



Strategies to Meaningfully Engage Medicaid HCBS Beneficiaries

2020 HCBS Technical Assistance Series
September 3, 2020 3:00-4:30 p.m. ET





Agenda

Opening Remarks

CMS

ACL

Background

Presentations (5)

Q&A/Interactive Discussion



OPENING REMARKS



Michele MacKenzie

Technical Director

Division of Long Term Services & Supports

Disabled & Elderly Health Programs Group

Center for Medicaid & CHIP Services

Centers for Medicare & Medicaid Services

Carlos Villalta

Program Analyst

Office of Policy Analysis & Development

Center for Policy & Evaluation

Administration for Community Living



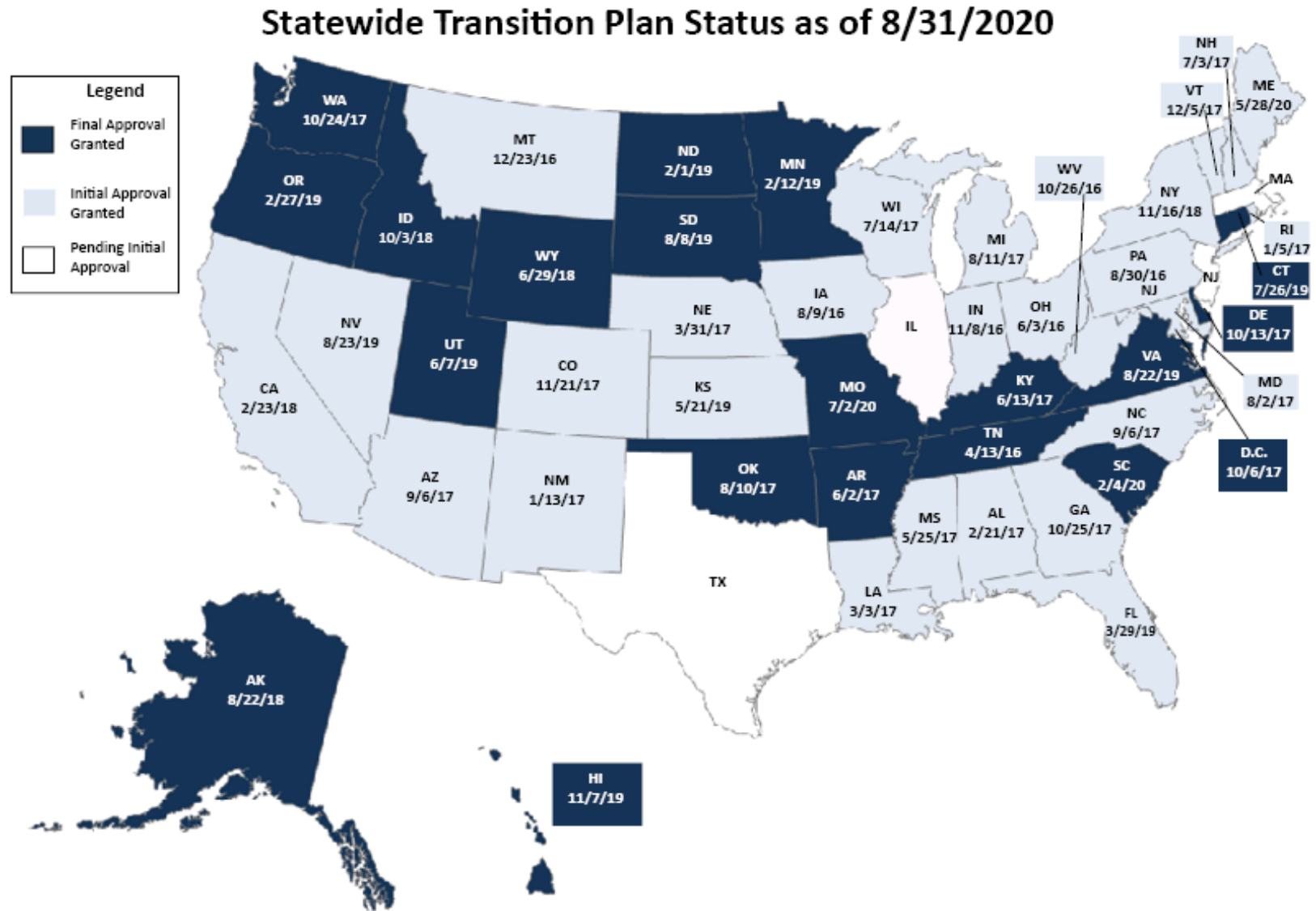
McGaffigan, Erin E., "It's not so Simple: Understanding Participant Involvement in the Design, Implementation, and Improvement of Cash & Counseling Programs" (2011). Graduate Doctoral Dissertations. 55.

