



NCAPPS

A National Environmental Scan of Technical Assistance Needs for Person-Centered Planning

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Introduction

To guide efforts of the [National Center on Advancing Person-Centered Practices and Systems \(NCAPPS\)](#), the Human Services Research Institute conducted an environmental scan to identify common themes in technical assistance (TA) needs for implementing person-centered planning in alignment with the [Home and Community-Based Services \(HCBS\) Final Rule](#) person-centered planning requirements. A list of the requirements can be found in [Appendix A](#).

As defined in the [NCAPPS Five Competency Domains for Person-Centered Planning](#), person-centered planning is a dynamic way to learn about the choices and interests that make up someone's idea of a good life and to identify the services and supports (both paid and unpaid) needed to achieve that life. The process is directed by the person with the helpers they choose. It is not something you do *to* a person, nor is it something you do *for* a person; instead, the person directs person-centered planning with support from a facilitator as needed and desired.

The planning process leads to the development of a person-centered plan co-created with the person. The plan is a “living document” that is revised as needed based on the person's preferences and evolving situation. Per the HCBS Final Rule person-centered planning requirements, the person-centered plan must reflect the services and supports that are important for the person to meet the needs identified through an assessment of functional need, as well as what is important to the person regarding preferences for the delivery of such services and supports.

Important factors in person-centered plan development and implementation include:

- Competent person-centered planning facilitation
- Plans that are written and formatted in a person-centered manner with goals that reflect the preferences of the person.
- Service delivery systems that implement the plan as written, and providers that deliver services and supports in a person-centered manner.
- A system in place to monitor and improve the quality of plans, their implementation, and the outcomes of person-centered goals.

Despite progress, states continue to grapple with how to effectively implement planning in a way that aligns with the HCBS Final Rule requirements. Many states continue to seek TA to support maintaining or coming into compliance with the requirements. This environmental scan seeks to understand common themes across those states that continue to need TA around person-centered planning.

This environmental scan was originally conducted in early 2024 and was updated in late 2024 to reflect new resources and heightened scrutiny site visit results related to person-centered planning findings since publication.

Process for Conducting Scan

To identify recurring TA needs across state systems, NCAPPS reviewed available state resources and quality reports, consulted national and state advocacy groups, consulted with other TA providers and national experts, and reviewed documents and resources recommended by federal partners at the Administration for Community Living (ACL) and the Centers for Medicare and Medicaid Services (CMS).

Interviews

In January and February 2024, NCAPPS conducted interviews with over 20 key informants including:

- ACL and CMS staff
- Advocates from the National Council on Independent Living and the National Association of Councils on Developmental Disabilities
- National subject matter experts from ADvancing States, the National Association of State Directors of Developmental Disabilities Services, and the National Association of State Head Injury Administrators

Key informants were selected based on recommendations from ACL and CMS due to their experience with supporting states to comply with the HCBS Final Rule person-centered planning requirements. Interviews were done in groups and lasted between 45 and 60 minutes. They were facilitated by three NCAPPS staff members with two staff members leading the interview and another taking detailed notes. Interview notes were then reviewed to identify themes. A detailed list of interview questions can be found in [Appendix B](#).

NCAPPS also facilitated a virtual group discussion with over 50 state representatives. A list of responses received during the discussion can be found in [Appendix C](#).

Document Review

CMS defines “presumptively institutional” settings as having any of the following characteristics:

- Any setting that is located in a building that is also a publicly or privately operated facility that provides inpatient institutional treatment;
- In a building on the grounds of, or immediately adjacent to, a public institution.
- Or any other setting that has the effect of isolating people receiving HCBS from the broader community of people not receiving HCBS.

States can submit evidence to CMS if they believe a setting has overcome its institutional presumption and is truly home and community based. These settings require what is known as a CMS-conducted “heightened scrutiny” review to determine whether they meet the requirements outlined in the HCBS Final Rule. CMS has conducted site visits to evaluate the state’s review processes and developed reports for these site visits which outline issues identified by CMS and

recommendations for the state to ensure compliance. States have also submitted corrective action plans (CAPs) to CMS to bring settings into compliance with the federal HCBS regulations. The CAP provides the state with additional time to bring settings into compliance with the regulatory criteria directly impacted by the COVID-19 public health emergency past the end of the transition period on March 17, 2023. HSRI conducted an in-depth review of Heightened Scrutiny Site Visit Reports and CAPs from 2019 to present (a summary of these is found in [Appendix D](#)). NCAPPS also reviewed reports and literature related to person-centered planning (an annotated bibliography of sources is found in [Appendix E](#)).

Summary of Findings

Findings from the interviews and document review are organized into the following three thematic areas:

1. **Person-centered planning and implementation**

This includes:

- Engaging the person
- Goal exploration
- Accountability
- Rights restrictions/modifications of additional conditions
- Meaningful choices and options
- Community integration
- Quality monitoring

2. **Staff competencies and community awareness.**

This includes:

- Knowledge of person-centered thinking, planning, and practice amongst staff, providers, case managers, people who use services and families.
- Knowledge of the HCBS Final Rule and regulations amongst staff, providers, case managers, people who use services and families.
- Training needs
- Community education needs

3. **Underlying systemic factors.**

This includes:

- Leadership
- Organizational/system culture
- Eligibility and service access
- Workforce capacity
- Quality and innovation

Person-Centered Planning and Implementation

The scan revealed states' need for TA around person-centered planning processes and how planning is implemented. States continue to have difficulties with fully and meaningfully engaging the person in the planning process.

Common challenges that states experience with regard to the planning process and the plan documentation, implementation, and monitoring include:

- Pre-planning activities, such as discussing the date, time, and location of the planning meeting with the person ahead of time, do not occur. Instead, people are told where and when they should show up and what the meeting agenda is without their input.
- Insufficient “discovery” processes for learning about the person, their preferences, interests, goals, communication style, and what matters to them. This can lead to a lack of detail within the plan about how best to support the person.
- Confusion around what constitutes “informed choice” for the person, how to discuss and explore different options, and how to document that the person made informed decisions during the planning process. People continue to be offered opportunities for “reverse integration” (such as bringing services into the setting) instead of true community integration. This extends to where people live, what services they receive, and strategies for meeting their goals.
- Minimal conversation, if any, occurs with the person about their interest in employment and opportunities for Competitive Integrated Employment (CIE). Facilitators of planning are unsure of how to have these conversations or where to refer people to for employment supports.
- No established agreement between the person and the people invited to their planning meeting around how to mitigate or resolve conflict that may occur if there is disagreement.
- No established procedures for people to request language interpretation or obtain materials in their preferred language or communication format.
- Language used within the planning process and plan documentation is not person-centered or plain and understandable to the person.
- Rights restrictions/modifications of the HCBS Final Rule additional conditions are placed on people without their knowledge or informed consent and are not documented in compliance with the documentation requirements outlined in the HCBS Final Rule. These dynamics seem to be most prevalent in provider-owned and -controlled settings.
- People are not provided the opportunity review the final version of their plan and grant informed consent by signing off on it, either physically or virtually. They do not receive a copy of their final plan, understand what is included, or who to reach out to if they need to make changes.

- Lack of systems or processes to share plans or information between the person, their loved ones, service providers, case managers, and direct support staff. Plans may be provider-specific at times and only include services offered by a single service provider leading to a lack of comprehensive coordination between the person's services and supports.
- After the plan is completed, little information is collected on the quality of the plan, its implementation, and whether it is effective in supporting the person's desired outcomes for their life. It is important to note that there is a variety of existing and future quality measurement frameworks that could support states in evaluating the quality of person-centered planning ([Appendix F](#)).

Staff Competencies and Community Awareness

The scan uncovered significant gaps in staff competency around person-centered thinking, planning, and practice, along with a lack of knowledge about the requirements outlined in the HCBS Final Rule and what they mean for service providers, direct support staff, case managers and the people they support. Specifics related to state implementation of the HCBS Final Rule person-centered planning requirements can get lost or muddled as information is passed down from the state agency to providers and case managers, and then to direct support staff and service users and families.

Key informants endorsed significant training needs for both administrative and frontline staff to be able to fully support effective and meaningful person-centered planning processes. Many staff members have had no training or very little training around HCBS Final Rule requirements in general and person-centered planning specifically. Staff can question why process changes are necessary, falling into a “we’ve always done it this way” mentality. Staff may lack creative or “outside the box” thinking needed to resolve complex issues and support people’s unique needs.

