Person-Centered Planning and Practice

FINAL REPORT
July 31, 2020

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Executive Summary

In 2019, two government agencies, the Department of Health and Human Services' (HHS) Administration for Community Living (ACL) and the Centers for Medicare and Medicaid Services (CMS), asked the National Quality Forum (NQF) to put together a committee of people with lived and professional experience in long-term services and supports (LTSS) and acute, primary, and chronic care. The Committee's goal is to give government agencies and the public a view that finds agreement across different partners and perspectives.

The Committee looked at five areas to help develop strong standards and focus on skills needed to do person-centered planning well. First, it wrote a person-first definition of person-centered planning. Second, the Committee listed key skills for persons who facilitate the planning process. Skills include relationship building, communication skills, philosophy, knowledge of local resources, and understanding policy and regulations that impact person-centered planning.

Third, the Committee looked at systems that provide services to people and what they can do to support person-centered planning. These features include processes, building blocks, information, and resources. Advice on how to keep person-centered planning as a primary goal is also needed. Fourth, the Committee looked at ways to measure the quality of person-centered planning.

Lastly, the Committee offered a research agenda to help strengthen person-centered planning in long-term services and supports. This includes home and community-based services (HCBS) and residential settings like nursing homes. Working with acute, primary, and chronic care systems is also important.

This report represents the final recommendations of the Committee.

Introduction

Recent transformations in the healthcare and human services delivery systems have focused on performance measures across payers and providers to improve outcomes, experience of care, and population health with the explicit goal of increasing a person's control of the planning and delivery of their healthcare services and supports within their chosen community. However, there is no national quality measure set for person-centered planning (PCP) nor a set of evidence-based strategies upon which to develop measures of PCP. Most notably, about 61 million Americans have disabilities; 21 million Americans are expected to be living with multiple chronic conditions by 2040; and many will require LTSS in community and institutional settings.[1]

In an effort to address LTSS that are predicated on a person's needs, preferences, goals, and desires, HHS is working with its partners and other federal agencies, states, consumers and advocates, providers, and other stakeholders to create 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.

Over the last several decades, advocacy groups for persons who are representative of the people who receive HCBS have emphasized the right to self-determination and the desire for individual self-direction of federal and state funded services and supports. Expansions in federal and state rules have reflected deeper governmental commitments to support these rights and opportunities. As part of self-determination, persons who have the desire to self-direct their services and supports have the right to do so within optional Medicaid services. In Medicaid self-directed service modalities, beneficiaires have employer authority to do things such as manage a budget, as well as hire, fire, schedule, and train their caregivers. Person-centered planning represents a critical component of self-direction as it permits the person to exercise even more control and direction over their services and supports.

CMS has made clear the federal commitment to person-centered practice and planning and established specific expectations and program guidelines in this area for its various programs. This report offers critical guidance for providers of HCBS as they strive to meet these person-centered planning expectations. For this reason, certain content embedded within the report is specific to the HCBS program structure. For example, there are references within the report to the separation of assessment from planning and to "conflict-free" case management, which stipulates that the person helping develop the person-centered service plan must not also be a provider of the HCBS services being delivered within that plan. These particular structures and requirements do not necessarily exist beyond the context of the Medicaid 1915(c) HCBS service model. However, this report is based on the premise that person-centered practice and planning is the right of all people receiving services, not just those supported by Medicaid-funded HCBS. Moreover, HCBS is embedded within a larger healthcare delivery system and people using HCBS services and supports may also move between other LTSS settings like nursing homes, as well as acute, primary, and chronic care. The person-centered plan must move with the person between these settings. The vast majority of the content and recommendations included have broad applicability across a variety of program types and levels of care.

Background

The Affordable Care Act requires states that receive federal funds develop systems that support independence and self-direction of people using HCBS.[2] In January 2014, CMS published the HCBS Settings Final Rule, which included requirements on the PCP process and components of the individualized person-centered service plan for persons who receive Medicaid funded HCBS under certain federal authorities.[3]

CMS and other HHS agencies have provided additional guidance regarding PCP in several areas. These include ACL'sNo Wrong Door program, the Substance Abuse and Mental Health Services Administration (SAMHSA) Certified Community Behavioral Health Clinics, SAMHSA Mental Health Block Grant Program, CMS' Long Term Care Facilities Rule, the Office of the National Coordinator (ONC), and CMS eLTSS data elements.[2]

HHS operating divisions are regularly asked by program officials for technical assistance related to person-centered thinking, planning, and practice implementation. States request guidance on various

issues including operational definitions, systematic changes to support PCP and service delivery, and how to select and implement structural, process, and outcome quality measures to evaluate the impact PCP has in state systems.[4]

In 2014, under contract with HHS, NQF convened an expert multistakeholder group to develop recommendations for the prioritization of measurement opportunities that address gaps in HCBS quality measurement. One important gap identified is in measures that promote PCP and support community living. The final report identified PCP as an important domain and described it as, "The processes by which a person directs the development of a plan, based on his or her goals, needs, and preferences, and the coordination of services and supports across providers and systems to carry out the plan."[5] This project builds upon previous NQF work with the goal of providing states and other individuals and entities with the guidance they need to develop meaningful systems to support person-centered thinking, planning, and practices.

Project Overview

NQF convened a multistakeholder Committee to address PCP and practice in LTSS systems. NQF solicited applications through a public 30-day nomination period and received a record high number of interested parties. The list of proposed appointees was subject to a public commenting period to obtain feedback on the many stakeholders selected to serve on the Committee.

Committee members represented a variety of stakeholders including self-advocates, caregivers, purchasers, providers, health professionals, health plans, suppliers, and experts in community and public health and healthcare quality. The Committee includes experts in PCP, family-centered care, shared decision making, self-advocacy, consumer engagement, HCBS, facility-based care, community inclusion, and Medicaid. The diversity of people who use LTSS required representation of self-advocates from the mental health, nursing home, dementia, and disability communities. The Committee reflected the diversity of experience and insight, as well as the historical experience of being marginalized and underserved. Its diverse membership underscores the need to find similarities and maximize inclusiveness to move the field forward.

Through a consensus-building process, stakeholders representing a variety of diverse perspectives met throughout the project to refine the current definition for PCP; develop a set of core competencies for performing PCP facilitation; make recommendations to HHS on systems characteristics that support PCP; conduct a scan that includes historical development of PCP in LTSS systems; develop a conceptual framework for PCP measurement; and create a research agenda for future PCP research.

Throughout the deliberations leading to the development of this report, the Committee considered the focus on the person and the context of their life to be at the center of the PCP process (Figure 1). The plan that emerges and its implementation is influenced by the competencies exhibited by the facilitator of the planning, by the existing characteristics of the person's healthcare system environment, and by the quality measurement and improvement efforts directly associated with each step of the PCP

process. The Committee emphasized that the development and implementation of the person-centered plan must account for dynamic changes that often occur in the care settings for lives of persons using LTSS as they transition between home care, residential care, and acute, primary, and chronic care settings.

