care homes
  - Day habilitation, sheltered workshops, and day treatment programs

- Today’s models allow people with disabilities to live their lives like people without disabilities
  - Supporting people to live in their own apartments or homes in the community, either alone or with roommates of their choosing.
  - Flexible, mobile services available to people in their own homes and communities (separation of housing and services).
  - Focus on opportunities for people to work in mainstream jobs alongside non-disabled peers.

- Movement away from models driven by professionals towards those that give people with disabilities more control
  - Agency models to consumer directed models, where the consumer hires, fires, and has day to day control over
  - Medical models towards recovery-oriented and peer models

### Civil Rights Laws: The Americans with Disabilities Act and Olmstead Enforcement

- U.S. Constitution as a tool for early institutional reform
  - Started by a public outcry about horrible conditions at institutions like Willowbrook in the 1970s
  - Focus on improving institutional conditions –
    - Constitution provided a basic right to safety and adequate treatment when in state custody
    - The Civil Rights of Institutionalized Persons Act (CRIPA) passed in 1980, giving the federal government authority to address unconstitutional conditions in public facilities

### Early Civil Rights Protections

- The Americans with Disabilities Act (1990)
  - Prohibits discrimination on the basis of disability in programs receiving federal financial assistance
  - Provides for access to public accommodations and transportation
  - Requires employers to provide reasonable accommodations for individuals with disabilities
  - Requires public agencies to provide programs and services to individuals with disabilities

  - Upheld the Civil Rights of Institutionalized Persons Act (CRIPA)
  - Required state and local governments to ensure that people with disabilities have the same opportunities as everyone else to live in the community and participate fully in community life
Early Civil Rights Laws (cont’d)

- Rehabilitation Act of 1973
  - Prohibits discrimination by recipients of federal money; predecessor to the ADA
  - Important impact on many issues – transportation, physical accessibility, etc. -- but not as much on integration as people had hoped.
- Education for All Handicapped Children Act of 1975
  - Opened doors of school to children with disabilities for the first time
  - Keeping children with their families became a real option; decrease in people entering institutions

The Americans with Disabilities Act

- Congress passed the ADA in 1990 “to provide a clear and comprehensive national mandate for the elimination of discrimination against individuals with disabilities.”
  - The ADA specifically finds that segregation, isolation, exclusion and institutionalization of people with disabilities is a “serious and pervasive problem”
  - ADA’s goal is to assure equality of opportunity, full participation, independent living, and economic self-sufficiency for individuals with disabilities.

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

- Two women in Georgia’s state hospitals claimed the state was violating the ADA by not providing them services in the community.
- In 1999, the Supreme Court held that Title II prohibits unjustified segregation of people with disabilities, relying on “two evident judgments” about institutional placement:
  1. “perpetuates unwarranted assumptions that persons so isolated are incapable or unworthy of participating in community life”
  2. “severely diminishes the everyday life activities of individuals,” including family, work, education and social contacts

Olmstead v. L.C. (cont’d)

- Held public entities are required to provide community-based services when:
  - Such services are appropriate; and
  - 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

When is the ADA’s Integration Mandate Implicated?

- Not limited to state-run facilities/programs
- Applies when government programs result in unjustified segregation by:
  - Operating facilities/programs that segregate people with disabilities
  - Financing the segregation of people with disabilities in private placements
  - Promoting segregation through planning, service design, funding choices, or practices.
**Who Does the Integration Mandate Cover?**

- ADA and Olmstead are not limited to individuals in institutions or other segregated settings
- They also extend to people at serious risk of institutionalization or segregation
  - Example: people with urgent needs on waitlists for services or people subject to cuts in community services; students with disabilities who are directly placed by schools into sheltered workshops or segregated day programs.