Lack of training also extends to state agency staff who may not understand what person-centered practices mean in the context of the work they do. State representatives indicated that their agencies rarely have organizational training or knowledge around person-centered planning and implementation can either fall to a singular “lead” staff member or no one at all. Key informants noted that many systems are currently experiencing workforce shortages that further exacerbate issues around recruiting and maintaining knowledgeable staff.

Key informants also described community education needs so that people who use services and family members can understand what to expect from HCBS and when planning processes and services are not person-centered.

Training and community education continues to be needed around the basics of what the HCBS Final Rule person-centered planning requirements are, why they are important, and what it means for people in the roles they occupy.

Underlying Systemic Factors

Plan documentation issues identified in the heightened scrutiny site visit reports can be viewed as “symptoms” of larger problems within the system. For example, a plan lacking a person’s signature may indicate that the person was not engaged in the development of the plan; or a plan that does not document a person’s choice among service options may reflect inadequate service capacity.

These underlying issues may point to systemic factors that impact states’ ability to effectively implement person-centered practices. These include lack of leadership buy-in to the importance of person-centered planning, organizational cultures that don’t align with person-centered values, complex eligibility processes that impact people’s ability to access services, lack of workforce capacity to support person-centered initiatives, lack of innovation around person-centered planning, and inadequate quality monitoring processes or indicators.

Our scan also revealed underlying systemic factors that promoted person-centered planning and practices. Many states have worked to improve the person-centeredness of their systems by:

- Conducting systemwide training initiatives
- Exploring Value Based Payment (VBP) models.
- Adjusting staffing ratios to allow case managers to have more time to connect with the people they support.
- Auditing plans based on the holistic view of the person.
- Embedding the HCBS Final Rule person-centered planning requirements into contracts and certification processes
- Bringing together state representatives, people in services, family members, service providers, case managers and direct support staff in workgroups, listening sessions, and other engagement efforts to learn from one another.

Recommendations for Technical Assistance

Based on the overarching themes identified through the environmental scan, NCAPPS recommends that future TA, Learning Collaboratives, and resources related to person-centered planning focus on the following topics:

- Documentation, monitoring, and implementation of rights restrictions/modifications of additional conditions of the HCBS Final Rule to safeguard rights
- Mitigation and resolution of conflict during the planning process
- How to offer and document informed choice and informed consent
- Meaningful engagement of the person and their loved ones during the planning process
- Measuring the quality and outcomes of person-centered planning

- Clarifying roles and responsibilities within the planning process and fostering collaboration among state agencies, case managers, service providers, and direct support staff
- Strengthening training and education about person-centered planning and the requirements of the HCBS Final Rule.

When asked which types of support they were most likely to use to support compliance with the HCBS Final Rule person-centered planning requirements, state representatives and key informants endorsed all the following:

- One-on-one individualized TA
- Peer-to-peer Learning Collaborative
- Guidance document, toolkit, or resource

Respondents showed the greatest preference for a guidance document, toolkit, or resource, followed closely by individualized technical assistance, and then Learning Collaboratives.

Findings revealed that where one state may experience challenges, another may demonstrate strength, highlighting the ongoing necessity for initiatives like Learning Collaboratives. Such initiatives support states to learn from one another and collectively work towards making systems more person-centered in alignment with the intent and spirit of the HCBS Final Rule.

About NCAPPS

The National Center on Advancing Person-Centered Practices and Systems (NCAPPS) is an initiative from the Administration for Community Living (ACL) and the Centers for Medicare & Medicaid Services (CMS) to help States, Tribes, and Territories implement person-centered practices. It is administered by the Human Services Research Institute (HSRI). NCAPPS partners with a host of national associations to deliver knowledgeable and targeted technical assistance. You can find us at <https://ncapps.acl.gov>

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Appendix A. Overview of the HCBS Final Rule Person-Centered Planning Requirements

Note: regulations under 1915(c) HCBS waivers, the 1915(i) State Plan HCBS benefit, and the 1915(k) Community First Choice benefit describe the Person-Centered Service Plan, including the content of the plan, the planning process, and the review of the plan. The person-centered assessment and planning requirements for 1915(c), 1915(i), and 1915(k) are very similar. Regulatory citations for all authorities are included at the bottom of each section with 42 CFR §441.301 governing 1915(c) waivers, 42 CFR §441.725 governing the 1915(i) state plan amendments (SPAs), and 42 CFR §441.540 governing 1915(k) SPAs.

Requirements for the Person-Centered Planning Process

The individual will lead the person-centered planning process where possible. The individual's representative should have a participatory role, as needed and as defined by the individual, unless State law confers decision-making authority to the legal representative. All references to individuals include the role of the individual's representative. In addition to being led by the individual receiving services and supports, the person-centered planning process:

- Includes people chosen by the individual.
- Provides necessary information and support to ensure that the individual directs the process to the maximum extent possible and is enabled to make informed choices and decisions.
- Is timely and occurs at times and locations of convenience to the individual.
- Reflects cultural considerations of the individual and is conducted by providing information in plain language and in a manner that is accessible to individuals with disabilities and persons who are limited English proficient, consistent with 42 CFR §435.905(b).
- Includes strategies for solving conflict or disagreement within the process, including clear conflict-of-interest guidelines for all planning participants.
- Providers of HCBS for the individual, or those who have an interest in or are employed by a provider of HCBS for the individual must not provide case management or develop the person-centered service plan, except when the State demonstrates that the only willing and qualified entity to provide case management and/or develop person-centered service plans in a geographic area also provides HCBS. In these cases, the State must devise conflict of interest protections including separation of entity and provider functions within provider entities, which must be approved by CMS. Individuals must be provided with a clear and accessible alternative dispute resolution process.
- Offers informed choices to the individual regarding the services and supports they receive and from whom.

- Includes a method for the individual to request updates to the plan as needed.
- Records the alternative home and community-based settings that were considered by the individual.

Regulatory citations: 42 CFR §441.301(c)(1), 42 CFR §441.725(a), 42 CFR §441.540(a)

Requirements for the Person-Centered Plan

The person-centered service plan must reflect the services and supports that are important for the individual to meet the needs identified through an assessment of functional need, as well as what is important to the individual with regard to preferences for the delivery of such services and supports (42 CFR §441.301(c)(2)). Commensurate with the level of need of the individual, and the scope of services and supports available under the State's 1915(c) HCBS waiver, the written plan must:

- Reflect that the setting in which the individual resides is chosen by the individual. The State must ensure that the setting chosen by the individual is integrated in and supports full access of individuals receiving Medicaid HCBS to the greater community, including opportunities to seek employment and work in competitive integrated settings, engage in community life, control personal resources, and receive services in the community to the same degree of access as individuals not receiving Medicaid HCBS.
- Reflect the individual's strengths and preferences.
- Reflect clinical and support needs as identified through an assessment of functional need.
- Include individually identified goals and desired outcomes.
- Reflect the services and supports (paid and unpaid) that will assist the individual to achieve identified goals, and the providers of those services and supports, including natural supports. Natural supports are unpaid supports that are provided voluntarily to the individual in lieu of 1915(c) HCBS waiver services and supports.
- Reflect risk factors and measures in place to minimize them, including individualized back-up plans and strategies when needed.
- Be understandable to the individual receiving services and supports, and the individuals important in supporting him or her. At a minimum, for the written plan to be understandable, it must be written in plain language and in a manner that is accessible to individuals with disabilities and persons who are limited English proficient consistent with 42 CFR §435.905(b).
- Identify the individual and/or entity responsible for monitoring the plan.
- Be finalized and agreed to, with the informed consent of the individual in writing, and signed by all individuals and providers responsible for its implementation.
- Be distributed to the individual and other people involved in the plan.
- Include those services, the purpose or control of which the individual elects to self-direct.
- Prevent the provision of unnecessary or inappropriate services and supports.

Regulatory citations: 42 CFR §441.301(c)(2)(i)-(vii), 42 CFR §441.725(b)(1)-(7), 42 CFR §441.540(b)(1)-(7)

Requirements for Documentation of Modifications in the Person-Centered Plan

For provider-owned or controlled settings, the written plan must document that any modifications of the additional conditions under 42 CFR §441.301(c)(4)(vi)(A) through (D) for 1915(c) waivers, for 1915(i) State Plan HCBS 42 CFR §441.710(a)(1)(vi)(A) through (D), and 42 CFR §441.530(a)(1)(vi)(A) through (D) for 1915(k) SPAs must be supported by a specific assessed need and justified in the person-centered service plan.

