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Gaining Stakeholder and Provider Buy-In of the HCBS Settings Rule, Including Examples for Educating Consumers, Families and Members

Division of Long-Term Services and Supports
Disabled and Elderly Health Programs Group
Center for Medicaid and CHIP Services

Objectives for Today's Session

- Explore viable alternatives to assist states in encouraging stakeholder and provider buy-in of the home and community-based services (HCBS) settings rule, its underlying principles and values, and the resulting changes that will impact system transformation;
- Share two states' experiences in helping to transform their HCBS systems through their commitment to stakeholder engagement;
- Include other examples of education, training and technical assistance that states have provided for stakeholders.

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The Goal: Community Inclusion

The underlying principle of the Home and Community-Based Services (HCBS) settings rule is

COMMUNITY INCLUSION

for all Medicaid HCBS participants.

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Create Transparency through Communication

More information leads to:

- A better understanding of the concepts underlying the settings rule;
- More opportunity to ask questions to resolve confusion, offer insight and suggestions;
- Greater likelihood that stakeholders will learn from their peers and the perspectives of others engaged in the goals, delivery and utilization of HCBS.

KNOWLEDGE EMPOWERS PEOPLE!!

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Knowledge Empowers People!

- States can accomplish transparency in a variety of ways:
  - Meetings, open door forums, conference calls;
  - Help desks;
  - Chat rooms;
  - Blogs, emails;
  - Newsletters;
  - Access to state "decision-makers";
  - Creating communities of practice for families, individuals served, providers, etc.

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Education, Training and Technical Assistance for All Members of the Stakeholder Community

VIRGINIA

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VIRGINIA'S MEDICAID PROGRAM
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Virginia: Stakeholder & Provider Buy-In

Managing Culture Change

HCBS is Systems Change

Systemic Change "a fundamental change in policies, processes, relationships, and power structures, as well as deeply held values and norms"

Srik Gopal & John Kania

Systemic Change required a change in Culture

Change Fatigue

Among the biggest obstacles to successful change is **"change fatigue"** (which occurs when people are asked to follow through on too many changes at once) and a lack of the capabilities needed to make major changes last.

Change Fatigue Report

- *2016 Redesign of the Developmental Disability Waiver*
- *Department of Justice Settlement Agreement*
- *New Expectation for providers and support coordinators*

Approach

- Start the change process with people who have disproportionate influence; get their buy in and shine the light on their success
- Look for ways to get people to experience the harsh realities that make change necessary
- Look for ways to redistribute resources toward "hot spots" – activities that require few resources but result in large change

"The Wall Street Journal Guide to Management"
by Alan Murray, published by Harper Business.

Providers

- Buy-in on the front end
- Provider Self-Assessment Process
- Organizational compliance
  - HCBS rights policy
  - Individual disclosure
  - Staff training
- Additional indicators of compliance
- Settings compliance
- Acknowledge challenges
- Education, Education, Education

Engage Stakeholders

- Developmental Disabilities Council
- The Virginia Arc
- Regional Quality Councils
- Going On The Road!
- University Center for Excellence in Developmental Disabilities
- Centers for Independent Living
- Virginia Network of Private Providers
- Education, Education, Education

Individuals & Families

Barriers

- Low expectations
- Concerns about health and safety
- Becoming legal guardian

Outreach

- Talking with individuals
- Talking with families
- Sharing information
- Education, Education, Education

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HCBS is Systems Change (cont.)

MANAGING COMPLEX CHANGE

Vision +	Skills +	Incentives +	Resources +	Action Plan	=	CHANGE
	Skills +	Incentives +	Resources +	Action Plan	=	CONFUSION
Vision +		Incentives +	Resources +	Action Plan	=	ANXIETY
Vision +	Skills +		Resources +	Action Plan	=	GRADUAL CHANGE
Vision +	Skills +	Incentives +		Action Plan	=	FRUSTRATION
Vision +	Skills +	Incentives +	Resources		=	FALSE START

Managing complex change requires FIVE COMPONENTS.

Source: The Managing Complex Change model was copyrighted by Dr. Mary Lippitt, founder and president of Enterprise Management Ltd., is 1987.

