

Strengthening Advocacy in the HCBS Settings Rule

Kate Brady, PhD ABD

Project Manager for HCBS Stakeholder Engagement

[National Center on Advancing Person-Centered Practices and Systems](#)

[Human Services Research Institute](#)

September 23rd, 2022





NCAPPS

Welcome

This is first in the Administration for Community Living's (ACL) Webinar Series on the role of stakeholders in ensuring high quality in Home and Community Based Services (HCBS) services.

In this session we invite you to hear the vision the administration has for advancing engagement with stakeholders and thereby the experiences of people receiving supports.

We will look at the rationale for engagement, the pathways available for input, and some model approaches for giving and receiving stakeholder feedback.



NCAPPS

Agenda

- Welcome and participant poll
- Alison Barkoff
 - *Principal Deputy Administrator currently serving as ACL's Acting Administrator and as the Acting Assistant Secretary for Aging.*
- Jill Jacobs
 - *Commissioner of ACL's Administration on Disabilities.*
- HCBS Settings Rule Stakeholder Engagement Overview
- Nancy Thaler
 - Senior Policy Advisor to ACL
- Model approaches to stakeholder engagement
- Questions and Answers
- Closing Poll

Webinar Logistics

- Participants will be muted during this webinar. You can use the **chat** feature in Zoom to post questions and communicate with the hosts.
- Toward the end of the webinar, our speakers will have an opportunity to **respond to questions** that have been entered into **chat**.
- The webinar will be live captioned in English.
 - Live English captions can be accessed by clicking the “CC” button at the bottom of your Zoom screen.
- This live webinar includes polls and evaluation questions. Please be prepared to interact during polling times.



NCAPPS

Alison Barkoff

Principal Deputy Administrator currently serving as ACL's Acting Administrator and as the Acting Assistant Secretary for Aging.

VISION FOR STAKEHOLDER ENGAGEMENT WITH HCBS

Jill Jacobs - *Commissioner of ACL's Administration on Disabilities.*

AOD VISION FOR STAKEHOLDER ENGAGEMENT WITH HCBS



The What and Who of HCBS

What are Home and Community-Based Services (HCBS)?

HCBS provide funded support for:

- Employment
- Transportation
- Homecare/home health
 - Medications
 - Housekeeping
 - In-home therapy (PT, OT, Speech, etc.)
- Activities of daily living
 - Bathing, dressing, toileting
 - Cooking
- Finances
- Assistive Technology and Home Modifications

Who receives HCBS?

- In 2018 more than 4.7 million people received Medicaid-funded HCBS
- Each state has its own system and decides to which populations they will offer HCBS waivers



Core requirements of the CMS HCBS Final Settings Rule (2014)

- Requires every state to ensure that services meet minimum standards for integration, access to community life, choice, autonomy, and other important consumer protections
- Person-centered planning
- States must receive final Statewide Transition Plan approval.
- All states and settings will be fully compliant with the following regulatory settings criteria:
 - Privacy, dignity, respect, and freedom from coercion and restraint; and
 - Control of personal resources.
- All states and provider-owned and controlled residential settings will be fully compliant with the following regulatory settings criteria:
 - A lease or other legally enforceable agreement providing similar protections;
 - Privacy in their unit, including lockable doors, and freedom to furnish or decorate the unit;
 - Access to food at any time;
 - Access to visitors at any time;
 - Physical accessibility; and
 - Person-centered service plan documentation of modifications to relevant regulatory criteria.



NCAPPS

Corrective Action Plans (State Flexibilities)

- CMS will authorize CAPs to continue federal reimbursement of HCBS beyond the end of the transition period, if states need additional time to ensure full provider compliance with the regulatory criteria NOT mentioned above. These include for example:
 - Access to the broader community;
 - Opportunities for employment;
 - Option for a private unit and/or choice of a roommate; and
 - Choice of non-disability specific settings.
- States must be able to show that their policies and procedures reflect the settings criteria and they have made efforts to implement the criteria to the fullest extent possible and work with CMS on a concrete, time-limited plan to come into full compliance with remaining criteria.
- States should seek stakeholder input when developing CAPs.



Opportunities for Engagement

Now

- Statewide Transition Plans
 - **View STPs:**
<https://www.medicaid.gov/medicaid/home-community-based-services/statewide-transition-plans/index.html>
- Heightened Scrutiny Packages:
 - CMS Site Visits
 - ACL Stakeholder calls

In the future

- Corrective Action Plans
 - States must be able to show that their policies and procedures reflect the settings criteria and they have made efforts to implement the criteria to the fullest extent possible and work with CMS on a concrete, time-limited plan to come into full compliance with remaining criteria.
- Waiver Amendments and Renewals



Who are the stakeholders we need to hear from?