The following requirements must be documented in the person-centered service plan:

- Identify a specific and individualized assessed need.
- Document the positive interventions and supports used prior to any modifications to the person-centered service plan.
- Document less intrusive methods of meeting the need that have been tried but did not work.
- Include a clear description of the condition that is directly proportionate to the specific assessed need.
- Include a regular collection and review of data to measure the ongoing effectiveness of the modification.
- Include established time limits for periodic reviews to determine if the modification is still necessary or can be terminated.
- Include informed consent of the individual.
- Include an assurance that interventions and supports will cause no harm to the individual.

Regulatory citations: 42 CFR §441.301(c)(2)(xiii)(A)-(H), 42 CFR §441.725(b)(13)(i)-(viii), 42 CFR §441.530(a)(1)(vi)(F)(1)-(8)

Appendix B. Key Informant Interview Questions

- **ACL and CMS staff:**

- Which of the person-centered planning requirements of the HCBS Final Rule have you found states to be largely out of compliance with or have the most issues with?
- Are person-centered plans easier to implement in some systems than others? (i.e., DD vs. Aging vs. Behavioral health) What are characteristics of a system that facilitates or hinders person-centered planning?
- What do you think are some of the most significant barriers for states as it relates to coming into compliance with the HCBS Final Rule PCP requirements?
- What could help states reach or maintain compliance with the HCBS Final Rule PCP requirements? i.e., individualized TA, peer-to-peer learning opportunities, resource documents, etc.

- **Advocates:**

- What are one or two improvements you would make to strengthen person-centered planning in your system?
- Has the state/states engaged advocates around person-centered planning or compliance efforts with the HCBS Final Rule? If so, what was that experience like?
- How can advocates help support states in maintaining and coming into compliance with the HCBS Final Rule PCP requirements?

- **Other TA providers/national subject matter experts:**

- What are the most common TA requests or asks you receive from states regarding person-centered planning?
- What methods of delivering TA to support person-centered planning do you find to be the most effective? (i.e., individual, group formats, peer-to-peer?)
- Are person-centered plans easier to implement in some systems than others? (i.e., DD vs. Aging vs. Behavioral health) What are characteristics of a system that facilitates or hinders person-centered planning?
- What are some of the barriers you have run into as a TA provider in supporting states around person-centered planning?
- What are your experiences with leadership buy-in as it relates to person-centered planning?
- What other resources, information, or contacts do you currently refer people to around advancing person-centered practices?

Appendix C. Interview Questions and Responses for February 15, 2024, Virtual Discussion with States

The following is a list of questions and responses received during a virtual discussion with state representatives regarding person-centered planning technical assistance needs. Participants were able to respond to the open-ended questions verbally, through Mentimeter, or using the chat box in Zoom.

1. What are one or two improvements you would make to strengthen person-centered planning in your system?

- Consistency in practices across delivery systems with Managed Care Organizations and Fee-for-Services
- Broadly implement the Council on Quality and Leadership Personal Outcome Measures and embed them into person-centered planning and driving person-centered support plans.
- Consistency across regions for plans.
- Training 101.
- Staff training.
- Give detailed training to case managers to teach them how to take their interviewing to the next level.
- Top-down buy-in.
- Improving our person-centered planning template (which we are in the process of) by integrating Personal Outcome Measures in the template.
- Get more people served as the lead of the person-centered planning work and training across the state.
- More creativity in supporting vocational aspirations and consistency in application.
- Provide person-centered thinking training to all of the agencies within the state to ensure all agencies are working in the same direction as a state.
- Broad training for case managers on how to engage clients in providing responses, and more detailed input.
- We have a personal profile questionnaire for individuals and I would change the questions to make them friendlier and applicable to people served.
- Training for the service recipient so they are better informed participants in their planning processes.
- Genuine buy-in from all team members including case managers, parents, families, and providers to think outside the box to achieve goals!
- Working on recruitment and retention of service coordinators to then be able to implement a consistent training. Turnover really hinders service delivery.
- Emphasizing the planning process – possibly incentivizing through tying to individual achievement and goals.

- Synthesizing what is learned in the training and actually using it. More paperwork for Services Coordinators does not mean that person-centered practices are actually happening.
- Engaging people who communicate without structured language systems.
- 201 training for social workers to take their interviewing to the next level.
- Ensure the individual is truly driving the process versus family or providers.
- Tips and tricks for help with resolving conflict or disagreement.
- Ongoing support on reflecting cultural considerations in planning.
- Clarification of what documentation is required to verify the planning process requirements have been met.

2. Which of the planning process requirements do you need support around?

- Ensuring the person-centered planning process is driven/led by the person.
- Member choices and informed consent: a system approach to member matching with providers.
- Ensure the individual is driving the meeting and not the provider or family. How to address conflicting goals between the guardian and individuals.
- Document consideration for other settings. Feeling the impact of workforce shortage on this one.
- Offer informed choices to the individual regarding the services and supports they receive and from whom. Include a way for the individual to request updates to the plan as needed.
- Documenting and requirements about reviewing rule modifications for the support plan.
- How to approach individual modifications imposed through integrated supports such as enabling technology and video monitoring.
- Cadence of client requested reviews given caseload size and having to accommodate meetings while having plan year obligations.
- Making sure all individuals' cultural considerations are considered and making the effort to provide tools in other languages, ensure language interpreters are present, etc.
- How to assure no harm when harm is assumed.
- Individuals feeling empowered around changes and their decision making around how changes occur.
- How to truly ensure informed choice and empowering the individual and the team to have effective conflict resolution. Additionally, better support/training around cultural considerations.
- More training about documentation requirements around how the state is meeting the planning process requirements.
- Workforce shortage with qualified case managers definitely affects the time and energy they are able to offer individuals during person-centered planning.

- More training on documentation requirements with an emphasis on case managers and direct service professionals who are documenting their interactions (quality of the documentation).
- Any documentation requirements regarding conflicts and disagreements. In practice, examples of this would be helpful.
- We have implemented the Charting the LifeCourse framework as well as additional questions for provider-owned, controlled, or operated settings that are built into our template for our person-centered plans.
- Possibly not enough implementation support? Workers are busy with their clients and have little administrative/offline time to learn about the HCBS Final Rule details. Rule interpretation is also a concern.

3. Which of the planning process requirements are you doing well?

- Scheduling the meeting at the time and place of the person's choosing. Inviting who the person wants to invite.
- Not there yet but make the person-centered service plan more reportable, with greater technical intelligence to reduce administrative burden and support coordinator/case manager burden.
- We are actively making changes within the state and spreading the word about the importance of informed choice and person-centered planning.
- Lowered case load numbers so case managers have more time to support the team with planning and implementing.
- We have changed our planning template to ensure consistency across the state. This led to increased training and outreach to people, their families, and all system stakeholders.
- Continuing to expand value-based payment methodologies to drive quality.
- Funded a number of initiatives to increase availability of training in person-centered planning.
- All service coordinators and providers have been training on the person-centered planning process and the HCBS Final Rule. We are making it easier to make updates to the person-centered plan.
- We offer choices of available support providers to the individual and/or guardian. We also try to ensure the process is conducted to reflect what is important to and for the person.
- A big piece of outreach/training is the person-centered planning can happen at many different places and times. We have several counties stepping up and showing others how to do it. They are showing policies and practice.

4. Which of the person-centered plan requirements, including documentation of restrictions, do you need support around?

- The rights modification process.
- Training case managers and planning teams on breaking down big goals into actionable steps.

- What actually constitutes a modification to the setting.
- Training on documenting using person-centered, plain/easy read language.
- Data gathering requirements for a modification.
- Documenting that the setting was chosen by the person when they may want another setting, but the policy requirements are not met to justify moving to a significantly more expensive setting.
- Providers who support challenging individuals still have a tendency to have blanket restrictions and need to change their mindset.
- Training about identifying what restrictions are.
- There are a lot of disagreements/misunderstandings on what a restriction is. Then, it seems not all restrictions have Human Rights Committee approval, what positive behavior supports have previously been tried, and what data gathering should be.
- Training for direct care staff on the HCBS Final Rule.
- Obtaining informed consent for restrictions.
- Who has to review/approve a modification?
- I feel we are good on plan structure, it's the effective, consistent implementation. Also, we need more work and support on self-direction.
- In the actual person-centered plan, having details that are important but not putting too much into this document to take away from the intent.
- Ensuring it is the person's goal(s) and collaboration between/with providers for supports/services.
- Ensuring the quality of the plan content and ensuring the plans are individualized.
- Reasonable plans for reductions for restrictions.
- How is "no harm" assessed and how is that reconciled against the person's choices in the equation of assuring no harm.
- Getting signatures from the providers, since COVID they are not coming in-person to meetings so we are trying to get electronic signatures, but it is very difficult.
- The prevention of any unnecessary or inappropriate services is interesting especially when there are varying opinions of how to meet needs. We see this around in-person supports, technology, or employment.
- How to reconcile few choices in housing or households versus where the person wants to live.