What We Learned

The Toolkit can be located from the home page of the DMAS website: www.dmas.virginia.gov

*6,500 page views since going live 9/10/18

A Public Policy Perspective

Public Policy: Laws, regulations and rules that **reflect societal values.**

Public policy *is the means by which a government maintains order or addresses the needs of its citizens through actions defined by its constitution.*

David White
What is Public Policy?

Education, Education, Education

A Historical Perspective: The Deep Dive

Buck v. Bell, 274 U.S. 200 (1927)

"Carrie Buck is a feeble minded white woman who was committed to the State Colony above mentioned in due form. She is the daughter of a feeble minded mother in the same institution, and the mother of an illegitimate feeble minded child."

- "A decision of the United States Supreme Court, written by Justice Oliver Wendell Holmes, Jr., the Court ruled that a state statute permitting compulsory sterilization of the unfit, including the intellectually disabled, "for the protection and health of the state" did not violate the Due Process clause of the Fourteenth Amendment.
- "It is better for all the world, if instead of waiting to execute degenerate offspring for crime, or to let them starve for their imbecility, society can prevent those who are manifestly unfit from continuing their kind."

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A Historical Perspective: The Deep Dive (cont.)

- **Ugly laws** - state laws which stated that persons with specified disabilities are “unfit for citizenship.” Some of these laws were called **unsightly beggar ordinances** and made it illegal for persons with "unsightly or disgusting" disabilities to appear in public.

- States laws that permitted school districts to **exclude** children with disabilities when school officials determined that it was too much of a burden or “inexpedient” to serve them, or because they produced a “nauseating” effect on others.

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A New Era in Disability Policy Emerges

1970's – a time of significant change representing changing attitudes, values and the start of the disability rights movement. This was partially spearheaded by returning Vietnam vets and other disability rights leaders.

- **Section 504 of the Rehabilitation Act**
- **PL-94 142: The Education of All Handicapped Children Act**
- **The 1990 Community Integration Mandate of the ADA**
- **The 1999 United States Supreme Court decision in Olmstead v. L.C.**

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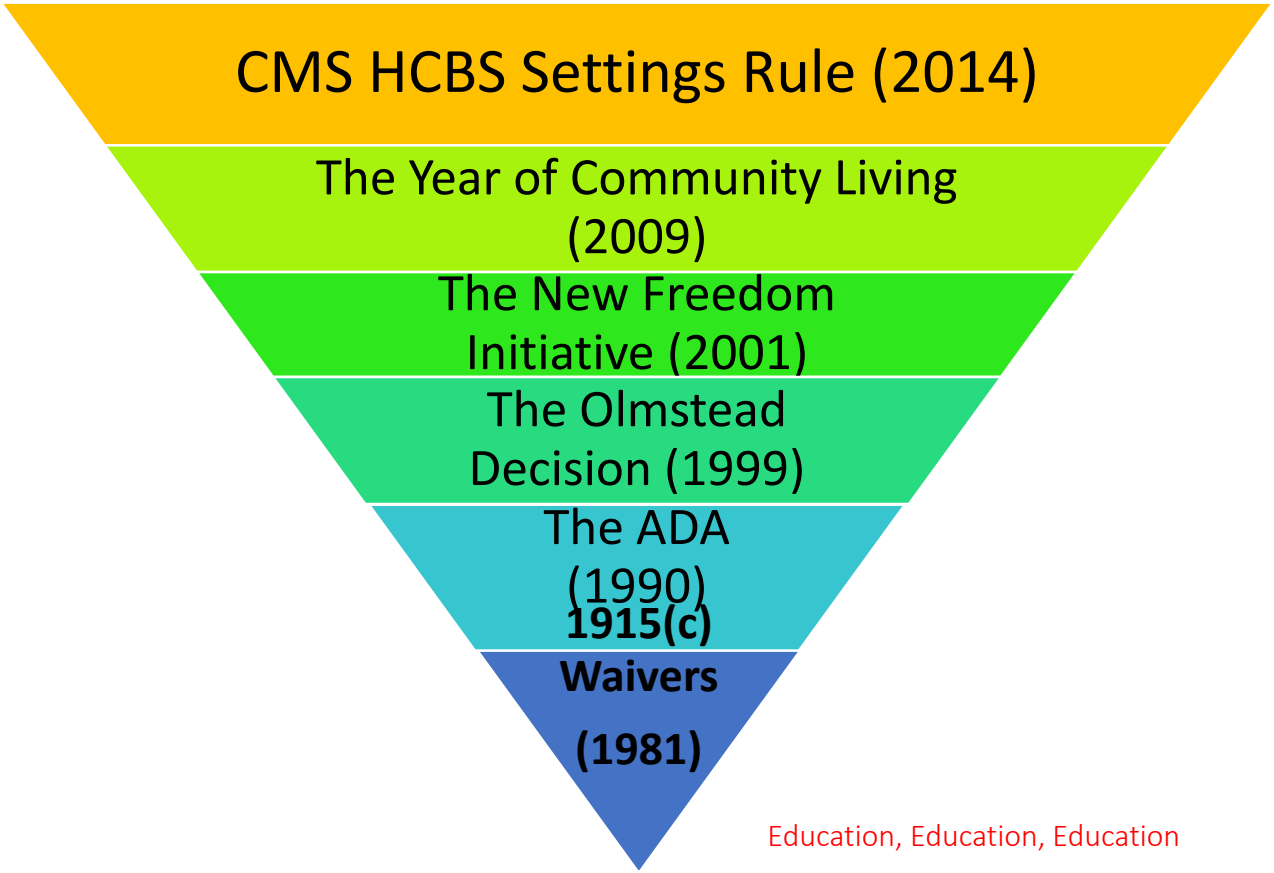
Public Policy