INDIVIDUAL PEOPLE WITH
DISABILITIES THEIR
FAMILIES, AND
NEIGHBORS

ADVOCACY GROUPS:
Parent Groups
Sibling groups
Self-advocate groups.

PROTECTION FROM HARM
RESOURCES:
State Protection & Advocacy
Ombudsman
Adult Protective Services

STATE INDEPENDENT
LIVING COUNCILS
&
CENTERS FOR
INDEPENDENT LIVING



Methods for Engagement



Show up and give in person public comment



Submit written comments from your organization



Coordinate templates for others to use in submitting comments.



Consult partners about submitting joint comments



Call your legislators and other elected officials

Tell us what you have been doing to engage with the HCBS Settings Rule

- Please put in the chat or in this Google Jamboard:
 - https://jamboard.google.com/d/1BK00DAIC_Ix_vFr3dhhpHKuNcwKFI33aQarWIqD3uhw/edit?usp=sharing



NCAPPS

Nancy Thaler

Senior Policy Advisor for the Administration for Community Living

STATE APPROACHES TO STAKEHOLDER ENGAGEMENT



Kirsten Murphy –

Executive Director of the Vermont Developmental Disabilities Council

HOW THE GREEN MOUNTAIN STATE IS INFLUENCING IMPLEMENTATION OF THE HCBS SETTINGS RULE



NCAPPS

Why is Stakeholder Input Important?



Foundational Value

- Nothing about us, without us.

Practical Reality

- Self-advocates and families can see what state agencies can not.



NCAPPS

How does Vermont DDC work with partners?

- **C**onduit for information.
- **C**onvenor of stakeholder meetings & town halls.
- **C**omposer of public comment for sign-on.



NCAPPS

Your State has promised that the DD Council will be involved in quality assurance.

Section 124(c)M

STATE QUALITY ASSURANCE – The Council will participate in the planning, design or redesign, and monitoring of State quality assurance systems that affect individuals with developmental disabilities.



NCAPPS

Act as a Trusted Messenger for the Home and Community Based Services (HCBS) Settings Rule

- **Become subject matter experts!**
 - Read everything -- Your State's waiver, CMS guidance, state quality strategy; not just the State Transition Plan.
- Use every opportunity for **comment**, written or oral.
 - Formal public comment vs. other comment.
 - Share comments widely.



NCAPPS

Act as a Trusted Messenger Regarding HCBS

- **Build partnerships** with other disability groups or HCBS programs – for example, Independent Living
- Explain the settings rule in **plain language**. Ensure that self-advocates and family members know about their new rights in provider-owned settings.
- **Gather Stakeholders** and invite State Decision-Makers – for example, host a “Town Meeting.”
 - Put information in Plain Language
 - Look for stories about services in advance
 - Coach speakers in advance
 - Follow-up with a written summary of key points



NCAPPS

What has the VTDDC done?



Conflict of interest free case management

- State claimed the rule did not apply.
- State asked for “the choice model.”
- State was put under a plan of correction.
- Timeline for the plan was reduced by CMS.

We built a relationship with CMS.

Renewed focus on the Settings Rule

- State filed a plan saying there were no settings that merited heightened scrutiny.
- CMS selected VT for review & a visit this summer.
- CMS asked the Council to host a stakeholder session.

Our relationship with CMS paid off!



NCAPPS

Tips for Stakeholder Engagement

- Set your terms and insist upon them – recording, time, location, etc.
- Ensure a safe space – consider confidentiality & conflicts of interest.