5. Which of the person-centered plan requirements, including documentation of restrictions, are you doing well?

- Individualized backup plans, addressing risk factors, opportunities to seek employment and work in competitive integrated settings.
- System to document modifications.
- Documenting any restriction and HCBS Final Rule compliance at the member level across HCBS programs.
- Person-centered language.
- Documenting past attempts to remove a restriction.

- We talk about all life domain areas, wants, dreams, and needs in these spaces. We incorporate technology into the conversation around meeting needs. Employment is included.
- Holding discussions prior to the planning meeting to know what other issues or concerns the person or family might have so those can be addressed as a team.

6. What barriers have you experienced to maintaining or coming into compliance with the HCBS Final Rule person-centered planning requirements?

- Provider buy-in
- Maintaining trained workforce with the churn in case managers.
- The “we’ve always done it that way” mentality.
- Providers moving people residentially for the benefit of the setting/provider and not what is best for the person.
- Overburdened case managers (too many administrative requirements to maintain quality as well as basic compliance)
- Vagueness of the language in the HCBS Final Rule.
- Having some family members struggling with being less restrictive or giving their loved one a bigger voice, choices and opportunities.
- Not having a system to capture the overall planning information to then create a person-centered service plan.
- Too many tasks for case managers to complete which results in turnover.
- We are in implementation of one standardized assessment and plan across HCBS and Intermediate Care Facilities. This has not been easy. We have had to ensure extensive training to people, families, providers, case managers, etc.
- Individuals/families viewing the HCBS Final Rule as additional red tape to access services. More boxes to “check” during a planning meeting.
- Emphasis on “healthy food choices” that at times conflicts with person-centered planning. Supports getting caught up in their perspectives of what they perceive to be best for the individual rather than their choice.
- Lack of understanding by the case manager and team of what the HCBS Final Rule is and why it is important.
- Computer assessment focuses on the functional assessment that often emphasizes ancillary contracts and not the person.
- Continuing to be audited from a technical or point by point view rather than looking at the holistic picture of the individual.
- Could we help to identify meaningful activities to the clients. We are aware that sometimes this is a debate where the client may be a “plus one” versus their daily activities and routines being their choice.
- When waivers don’t include case management as a service and individuals refuse case management (as they are allowed to do), sometimes person-centered plans are not comprehensive or tailored as a result.

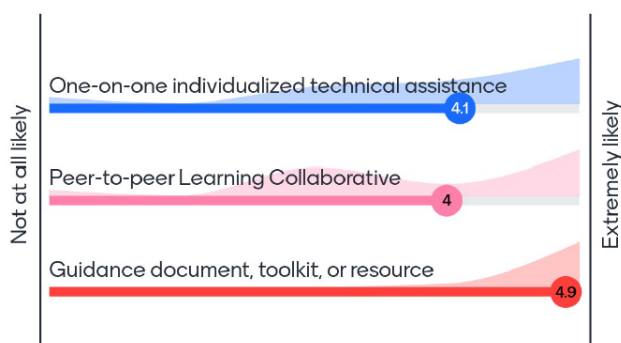
- We have realized that in training we need to support case managers differently. Teaching them how to do good person-centered planning but also overlap into Medicaid authorization and oversight. This has been hard for them.

7. Has anything helped when it comes to compliance?

- We had a strong history of person-centered planning prior to the HCBS Final Rule requirements. CMS trainings and webinars have been helpful at times.
- Developed an archive of questions and answers making them available to all staff based on case management questions.
- Hosting staff and provider webinars has been helpful. We have included our consultants when needed as panelists to help with awareness and implementation. We also provided a handout showing changes.
- Going into every provider orientation and training on the HCBS Final Rule. Giving examples and making it a non-negotiable part of provider certification.
- Open communication between all stakeholders and state staff. The development of a stakeholder workgroup that focuses on full implementation including people supported, families, etc.
- Embedding it into existing processes such as credentialing, recredentialing, quality management, the person-centered service plan template, training, settings, committees, etc.
- National Association of State Directors of Developmental Disabilities Services (NASDDS) learning groups.
- Having a specialized team focus on HCBS Final Rule compliance for settings and then having case managers focus on the person-centered plan.
- Having licensed social workers gave us a great knowledge base to start with. They are able and willing to learn!

8. How likely would you be to use the following types of support to maintain or reach compliance with the Home and Community-Based Services person-centered planning requirements?

- One-on-one individualized technical assistance
- A peer-to-peer Learning Collaborative
- A guidance document, toolkit, or other resource
- Anything else?



Appendix D. Review of Heightened Scrutiny Site Visit Reports Table

All documents drawn from:

<https://www.medicaid.gov/medicaid/home-community-based-services/statewide-transition-plans/index.html>

| State and Date | Applicable Waivers | Settings | Notable Violations Related to Person-Centered Planning | Additional Notes |
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| Alabama December 2022 | <p>1915(c) HCBS Waivers:</p> <p>Home and Community-Based Waiver for Persons with Intellectual Disabilities, AL.0001</p> <p>Home and Community-Based Services Living at Home Waiver for Persons with Intellectual Disabilities, AL.0391</p> <p>Community Transitions Waiver, AL.0878</p> <p>Home and Community-Based Waiver for the Elderly and Disabled, AL.0068</p> | Residential Group Homes, Apartment, Host-Home | <ul style="list-style-type: none"> Service plans do not explore choice upon admission, for future residence, or for financial control or institutions. Service plans do not provide valid justification for rights restrictions (e.g., implemented due to “bad behavior” Restricted choice over private rooms. Lack choice in decorations in rooms (claim per painting, however painting completed). No control over individual schedules or activities. Personal choice not implemented in service plans for social activities (other than church for some residents). Community access is restricted without documentation. Legality of drug testing is questioned. | <ul style="list-style-type: none"> The state CAP indicates they assessed the problem as one of a workforce shortage, heightened due to the pandemic, and a training and development issue. Describing the importance of training and retaining staff familiar with the HCBS Settings Rule as key to their future compliance and best practices. Institutional “unintentional” restrictions. |
| California June 2023 | <p>Section 1915(c) HCBS Waiver for Californians with Developmental Disabilities</p> <p>Section 1915(i) HCBS State Plan Amendment</p> <p>Section 1915(c) California Self Determination Program Waiver for Individuals with Developmental Disabilities</p> | Residential Care Facilities for Elderly; Non-Residential Work Program | <ul style="list-style-type: none"> Service plans are not reviewed with residents. Service plans do not document preference for employment. Service plans do not offer choice in community activities. Service plans do not provide choice of setting. Denied choice in roommate preference. Chemical restraint is applied in a preventive manner and for ongoing behavior compliance rather than as needed. | <ul style="list-style-type: none"> The site report noted that some staff did read the service plans but were mostly informed about the service user from the administrator. Lack of qualified health care professionals in staffing may be contributing to some of the concerns. The CAP is driven by additional technical assistance, grants to |