Figure 1. Person-Centered Planning Process
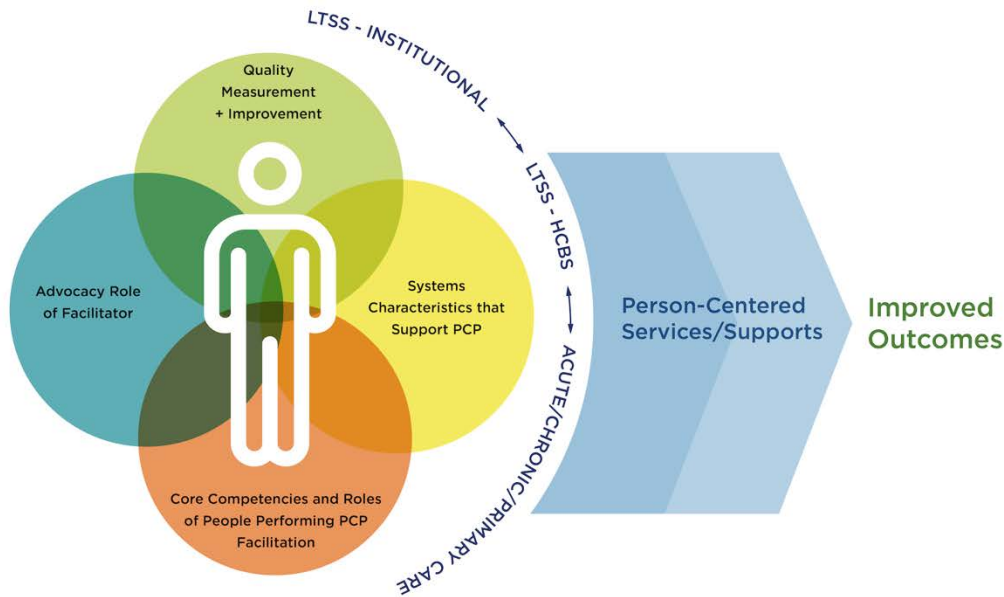
Person-Centered Planning Definition

The multistakeholder PCP Committee updated an existing definition of PCP for purposes of developing competencies for practice and recommendations on systems and organizational characteristics that support person-centered thinking, planning, and practices. Concepts, enhancements, and necessary components of the definition were derived from HHS policy documents, prior NQF work, state examples, and the work of consumer advocacy groups and other sources.

Person-centered planning is a facilitated, individual-directed, positive approach to the planning and coordination of a person's services and supports based on individual aspirations, needs, preferences, and values. The goal of person-centered planning is to create a plan that would optimize the person's self-defined quality of life, choice, and control, and self-determination through meaningful exploration and discovery of unique preferences and needs and wants in areas including, but not limited to, health and well-being, relationships, safety, communication, residence, technology, community, resources, and assistance. The person must be empowered to make informed choices that lead to the development, implementation, and maintenance of a flexible service plan for paid and unpaid services and supports.

In developing the definition for PCP, the Committee reviewed multiple iterations developed by NQF staff, and drew upon previous definitions such as those in the 2016 NQF HCBS Committee final report, CMS' HCBS Settings Final Rule, and language from other relevant state and federal programs. The Committee input directed the refinement of the definition by ensuring that the language is less "medical," and more accessible to the general public. With these issues in mind, the Committee developed the following definition, which seeks to empower the person in the process of planning their own life and is directed toward the person. To this end, the definition varies from the rest of the report in that it is offered in simpler, second-person language:

Person-centered planning is an approach to support you in living the kind of life you want for yourself. The plan includes organizing your supports and services. You are able to explore all areas of life that are important to you. You can can choose to made a plan with the support of people you are close to. You decide the kinds of supports and services you need. You also decide how to organize them in a way that works for you. You are in charge of the meetings. You decide who comes to the meetings. You decide where and when they happen. This type of planning goes on for the entire time you use support. You can change any part of the plan you want at any time. It is not done just during a planning meeting. Decisions are usually made in a meeting or a series of meetings. Focus on the following to make sure the planning process stays centered around you:

- The talks you have in the meeting should be about your life. This means your goals, dreams, needs, wants, things you like and don't like, and what is important to you.
- You are in charge of your plan. You should be supported to lead the meeting as much as you would like. This can include running the meeting yourself. There may also be someone else called a facilitator there to help. He or she will make sure the meeting stays focused on what is important to you.
- Person-centered planning takes a positive approach, meaning it is based on what you are good at or like.
- You are in charge of inviting whomever you would like to have at your meeting. This could be family, friends, or the people who give you support or care that you need.
- The members of your person-centered planning team are there to help you think about the kind of life you want for yourself.

You will need to prepare for the meeting before it happens. It is important that you have all the help you need to prepare for the meeting. In a good person-centered planning meeting, you will talk about a lot of things. Some examples may be how to get control over and make decisions in your life and the services you use. To do this, your team will want to learn more about many areas of your life, such as the following:

- The relationships that are the most important to you and who you want to spend time with
- The best ways to talk or write to you
- Where you want to live and what you want your home to be like
- The community that you want to be in

- Activities or hobbies you would like to do
- Help that you might need, like getting to places you need to go or preparing meals
- Your finances and budget
- People and resources in your community that are important to you
- Jobs and education
- Challenges to your goals, including your health
- Things that are important for your health, safety, and overall quality of life

Your service and support teams and healthcare providers need to be aware of and respect your plan. This is true even if you change where you are living or where you are getting healthcare. You should review your plan and think about any changes that are needed every time there is a big change, including where you live or get healthcare. As you make your plan with your providers or teams, there are some important rights you should be aware of:

- Person-centered planning is based on the belief that you have the right to make choices. This may mean to take some risks in trying new things.
- In some situations, there might be limits placed on decision making. Your plan may be changed to make sure certain safety risks are thought about. This does not mean that you have no role in changes in your plan. Even in these situations, there are rules in place to protect your rights. These should be explained to you in your meeting.
- The people supporting you to make your person-centered plan should talk with you about your supports and services. You can then make the choices that feel right to you based on your preferences and values. You also don't have to agree to recommended services that you don't want to have.
- The things that are important to you in your life may change over time. Your planning process and plan should change along with you. You can change your plan at any time. It must be revisited at least every year.

Core Competencies of People Performing PCP Facilitation

PCP facilitation requires a set of skills and competencies leading to the discovery and documentation of a person's desired outcomes, preferences, values and needs, and the parallel creation of a unique plan that considers the assessment, planning, and coordination of services and supports focused on the person. The facilitator must support the person to direct the development of a plan that describes the life he or she wants to live in the community. The facilitator helps the person build necessary services and supports around the plan to ensure coordination and implementation across providers, settings, and systems, as well as to ensure fidelity with the person's expressed goals, needs, preferences, and values.