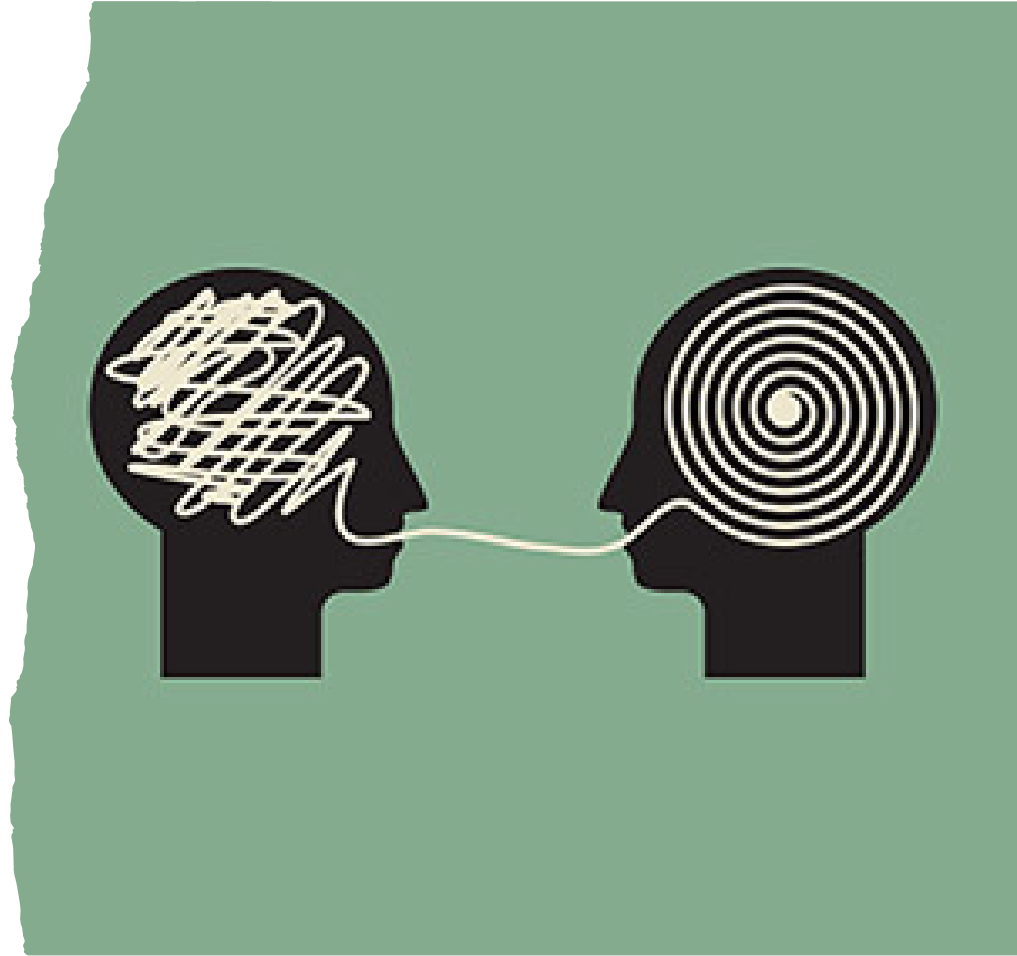




NCAPPS

Tips for Stakeholder Engagement

- Insist meeting materials are accessible.
 - Send materials in advance
 - Need to know vs nice to know
 - Use plain language
- Ask open-ended questions.





PA Stakeholder Engagement



NCAPPS

Lisa Tesler
Sally Gould-Taylor

**September
23, 2022**



PENNSYLVANIA
DEVELOPMENTAL
DISABILITIES
COUNCIL



**Temple
University**

College of Education
and Human Development

Institute on Disabilities

Information Sharing and Advisory Committee

- Led by the Office of Developmental Programs
- Every Day Lives
- Focus on quality
- Broad Stakeholder Group
 - DD Act Network
 - Self Advocates
 - Families
 - Providers

PADDC and Temple Partnership

- Council HCBS Final Rule Grant (2017-2021)
 - Advocacy, education and monitoring
 - Authentic and meaningful implementation of the Final Rule and its underlying philosophies
- Institute on Disabilities at Temple
 - The Institute was awarded this grant and partnered with several statewide organizations including Disability Rights PA, PA Health Law Project and Self-Advocates United as One (SAU1) to carry out the work of the grant.
 - <https://disabilities.temple.edu/programs-services/policy/home-and-community-based-services/hcbs-living-my-life-my-way-mark>

Coalition for Inclusive Community

- Came together to support State Center Closures
- All three DD Network Partners
- Advocacy leaders
 - Self Advocate Organizations
 - Statewide Family Advocacy Groups
 - Centers for Independent Living
 - Arc of PA

Additional Support

- Providing Model Comments
- Convening small groups of families and self advocates
- Explaining HCBS Final Rule
- Providing Plain Language resources
- Social Media Engagement



NCAPPS

How To Contact Us

Lisa Tesler

PA Developmental Disabilities Council

ltesler@pa.gov

Sally Gould-Taylor, PhD

Institute on Disabilities, PA UCEDD

College of Education and Human Development

Temple University

sgould-taylor@temple.edu





NCAPPS

Elouise Woods

Vicki Hicks Turnage

James Tucker – *Director*, Alabama Disabilities Advocacy Program (ADAP)