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| | Section 1915(c) Home and Community-Based Alternatives Waiver Section 1915(c) Assisted Living Waiver | | <ul style="list-style-type: none"> • Lack food choices, including outside dining hours. • Right to refuse video camera surveillance in personal care spaces. • Restricted use of television and audible device in shared rooms. • Limited access to visitors. • Smoking times regimented and restricted. • Lack choice in home health care agencies. | <p>the clinical workforce, certification and professional development programs, and stipends for attending trainings.</p> <ul style="list-style-type: none"> • Lack of adherence to person-centered planning appears to be from the top, given the administrators of the facilities lack of buy-in and knowledge of these standards. |
| Florida December 2022 | 1915(c) Long-Term Care (LTC) 1915(c) Developmental Disabilities Individual Budgeting (iBudget) Waivers | Assisted Living, Group Home, Non-Resident Training Center, Adult Day Center, Residential Community | <ul style="list-style-type: none"> • Staff not aware they are responsible for person-centered planning. • Group choice, but not individual choice in community access. • Overall community access restricted. • Lack of choice in having visitors at any time. • Lack of privacy (e.g., names on doors, grooming schedules posted). • Lack of individualized choices for employment opportunities. • Options for receiving services in the community is limited (they would need to move out to remove restrictions to access community). | <ul style="list-style-type: none"> • Much of the state's response includes compliance measures such as posting the Ombudsman's number, posting the grievance procedure and/or having a procedure to address complaints. • Staff lack of awareness of person-centered planning as a regulatory policy is not clearly addressed. • Bill of Rights is mentioned in the corrective plan, but it is not clear how the providers intend to implement it into practice given the overall lack of understanding of person-centered planning. • Empty threat "Landlord letters" and fear of being sent to the "Lodge" are used to control residents into compliance and silence regarding standard of living. |
| Idaho November 2023 | 1915(c) HCBS Waivers: | Residential Habilitation, | <ul style="list-style-type: none"> • There is no oversight system for person-centered planning. | <ul style="list-style-type: none"> • Staff noted that there were existing modifications, but modifications were not |

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| | Developmental Disabilities Waiver, ID.0076 Aged and Disabled Waiver, ID.1076 | Residential Assisted Living Facilities, Certified Family Home | <ul style="list-style-type: none"> • Full responsibility for planning seems to be with service providers. There is not a case management function that is independent of settings. • Roles for case managers and service providers regarding the development and implementation of the plan are not clearly defined. • No evidence in the plans reviewed to indicate how the setting was selected or if choices were provided. | <p>documented in any of the plans reviewed.</p> <ul style="list-style-type: none"> • Plans contained very little person-centered information. |
| Illinois December 2022 | <p>1915(c) HCBS waivers:</p> <p>Persons with Disabilities, IL.0142</p> <p>Persons who are Elderly, IL.0143</p> <p>Persons with HIV or AIDS, IL.0202</p> <p>Illinois Supportive Living Program, IL.0326</p> <p>Persons with Brain Injury, IL.0329</p> <p>Adults with Developmental Disabilities, IL.0350</p> <p>Residential Waiver for Children and Young Adults with Developmental Disabilities, IL.0473</p> | Residential Group Homes, Nursing Facility, Assisted Living Facility, Independent Living Facility | <ul style="list-style-type: none"> • Service plans do not indicate individual interests. • “Behavior plans” are unsigned by participants. • No choice of roommates. • Lack of choices given for employment. • Not informed of non-disability setting options for residence. • Choices of activities are based on availability not on interest or preference. | <ul style="list-style-type: none"> • Dignity of residents not grasped in understanding lack of choice of activities. • Behavior plans suggest compliance rather than skill building and recovery support counseling skills of staff. • Technical assistance is recommended for the lack of informed choices given toward activities, interests, and daily living. • The state conducted trainings on person-centered planning templates and changed policies to adhere to it, addressing individualized assessment. |
| Indiana December 2022 | <p>1915(c) HCBS Waivers:</p> <p>Aged and Disabled Waiver, IN.0210</p> | Assisted Living, Community Based Day Setting, Intentional Community | <ul style="list-style-type: none"> • Unable to choose where and with whom they have meals (assigned seats). • Administrator states her role is only to address physical needs, not person-centered planning. | <ul style="list-style-type: none"> • Staff lack a deeper understanding of what it means for people to have control over their own lives and how to facilitate that. • Staff ask for more training. |

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| | <p>Traumatic Brain Injury Waiver, IN.4197</p> <p>Community Integration and Habilitation Waiver, IN.0378</p> <p>Family Supports Waiver, IN.0387</p> | | <ul style="list-style-type: none"> Staff planning is based on generalized notions about the population, rather than planning for the individual (e.g., "older people prefer to stay indoors"). | <ul style="list-style-type: none"> Need to address how to assess a person's specific individualized need rather than prescribed needs of "population." Administrative staff refer to residents as "patients" and they label clothing by resident names (lacks adult dignity). |
| <p>Kansas</p> <p>May</p> <p>2022</p> | <p>1915(c) HCBS Waivers:</p> <p>Intellectual/Developmental Disabilities Waiver, KS 0224</p> <p>Physical Disability Waiver, KS 0304</p> <p>Home and Community Based Services for the Frail Elderly, KS 0303</p> | <p>Assisted Living, Residential, Sheltered Workshop, Day Services Campus</p> | <ul style="list-style-type: none"> Service plans do not indicate interests in employment, community engagement. Options outside the facility for activities are not explored. Not allowed choice of roommates and cannot change rooms. Options for transportation are not explored and are discouraged. Service plans do not individually indicate reasons for locking up ID, SNAP cards, and money. Not given option to shop for themselves (staff bring food back to facility). | <ul style="list-style-type: none"> No sense that the providers infuse the importance of choice into interactions. Lack of attention to quality of life ingrained in policies. As part of the TA, the state discussed a 1 on 1 Community Connections program with Wichita State University to improve policies and procedures. Setting relies on "reverse integration" to bring the community to the setting so residents 'won't have to' leave to get the hair done or have lunch in the community. |
| <p>Minnesota</p> <p>December</p> <p>2022</p> | <p>1915(c) HCBS Waivers:</p> <p>Brain Injury, MN.4169</p> <p>Community Alternative Care, MN.4128</p> <p>Community Access for Disability Inclusion MN.0166</p> <p>Developmental Disabilities MN.0061</p> <p>Elderly Waiver MN.0025</p> | <p>Assisted Living, Nursing Facility</p> | <ul style="list-style-type: none"> Service plans do not contain information about individual needs and goals. Choices for community integration is lacking in service plans (planning for Dairy Queen and fishing, or rely on family for outings) | <ul style="list-style-type: none"> Staff rely on external case managers to do person-centered planning and provide individualized care ('community integration is the job of the case manager, not other staff'). Staff are unaware of rules criteria. Review of service plans could not demonstrate community integration. Integration did not |

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| | | | | seem to be a priority in person-centered planning. |
| Montana *September 2023 (Letter N.D.) | 1915(c) HCBS Waivers: Big Sky Waiver, MT.0148 Developmental Disabilities Comprehensive Waiver, MT.0208 Behavioral Health Severe Disabling Mental Illness Waiver, MT.0455. | Assisted Living, Medical Center, Health Clinic | <ul style="list-style-type: none"> Individuals are restricted choice in selecting a roommate | <ul style="list-style-type: none"> No individuals in the settings receive Medicaid HCBS; State requests quarterly reporting that person-centered planning requirements are met per need. |
| North Dakota April and July 2019 | None noted | Residential on grounds of state ICF Day program that was relocated from the grounds | <ul style="list-style-type: none"> None found | <ul style="list-style-type: none"> Review of state responses determined the site is in compliance with the Settings Rule. |
| New York October 2023 | None noted | Assisted Living, Adult Day Living Programs, Habilitation Programs | <ul style="list-style-type: none"> Service plans were not available for review. No evidence person centered service plans exist. Lack of training on choice for non-disabled residential settings options Residents must request to change their assigned seating for dining as policy. No evidence staff are trained in HCBS settings rules. Community integration activities are decided by staff not by resident choice, interest, and goals. Individual choice not offered in activities, decisions based on groups (residents in large day room in front of TV or listening to music, watching table games) | <ul style="list-style-type: none"> Not clear who was providing training in the facilities. Pervasive lack of person-centered planning, training for it, or dignity of choice for individuals. “Medical model” noted in site report. |

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| Ohio November 2022 & April 2019 | 1915(c) HCBS Waivers: Assisted Living, OH.0446 PASSPORT, OH.0198 MyCare Ohio, OH.1035 Ohio Home Care, OH.0337 Individual Options, OH.0231 Self-Empowered Life Funding, OH.0877 Level One, OH.0380 | Assisting Living, Adult Day Center | <ul style="list-style-type: none"> • Service plans focus on medical care and not individual wants and needs. • Service plans do not address individual access to the community. • Residents not allowed to choose their own roommate. • Individuals are not given choice over their own individualized schedules. • Service plans do not reflect exploration of employment options. • Policies do not reflect individualized choice in managing personal resources (when entering facility) • Lack of support for individualized needs (e.g., difficulty making phone calls due to small numbers on the phone). • Service plans do not indicate reasons for restrictions or modifications using assessments. | <ul style="list-style-type: none"> • Both administrator and staff were unaware of settings rule, regulations, and trainings regarding person centered planning. • One of the facilities has a resident council that was cited in the report to assist with remediation of policy issues. • Staff indicate limited understanding of coercion. |
| Oregon April 2019 | 1915(c) HCBS Waivers: Aging and Physically Disabled Waiver, OR.0185 Children's Home and Community-Based Services Waiver, OR.0117 Adults' Home and Community-Based Services Waiver, OR.0375 Medically Involved Children's Waiver, OR.0565 Medically Fragile (Hospital) Waiver, OR.40193 Behavior (Intermediate Care Facilities)/Intellectual | Residential Treatment Homes, Residential Treatment Facility | <ul style="list-style-type: none"> • Choice of setting is not provided from among a variety. • Service plans do not indicate individual control over their schedules. • Person is not allowed choice of roommate or ability to decorate living units. | <ul style="list-style-type: none"> • CMS requested evidence that residents are allowed to select the residence/housing of their choosing. • Otherwise in compliance after scrutiny. |