The Committee noted that there are many desirable characteristics, attributes, skills, and knowledge for PCP facilitation. During the discussion, an overarching theme of the competencies emerged, including the anchoring principle that a facilitator must first and foremost be an advocate for the person and the

life that the person wants to live. Each of the competencies should deepen the facilitator's ability to serve as an advocate for the person. The Committee was especially mindful that the facilitator may in fact be the person him- or herself, the person's friend or family member, or a peer supporter. Such persons may or may not have had formalized training in PCP methods and approaches, but nonetheless are powerful facilitators specifically because they are well positioned to advocate.

The Committee also noted that the characteristics, attributes, skills, and knowledge discussed were focused on the facilitation of the planning meeting itself, but also relate to critical activities that are natural extensions of the planning meeting, including coordination roles associated with preplanning before the meeting as well as plan implementation and maintenance that follow. The Committee made a distinction between meeting facilitation roles and coordination roles, noting that facilitators may or may not serve in coordinating roles.

Facilitator Role

The primary responsibility of the facilitator is to join with the person in an advocacy and empowerment role to support and amplify their voice as needed in the context of PCP and in implementing the plan. This role requires considerable flexibility to accommodate various levels of self-advocacy skills and empowerment of each person, up to and including the person self-directing all aspects of the planning process. The planning process is severely challenged without the knowledge skills and abilities necessary to advocate and support empowerment in a manner free from conflicts of interest. Conflicts of interest as well as real and perceived bias are important to avoid in order to optimize the advocacy and empowerment role of the facilitator. In practice, this principle may become nuanced. For example, there are many instances where the facilitator is prohibited from working for an agency that provides supports to the person; this is especially common for HCBS. However, bringing in outside facilitators that do not work for the facility provider can be very challenging inside of institutional LTSS settings. This also does not account for common circumstances in HCBS settings, such as case managers working for managed care organizations.

Facilitator responsibilities also include providing information and guidance to people using or seeking services and supports; facilitating the planning meetings as requested by the person; suggesting creative strategies to address the needs and desires of the person; and monitoring the effectiveness of the PCP process and service implementation. Several additional core competencies are needed to support the person in identifying their goals, needs, preferences, and values. These competencies are classified below into five categories: foundational skills, relational and communication skills, philosophy knowledge, resource knowledge, and policy and regulatory knowledge (Table 1). The Committee also identified several characteristics that are desirable, but did not consider these to be competencies per se. Each of these is described in further detail in the sections below. PCP includes all information needed to inform the process. The plan should be reviewed on a regular basis to assure that changes in the person's goals and needs are captured and appropriate adjustments to services and supports are made. Using completed assessments is important in the planning process. However, the assessment process is separate from the planning process. Application of these competencies will, to some extent, dictate the level to which the person directs the planning process, receives support appropriately as needed, and

achieves the end result—namely, successful implementation of a plan for advancing the person's goals and meeting needs the person deems important.

The Committee noted that the list of competencies for facilitation may seem daunting, and stressed that the expectation is not that any one human would possess all of the skills, knowledge, and attributes identified.

Skills: Foundational

The foundational skills for serving as a facilitator of PCP relate to forming a rapport with the person; understanding their needs and wants; and empowering them to make decisions about goals in the context of needed supports and services. The personal characteristics and attributes of the person facilitating the person's plan play an important role in ensuring that the plan is appropriate.

Table 1. Core Competencies for Person-Centered Planning Facilitation

Core Competencies for Person-Centered Planning Facilitation		
Skills		
Skills: Foundational *Understanding the Person* • Informed decision making • Contextual understanding • Applying effective freedom • Group power dynamics • Understanding disparities *Empowering the Person* • Advocacy role • Strengths-based thinking • Yielding control • Training the person to lead the process • Creating a culture of high expectations • Supporting empowerment development • Navigating complexity of choice	**Skills: Relational and Communication** *Relational Skills* • Negotiation • Engagement • Dispute resolution • Team building • Plan documentation and distribution *Communication Skills* • Active and reflective listening • Motivational interviewing • Alternative communication methods • Health literacy • Empathy	
Knowledge		
Knowledge: Philosophy *Generating purpose and meaning* • Cultural perspective • Effective freedom • Empowerment • Dignity of risk • Presumption of competence • Supported decision making • Trauma-informed approach *Contextual Philosophy* • Independent living philosophy	**Knowledge: Resources** *System Resources* • LTSS and medical system • Safety net providers • Gaps in services and supports • Service load or service coordination management • Legal issues *Community Context Resources* • Community assets and resources	**Knowledge: Policy and Regulation** *Laws* • Americans with Disabilities Act • Individuals with Disabilities Education Act (IDEA) • Older Americans Act • Age Discrimination Act • 21st Century Cures Act – Division B *Regulations* • CMS HCBS Settings Final Rule

• Understanding of living best life • Recovery • Ableism and ageism *Advocacy* • Self and systems advocacy • Human rights • Model of independent living	• Populations and subgroups • Local advocacy groups *Planning Specific Resources* • Process elements and experts • Content elements and experts • Technological solutions	• CMS Interpretive Guidelines 42CFR 482.13a • LTC Ombudsman Final Rule • Requirements for LTC Facilities • PCP for LTC Facilities *Court Decisions* • Olmstead v. L.C. • Jimmo v. Sebelius

It is also critical to have foundational skills related to understanding and empowering individuals. The person must be supported in leading the planning process. The person's choices include identifying who joins the meeting, the roles each person has (e.g., who will facilitate), location, schedule, and the meeting agenda. Facilitators must also help the person to identify the site and time of meetings, which should be designed to accommodate the person and those individuals the person has invited to join. The facilitator must have the skills to support the person to drive the agenda, which should include any issue that the person wants to discuss. The facilitator must have strong interpersonal skills including reflective listening, high levels of empathy, and team building.

Understanding the Person

- **Informed decision making**—The ability to help the person understand what the options are and to support the exploration of potential options in order to enhance decisions. Ability to ensure principles of health literacy and adult learning needs are met and to incorporate and address uncertainty in the planning process.
- **Gathering contextual understanding**—The ability to discover the individual, family, community, and other environmental contexts, and apply the understanding in the development of the person-centered plan.
- **Applying effective freedom**—The ability to discover the factors that lead to the successful implementation of the person's freedoms and choices and effectively apply them in the development of a person-centered plan.
- **Navigating group power dynamics**—PCP leads to the person having more control and direction. In some instances, the person's control may be limited by the people around them, even those who care deeply for the person. The facilitator has the ability to discern differences in social power across social relationships, including the family, caregivers, systems, and broader social and cultural dynamics—and to effectively engage those power structures to maintain the integrity of the PCP process.
- **Understanding disparities, conditions, and disabilities**—The facilitator understands the influence of the person's race, gender, sexual orientation, culture, and other factors and successfully incorporates them into the planning process. The facilitator also has a general understanding of the conditions and disabilities or conditions that the person may have.