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The Message

- HCBS regulations are a much needed modernization of our home and community based services system.
- We must all change, grow and do better.
- Innovation in HCBS is possible.
- The lives of individuals receiving HCBS depend on it.
- We will not compromise on *real* systemic and cultural change.

Education, Training and Technical Assistance for All Members of the Stakeholder Community

IDAHO

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FROM TRANSITION TO TRANSFORMATION

Idaho's lessons learned in the HCBS state transition process

SO THE JOURNEY BEGINS – THE BLESSINGS OF FEDERAL REGULATIONS AND LAWSUITS

- KW vs Armstrong and HCBS final rule -
- How compliance with Federal regulations and the KW settlement agreement supported the opportunity for transition and transformation.

IDAHO SERVICE PROVIDERS IMPACTED BY HCBS TRANSITION

- Residential assisted living facilities
  - Provider owned or controlled
- Certified Family Homes serving non-family
  - Home setting where participant lives in CFH provider's home
- Developmental Disability Agencies
  - Agencies teaching functional and behavioral skills in the home, community, or center
- Adult Day Health
  - Center and community based support

THE CHALLENGES OF CHANGE
"BUT WE'VE NEVER DONE IT THAT WAY BEFORE."

- Getting the word out – information broadcasting
  - Methods of information distribution
    - Webinars
    - Email
    - USPS
    - MedicAide Newsletter
    - In-person meetings
- Tell us what you think – providing two way communication platforms
  - Email address
  - Phone lines
  - Staff contact information

THE CHALLENGES OF CHANGE "BUT WE'VE NEVER DONE IT THAT WAY BEFORE." (CONT.)

- Carrot vs Stick – **ASSISTING** providers with compliance
  - Assessing the gaps
    - In Idaho Administrative Procedures Act (IDAPA)
    - Phone interviews with providers to identify potential service gaps
  - Self assessment tools – sent to every provider prior to onsite assessment
  - Onsite assessments
  - Technical assistance –
    - Allowing time to come into compliance
    - State staff providing guidance and assistance for compliance
- Continuing the march – ongoing oversight

THE TRANSITION PLAN IS APPROVED NOW THE TRANSFORMATION

Putting the right people first
Community NOW! – a deliberate change in focus

- Putting self-advocates "at the front of the line."
  - Community NOW!
    - Designed to make the voice of the adult with intellectual and developmental disabilities the focus
  - Statewide listening tours and training
  - MyChoiceMatters.Idaho.gov
- Be careful what you ask for – CNOW recommendations for systems change
  - MyChoiceMatters.Idaho.gov

CULTURAL TRANSFORMATION

- Presumed competence
- Person-centered thinking
- Supported Decision Making
- Individual rights
- Quality outcomes - how adults with intellectual and developmental disabilities view the services they receive

CONTINUING THE JOURNEY

Pushing the ball forward one inch at a time.