ALABAMA'S HCBS STAKEHOLDER ENGAGEMENT



NCAPPS

Alabama

- Decided to monitor HCBS settings vigorously
- Incorporated monitoring results into two public comments in Fall 2022 and Spring 2022
- Conducted multiple listening sessions with stakeholders to support public comments
 - In state
 - With Federal Partners



NCAPPS

Alyssa Lee, PsyD - *Public Policy Research and Development
Director*

Georgia Council on Developmental Disabilities

GEORGIA'S HCBS STAKEHOLDER ENGAGEMENT



Resources and Toolkits



HCBS Settings Rule Implementation – Moving Forward Toward March 2023 & Beyond

- Designed for state programs to strengthen their infrastructure and develop stronger HCBS for beneficiaries
- Toolkit contains four modules
 - State strategies to help increase the share of long-term services and supports (LTSS) provided in community-based settings (history/context of LTSS reform and rebalancing)
 - Tools designed to assist states with policy and programmatic strategies (describes key elements of HCBS systems that are economically sustainable and equitable for all individuals with LTSS needs)
 - Cases studies of innovative programs and creative ways states are leveraging available federal authorities to transform LTSS systems (describes the various Medicaid authorities that states can choose from to cover their HCBS programs)
 - Links to resources (provides examples of state models of care and strategies to reform LTSS systems and expand HCBS)
- Go to <https://www.medicaid.gov/medicaid/home-community-based-services/guidance/home-community-based-services-final-regulation/index.html>



This Rule Rules! The HCBS Settings Rule and You

- Published a toolkit for advocates, families, and administrators on how to ensure that people with disabilities receive Medicaid-funded HCBS in integrated settings that offer full access to the community
- Includes four different resources
 - A resource for advocates and their families that explains what the new HCBS rule means and how to make their voices heard as their states make their transition plans. It also includes scripts for writing to their state's Medicaid agencies on how they think their state's HCBS program needs to change
 - A resource for state administrators and professionals on how to come into compliance with the new rule. It includes detailed guidance on the implications of the new rule, suggestions for elements to be included in the transition plan, and examples of useful tools and questionnaires for accessing provider compliance.
 - A research brief explaining how scattered-site supported housing can help states meet the integration and choice standards in the new rule.
 - A fact sheet on integrated housing for people with disabilities.
- Go to <https://autisticadvocacy.org/policy/toolkits/hcbsrule/>



Additional Resources

VIDEOS

- [HCBS Video: Overview](https://www.youtube.com/watch?v=xnbtb5Jpz7c) (7:26 minutes) at <https://www.youtube.com/watch?v=xnbtb5Jpz7c>
- [HCBS Video: What does the Rule Guarantee?](https://www.youtube.com/watch?v=8sJI-LF5ufg) (5:17) at <https://www.youtube.com/watch?v=8sJI-LF5ufg>
- [HCBS Video: Provider Requirements for Residential Settings](https://www.youtube.com/watch?v=sjy334aMXXk&feature=youtu.be) (6:32) at <https://www.youtube.com/watch?v=sjy334aMXXk&feature=youtu.be>
- [HCBS Video: Rights Restrictions & Modifications](https://www.youtube.com/watch?v=Vg5DA_ouOwY) (3:44) https://www.youtube.com/watch?v=Vg5DA_ouOwY
- [HCBS Video: Your Services Should Be All About You](https://www.youtube.com/watch?v=-xqtlIDcAkM) – for people receiving HCBS that discusses rights and choice. <https://www.youtube.com/watch?v=-xqtlIDcAkM>

INTERACTIVE GUIDES

- [HCBS Guide: Your Right To A Community Life](https://www.c-q-l.org/resources/guides/hcbs-guide-your-right-to-a-community-life/) (for people receiving HCBS) <https://www.c-q-l.org/resources/guides/hcbs-guide-your-right-to-a-community-life/>
- [HCBS Guide: Supporting The Right To A Community Life](https://www.c-q-l.org/resources/guides/hcbs-guide-supporting-the-right-to-a-community-life/) (for staff who support people receiving HCBS – focuses on community) <https://www.c-q-l.org/resources/guides/hcbs-guide-supporting-the-right-to-a-community-life/>

Please put any questions in the chat and give us your honest feedback in the on-screen poll.

Thank you.



NCAPPS