Empowering the Person

- **Advocacy**—The advocacy role is central to facilitating PCP. The facilitator must be as free as possible from conflicts of interest with providers, payers, and others who may have some social or structural power over the person. The advocacy role also means that the facilitator supports the person in speaking up for their interests, and models the behavior when appropriate and when asked by the person.
- **Strengths-based thinking**—Focus is on the positive attributes of a person. The process is person-led and centered on strengths-based outcomes and positive attributes. Facilitators interact and respond with a positive focus.
- **Yielding control**—The ability to have planning driven by the person through self-direction and self-determination, including supporting people to initiate planning while maintaining the role of facilitator. One important goal is to help the person to determine what is important to them.
- **Training the person to lead the process**—Facilitators need the skills necessary to encourage and teach people how to lead their own meetings and develop their own plans. The facilitator should ensure that, if desired, the person gains skills and confidence to lead their own meetings.
- **Creating a culture of high expectations**—Facilitators need to be skilled in creating a nurturing environment where people feel secure about expressing their desires for their life, where the goal is success and where people are confident that they will receive encouragement and support.
- **Empowerment**—The facilitator understands and acts in an empowerment role supporting the person to take control of decisions and activities that impact their life. The facilitator understands that empowerment is often a process that requires supporting the person to break free from internalized oppression over a period of time. Facilitators need to be able to work in contexts where the person chooses to move into a position of facilitating their own planning process, which requires the facilitator to maintain role flexibility from being the primary facilitator to acting solely in a consulting capacity.
- **Navigating complexity of choice**—Too many choices may overwhelm some people. Excess of choice often leads people to be less satisfied once actual decisions are made. Facilitators must possess the skills necessary to assist people to navigate choices in the planning process.

Skills: Relational and Communication

Building relationships and maintaining positive communication are central to facilitating PCP. Through strong relational and communication skills, the facilitator can keep a creative, individualized approach to planning and can help identify non-standardized supports and services. Building good relationships and communicating with the person effectively are integral to ensuring the plan is the person's life vision. The plan is longitudinal and flexible, and it changes as new opportunities and challenges arise. The facilitator ensures that the process accommodates the person's communication needs. As discussed above, facilitators must be able to flexibly apply these skills to accommodate various degrees of self-empowerment, self-advocacy skills, and the interests of each person.

Relational Skills

- **Negotiation**—Facilitators have skills that elicit and negotiate goals effectively: the ability to establish trust, listen, and identify and recommend solutions to potential barriers and understand a person's history, context, and values. Facilitators elicit all challenges and barriers, including those not readily transparent, such as conflicts of interest among people involved in providing support, subtle power relationships, underlying disputes, an unsafe living environment, abusive caregiver(s), mental and behavioral disorders including substance use disorders and mitigation of problems.
- **Engagement**—When negotiating goals—or interventions to address goals—facilitators engage with the person and those supporting them to plan. They assist the person in controlling the meeting and provide information about the risks and benefits of options.
- **Dispute and conflict resolution**—The person's goals and objectives drive the plan. The person pursues the goals they have defined. In the course of planning, some disputes or deeper conflicts may arise between the person and people who have formal (e.g., legal guardian) or informal (family member) influence over the person. Facilitators need basic mediation skills to be able to help uncover the interests of the various parties, support the exploration of varying perspectives, and assist in reaching a stable resolution.
- **Team building**—Building the plan is a collaborative task, and the facilitator is competent in team building, including identifying the goal and function of the team, clarifying roles and strengths of each member, managing interpersonal dynamics, and fostering an environment of learning and advocacy with the person. Team building keeps the group of individuals around the person in a contributing, cohesive unit. The team of people is organized to work together cooperatively to meet the person's needs.
- **Plan documentation and distribution**—Implementation is just as important as the plan. Documenting and appropriately sharing the plan with those engaged with the person is critical to facilitation.

Communication Skills

- **Active and reflective listening**—Facilitators use active listening throughout the planning process—giving their full attention, and using body language and responses that demonstrate their consideration and understanding of what the speaker is communicating. The goal of active listening is to ensure the speaker feels heard and understood. Facilitators use reflective listening, paying special attention to the content, feelings, and meaning behind the message and reflecting back to the speaker to demonstrate understanding and clarify the message. The purpose of reflective listening is to act as a mirror or reflection of the speaker to optimize their communication.
- **Motivational interviewing**—Motivational interviewing is an approach for addressing ambivalence, and is most often used to help set goals for people targeting a change in their lives. In the context of PCP, motivational interviewing is an important tool to further encourage the exploration of the person's needs and desires. The facilitator listens and reflects back the person's thoughts so that the person can hear their reasons and motivations expressed back. This is not to say that every facilitator must be an expert in motivational interviewing, but the

facilitator should understand and apply the principles to ask open-ended questions and encourage a deeper and more holistic understanding.

- **Alternative communication methods**—No two people communicate precisely the same way. Facilitators need to be able to account for the preferred communication methods of the person, including addressing communication barriers. Persons with hearing loss, visual, or cognitive disabilities will likely need augmentative and alternative communication to support the planning effort, and barriers should be factored into the content of the plan.
- **Health literacy**—Improving the ability of the person to obtain, process, and understand health information and services needed to make decisions.
- **Empathy**—Facilitators themselves benefit from active listening to develop genuine empathy for the person's experiences; affirm the validity of the person's viewpoints; and help others in understanding the context in which the person interacts with their environment.

Knowledge: Philosophy

PCP is based on the premise that everyone has preferences that form the foundation for how they want to live their lives and achieve their dreams, goals, and desires. The focus is on these preferences, not on the person's conditions or cognitive level. The circumstances of people's lives with significant impairment may make that challenging. The person facilitating the plan has competencies in the philosophical underpinnings of person- and family-centered thinking, planning, and practice. This includes resources and informed choices that create freedoms, acknowledging that risks are a fundamental right and that empowerment of the person is foundational to the approach.

Generating Purpose and Meaning

- **Cultural perspective**—It is not expected that each approach to PCP will resonate with every person in our highly diverse society. Variation in culture has a deep impact on what is meaningful to the person. The facilitator must recognize cultural factors such as individualism and collectivism, relationships to power, avoidance of uncertainty, relationships to time, and other cross-cultural differences that need to be understood and addressed in the PCP process.
- **Effective freedom**—The freedom of articulating the plan must accompany access to resources and the power to use them. Freedom is not simply a set of rights, but also consists of the material means and resources to fulfill one's desires. The implication is that freedom by circumstance must be augmented by freedom that is achieved, not only by material means but also through decision making. Facilitators recognize that all persons have limitations related to resources but strive to maximize those of the person to reach their goals.
- **Empowerment**—The empowerment philosophy is based on the premise that human beings have the capacity to make choices and are responsible for the consequences of their choices. In practice, this means optimizing the power and control of the person as they make and implement their plan.
- **Dignity of risk**—Dignity of risk is the idea that self-determination and the right to take reasonable risks are essential for dignity and self-esteem. The goal of PCP is not to avoid risk in the lives of older adults and people with disabilities. The task instead is to work hard to help find the amount of risk that person is willing to take to live their best life on their terms. Dignity of risk also acknowledges that making decisions that result in negative consequences helps people

learn and is part of the human experience. Whether the team approves of the person's decision or not, the person still has the right to make it.