"And let us not be weary in well doing: for in due season we shall reap, if we faint not."
St. Paul

Additional Resources from States' Work With Stakeholders (1 of 5)

- **DC:** posts annual updates from their STP for public comment, including a tracked changes version as well as an update on the validation results for each setting and their progress in remediating issues of non-compliance. See: https://dhcf.dc.gov/release/public-notice-district-columbia-home-and-community-based-services-settings-statewide
- **MN:** created a provider practice guide (organized by setting categories) to help providers not only come into compliance with the HCBS requirements, but to also elevate the conversation to improving service delivery; created a portal for providers. See: https://mn.gov/dhs/assets/102517-hcbs-best-practices-guide_tcm1053-318393.pdf

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Additional Resources from States' Work with Stakeholders (2 of 5)

- **CO:** has an online virtual provider assessment, validation, remediation program so providers can complete questions and upload information for a transparent, consistent tracking system.
- **NC:** has a page for the Participant Survey Experience including a brief explanation, a link to a survey presentation, the slides, and methods of completing the survey, including online. See: https://www.ncdhhs.gov/about/department-initiatives/home-and-community-based-services-final-rule/survey-my-individual
- **OH:** has all Heightened Scrutiny packages listed on its website for review; categorized by residential and non-residential, then by county. See: https://www.medicaid.ohio.gov/INITIATIVES/HCBS-Transition#1885208-non-residential-settings

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Additional Resources from States' Work with Stakeholders (3 of 5)

- **HI:** uses stakeholder involvement at various points in the assessment and validation review process. My Choice, My Way work group reviews and approves all findings when sites are elevated for heightened scrutiny. State includes self-advocates and family members as part of the heightened scrutiny review team. See: https://medquest.hawaii.gov/en/members-applicants/already-covered/my-choice-my-way.htm
- **KY:** enlists the assistance of self-advocates and families in the design of the validation approach to provider self-assessments; uses stakeholder work groups to help review provider transition plans and evidentiary packages that have been submitted by providers for heightened scrutiny review.

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Additional Resources from States' Work with Stakeholders (4 of 5)

- **TN:** has developed a unique approach to stakeholder engagement partnering with providers and contracted entities to review settings for compliance and to engage advocacy organizations in the review process.
- **WA:** stakeholders are one of the information sources used to identify a setting for potential Heightened Scrutiny.
- **WY:** developed materials that included Transition Taskforce Member input on key areas of compliance. "The WY HCB Setting Changes-Improving Lives: HCB Setting-Improvement Strategies, Guidance for Case Managers, Providers, Participants, & Guardians" http://www.mrsi.org/HCBS%20Changes%20Improving%20Lives.pdf

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Additional Resources from States' Work with Stakeholders (5 of 5)

- **TX:** works with an IDD System Redesign Advisory Committee to design and implement an acute care services and LTSS system for people with IDD that includes goals such as providing Medicaid services to more people in a cost-efficient manner, by providing the type and amount of services most appropriate to the person's needs, improving access to services and supports, and improving assessment of each person's needs, available supports and functional needs.

See: https://hhs.texas.gov/about-hhs/leadership/advisory-committees/intellectual-developmental-disability-system-redesign-advisory-committee

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Specific Topics Addressed by States (1 of 2)

- "About the Rules for Home and Community-Based Settings": HI, OH, UT
- "Guidance on Achieving Compliance for Settings": AK
- "Frequently Asked Questions (FAQs)": CA, CO, HI, OR, VA, WI
- "What Does This Mean for Me? Information for Consumers": OH
- "Information for Advocates": TN, UT, WA, WY
- Newsletters Q and As: IN, NY

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Specific Topics Addressed by States (2 of 2)

- November 8, 2018 webinar: "Innovative State Approaches to Promoting Compliance with the Federal HCBS Settings Criteria", ACL shared a slide entitled "Public Engagement: *Promising State Strategies"* which includes 11 examples from many states. See: ACL HCBS TA Series—Consolidated Slide Deck FINAL_(11-8-2018).pdf. See also https://hcbsadvocacy.org/learn-about-the-new-rules/