HCBS Beneficiary Input Opportunities

Required

- Initial HCBS State Transition Plan
- Heightened Scrutiny
- Final HCBS State Transition Plan
- Major Modifications to HCBS State Transition Plan


21 Final
26 Initial
4 Pending





HCBS Beneficiary Input Opportunities

Suggested

- Quality Improvement
 - Person Centered Systems
 - Service Options
 - Network Adequacy
 - Appeals
 - Grievances
 - Reimbursement
- 

PRESENTERS

HCBS Beneficiary Perspective

Name: Chester Finn

Title: Self-Advocate

HCBS Beneficiary Engagement

Name: Mark Friedman, Ph.D.

Title: CEO

Organization: Blue Fire Consulting, Inc.

Name: Erin McGaffigan, Ph.D.

Title: Principal

Organization: Collective Insight, Policy & Research
Fellow, LeadingAge LTSS Center @UMass Boston

HCBS Beneficiary Education

Name: Jamie Ray-Leonetti

Title: Associate Director of Policy

Organization: Temple University's Institute on
Disabilities

HCBS Coalitions

Name: Kate Brady, Ph.D. ABD

Title: Deputy Director

Organization: Georgia Council on Developmental
Disabilities

HCBS Resources

Name: Alison Barkoff, JD

Title: Director of Advocacy

Organization: Center for Public Representation

HCBS Beneficiary Perspective



Chester Finn
Self-Advocate

HCBS Beneficiary Engagement Frameworks



Dr. Mark Friedman, Ph.D.

CEO

Blue Fire Consulting, Inc.

Why is Engagement Important?

Increased influence/credibility for you

- with funders/politicians

- Stakeholders support



What are the fundamental principles?

- A seat at the table
- “Nothing About Us Without Us.”



Public Comment vs. Engagement?

What is the difference between Public Comment and Engagement?



Plain Language

Reports in Plain Language?



11 TIPS FOR WRITING
**IN PLAIN
LANGUAGE**

How to obtain Beneficiary Engagement?

One time vs. ongoing

One way vs. two-way.

Town Hall Meeting



Ladder of Engagement



Ladder of Engagement

8. Everyone as Partners
7. People as Leaders
6. Leader-Led, People-Driven
5. People as Consultants
4. People as Informants
3. People as Tokens
2. People as Decorations
1. People are Manipulated