**What is a Segregated Setting?**

- Have institutional qualities, including:
  - Congregate settings with primarily or exclusively people with disabilities; or
  - Reglementation in daily activities, lack of privacy/autonomy, limits on ability to freely engage in community activities; or
  - Settings that provide for daytime activities primarily with other people with disabilities
- Examples: DD facilities, psychiatric hospitals, nursing homes, adult care homes, sheltered workshops, segregated day 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

**Need for Olmstead Enforcement**

- Despite progress, too many people with disabilities still remain unnecessarily in institutions or other segregated settings
  - Including DD facilities, psychiatric hospitals, nursing homes, board and care homes, sheltered workshops, and other segregated day settings
- Many others at serious risk of entering institutions or segregated settings
  - Including people on waitlists for services, repeatedly using emergency rooms or interacting with police during a mental health crisis, homeless individuals with disabilities, or students in the school-to-sheltered workshop

**Olmstead as a “Tool” to Address These Problems**

- Using Olmstead to create statewide, systemic reform activities:
  - Increasing the capacity of community services that are critical for successful community tenure
  - Expanding the supply of affordable, permanent community housing

**Olmstead as a “Tool” to Address These Problems**

- Ensuring that individuals are given a meaningful choice for the most integrated setting
  - Ongoing “in reach” to people in segregated settings:
    - Education about integrated housing and services
    - Visits to integrated settings and virtual tours
    - Engagement with peers who have transitioned
    - Family-to-family supports
Range of Olmstead Activities

- Challenges around a wide range of settings: public and private psychiatric facilities, nursing homes, and DD facilities; private board and care homes; sheltered workshops; segregated educational facilities
- Wide range of populations: adults and children with psychiatric, intellectual, developmental, and physical disabilities
- On behalf of people currently segregated and at risk of being segregated

Range of Olmstead Activities (cont’d)

- Active enforcement by Department of Justice and private plaintiffs
- Enforcement activities include:
  - In court litigation and court decisions
  - Statewide settlement agreements
  - Guidance from the Department of Justice (agency charged with enforcement)

Major Themes from Olmstead Activities

- Not just about moving people out of or preventing their entry into segregated settings; focus on creating quality community alternatives
- Not just about where people live, but also how they spend their days, whether as a student in school or an adult in daytime activities like work or daytime programming.
- Both community services and integrated housing options are essential
- Lack of affordable community housing is one of the biggest barriers to community living; people on SSI “priced out” of most housing without a rental subsidy

Major Themes (cont’d)

- Both Medicaid-funded community services and federal affordable housing programs are critical to Olmstead implementation for adults.
- Rebalancing funding for community services easier than for housing: Medicaid only covers room and board in institutions and cannot pay for rent in the community. Affordable housing critical.
- Need to bring together and engage all relevant players and stakeholders – state disability and Medicaid agencies, state and local housing authorities, disability and homeless providers, housers, consumers, families, children's and education advocates, and homeless and disability advocates

Examples of Olmstead Cases Regarding Residential Services

- People in or at risk of entering public institutions
  - US v. Virginia: Focus on people in or at risk of entering state-operated ICFs. Settlement relief includes HCBS waivers, range of crisis services, integrated housing, family supports, supported employment, and enhanced case mgmt.
  - Other examples: DRNJ v. Veliz (one re psychiatric hospitals, one re developmental centers); US v. Georgia (ICFs and psychiatric hospitals); US v. Delaware (psychiatric hospitals)
- People in or at risk of entering privately operated facilities
  - Steward v. Perry (Texas): Focus on people with IDD in or at risk of entering private nursing homes. Relief includes expansion of HCBS waivers; medical and nursing services in the community; employment and meaningful day activities.
  - Other examples: Ligas v. Hamas (IL) (private ICFs); O'Toole v. Cuomo/US v. NY (adult homes); Williams v. Quinn (IL) (private IMDs)

Types of Non-Residential Settings that Have Been Successfully Challenged Under the ADA

- 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)
**Progression of Olmstead Litigation Regarding Day Services**

- Supported employment services (to facilitate employment in competitive wage jobs in integrated settings) part of remedy for people leaving or diverted from institutions
  - Examples: settlements in GA, DE, NC and VA

- Challenge to over-reliance on providing employment services in segregated settings (i.e., sheltered workshops)
  - Example: *Lane v. Kitzhaber/US v. Oregon*: court found that ADA applies to all of a public entity’s services, including employment; settlement to expand opportunities for integrated employment