  ACL three part Setting Rule Webinar Series.
- During the same webinar, ACL provided the following resources: Advocacy Toolkit: http://hcbsadvocacy.org

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Resources (1 of 8)

CMS Central Office Contact—Division of Long-Term Services and Supports:

- **HCBS@cms.hhs.gov**

HCBS Statewide Transition Plan Website:

- **https://hcbsstp.com**

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Resources (2 of 8)

State Resources: About the Rules for HCBS Settings:

- **HI: HCBS Final Rule Summary:** https://medquest.hawaii.gov/en/members-applicants/already-covered/my-choice-my-way.htm
- **OH: Overview of HCBS Regulations:**

http://dodd.ohio.gov/_layouts/15/osssearchresultscustom.aspx?k=Easy%20Read%20Guides

- **OH: Inclusive Service Delivery**

http://dodd.ohio.gov/Training/Lists/Course%20Catalog/DispForm.aspx?ID=33

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Resources (3 of 8)

- **UT: Key Provisions of the HCBS Rule:**

https://health.utah.gov/ltc/hcbstransition/Files/HCBS_Rule_and_Transition_Planning_Resources.pdf

State Resources: Guidance on Achieving Compliance for Settings:

- **Alaska: Fact Sheet: Achieving Settings Compliance:**

http://dhss.alaska.gov/dsds/Documents/transitionPlanHCBS/EvidenceofCompliance.pdf

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Resources (4 of 8)

State Resources for Frequently Asked Questions:

- **CA: HCBS FAQs, General, Consumer-Related and Provider-Related:** https://www.dds.ca.gov/HCBS/HCBS-Rules-FAQ.cfm
- **CO: Facts on HCBS Settings Requirements:**

https://www.colorado.gov/pacific/sites/default/files/FAQ%204-Employment%20Final%201-31-19.pdf

- **HI: Next Steps for Consumers, Providers, Advocates:**

https://medquest.hawaii.gov/content/dam/formsanddocuments/resources/member-resources/my-choice-my-way/MyChoiceMyWay.pdf

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Resources (5 of 8)

- **OR: Specific HCBS Resources:**

https://www.oregon.gov/DHS/SENIORS-DISABILITIES/HCBS/Pages/Resources-Oregon.aspx

- **OR: Frequently Asked Questions:**

https://www.oregon.gov/DHS/SENIORS-DISABILITIES/HCBS/Documents/HCBS%20FAQs.pdf

- **VA: HCBS Toolkit FAQs:** https://www.dmas.virginia.gov/files/links/1731/FAQ%20All%20Settings.pdf

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Resources (6 of 8)

WI: FAQs About Door Locks in Adult Long-Term Care Residential Settings:
https://www.dhs.wisconsin.gov/publications/p01817.pdf

State Resources: Information for Advocates:

- **TN: HCB Settings and Person-Centered Planning for Advocates and Families:**

https://www.tn.gov/content/dam/tn/tenncare/documents/NewRulePresentationforConsumersFamilies.pdf

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Resources (7 of 8)

- **UT: An Advocate's Guide to Consumer Rights:**

http://nsclcarchives.org/wp-content/uploads/2014/04/Advocates-Guide-HCBS-Just-Like-Home-05.06.14-2.pdf

- **WA: Informing Families:**

https://www.dshs.wa.gov/dda/resource-links

- **WY: HCB Settings for Advocates and Families:**

https://health.wyo.gov/wp-content/uploads/2017/01/HCB-Setting-Changes-Improving-Lives-Final.pdf

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Resources (8 of 8)

State Resources: Newsletters:

- **NY: OPWDD Newsletter:**

https://opwdd.ny.gov/sites/default/files/documents/2019_Spring_News.pdf

- **IN: Newsletters:**

https://www.in.gov/fssa/da/4917.htm

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Questions and Answers

Feedback

Please complete a brief survey to help CMS monitor the quality and effectiveness of our presentations.

Please use the survey link: https://www.research.net/r/GNGRNGT

WE WELCOME YOUR FEEDBACK!!

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