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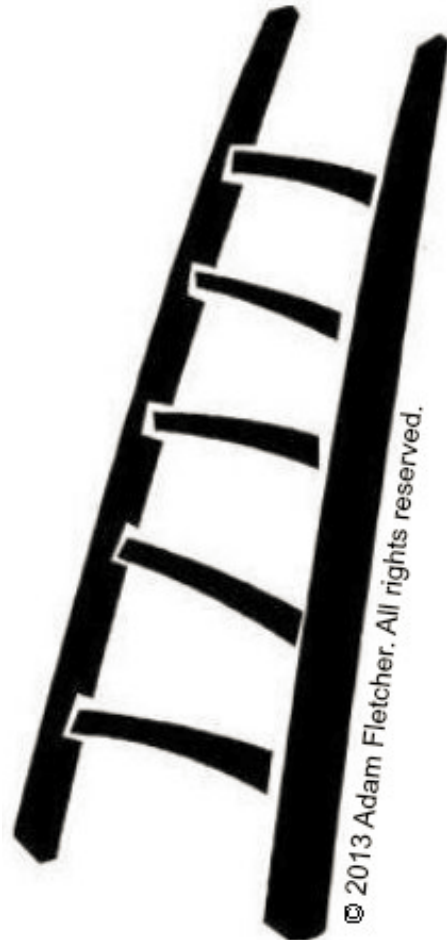


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How to obtain deeper engagement?

Ongoing Collaboration.



Engagement as Partnerships?

Work Groups

Task Forces

Advisory Committees

Ongoing, Two-Way.



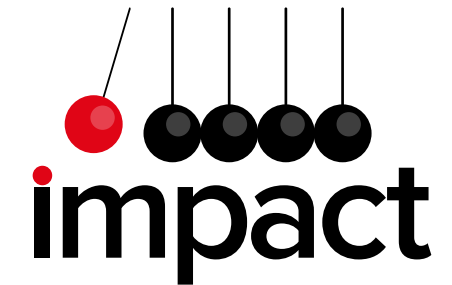
Engagement as Partnerships?

Work Groups

Task Forces

Advisory Committees

Ongoing, Two-Way.



Successful Engagement



References

- Free weekly Zoom training to support beneficiaries. www.disabilityzoom.com
- Guidelines for Participant Engagement (NCAPPS)
https://www.hsri.org/files/uploads/publications/NorthDakotaGuidelinesforParticipantEngagement200729_Accessible.pdf
- Friedman, M., Beckwith, R., & Conroy, J. W. (2016, September). Effective Practices for Supporting Individuals with Complex Needs in Leadership Roles. Journal of Inclusion. Retrieved from
https://www.researchgate.net/publication/308046820_Effective_Strategies_for_Supporting_Individuals_With_Complex_Needs_in_Leadership_Roles
- Engagement Strategies for the Medicaid Population,
<https://www.ipfcc.org/bestpractices/medicaid-engagement.html>.

Making Engagement Work



Dr. Erin McGaffigan, Ph.D.