Developmental Disabilities)
Model Waiver, OR.40194

1915(i) State Plan HCBS:

Home and Community-
Based Services State Plan
Option

1915(k) Community First
Choice:

Community First Choice
State Plan Option State Plan
Amendment

Pennsylvania May 2024

1915(c) HCBS Waivers:
Community Health Choices,
PA.0386

OBRA, PA.0235

Consolidated Waiver,
PA.0147

Community Living Waiver,
PA.1486

Person/Family Directed
Support Waiver, PA.0354

Adult Autism Waiver,
PA.0593.

Community Homes,
Life-Sharing, Older
Adult Daily Living
Center, Personal
Care Home, Day
Habilitation

- Person-centered planning was inconsistent across setting types and waivers.
- Documentation of modifications was inconsistent.
- Blanket restrictions were placed on participants of Adult Day Centers due to state code which does not allow them to leave the facility without staff.
- Over-delegation of service coordination authority to provider case managers in ways that could be at odds with requirements for conflict-free case management.

- There are separate documents that comprise the full plan rather than an all-inclusive service plan.
- Managed Care Organizations have developed separate plan templates which has led to significant variation in people's experiences of person-centered planning. None of these templates included information about modifications.
- Service providers assign a case manager who provides information to the state service coordinator.
- Staff interviewed had extensive knowledge of person-centered planning.

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| South Carolina March 2023 | 1915(c) HCBS Waivers: Community Supports Waiver, SC.0676 Head and Spinal Cord Injury Waiver, SC.0284 Intellectually Disabled and Related Disabilities Waiver, SC.0237 | Residential Care Facilities, Training Homes, Activity Centers, Supervised Living Programs | <ul style="list-style-type: none"> • Restricted access to medication is not documented in service plans (locks) • Service Plans do not indicate personal interests or choice for activities. • Service plans do not indicate choice for inclusion into the community. • Service plans do not indicate employment options. • Room decorations do not reflect personal choice. • No choice to eat when they want, restricted times. • Not permitted to have visitors of their choosing | <ul style="list-style-type: none"> • Some staff have no awareness of person-centered settings rules, other times they know the regulations but do not implement them. • Administrators tell staff what to say to cover up violations. (menus from 2015) • Staff would not permit residents to speak to Site Visit Team without them present even in their private rooms. |
| South Dakota August 2024 | 1915(c) HCBS Waivers: Home and Community-Based Options and Person Centered Excellence (HOPE) Waiver, SD.0189 Assistive Daily Living Services (ADLS) Waiver, SD.0264 Community, Hope, Opportunity, Independence, Careers, Empowerment, Success (CHOICES) Waiver, SD.0044 Family Support 360 Waiver, SD.0338 | Day Services, Group Home, Supervised Living, Assisted Living Facilities, Community Living Home | <ul style="list-style-type: none"> • Modifications were observed but were not documented in plans. • No evidence in plans reviewed that options for choice of setting were offered, including non-disability specific settings. | <ul style="list-style-type: none"> • Contracted case management agencies interviewed used the same case management platform which was designed in line with the principles of person-centered planning to develop plans. • No indication in plans as to whether different options for choice of setting was provided. |
| Texas April 2023 | 1915(c) HCBS Waivers: Community Living Assistance and Support Services (CLASS) | Intentional Community, Assisted Living, Day Habilitation | <ul style="list-style-type: none"> • Service plans scant with person-centered information. • Service plans not available. • Plans seemed service-based rather than person-centered, goal language applicable to available services not a person's preferences. | <ul style="list-style-type: none"> • Several assisted living facilities only had a handful of HCBS participants living there (out of 40-60 people). Staff had no/minimal knowledge of the Rule, and one had just decided to stop offering Medicaid |

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| | <p>Deaf Blind with Multiple Disabilities (DBMD)</p> <p>Home and Community-Based Services (HCS)</p> <p>Texas Home Living (TxHmL)</p> <p>1115: STAR+PLUS HCBS Demonstration</p> | | <ul style="list-style-type: none"> • Service plans didn't contain information about settings options. • Plans included identical/boilerplate information that was copied and pasted. • Plans don't contain information about the person's preferences. • Service plans based on parents' preferences rather than the person's (e.g., not exploring options for employment because the parents of adults didn't want that included, having a camera in an adult child's bedroom because of the parents' comfort level) • Service plans didn't include justifications on restrictions. • No service plans (MCO did not provide them) • Blanket restrictions applied to all (e.g., food locked in cabinets, limits on cigarettes, visitor policies) and were not accompanied by modifications to person-centered plans. • No record of staff training | HCBS because of compliance issues. |
| Vermont November 2022 | Section 1115 demonstration: Project Number 11-W-00194/1. | Therapeutic Care Residence | <ul style="list-style-type: none"> • Service plans indicated limit engagement in outside activities (was 2-3/week after pandemic), no individualized planning. • Service plans indicate no record of job exploration or discussions about work. • Service plans do not indicate choice about residence. • Service plans do not document reasons for restricted access to visitors and phones | <ul style="list-style-type: none"> • Staff do not have any recollection of receiving HCBS training. • Longtime staff understand the regulations, while staff employed less than one year do not. • There were limited opportunities to speak with participants (7 away at the time). |
| Virginia September 2024 | <p>1915(c) HCBS Waivers: Community Living, VA.0372</p> <p>Family and Individual Supports, VA.0358</p> <p>Building Independence, VA.0430.</p> | <p>Day Support Programs, Residential Group Homes, Adult Medical Day Care</p> | <ul style="list-style-type: none"> • Modifications were observed but were not documented in plans. • Service providers are sometimes not invited to participate in person-centered planning meetings or don't receive a copy of the plan from Managed Care Coordinators/Managers. | <ul style="list-style-type: none"> • Several plans reviewed complied with regulatory requirements. |

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| Wisconsin January 2020, July 2021, December 2022 | 1915(c) HCBS Waivers: Family Care Waiver, WI.0367 Include, Respect, I Self-Direct Waiver, WI.0484 | Community-Based Residential Facilities, Adult Apartment Complexes, Adult Family Home | <ul style="list-style-type: none"> • Service plans do not indicate individualized exploration of volunteer or employment opportunities and activities (puzzles and magazines and tv in activity room) • Service plans do not indicate individualized access to the broader community. • Service plans do not indicate choice of setting (including) in court-ordered circumstances. • Individuals lack autonomy and choice regarding choices in their physical environment (rooms are scant with decorations-coloring pages and pictures). • Wants and needs were not noted in service plans. • Service plans do not indicate modifications for individualized locks, food, or visitor policies. • No training specific to PCP was noted. • Service plans did not indicate residents had a choice in selecting their residential setting or services at the setting. | <ul style="list-style-type: none"> • Technical assistance on PCP needed. • Overall lack of individualized service plans, attention to personal needs and autonomy. |
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Appendix E: Annotated Bibliography

This document review is a compilation of selected published reports and articles focused on person-centered planning and practices in HCBS. The review contains foundational NCAPPS documents on person-centered planning and practice. CMS and ACL staff recommended reports are also included in this review along with materials addressing PCP in the context of HCBS settings. These additional materials were identified through colleague referral and online searches for peer-reviewed articles and published reports for terms related to “person-centered planning” and “home and community-based services,” “long-term services and supports,” or “services.” Note: “person-centered” is sometimes spelled “person-centred” in international sources.