**Examples of Olmstead Enforcement Regarding Segregated Educational Settings**

- DOJ Findings Letter against the State of Georgia
  - Statewide educational program where students with behavioral disabilities are educated in separate schools or separate classrooms (usually in separate wings) violates the ADA
    - Causes unnecessary segregation of students with disabilities from their peers
    - Fails to provide equal opportunities to students with disabilities including inferior academic curriculum, less qualified teachers, lack of extracurricular opportunities, and inferior facilities

- S.S. v. Springfield, Massachusetts
  - ADA litigation in federal court challenging segregated day school for students with behavioral disabilities

**Progression of Olmstead Litigation Regarding Day Services (cont’d)**

- Challenge to over-reliance on segregated employment and other day settings (i.e., sheltered workshops and day habilitation); remedy includes expansion of supported employment and “wraparound” integrated non-work day services (typical recreational, social, & educational activities)
  - Example: settlement in US v. Rhode Island

- Future Olmstead litigation will likely challenge over-reliance other types of segregated day services, such as day habilitation and day treatment

**Does Olmstead Require States to Provide a Choice of Segregated Services?**

- Some parents have tried bringing Olmstead claims to stop closures of state-operated ICFs, citing the decision’s language that “there is no federal requirement to impose community services on people who do not want them.”
- Courts have found, consistent with DOJ’s interpretation, that the ADA and Olmstead require states to provide services in integrated settings and not an obligation to provide them in institutions or segregated settings.
- Courts have also found that there is no right to remain in a particular institution or segregated setting if a state chooses to close them.
- This same rationale would apply to segregated day settings.

**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”
  - 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.”
  - To “be a tool to assist states with adhering to the Olmstead mandate and the requirements of ADA”
**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 (residential and non-residential) provided under any of the HCBS authorities
  - 1915(c) waivers
  - 1915(i) HCBS state plan services
  - 1915(k) Community First Choice option
- Applies to all HCBS provided through 1115 Demonstration waivers and 1915(b)(3) managed care

**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

**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

**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

**Settings That Can Never Be HCBS**
- Nursing facilities
- Intermediate Care Facilities for Individuals with Intellectual Disabilities (ICF–IIDs)
- Institutions for Mental Diseases (IMDs)
- Hospitals

**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
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

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 has not provided specific examples of non-residential settings that isolate
  - But it has made clear the “settings that isolate” guidance applies to non-residential settings too

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 – all initial plans were already due to CMS.
- Transition plans may be as long as five years
- Plans may be updated during the transition process.
- To assist states with their transition plans, CMS has issued a “toolkit” with “exploratory questions” for residential and non-residential settings, a description of the “heightened scrutiny” process, and several “Frequently Asked Questions” documents.

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
- Whenever a state substantively amends the plan, the new plan must be put out for public comment.
- THIS IS A CRITICAL OPPORTUNITY FOR ADVOCACY!

CMS Q&A (Dec. 2014):

Public Input

- State must respond to public comments – explaining why it did or did not make a change in response – before submitting transition plan to CMS
- State must seek additional public comment for any substantive change in a transition plan
  - Examples: additional assessment findings, changes in/new milestones, etc.
- States are encouraged to have a process for ongoing transparency and input from stakeholder on implementation of the plan

CMS Q&A (Dec. 2014):

Residential Settings

- Individuals must be given an option of a non-disability specific setting and of a private unit
  - Non-disability specific residential setting includes getting services in own home/apartment or provider owned setting with people with and without disabilities
  - Person-centered plan should document the options and different types of settings considered
- Regulation does not set a size limit for residential settings but states can set size restrictions/limitations
CMS Q&A:
Residential Settings (cont’d)
• Settings on the grounds of or adjacent to private institutions
  not per se unallowable but may be “settings that isolate” (ones
  on the grounds of or adjacent to public institutions are
  presumptively institutional)
  – States can set higher standards and prohibit all residential settings on
    the grounds of any institution

CMS “Exploratory Questions” Regarding
Residential Settings
• Lays out specific questions regarding each required HCBS
  characteristic that states may (but are not required) to use in
  their assessment of residential settings
  – Questions include ones about control over own schedule and
    activities, access to the broader community and transportation,
    choice of roommates, and privacy and autonomy.