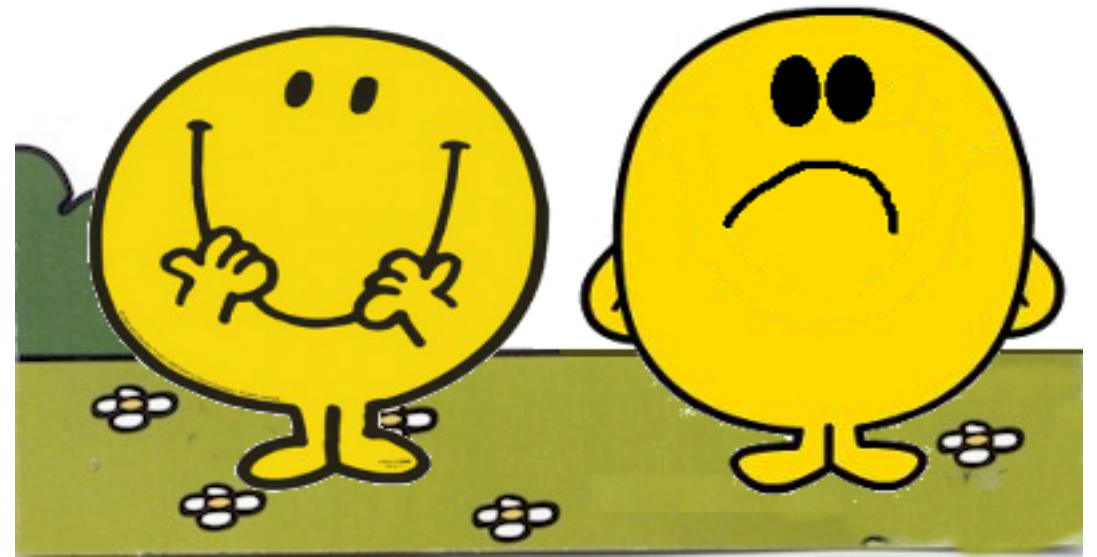
Principal

Collective Insight

Policy & Research Fellow, LeadingAge LTSS Center
@UMass Boston

People often point to good or bad experiences with engagement.

- “It didn’t work for us.”
- “It improved our program.”
- “It takes too much time.”
- “People were angry.”
- “It improved our outreach.”
- “I had no impact.”