The Effectiveness of Person-Centred Planning for People with Intellectual Disabilities: A Systematic Review

The objective of this study was to assess the effectiveness of PCP on outcomes for individuals with intellectual disabilities across an age range. Several electronic databases were reviewed for the impact of PCP on persons with ID between 1990 and 2014. Researchers used a range of search terms focused around ‘person-centered planning’ for the study. Fifty-nine papers were read in full. The researchers evaluated 16 studies which met the inclusion criteria. The report concluded that while the overall quality of evidence was low, results were mildly suggestive that PCP may have a positive impact on some outcomes for individuals with ID, especially regarding impact in the areas of community-participation, participation in activities, and daily choice-making. However, the authors call for clearer descriptions of PCP and its components, concluding that because these results do not indicate that PCP can cause a ‘radical transformation’ for people with intellectual disabilities, larger scale studies of PCP implementation are needed.

<https://pubmed.ncbi.nlm.nih.gov/27394053/>

Effects of Person-Centred Planning and Practices on the Health and Well-Being of Adults with Intellectual and Developmental Disabilities: A Multilevel Analysis of Linked Administrative and Survey Data

A PCP and practice approach is one that is driven by service users' individual preferences, needs and priorities. The approach has been identified as a best practice and is codified in policies that encourage and, in some contexts, require state systems of home and community-based services to adopt and demonstrate person-centered practice. However, there is insufficient research on PCP's direct impact on outcomes for service users. This study aims to contribute to the evidence base in this area by investigating the association between service experiences and outcomes of adults with intellectual and developmental disabilities (IDD) receiving state-funded services.

<https://onlinelibrary.wiley.com/doi/10.1111/jir.13015>

Facilitators and Barriers to Person-Centered Planning from the Perspectives of Individuals Receiving Medicaid Home and Community-Based Services and Care Managers

This study investigated both the facilitators and barriers of person-centered planning by evaluating the experiences of individuals receiving Medicaid HCBS and care managers who practice PCP in three states. Researchers recruited from health plans and used a semi-structured interview guide to conduct interviews with 13 HCBS recipients and 31 care managers. In addition to interviews, the research team evaluated assessment instruments used in the three states and the person-centered plans of the HCBS recipients. From HCBS recipients' perspectives, the study found that facilitators of PCP are choice and control, personal goals and strengths, and relational communication, while barriers of PCP are medical orientation of the care plan, administrative and systemic barriers, and competencies of care managers. From care managers' perspectives, facilitators of PCP are communication and the development of measurable goals, while barriers to PCP are administrative and systemic barriers.

<https://doi.org/10.1016/j.dhjo.2023.101473>

Guide for Improving Processes for Documenting and Implementing Modifications and Rights Restrictions in Home and Community-Based Services

This resource was created for state human service agency administrators interested in improving processes for identifying, documenting, implementing, and phasing out modifications in compliance with the person-centered planning requirements of the Home and Community-Based Services Final Rule within provider-owned and controlled settings. It outlines seven recommended steps for human service administrators to pursue in collaboration with community partners and advocates.

<https://ncapps.acl.gov/docs/Resources/NCAPPS%20Guide%20for%20Improving%20Processes%20for%20Documenting%20and%20Implementing%20Modifications%20and%20Rights%20Restrictions%20in%20Home%20and%20Community-Based%20Services-A.pdf>

The HCBS Settings Rule: Looking Back and Forging Ahead

This report, based on interviews with people representing state and national disability organizations and advocacy groups as well as published sources, provides recommendations for the continued implementation of the HCBS Settings Rule after the transition phase. The recommendations center on five key components to successful implementation of the Rule: (1) effective person-centered planning, (2) transparent and multifaceted stakeholder engagement, (3) simplified and responsive individual complaint/grievance systems, (4) strategic site visits for ongoing monitoring, and (5) clearly defined oversight and enforcement roles for CMS and states on the HCBS settings requirements.

https://healthlaw.org/wp-content/uploads/2024/06/HCBS-Settings_Looking-Back-and-Forging-Ahead-axs.pdf

How to Expand Supported Decision-Making and Increase Informed Choices

To reduce the restrictions on choice and rights that are the outcomes of guardianship, a national movement is growing to advance supported decision-making (SDM) as an alternative to guardianship. The purpose of this publication is to introduce SDM and to suggest ways that more people can benefit by relying on supporters to help make decisions and to reduce reliance on guardianship. The strategies discussed are intended for use by a range of audiences interested in increasing people's ability to make informed decisions.

[https://ncapps.acl.gov/docs/Resources/How%20to%20Expand%20Supported%20Decision-Making%20and%20Increase%20Informed%20Choices%20\(1\).pdf](https://ncapps.acl.gov/docs/Resources/How%20to%20Expand%20Supported%20Decision-Making%20and%20Increase%20Informed%20Choices%20(1).pdf)

Human Services Provider Agency Toolkit for Self-Determination

Self-determination is the right of all people to participate in and approve of the design of their personal support systems, to fully engage in their communities, and to make choices in their daily lives. Though the ultimate exercise of self-determination is having people direct their own supports, not every individual receiving HCBS may be eligible for or interested in the self-directed services available where they live. Provider-directed services, such as community-based group homes, structured employment, day programs, or shared living will continue to be part of the array of options available to people needing support. Human services providers, however, can infuse self-determination in every aspect of service delivery by helping people exert greater control over their environments and make choices about their everyday lives. Created through NCAPPS technical assistance, this guide contains strategies and resources to assist HCBS providers in championing self-determination among the people they serve.

<https://ncapps.acl.gov/docs/Resources/NCAPPS%20Human%20Services%20Provider%20Agency%20Toolkit%20for%20Self-Determination.pdf>

Issue Brief: Person-Centered Planning

This issue brief provides information for State Mental Health Authorities (SMHA) about strategies for promoting person-centered planning (PCP) to enhance the quality of behavioral health services and the valued recovery outcomes of those that use them.

<https://store.samhsa.gov/product/issue-brief-person-centered-planning/pep24-01-002>

NCAPPS Yearly Summaries of Technical Assistance Activities

NCAPPS provides technical assistance to State agencies, Tribes, and Territories to advance person-centered thinking, planning, and practices that support people with disabilities and older adults with long-term service and support needs. NCAPPS launched in the spring of 2019 with a cohort of fifteen States. In 2021, a second cohort of nine States and one Territory was selected to receive 100 hours of technical assistance per year for two years; five of these States had also participated in Cohort 1. At the end of each technical assistance year, NCAPPS published summaries of each state's activities to enhance person-centered thinking, planning, and practice.

Year 1: https://ncapps.acl.gov/docs/NCAPPS_Y1TASummary_August%202019.pdf

Year 2: https://ncapps.acl.gov/docs/NCAPPS_Y2TASummary_200724.pdf

Year 3: https://ncapps.acl.gov/docs/NCAPPS_Y3TASummary_210310.pdf

Year 4: https://ncapps.acl.gov/docs/NCAPPS_Y4TASummary_508.pdf

Year 5:

https://ncapps.acl.gov/docs/Technical_assist/NCAPPS%20Y5%20TA%20Summary%20Accessible.pdf

NQF Person-Centered Planning and Practice Final Report

This report documents the effort to address long-term services and supports (LTSS) that are predicated on a person's needs, preferences, goals, and desires. Health and Human Services (HHS) in collaboration with its partners and other federal agencies, states, consumers and advocates, providers, and other stakeholders, convened to generate recommendations to, refine the current definition(s) for PCP, develop a set of core competencies for performing PCP facilitation, make recommendations to HHS on systems characteristics that support person-centered thinking, planning, and practice, develop a conceptual framework for person-centered planning measurement; and conduct an environmental scan including the historical development of PCP in LTSS systems to include a research agenda for future PCP research. These recommendations will support the continued creation of a sustainable system where older adults and people with disabilities have choice, control, and access to a full array of quality services that assure optimal outcomes including independence, good health, and quality of life.

https://www.qualityforum.org/Publications/2020/07/Person_Centered_Planning_and_Practice_Final_Report.aspx

Outcomes of Person-Centered Planning in Medicaid Home- and Community-Based Services

Using the 2018-2019 National Core Indicators-Aging and Disability survey, which included responses from 5,849 adult Medicaid HCBS recipients across 12 states, this study reports that person-centered planning measures were consistently associated with a lower likelihood of unmet service needs and a greater likelihood of achieving community living outcomes. 72% of Medicaid HCBS recipients reported being involved in decision-making, 72% indicated that their service plans reflect their preferences, and 47% attended meetings that scored "high fidelity" on the person-centered planning fidelity scale. However, the study concludes that the delivery of HCBS services is in need of additional standardized measures for enhancement.