CMS Q&A:
Non-Residential Settings
• Although facility and site-based day service settings are not per
  se prohibited, they must be closely examined and may be
  unallowable “settings that isolate”
  – States have flexibility to limit or even prohibit facility or site-based
    day services (including sheltered workshops)
  – Pre-vocational services are not limited to being provided in facility or
    site-based settings (like sheltered workshops) and may be offered in
    the community

CMS Q&A:
Non-Residential Settings (cont’d)
• Day services offered in any institutional setting (ICF, hospital, or
  nursing home) or on the grounds or adjacent to a public
  institution are presumed unallowable
• Day services on the grounds of or adjacent to private
  institutions are not automatically presumed to be non-HCBS
  but must be closely examined and may be unallowable
  “settings that isolate”
  – States have flexibility to limit or even completely prohibit all day
    settings in or on the grounds of all institutions

CMS Q&A:
Non-Residential Settings (cont’d)
• States can get FFP for settings that are not currently in
  compliance with the rule during the transition period
  – January 12, 2015 Joint statement by disability and aging advocates
    (including Bazelon), NASDDDS and ANCOR highlight that this
    guidance addresses misinformation that people are facing imminent
    risk of losing services

CMS “Exploratory Questions” Regarding
Non-Residential Settings
• Lays out specific questions regarding each required HCBS
  characteristic that states may (but are not required) to use in
  their assessment of non-residential settings
  – Questions include ones about geographic location, access to the
    broader community and transportation, opportunities for
    employment, and choice of non-disability specific settings
  – For employment, asks about comparability with other workers to
    negotiate work schedule, get breaks/lunch times, and get leave and
    medical benefits
**CMS “Exploratory Questions” Regarding Non-Residential Settings (cont’d)**

- The nature of day services (clinical/medical vs. rehabilitative vs. employment) as well as the duration (i.e., short-term vs. long-term services) may impact how to comply with the rules
- Whether the “right” service is being provided is relevant
  - For people who want competitive employment, should look at the duration and expected outcomes of the service being provided

**Some Day Service Settings Will Need to Be Closely Examined**

- As recognized in several state transition pans, some day service settings, as currently structured, may have trouble meeting the affirmative requirements of the regulations or have characteristics of “settings that isolate” including:
  - Pre-vocational services in sheltered workshops
  - Day habilitation
  - Day treatment

**CMS Q&A (June 2015): Heightened Scrutiny**

- CMS review the heightened scrutiny request to determine:
  - Each and every one of the affirmative HCBS qualities is met;
  - People in the setting are not isolated from the greater community; &
  - Strong evidence that the setting does not have the qualities of an institution
- CMS’ heightened scrutiny review will require evidence that all participants in the setting are afforded the degree of community integration required by the rule
  - “Providing documentation that a percentage or ‘some’ participants have community access will not be considered sufficient”

**CMS Q&A: Heightened Scrutiny (cont’d)**

- Suggestions of information a state should include:
  - Licensure requirements/state regulations/provider qualifications that are distinct from those required for institutional settings
  - Physical proximity to community resources (stores, library, etc.), activities, and public transportation
  - Service definition that support the HCBS settings requirements
  - Varied schedules based on interest and choice
  - Choice of setting (including choice of a non-disability specific setting)
  - On site visit, including participant interviews conducted by independent entity outside the presence of provider

**CMS Q&A: Heightened Scrutiny (cont’d)**

- To justify allowing an HCBS setting in, on the grounds of or adjacent to an institution:
  - Must prove that there is a meaningful distinction between the facility and HCBS setting and that the latter is integrated in and supports full community access
- To show a setting does not isolate, evidence must prove that:
  - People without disabilities in the same community would consider it part of their community and not associate it with the provision of services to PWD
  - People in the setting regularly engage in community activities other than those organized by a provider and in a way that fosters relationships with community members unaffiliated with the setting