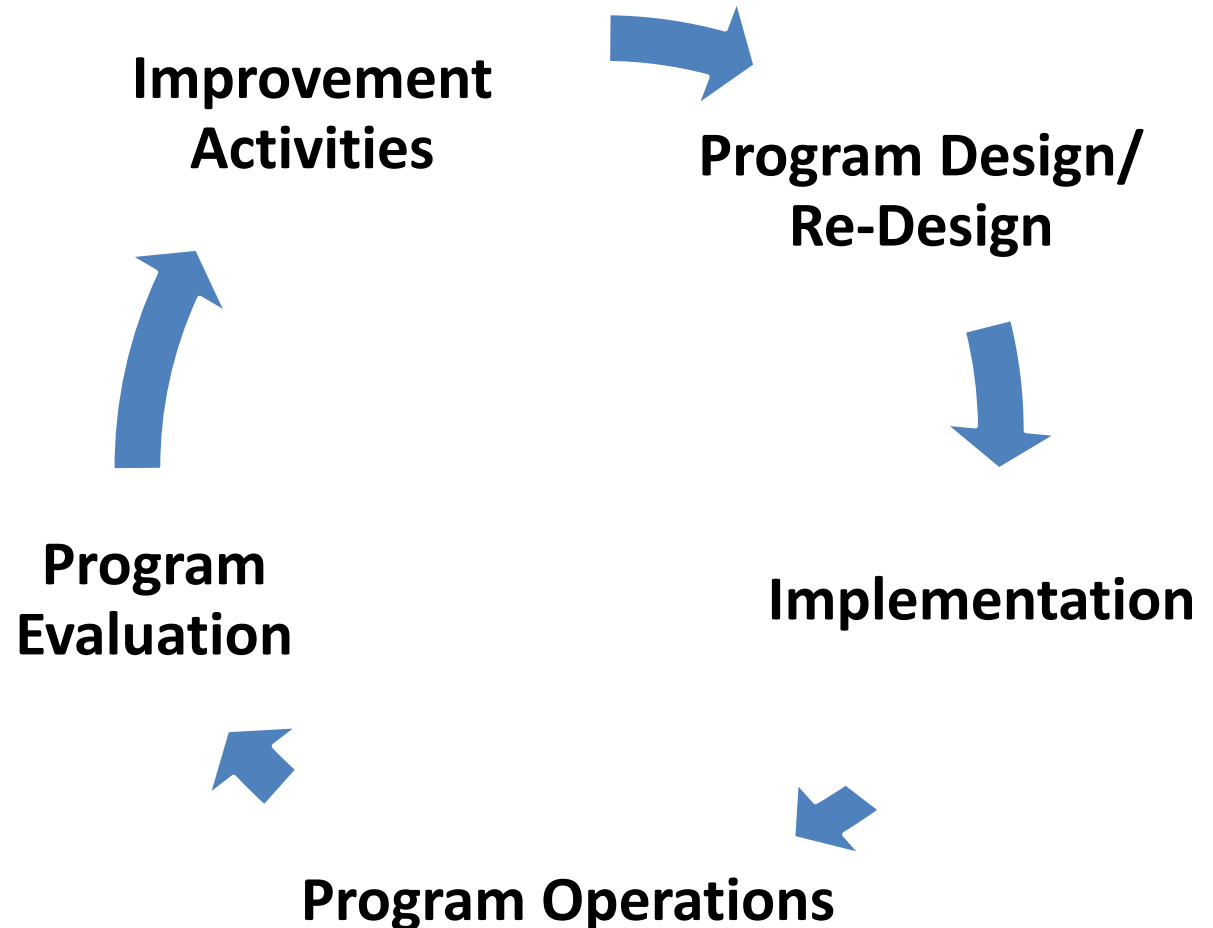


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Let’s review what makes a difference...


Engage early and often to build trust. Engagement is possible (and important) at every phase of program design and improvement.

Make a match between engagement frequency and the windows of opportunity for influencing change.





Plan out your process. The process will matter.

- Identify and address accessibility and cultural needs; create meaningful incentives.
 - Create transparent, two-way communication methods that support timely updates, education, and feedback loops.
 - Use facilitation strategies that support constructive, honest, equal participation.
 - Apply transparent decision-making strategies that strive for consensus building.
 - Devote staff time and resources to make it happen.
- 

There are multiple stakeholder lenses. Think about who may be missing and how to bring them to the table.

- **Beneficiaries**
- **Family Members**
- **Caregivers**
- **Providers**
- **Advocates**
- **Cultural**
- **Language**
- **Age**
- **Disability**
- **Geography**

Who is missing?

How can we reach them?

Who do you represent?

How are you able to represent them?

Do you have a stake in the status quo that should be recognized?

Your goals should inform the engagement approach you choose.

Often Engaged Only Once, One Way

Often Engaged Multiple Times, Two Way

**Surveys/
Interviews**

**Public
Comments**

**Focus
Groups**

**Public
Forums**

**Work
Groups**

**Advisory
Groups**

I'm the Expert. Listen, Learn

We are Experts. Problem Solve

Use more than one approach for broader inclusion.

Key Takeaways

- People's experiences with engagement vary and influence their future desire to be involved.
- Your decisions about timing and process will influence people's experiences.
- Remember that there are multiple stakeholders; don't forget the Beneficiary lens.
- There is more than one engagement method, think about what you are trying to achieve and strive for more than one approach for broader inclusion.

HCBS Stakeholder Education and Advocacy in Action



Jamie Ray-Leonetti

Associate Director of Policy

Temple University's Institute on Disabilities

College of Education And Human Development

jamie.ray-Leonetti@temple.edu




INSTITUTE ON DISABILITIES AT TEMPLE UNIVERSITY

VISION

A society where all people are valued and respected,
and have the knowledge, opportunity and power to improve their lives and the lives of others.

MISSION

We learn from and work with people with disabilities and their families in diverse communities across Pennsylvania to create and share knowledge, change systems, and promote self-determined lives so that disability is recognized as a natural part of the human experience.



THE PENNSYLVANIA HCBS PROJECT

- Addresses system change in HCBS
 - Methods: Education, advocacy, monitoring, reporting
 - Project Lead: Institute on Disabilities at Temple University
 - Funding: PA Developmental Disabilities Council
 - Partners:
 - Disability Rights PA (state P&A)
 - Self-Advocates United as One (SAU1)

PA PROJECT METHODS: ADVOCACY AND EDUCATION

- “Train-the-Trainer” model
- Educate self-advocates and families on importance of HCBS Final Rule
- Trainers are self-advocates and family members
 - Help development of training modules
 - Focus on person-centered planning

PA PROJECT METHODS: MONITORING AND DATA COLLECTION

- Independent Monitoring for Quality (IM4Q) reports used baseline
 - IM4Q collects data through interviews with people with developmental disabilities
 - Quality indicators [National Core Indicators (NCI)] and additional questions
 - Human Services Research Institute's (HSRI) document for select questions most aligned with the Rule
- Aggregate data will be:
 - used in trainings to demonstrate need
 - provided to Disability Rights PA for monitoring
 - shared with the advisory committee for guidance