- **Presumption of competence**—Presuming competence means assuming that the person has the capacity to understand, think, and learn. It also acknowledges that a person knows what they like and don't like. However, people may have varying levels of competence in different areas of their lives. Someone may not be able to manage finances without help, but may be able to direct how they want to spend their resources and can always express preferences.

- **Supported decision making**—Mechanisms for supporting decision making without resorting to guardianship need to be used where appropriate. These include powers of attorney, healthcare advance directives, representative payeeships, and other options. Supported decision making is a new construct for allowing the person to get help in making their own decisions from trusted family members, friends, and professionals. A person-centered plan may include revocation of an existing guardianship and replacement by an alternative mechanism of support for the person.

- **Trauma-informed approach**—There is increasing recognition that a history of trauma plays a critical role in the health and well-being of many persons in LTSS and other settings. Left unaddressed, trauma can pose a significant challenge to the person's goals. Facilitation of PCP acknowledges this, and it should seek a trauma-informed approach to realize the impact of trauma, recognize the symptoms of trauma in clients, families and staff, and integrate trauma knowledge into policies, procedures and practices.[5]

Contextual Philosophy

- **Independent living philosophy**—The independent living movement is founded on the notions of work for self-determination, equal opportunities, and respect. Every person, regardless of disability, has the potential and the right to exercise choice and to determine what is best for themselves. The goals of this philosophy are similar to those that generate purpose and meaning.

- **Understanding of living best life**—Living one's best life is subjective and involves taking actions that help the person hone, expand, or maintain their interests, talents, and passions. The facilitator supports the person right to articulate what his or her best life looks like, and to tailor their plan to fit their ideal.

- **Recovery**—This principle is central to the recovery and recovery-oriented care movement which has driven transformation in behavioral health for the last several decades. The recovery model as expressed in the behavioral health community is centered on the idea that it is possible to regain well-being, health, overall quality of life, and hopeful vision of the future even in those situations where a person continues to have symptoms or challenges. SAMHSA has defined recovery as, "A process of change through which individuals improve their health and wellness, live a self-directed life, and strive to reach their full potential."[6] The principles of recovery are consistent with those of person-centered thinking, planning, and practice and they recognize that building or rebuilding a good life worth living is possible for all people regardless of their functional status.

- **Ableism and ageism**—Good facilitation implies an understanding of the context of the person. This includes the history of the disability rights and independent living movement, the cultural

model of disability, and ableism and ageism. Ableism and ageism are forms of discrimination in favor of people of able mind and body or a younger age, and devalue people based on their age or developmental, intellectual, psychiatric, or physical disabilities. Facilitators understand the challenges faced by persons who encounter these forms of discrimination, and operate under the assumption that the person is a co-equal member of the team and in society. Facilitators help foster positive disability and age-related identity.

Advocacy

- **Self, individual, and systems advocacy**—Facilitators should have good familiarity with how people can advocate for themselves to meet their individual needs (i.e., self-advocacy). They should also be familiar with systems advocacy, which refers to changes in policies, rules, and laws that determine how services are provided.
- **Human rights and responsibilities**—Facilitators must understand basic human rights and responsibilities, such as the rights to life and liberty, freedom from torture or slavery, rights to expression and opinion, rights to work and be educated, among others. It is particularly important to stress an understanding of the right to exercise these free from discrimination, including discrimination based on age and disability.
- **Independent living model**—The independent living model puts forward the proposition that perception of disability is more heavily influenced by societal notions than by a person's actual impairment or difference and supports independence for persons with disabilities. It looks at ways of removing barriers that restrict life choices for disabled people. When barriers are removed, disabled people can be independent and equal in society with choice and control over their own lives. This model is important to PCP because the traditional medical model does not fully explore the personal experience of disability or help to develop more inclusive ways of living.

Knowledge: Resources

The focus must continually be on the person with whom the plan is developed. The person should not simply be inserted into available or standardized services and supports that may not be needed nor wanted. Providing good resources to the person is an important part of avoiding unintended and detrimental consequences, such as the person becoming disengaged in the process, disempowered by deferring to family members or others, professional decision making, or displaced by service providers. The general strategy for avoiding these consequences is to presume competence and capacity by the person, allies, and the community; to provide assistance when the current situation involves unmet needs; and to ensure that the person has the ability to identify available resources.

The facilitator must have a working knowledge of how to access information and assistance of long-term services, supports, and the larger healthcare system; how to handle legal issues; and other solutions for the person for whom they are supporting to develop the plan.

Information on community resources must be available to all individuals participating in the PCP process. The person must have access to people who can map out general community resources and options for community involvement. The person-centered facilitator may also be the case manager

whose job includes these functions. However, as facilitators increasingly become independent of the formalized case management function, they will need to know how to access secondary information and referral networks, such as local No Wrong Door systems for local services and support options as they build their own knowledge base. The goal is to identify resources to meet unmet needs and develop collaborative agreements to resolve barriers and ensure effective resource use. At the person's plan level, the person determines the best ways to investigate and become engaged in their community. Providers also seek to maintain or amplify the community connections the person currently enjoys in planning services and supports.

System Resources

- **LTSS and medical system**—People will need resources and support identifying what support is needed, where to get support, how services are funded, and what resources are available to them. This is an informational responsibility for facilitators.
- **Safety net providers**—Facilitators identify providers who, by mandate or mission, offer access to healthcare regardless of the person's ability to pay. Planning is often provided to persons with limited resources including the uninsured, Medicaid beneficiaries, and other vulnerable populations.
- **Gaps in services and supports**—It is also important to understand what is not accessible to the person, and to help identify creative solutions that fill gaps in services and supports.
- **Service load or service coordination management**—In some markets, service providers may have insufficient resources to meet demand, thus impeding their ability to assist the person. Facilitators must know how to stay up-to-date on current service loads and how to locate desired services and resources.
- **Legal issues**—Facilitators understand how to connect the person to resources that he or she may need, such as legal representation, protective services, advance care planning, and other forms of legal decision support.

Community Context Resources

- **Community assets and resources**—To support the person's vision for their engagement with their community, the facilitator must have a working knowledge of the resources available, including housing supports, employment resources, safety net providers, such as food pantries and clothing donations, transportation, culturally specific resources, libraries, volunteer programs, faith communities, and myriad other community resources. Connecting the person to community resources leads to greater inclusion as a valued member of community and society.
- **Populations and subgroups**—The facilitator understands the dynamics of the person's community including the populations and subgroups. Effort is taken to understand under-engaged groups. Facilitators are knowledgeable of advocacy and consumer communities, such as health peer support, intellectual and developmental disability (IDD) self-advocacy groups, independent living groups, older adult advocacy groups, etc.
- **Local advocacy groups**—The facilitator is aware of local advocacy groups and the key individuals within those groups who can assist the person to reach their goals.