**CMS Q&A: Heightened Scrutiny (cont’d)**

- CMS highly recommends states to conduct site visits
  - Including on-site observations, record reviews, gathering information from stakeholders, and interviews of participants and staff
- Public notice is required for heightened scrutiny requests:
  - State must included in statewide transition plan, listing affected settings by name and location and include any and all justifications from the state (including review reports, interview summaries, etc.)
  - Information must be widely disseminated and subject to formal public comment requirements (including state responding)
### CMS Q&A: Tiered Standards

- States have flexibility to set different standards for existing and new settings through their statewide transition plan
  - Existing settings must meet the minimum standards in the rules but the state “may suspend admission to the setting or suspend new provider approval/authorizations for those settings”
  - State may set standards for “models of service that more fully meet the state’s standards” and set a “tiered standard so that only those [settings] meeting the optimal standards established by the state will be developed in the future”
  - The tiered standard can extend beyond the transition plan timeframe
  - This allows states to “close the front door” to settings/services

### Trends in Statewide Transition Plans

- Most are “plans to plan,” laying out a framework for the assessment process
  - Actual assessment of settings in most states have yet to be completed; in these states, they will have to submit an updated plan to CMS after public comment on the results of the assessment
- Varied approaches to assessing settings
  - Good state plans are using multiple sources of information – regs/certification standards, provider assessments, information from participants and stakeholders, other data sources (like National Core Indicators data) and on-site visits
  - Poor state plans rely primarily on paper review and provider self-assessments (where there are potential conflict of interest issues)

### Trends in State Transition Plans (cont’d)

- Some states are using the HCBS regs are a real opportunity to modernize services to support full integration
  - Including phasing out sheltered workshops, setting size limits on residential settings, and expanding capacity of non-disability specific settings); other states are attempting to keep the status quo
- Varied approach to presumptively institutional settings, especially “settings that isolate”
  - Some states are being rigorous in identifying settings that are presumed institutional (such as settings on the grounds of institutions, campuses, and sheltered workshops)
  - Other states are only identifying settings on the grounds of adjacent to public institutions and have said they will seek “heightened scrutiny” to continue funding these settings

### CMS Responses to State Transition Plans

- CMS has set out the steps for its review of STPs:
  1. Send back plans that do not meet the public comment requirements
  2. Issue a “Clarifications and/or Modification required for Initial Approval” (CMIA) Letter for plans with issues that must be resolved prior to Initial Approval
  3. Give “Initial Approval with Milestones and Resubmission Date” for STPs that are sufficient, but systemic and/or site-specific assessments have not been resolved yet
  4. Give “Final Approval” to STPs that meet public comment requirements and provide all necessary information, including systemic assessment, site specific assessment, settings presumed to have institutional characteristics, information regarding heightened scrutiny or the state’s decision to let the presumption stand, and clear remedial steps with milestones are delineated

### CMS Responses to State Transition Plans (cont’d)

- All states, other than VT and AZ (who have 1115s), have submitted initial STPs
- CMS sent several STPs back this spring/summer for failure to meet public comment requirements
- 36 states have received CMIA Letters
- No STPs have received initial or final approval
- There has been one heightened scrutiny review through an individual waiver renewal and transition plan (North Dakota)

### Themes from CMIA

- Public Comment
  - STPs must include a summary (not just a compilation) of comments; must give specific response to comments (not just “considering it”)
  - Public comment required for completed assessment and HS evidence
- Setting descriptions
  - STPs must include a complete list of settings used in each individual waiver with the # of settings and # of participants in those settings
- Systemic settings assessments
  - STP must crosswalk state standards to each HCBS requirement and note if in compliance, in conflict, or silent; must include plan to remediate when in conflict or silent
Themes from CMIAs (cont’d)

- Individual setting assessments
  - All settings must be adequately assessed; provider self-assessments not enough and must validated; participant surveys must be able to be tied to specific setting (so NCI is problematic); must have criteria for on-site visits
- Heightened scrutiny process
  - Using location alone not sufficient to identify all “presumptively institutional” settings; must have a process for identifying “settings that isolate;” cannot use “private residence” presumption in congregate settings
  - “Choice” not relevant to HS analysis