PA PROJECT METHODS: Engaging Self-Advocates

- Engage early, engage often
- #Inclusion4AllPA Social Media Campaign and Educational Visits



WHAT SELF-ADVOCATES TOLD US ABOUT THEIR ENGAGEMENT


- We want to train each other about the HCBS Final Rule
- We want to design our own training, so that the training is in OUR OWN WORDS
- We want to decide what is important to US about this Rule
- We want a seat at the table, and we want to be heard at the table

SELF-ADVOCATE ROLES

- Decide how training will be delivered
- Decide what training materials will look like and what those materials will say
- Decide who will present the training
- Decide where, when and how training will be given



ENSURING THE SELF-ADVOCATE VOICE IS HEARD AT THE TABLE

- HCBS Project Advisory Committee
 - Virtual Focus Groups
 - PA Office of Developmental Programs – Information Sharing Advisory Committee (ISAC)
- 

LEARNING FROM RENEE – EDUCATION AND ENGAGEMENT IN ACTION



HCBS Coalitions in Action



Dr. Kate Brady, Ph.D. ABD

Deputy Director

Georgia Council on Developmental Disabilities



Our Experience

Engagement


STP



STATE OF GEORGIA
STATEWIDE TRANSITION PLAN



Coalition Characteristics

- Formed partnerships early
 - Engaged often with one another
 - Developed & clarified roles and responsibilities
- 

If nothing else...



Public Comment Process: Ideal

- Publication of Notice
- Public Comment – at least 30 days
- Response to Public Comment



Public Comment Process: Essentials

- Engagement
- Timeline
- Modes and accessibility of input



Public Comments Process: Concerns

- Little to no early engagement
- Highly un-publicized public comment period
- Singular entry points for public comment



Strong STPs Include:

- Data collection
- Settings out of compliance
- Remediation plans
- Heightened scrutiny list
- State budget constraints and regulations hindering HCBS
- Federal obligations strengthening STP



STATEWIDE TRANSITION PLAN

In your STP comments include:

- Settings:
 - Individual
 - Provider owned
 - Non-disability specific
- Remediation
- Ongoing monitoring
- Heightened scrutiny



STATEWIDE TRANSITION PLAN

Resources for Stakeholder Engagement Around the HCBS Settings Rule



Alison Barkoff

Director of Advocacy

Center for Public Representation

abarkoff@cpr-us.org



Center for Public
Representation

HCBS Advocacy Coalition

- HCBS Advocacy Coalition is a coalition of more than 20 national disability and aging organizations working with federal agencies and state advocates to **ensure the successful implementation of the HCBS Settings Rule**. It includes:
 - Self-advocacy, family, provider, aging and other advocacy organizations with networks across the country
 - ACL-funded networks, including the Protection and Advocacy Agencies, DD Councils, Centers for Independent Living, and the University Centers on Disabilities

Stakeholder Education and Engagement is Critical

- The HCBS Settings Rule is an unprecedented opportunity for state stakeholders to help shape the future of their disability service systems
 - People receiving services and their families are in the best place to give input and how current services do or do not meet the rule and areas where gaps in services limit their choices
 - Advocacy organizations are important to identifying systemic issues and engaging self-advocates and families in commenting on state plans
 - P&As and ombudsmen play a special role given their access to settings, especially around heightened scrutiny

Coalition Support for Stakeholder Engagement

- Develop education materials for different audiences about the importance of the rule and how to provide public comment
- Maintain a website that tracks open public comment periods, CMS approvals, guidance documents from CMS and ACL, and other materials developed by the coalition and other advocates – www.hcbsadvocacy.org
- Help bring together state advocates and provide technical assistance during public comment opportunities on STPs
- Regularly provide input to CMS and ACL on rule implementation based on experiences working with advocates across the country