Planning Specific Resources

- **Process elements and experts**—Facilitators are process experts in how to conduct PCP and know how to train others in the process. Facilitators know of other sources to support the process—both materials and individuals that can supplement their expertise. However, people facilitating their own planning process may not have the level of training necessary to train others. Also, people facilitating for themselves may not possess all the legal, provider, and other knowledge necessary to effectively implement the plan, and will often require additional expertise to support these areas.
- **Content elements and experts**—Facilitators must minimally be able to identify materials and people that can supply content to inform the plan.
- **Technological solutions**—Facilitators are aware of technological resources that may serve as solutions to aid the planning process and implement the person's plan.

Knowledge: Policy and Regulation

In addition to knowledge of how to actually conduct the planning process, an individual facilitating PCP needs to understand the broader systems environment. This includes a good understanding of laws, federal and state regulations, local policies, and court decisions. Not every facilitator needs to have all the legal and program knowledge described here. For instance, a person working in the IDD field may not need to know a great deal about the Older Americans Act other than it funds their local aging program. Facilitators should be familiar with the laws that protect the rights of the individuals they are supporting.

Laws

- **Americans with Disabilities Act**—Outlines the civil rights of Americans with disabilities, prohibiting discrimination based on disability, comparable to the rights of nondiscrimination based on race, religion, sex, national origin, and other characteristics from the Civil Rights Acts. Facilitators should be familiar with the basic tenets of the act, such as employment rights; public entity prohibitions at the local level including transportation, access, and public housing; public accommodation requirements for persons with disability; and telecommunication rights.
- **Individuals with Disabilities Education Act (IDEA)**—This act ensures that students with disabilities have access to free appropriate public education, among other rights. The goal of IDEA is to provide those who have disabilities the same opportunities as those who do not.
- **Older Americans Act (OAA)**—The purpose of the OAA is to assist older people to secure equal opportunity to the full and free enjoyment of certain objectives, including financial security, housing, protection of rights, and participation in the community. It provides services for older adults, including PCP services provided by aging and disability resource centers.
- **Age Discrimination Act**—The Age Discrimination Act prohibits discrimination on the basis of age in programs and activities that receive federal financial assistance.
- **21st Century Cures Act – Division B: Helping Families in Mental Health Crisis Reform Act of 2016**—This act updates the direction of mental and substance use disorder treatment in the nation. The act supports individuals and families to access evidence-based programs and practices.

Regulations

- **CMS Home and Community-Based Services Settings Final Rule**—This outlines requirements for several Medicaid authorities under which states may provide HCBS. The regulations enhance the quality of HCBS and provide additional protections to individuals using services under Medicaid.
- **CMS Interpretive Guidelines 42CFR 482.13a**—This clarifies expectations of providers to address and resolve complaints and grievances in a timely and transparent manner. Providers should document, collect, and analyze this information in quality improvement efforts.
- **State Long-Term Care Ombudsman Final Rule**—This rule, described in 45 CFR Parts 1321 and 1324, requires states' long-term care (LTC) ombudsmen to take a person-centered approach and resolve issues related to the rights, health, safety, and welfare for persons living in long-term care facilities. Ombudsman programs must resolve complaints; provide information to residents about LTSS; ensure access to services; and represent the interests of residents before other governmental agencies.
- **Medicare and Medicaid Programs Reform of Requirements for Long-Term Care Facilities**—The rule made major changes to improve the care and safety for LTC residents by reducing unnecessary hospital readmissions and infections, increasing quality of care, protecting residents from abuse, and strengthening safety. Compliance is essential for LTC facilities because adherence is a requirement for participation in Medicare and Medicaid.
- **Comprehensive Person-Centered Care Planning for LTC Facilities**—Requirements in 42 CFR 483.21 mandate that facilities develop a baseline care plan within 48 hours of a person's admission to direct the care team while a comprehensive care plan is developed that incorporates the resident's goals, preferences, and services that are to be furnished to attain or maintain the resident's highest practicable physical, mental, and psychosocial well-being. The care plan focuses on medical needs and should be separate and distinct from a person-centered plan that sets forth the goals, wants, and needs of the person.

Court Decisions

- **Olmstead v. L.C.**—The U.S. Supreme Court, relying on the Americans with Disabilities Act, held that persons with disabilities have the right to live in the community rather than in institutions if determined that community placement is appropriate.

- **Jimmo v. Sebelius**— The settlement in the Jimmo case states that Medicare does not require someone's condition to improve in order for them to continue receiving therapy services; a person is eligible to receive therapy services needed to maintain functioning.

Facilitator Personal Attributes

The Committee also noted characteristics and attributes of an individual that particularly lend themselves to strong PCP facilitation. The Committee made a distinction between these and other core competencies in the sense that competencies relate more especially to knowledge and skills, and are easier to train and test.

- **Self-awareness**—Self-awareness is a key component of PCP. The facilitator must be cognizant of their own cultural assumptions, psychological development and temperament, personality dynamics, and prejudices to avoid imposing their beliefs on the process.
- **Respectful**—The facilitator applies the understanding that all persons are deserving of respect. Respect for all individuals can coincide with challenges to their ideas.
- **Minimizing cognitive biases**—The facilitator should have a working knowledge of biases that may influence their own thinking—such as the halo effect, confirmation bias, and implicit stereotypes—to minimize their effect on the planning process.
- **Empathy and emotional intelligence**—Facilitation of PCP involves forming an understanding of and articulating the person's desires, goals, needs, and wants, which in most cases will involve an emotional component. The facilitator must understand the person from the person's perspective.
- **Cultural humility and competency**—PCP takes into account the whole person, including the complexity of his or her worldview. Facilitators must be able to view all cultures with humility, and communicate with and effectively interact with people across cultures. This involves awareness of one's own worldview and a positive attitude toward cultural differences.
- **Openness to learning**—Willingness to learn is an important skill in facilitating PCP. Facilitators must show genuine curiosity about the person. Genuine interest in the person and being open to learning are key in keeping the plan focused on the person.
- **Critical and creative thinking**—Problem-solving ability, and critical and creative thinking in particular, are important in identifying resources and solutions. PCP requires the facilitator to identify resources and solutions through using critical and creative thinking. Critical thinking is self-directed, self-disciplined, self-monitored, and self-corrective thinking. It entails effective communication, problem-solving abilities, and a commitment to overcome personal biases. Creative thinking involves identifying ideas and solutions.
- **Personal integrity**—In the context of PCP, personal integrity means being free from conflicts of interests, clear values of caring for the person, acting in accordance with those values, and acting consistently over time.

Systems Characteristics that Support Person-Centered Thinking, Planning, and Practice

As healthcare systems across clinical and LTSS settings (home and community services and institutional services) increase access to PCP services, programs will also increasingly need to use universal elements of person-centered thinking, planning, and practices. For example, state Medicaid agencies are reconfiguring systems to support PCP and service delivery, and adopting various programmatic aspects across HCBS and in institutional settings, such as hospitals and nursing homes.