CMS’ Heightened Scrutiny Review in North Dakota

- North Dakota submitted 3 group homes and 2 apartments (with 10 total individuals) and a day program on the grounds of an ICF through the heightened scrutiny process
  - CMS review included 2 on-site visits, where they meet with the individuals in the settings, their providers, and stakeholders (incl. P&A, the Arc, and UCEDD) and observed the activities of the individuals over multiple days
  - CMS determined that the day program did not overcome the institutional presumption because “the majority of individuals receive most of their services at the facility-based program and are not integrated in the greater community”

What is the Relationship Between the HCBS Rules and Olmstead Compliance?

- States can use the HCBS settings rules to further Olmstead compliance by rebalancing away from providing services in segregated settings and ensuring system capacity to provide all HCBS participants a choice of receiving services in the most integrated setting.
- BUT states’ obligations under Medicaid (including the HCBS settings rules) and the ADA are separate and independent.
  - A determination that a setting complies with the HCBS rules does not necessarily mean that it is an “integrated setting” under the ADA
  - CMS’ approval of a state’s transition plan does not necessarily mean that the state is in compliance with the ADA and Olmstead.

Advocacy to Align States’ HCBS Transition Process with Olmstead Compliance

- Transition plans are an opportunity to move your state’s system towards real integration and community membership and further Olmstead compliance.
- HCBS rules create an opportunity for expansion of services like supportive housing and supported employment.
  - HCBS rules require that all HCBS participants be given an option of a non-disability specific setting. Advocates should ensure that state transition plans include an evaluation of existing capacity in such settings and a plan to expand capacity as needed to meet this requirement.
Advocacy to Align States’ HCBS Transition Process with Olmstead Compliance (cont’d)

- Ensure that states carefully examine all settings for compliance with HCBS requirements and identify residential and day program settings presumed to be non-HCBS
  - These settings include settings in/on the grounds of/adjacent to institutions and “settings that isolate”

Advocacy to Align States’ HCBS Transition Process with Olmstead Compliance (cont’d)

- Actively comment on any settings identified (or that should be identified) through the “heightened scrutiny” process
  - Use the “exploratory questions” as a framework
  - Comment at the state level; if state not responsive, comment to CMS
- Encourage your state to set high standards for implementing the HCBS rules.
  - The HCBS rules set the floor; states can set higher standards.
  - For example, states could prohibit settings in/on the grounds/adjacent to institutions, set size or concentration limits for residential settings, or limit/prohibit facility-based programs like sheltered workshops.

Workforce Innovation and Opportunity Act

- Goal is to increase employment of people with disabilities in integrated employment settings; attempts to significantly limit the use of 14(c), particularly for transition-age youth:
  - Defines and prioritizes integrated employment as work at or above minimum wage, with wages and benefits comparable to people without disabilities and fully integrated with co-workers without disabilities
  - Requires anyone under 24 to explore and try integrated employment before they can be placed in a sub-minimum wage setting; prohibits schools from contracting with sub-minimum wage providers
  - Align with expectation of inclusion students with disabilities

WIOA (cont’d)

- Additional relevant provisions to increase access to integrated employment for people with disabilities:
  - Requirement for formal cross-agency cooperative agreement between voc. rehab., state IDD agency, and Medicaid agency
  - Requirement that at least 15% of voc. rehab. funds be used for pre-employment transition services
  - Definition of supported employment clarified to make clear that it is integrated, competitive employment
  - Post-employment support services extended from 18 to 24 months
  - Requirement that at least half of supported employment state grant funds used to youth (up to age 24) with most significant disabilities
- Recent NPRMs from DOL and DoEd

WIOA (cont’d)

- Created Advisory Committee on Increasing Competitive Integrated Employment for Individuals with Disabilities
  - Representatives include federal agencies (DOL, CMS, SSA, RSA), providers, national experts, representatives from national disability advocacy groups, and self-advocates
  - Charged with making recommendations about way to increase competitive integrated employment for people with significant disabilities and about use of 14(c) certificates for subminimum wage
  - Interim report with findings, conclusions and recommendations sent to Congress and the US Labor Secretary September 15, 2015
WIOA (cont’d)