Opportunities for Public Input

- State must provide at least a 30-day public comment period on their statewide transition plan and heightened scrutiny review
- 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.
- States are encouraged to have a process for ongoing transparency and input from stakeholders on implementation of the plan

Input from Self-Advocates and Families

- Self-advocates and families sometimes can be intimidated about giving public input because the STP is very complex and long
- But they are the best experts on what does and doesn't comply with the Rule in their services, the choices they were given for services, and what services they weren't offered but would like.
- They can provide specific examples about:
 - Choice of services (including choice of non-disability specific settings)
 - Community integration and access
 - Protection of individual rights (privacy, visitors, access to food, etc)
 - Independence and control (choice in activities, setting own schedule)

Resources for Self-Advocates & Families

- HCBS Coalition and our members have developed resources to help self-advocates learn about the Rule and comment, including:
 - Worksheet for self-advocates:
<https://www.aucd.org/docs/policy/HCBS/CQL-HCBS-AdvocateGuide2018Final%5b1%5d.pdf>
 - ASAN's Easy Read toolkit:
<https://autisticadvocacy.org/policy/toolkits/hcbsrule>
 - CQL video series for self-advocates:
https://www.youtube.com/watch?v=xnbtb5Jpz7c&feature=emb_title

Input from Advocacy Organizations

- Advocacy organizations are critical to giving input on systemic issues in the STP, including:
 - Settings assessment and validation process
 - Provider-owned settings requirements and modification process
 - Statewide capacity and choice of non-disability specific settings
 - Remediation of non-compliant settings
 - Ongoing monitoring process
 - Identifying settings that are “presumptively institutional” that must go through heightened scrutiny

Input from Advocacy Organizations (cont'd)

- Advocacy organizations also play an important role in facilitating input from self-advocates and families, including through:
 - Outreach to self-advocates and families during a public comment period
 - Providing summaries of the important issues in the STP
 - Providing support to self-advocates in writing comments

Resources for Advocacy Organizations

HCBS Advocacy Toolkit:

(available at <https://hcbsadvocacy.org/disability-advocacy-organizations-resources/>)

- The Medicaid HCBS Settings Rule: What You Should Know
 - Detailed **overview of the Rule** and its requirements
- The Medicaid HCBS Settings Rule: Heightened Scrutiny
 - Describes the **heightened scrutiny requirements** in the rule & guidance
- How to Advocate for Truly Integrated Community Settings
 - Detailed **strategies for heightened scrutiny assessments**

Other Resources

- White Paper on **Outcomes and Metrics** to Support States' Implementation of the HCBS Settings Rule (<https://hcbsadvocacy.org/2020-outcomes-paper/>)
 - Developed with national experts, identifies individual, provider and statewide outcome measures to evaluate progress in implementation
- Identifying, Evaluating & Remediating **“Settings That Isolate”** in the Context of CMS Guidance on Heightened Scrutiny Requirements (together with the Community Living Policy Center, <http://materials.ndrn.org/HCBS/HCBS-Settings-Heightened-Scrutiny-CLPC-Document-Feb-2020.pdf>)
 - Summarizes the results of CMS' Heightened Scrutiny Pilot and provides recommendations for stakeholder comment on heightened scrutiny packages

Assistance

- We're happy to assist state stakeholders. You can contact us at hcbsadvocacy@gmail.com
- We keep our HCBS Advocacy Website updated – check it regularly for updates on open STPs, new resources, etc.:
 - www.hcbsadvocacy.org
- You can also check out CMS' HCBS Settings Rule Website:
 - www.medicaid.gov/hcbs



Questions?



Feedback

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

Please use the survey link: <https://www.surveymonkey.com/r/EngageBeneficiaries>

WE WELCOME YOUR FEEDBACK!