For the purposes of this project, ideal systems characteristics have been categorized into distinct areas as follows: leadership, person-centered culture, participant stakeholder engagement, eligibility and service access, person-centered planning and monitoring, finances, workforce capacity and capabilities, collaboration and partnership, and quality and innovation (Table 2). These categories are the main

expressions of various individual programmatic aspects, services, and attributes of interest. The categories are meant to be a guide for addressing basic PCP aspects of any program. In addition to actual program characteristics and focus areas, information on barriers and opportunities is also provided based on input from key informants with experiences related to PCP and LTSS.

Discussions of each category are presented below, along with a discussion of potential opportunities and barriers as well as attributes necessary for ensuring programmatic person-centeredness.

Leadership

PCP is just one component of person-centered practices, which is a broader set of planning, providing, and organizing services rooted in listening to what people need and want in order to more deeply connect with them in their own care. Person-centered practices require strong leadership. Leaders directly overseeing services, as well as owners of service-providing organizations and corporate leaders, should demonstrate the value of person-centered practices by actively participating in training opportunities, promoting person-centered practices in all functional areas within an organization, and consistently communicating the importance of person-centered practices as a means to reach the vision and promise of person-centered thinking, planning, and practice. They should also ensure sufficient resources are available. Measures of person-centered practices should be part of regular quality improvement activities, and leadership should intentionally promote the use of person-centered practices with other community systems including justice, education, healthcare, and social service agencies. Leaders should implement community education strategies that promote understanding and respect for the populations they serve, especially among disenfranchised and stigmatized groups.

Table 2. Summary of Systems Characteristics Supporting Person-Centered Planning Facilitation

Systems Characteristics for Person-Centered Planning
Leadership • Implementation of person-centered practices (including PCP) comes from vision and strategy • Leaders implement PCP training, communicate its importance, direct resources, and create accountability through measurement
Person-Centered Culture • Naturally derived from leadership • Culture should be based on listening and engagement with communities served • Focus is not just values and principles, but also practices
Participant Stakeholder Engagement: Nothing About Us Without Us • Develop advisory councils and participant review of policy changes • Ensure representation of participants on key committees
Eligibility and Planning • Determine eligibility and make appropriate referrals to services, not based on potential paid services but to support the person's choices and self-determination in order to reach their desired outcomes • Use No Wrong Door models
Person-Centered Planning and Monitoring • Service plans should align with PCP • Service planning and delivery should align with PCP. People, not forms, should guide the process.
Finances

• Ensure that programs are adequately funded • Do not limit PCP to only billable services and supports
Workforce Capacity and Capabilities • Programs must be adequately staffed • Staff must be trained and maintain expertise
Collaboration and Partnership • Engage program participants, advocacy organizations, and the larger community • Engage other systems including acute, primary and chronic care; housing; employment; education; transportation; faith communities, etc.
Quality and Innovation • Regular evaluate performance and the creation of accountability • Document unmet needs • Use engagement data to drive innovation and improvement
Barriers and Opportunities • Program implementation occurs at the state level; hence, barriers and opportunities are unique • Establishment of state and federal regulations, including oversight, is a key opportunity

Leaders should have a clear vision and strategy for delivering person-centered practices, including PCP. Leadership should actively support this strategy and appropriate resources as necessary, including providing all members of the team with sufficient time and other support needed to develop PCP competencies and to work with individuals to establish relationships, knowledge, and plans. In turn, leaders should demonstrate these principles by engaging staff in developing the strategy; soliciting input about practices that create barriers to person-centered approaches; and involving staff in addressing these issues. All staff and leadership should be formally held accountable for delivery of PCP as defined in the strategy. Person-centered practices should inform all policy and guidance materials within the organization. Staff should understand how to demonstrate person-centered principles in each encounter with the people they are supporting.

The communication strategy should align policy and practice with person-centered principles and values, and include a feedback loop to collect stakeholder input. The strategy must also include various modes of communication that best suit all stakeholders and are transparent and user friendly.

Policies, regulations, and guidance documents should be updated and fully implemented to ensure active promotion of and engagement in person-centered practices.

Person-Centered Culture

Staff should routinely communicate about person-centered practices in all aspects of the service delivery system. Person-centered principles should be demonstrated through the use of studies, stories, and other data during oversight meetings, utilization reviews, monitoring reviews, trainings, and feedback to all components of the system. Leaders and managers should regularly engage with service users, family members, and caregivers to gain their perspectives on how to improve their experience. Communications should include and articulate a clear set of person-centered principles to guide the practices of all staff across the organization. Providers should consistently demonstrate behavior that upholds dignity and respect for the person and their supporters. They should honor and embrace the

individuality and cultural diversity that informs the planning and provision of services and supports. While a facilitator may be focal in plan development, it is important that all parties understand and uphold their role in implementing the plan and engaging other parties in managing and adapting the plan. Facilitators should instill confidence and buy-in for shared responsibility and flexibility. The ability of supporters to transfer knowledge and understanding of the person's preferences, adaptive learning style, and health literacy when they transition through episodes of acute treatment, rehabilitative care, and other new service environments is paramount. Supporters maintain communication and collaborate and advocate with different providers throughout transition processes.

It is just as important for the values and principles of the culture to be addressed as it is for the practices within it. Practices and routines within the culture that directly prevent person-centered care provision—such as fixed meal times in communal settings like nursing homes, regimented bathing schedules, direct care task lists, and other routine approaches to care—can significantly impact the ability to implement a person-centered plan. Organizations must strive to support community integration and help individuals engage with natural community opportunities. Providers should avoid, to the extent possible, services that are segregated from the community by disability status or replicating activities that can be obtained from integrated settings. Changing language, trainings, expectations, forms, and philosophies can only go so far in changing culture. Behavior and systems of care delivery also need to change. Agencies should work with all stakeholders—including people who use services, families, caregivers, service providers, case managers, and others—to develop and implement assessment, service planning, and service plan monitoring procedures that fully align with finding a balance between dignity of choice/risk and supports provided. Assurances that the person has demonstrated an informed understanding of their choices should also be noted and collected. It is important to recognize that health literacy is not fundamentally a person's responsibility, but is rather a responsibility of the systems that are in place to care for an individual to meet the person where they are.

Participant Stakeholder Engagement: Nothing About Us Without Us

Ongoing structures and processes supporting the engagement of participants and their allies is essential to supporting the transformation of systems to become more person-centered. Systems need to develop policies and procedures, such as participant advisory councils, participant review, and comment periods on program and policy changes. Systems also must consider how to engage with day-to-day unpaid workers, such as family and friends, or family and friends who might be paid caregivers. Formal training should be offered to participants on key system components and processes, such as state legislative processes, state agency structure, policy, and quality measurement and improvement. Systems should develop formal policies to hire people with disabilities in administrative and provider functions. States are required to solicit public comment on a number of Medicaid authorities found within the HCBS Settings Final Rule, 1115 Demonstrations, and 1915(b) managed care waivers. These processes should be generalized across the LTSS, as well as primary, acute, and chronic care systems. Participants engaging in formal roles in organizations need to be reimbursed for their efforts.