- Highlights of recommendations in Interim Report:
  - Transitions to Career Subcommittee: increasing early work experiences, postsecondary education opportunities, and creating family expectations for competitive integrated employment (CIE)
  - Complexity and Needs Subcommittee: aligning federal policy, practice and funding to prioritize and incentivize CIE, addressing real and perceived disincentives to employment caused by concerns about loss of benefits, and improving quality through development of uniform outcome measures

So What Does A Real Life in the Community Look Like?

Key Principles of Community Integration

- Developed in May 2014 by the Bazelon Center, the “Key Principles” represent a consensus of 28 national cross-disability organizations about what community integration is.
- General principles:
  - Have the opportunity to live like people without disabilities: have a job, a place to call home, and community engagement with friends and family
  - Have control over their own day (work, education)
  - Have control over where and how they live

Key Principles of Community Integration (cont’d)

- Employment: Opportunity to work in non-segregated regular workplaces at the same wages as people without disabilities. Access to services to support employment as needed and a choice other than segregated day services.
- Housing: Opportunity to live in own home with supports, not just congregate housing or complexes for people with disabilities. Decide where live, with whom, control over daily activities, and housing not conditioned on services/treatment.
- Choice: Opportunity to make informed choice – requires full and accurate information including opportunities to visit integrated settings, connect with peers in those settings, explore and address any concerns.
- Public funding: Should support these principles. Currently, public funding has institutional bias.

What Does Evan’s Life Look Like?

- Inclusion in school and community growing up
  - Participation in extracurricular school activities (like the marching band), as well as Special Olympics
  - Attended sleep away summer camp, first as a camper then as a staff member
  - Active in our synagogue
  - Focus and expectation throughout school was independent living and a job after graduation
What Does Evan’s Life Look Like? (cont’d)

• Lives independently in his own apartment, with a roommate of his choice
  – Has supported from a case manager who helps with independent living skills (grocery shopping, budgeting, transportation, etc.)
• Works at a fitness center at a community center.
  – Has support from a job coach and natural supports from co-workers.

What Does Evan’s Life Look Like? (cont’d)

• Active social life
  – Has a girlfriend, recreational activities (works with a trainer at the gym, bowling league), and part of acting group.
• Engaged self-advocate
  – Member of Georgia Council on Developmental Disabilities and graduate of “Partners in Policymaking”
• Beloved and valued family member
Key to the Successes in Evan’s Life

• High expectations for Evan throughout his life
• Strong family support, including a willingness to allow him to take risks and fail
• Strong natural supports – close relationships with co-workers, neighbors, community members who know and care about Evan
• Encouraging Evan to advocate for himself
• Evan’s determination, tenacity and great personality.

Challenges in Evan’s Life

• Having to overcome low expectations or stereotypes by other people.
• High turnover of support staff. It is hard to repeatedly build trusting relationships.
• Handling change; changes in routine are hard for him to handle.
• Finding the job that was the right fit for him.

Take Aways

• Recent federal polices – the HCBS rules, recent Olmstead enforcement, and WIOA – have created opportunities to transform states’ IDD systems to better support integration, employment, and inclusion of people with disabilities.
• Advocate, advocate, advocate!!! Stakeholders must have a voice and can influence how these federal policies are implemented at a state level.

Resources

• Olmstead resources:
  – www.ada.gov/Olmstead (Department of Justice)
  – http://www.bazelon.org/Where-We-Stand/Community-Integration.aspx (Bazelon Center)
• HCBS Settings Rule resources:
  – www.hcbsadvocacy.org (sponsored by national advocates)
  – www.medicaid.gov/hcbs (CMS)
• WIOA resources:
  – www.doleta.gov/WIOA/ (Department of Labor)
  – www2.ed.gov/about/offices/list/osers/rsa/wioa-reauthorization.html (Department of Education, RSA)
  – www.dol.gov/odep/topics/WIOA.htm (Advisory Committee)