<https://doi.org/10.1093/geront/gnae017>

A Person-Centered Approach to Home and Community-Based Services Outcome Measurement

Person-centered outcome measurement has not been satisfactorily defined and is commonly misunderstood by those in the research measurement field. Because the central goal of HCBS is to support people with disabilities to direct the lives of their choosing, the researchers contend that the field's form of assessment and measurement should also reflect the concept of person-centered care. This study evaluated the need for an HCBS outcome measure which accounts for preferences, needs, and desires of the service recipient to determine the outcomes for people with disabilities. This project defines person-centered measurement within the context of the CMS Final Settings Rule. When person-centered measurement tools are not used, the data collected is aligned with standards for living and benchmarks for progress that are defined by someone other than the person with the disability. This is a form of "non-person-centered measurement" in which life benchmarks assume that all people with disabilities seek the same life outcomes with respect to employment, education, housing, and social relationships.

<https://pubmed.ncbi.nlm.nih.gov/36817716/>

Person-Centered Gerontological Nursing: An Overview Across Care Settings

Gerontological nurses are responsible for delivering person-centered care across health care settings. Gerontological nurses specialize in providing physical, psychosocial, spiritual, and other comprehensive needs of older adults. This study provides a review of person-centered care for older adults across healthcare care settings. In HCBS settings, providing person-centered care to older adults means that when gerontology nurses attend to individuals' priorities, they reduce the treatment burden and fewer medications are added. Person-centered care in HCBS settings is ultimately associated with improved care recipient and caregiver satisfaction, lowered burnout rates among providers, lower stress levels among health care staff, and fewer hospitalizations and emergency department visits among recipients of services.

<https://pubmed.ncbi.nlm.nih.gov/33497445/>

Person-Centered Planning: Choosing the Approach that Works for the Person

Despite consensus regarding the content and conduct of person-centered plans (such as the person-centered planning requirements in the HCBS Final Rule), there has been less promising practice guidance on how to tailor the duration and extent of the planning process to the needs and wishes of the person. To be truly person-centered, the content and extent of the planning process should be tailored to the person's unique life circumstances. The intent of this resource is to reinforce the importance of aligning person-centered planning approaches with the wishes and needs of the person for whom the plan is being developed, rather than adopting a one-size-fits-all approach.

<https://ncapps.acl.gov/docs/Resources/NCAPPS%20Person-Centered%20Planning%20Choosing%20the%20Approach%20that%20Works%20for%20the%20Person%20Accessible.pdf>

Person-Centered Thinking, Planning, and Practice: Representative Examples of State Definitions

Although there are now a range of strong national definitions of person-centered thinking, planning, and practice, many state human service agencies find it important to develop their own local definitions for use in policy statements and implementation protocols. This environmental scan serves as a starting point for state, tribal, and territory human service agencies as they operationalize person-centered approaches in their local contexts.

https://ncapps.acl.gov/docs/NCAPPS_Definitions_RepresentativeExamples_200930.pdf

Staff Stability Through Service: Promoting a Person-Centered Culture for Work and Care in Long-Term Services and Supports Environments

The goal of the SERVICE Model of Leadership is to provide quality healthcare and person-centered care through organization-wide cultural practices. The domains of the SERVICE Model of Leadership (culture) include: (S) service to others (E) valuing and promoting education and learning; (R) valuing and promoting the respect, dignity, and personhood of others (V) establishing a vision and guiding principles for the organization; (I) inclusion of everyone as a partner in the progression of the project (C) active communication and exchange of expectations and information (E) encouraging self-knowledge and ongoing enrichment for self and others.

<https://pubmed.ncbi.nlm.nih.gov/34704868/>

Systemic Barriers Hinder Person-Centered Home and Community Based Services (HCBS): Perspectives of Service Users and Professionals

This study focuses on system-level issues to synthesize the perspectives of HCBS professionals and users on systemic barriers that affect person-centered HCBS delivery through semi-structured interviews with 20 HCBS users and 22 HCBS professionals. Qualitative analysis generated three themes: (1) workforce considerations; (2) resources and service access; and (3) infrastructure for feedback.

<https://doi.org/10.1016/j.dhjo.2024.101629>

Technical Assistance Needs for Realizing Person-Centered Thinking, Planning and Practices in United States Human Service Systems

This paper summarizes and analyzes seven common themes that emerged from the technical assistance applications at the inception of NCAPPS, providing a unique window into human service system administrators' priorities for achieving more person-centered human service systems and the conditions that may promote, or hinder systems change.

<https://www.emerald.com/insight/content/doi/10.1108/JICA-05-2020-0032/full/html?skipTracking=true>

Appendix F: Current and Future Quality Measurement Frameworks for PCP and HCBS

- **CAHPS® Home and Community-Based Services Survey:** “The Consumer Assessment of Healthcare Providers and Systems Home and Community-Based (HCBS CAHPS®) Survey is the first cross-disability survey for adults receiving long-term services and supports from state Medicaid home and community-based services and supports (HCBS) programs. The HCBS CAHPS Survey is a questionnaire with a maximum of 69 core items developed for measuring experience with the Medicaid HCBS delivered by providers. Core questions cover topics such as getting needed services, communication with providers, case managers, choice of services, medical transportation, and personal safety, as well as community inclusion and empowerment.”
 - <https://www.medicaid.gov/medicaid/quality-of-care/quality-of-care-performance-measurement/cahps-home-and-community-based-services-survey/index.html#:~:text=The%20Consumer%20Assessment%20of%20Health%20care%20Providers%20and%20Systems,home%20and%20community-based%20services%20and%20supports%20%28HCBS%29%20programs>
- **CQL Personal Outcome Measures®:** “The Council on Quality and Leadership Person-Centered Outcome Measures is a person-centered discovery tool to explore the presence, importance, and achievement of personally defined outcomes, along with the supports that help people attain their individual goals and dreams. In a Personal Outcome Measures® interview, 21 indicators are used to gain valuable insight into the lives of youth, adults, and older adults with intellectual and developmental disabilities, and psychiatric disabilities. The interview covers a variety of topics, including choice, health, safety, social capital, relationships, rights, employment, and more.”
 - <https://www.c-q-l.org/tools/personal-outcome-measures/>
- **National Core Indicators:** “National Core Indicators®-Intellectual and Development Disabilities (NCI®- IDD) and National Core Indicators for Aging and Disability™ (NCI-AD™) can be used to assess in greater depth the experience of people who receive supports as it relates to person-centered practices and supports. NCI®- IDD and NCI-AD™ are voluntary efforts by State Medicaid, aging, and disability agencies to measure and track their own performance. The core indicators are standard measures used across states to assess the outcomes of services provided to individuals and families.”
 - <https://idd.nationalcoreindicators.org/>
 - <https://nci-ad.org/>
- **NCQA Person-Centered Outcome Measures:** “The John A. Hartford Foundation, The SCAN Foundation, and Gordon and Betty Moore Foundation, the National Committee for Quality Assurance (NCQA) joined forces with individuals and families, research experts and care organizations to develop the person-centered outcome (PCO) measures. Person-centered outcomes are personalized, structured, measurable goals identified by a person with complex health status or their care partner around what

matters most to them at that time. These person-centered outcomes can be used for both care planning and quality measurement. NCQA identified two methods of tracking progress toward person-centered outcomes: goal attainment scaling and patient-reported outcome measures (PROMs)."

- <https://www.ncqa.org/hedis/reports-and-research/pco-measures/>
- ***Shirley Ryan AbilityLab RRTC HCBS Outcome Measures:*** "The aim of this project is to develop and test a set of HCBS outcome measures. The measures will focus on non-medical person-centered domains of life that are important to people receiving HCBS."
 - <https://www.sralab.org/research/labs/rrtc-home-and-community-based-services/projects/development-and-testing-hcbs-outcome-measures>
- ***University of Minnesota RTC/OM HCBS Outcome Measures:*** "The University of Minnesota's Institute on Community Integration Research and Training Center on HCBS Outcome Measurement evaluates measures of the quality of life experienced by people with disabilities as a result of receiving services and supports. The five-year project is designed to conduct its work in six related phases. Each phase targets an important aspect of quality measurement, including social validation of the National Quality Forum (NQF) framework, measure development and validation, developing a database of measures, examining implementation practices of data collection programs, and identifying important risk adjusters. One of the Center's key products will be a set of measures submitted for endorsement by the NQF."
 - <https://rtcom.umn.edu/>