Eligibility and Service Access

Organizations should implement the system-wide use of PCP and coordinate with health providers, local education agencies, child protection, and other social services agencies to determine eligibility and make appropriate referrals to services. The focus of intake, referral, and assessments should not be on potential paid services, or other nonpaid services and supports, but on the needs of the person and the goals and outcomes a person wants for their life. The assessment should be developed using survey research methodologies, including focus groups, interviews, and discussion with people and their families, caregivers, friends, and neighbors, and if appropriate should employ psychometric testing uniformly applied by trained assessors. Assessment and PCP must not be conflated. They inform each other in an ongoing learning process.

A No Wrong Door model of service access should be employed with PCP facilitation as the model for interacting. Access support should be for all payers, populations, and programs. Access to staff, case managers, and other personnel should be free from conflicts with other service providers.

Person-Centered Planning and Monitoring

Person-centered planning should align with federal, state, and local PCP policies found in statute, regulations, and guidance, and should be driven by stakeholder engagement. The process includes identifying strategies the person can use to lead their own planning (if desired),resolving disagreements, addressing what is important to and for the person, and figuring out how the person and their team will identify and plan for any known risks the person may encounter when learning or engaging in new experiences.

The person-centered plan monitoring process should ensure that: service plans address the needs and preferences of the person; supports are implemented as identified and authorized; reasonable risk is accepted and includes steps for mitigation; and any modifications to a person's preferences are identified and include data collection reviews to test the effectiveness of the modifications and conditions under which they can be lifted. The plan monitoring process may become nuanced in some cases, such as with increasing dependence due to cognitive decline, dementia, or other serious illnesses. When this occurs, people are increasingly more dependent on others to help them acquire and achieve quality care. Care planning should include the needs of the family, as appropriate. As providers strive to consider the person in the context of unpaid or family supports, the system can more effectively care for people by accounting for the needs of the people tasked with day-to-day support. In these stages of care, plan monitoring must include identifying and documenting family and friend caregivers, account for the caregivers' needs, and include those needs in the person's plan.[7]

State programs often employ specific approved forms in the planning process. Such forms should not be conflated with the process itself. Instead, they should be designed as tools to support the essential creative advocacy role of the facilitator, or the person planning for themselves. Further, the person-centered plan should not be conflated with the outcome, but instead seen as an essential step in the implementation of services and supports that lead to the outcome. The system should support the accommodation of alternative communication approaches through resources and trainings. Cultural

competency and humility should be addressed system-wide with person-centered diversity training as a requirement for all personnel in the system.

Finances

Organizational contracts should require PCP for all people using services, training in person-centered principles for all staff, and requirements for performance measures and quality reporting standards related to person-centered requirements. Contracts should include performance improvement activities for unacceptable performance.

Service planning should demonstrate person-centered values (i.e., dynamic, responsive, and flexible for each person). The service planning and authorization process should also ensure that services are designed around personal goals and objectives, can change as needed, do not dissuade the person from embarking on new opportunities, and are implemented in a timely fashion. Financing decisions around PCP and implementation processes should ensure these flexibilities exist. Self-directed models are important considerations for supporting the implementation of person-centered plans in a flexible manner. The PCP should not be limited to services and supports that are provided and/or financed by any one agency, organization, or particular system. Sustainability of financing should be a priority.

Workforce Capacity and Capabilities

Organizations should ensure that all staff receive training in PCP and that staff demonstrate knowledge, skills, and abilities needed for their responsibilities. Staff should develop and maintain their expertise through support and mentoring from their supervisors and by receiving ongoing training. In particular, person-centered facilitators and case managers demonstrate knowledge of person-centered assessment, planning, and monitoring.

Staff should apply person-centered practices in the context of their job duties, and they also should use person-centered discovery tools to identify learning needs for each employee during hiring, onboarding, and performance reviews. Unpaid caregivers and family members who are paid should be supported in a variety of ways including respite, training, and inclusion in the PCP process when the person finds value.

In addition to their training, paid caregivers should be supported in implementing necessary person-centered skills. They are routinely part of ongoing activities with the persons they support and are therefore valuable members of the overall support team.

Collaboration and Partnership

Organizations should ensure that people who use supports and those supporting them (including families and paid and unpaid caregivers) receive training in PCP and what should be expected from a person-centered system, including the planning process and the service delivery. Organizations should ensure opportunities are provided to people who are using PCP services (including families and caregivers supporting them) so they can be involved in new program developments and that they have a valued role in providing feedback regarding the system as well as advising on policy decisions. People

using services and families/caregivers should be involved in planning, implementing, analyzing, and reviewing the system via formal procedures (e.g., advisory groups, steering committees, etc.). Changes in program design should be transparent.

Organizations should also cultivate ongoing partnerships with other systems and promote community integration for people needing supports. Other systems include the acute, primary, and chronic care systems; housing; employment; education; transportation; Veterans Administration; safety net providers; Centers for Independent Living; faith communities, etc. As system integration seeks to address social determinants of health, mechanisms for developing and sharing a single plan for each person that incorporates all the system-specific planning processes to create and maintain a single plan should be the goal. Conflicting policies across systems should be addressed through the lens of a person-centered perspective. Organizations should educate partners, promote understanding and inclusion for the populations they serve, and advocate for their representation on advisory boards or training initiatives.

Organizations should cultivate positive relationships with advocacy organizations and employ routine methods to listen to and seek their input when identifying opportunities to improve person-centered practices.

Quality and Innovation

Organizations should determine and clearly state the person-centered practices to which they hold themselves accountable throughout the organization, including how providers are licensed or certified, how administrative oversight is conducted, and throughout service delivery. The organization's mission, vision, and values should directly connect to the practices. Organizations should have transparent internal performance excellence systems that include the frequency by which they evaluate each aspect to determine progress and areas for improvement. The results of the performance evaluations, including improvement plans, should be publicly reported and easily accessible. Data collection should be standardized in order to have uniform information to compare across the organization and across organizations. The entire system should employ service user and family/caregiver engagement data to drive quality; routinely identify opportunities for improvement; and share learning across all system components through quality improvement plans. PCP competencies such as active and reflective listening and dispute resolution should be used in interactions.

The quality of the PCP process should be monitored through the development and implementation of fidelity scales—tools to measure the level of implementation of evidence-based practices. Quality measurement of person-centered plans should use evidence-based standards that focus on outcomes as identified by the person (e.g., meeting goals in the person-centered plan). Gaps in amount, duration, and scope of services and supports should be documented. Planning should take place and be implemented to close those gaps. Organizations should ensure that people who use services, as well as their families and caregivers, have opportunities to be involved in new program developments and have a valued role in providing feedback regarding the system and advising on policy decisions. People using services and families/caregivers should be involved in planning, implementing, analyzing, and reviewing

the system via formal procedures (e.g., advisory groups, steering committees, etc.). Efforts should be undertaken to raise awareness of people who use services and their support systems in what should be expected from a person-centered system, including the planning process as well as service delivery. Changes in program design should be transparent to people using services—from planning to implementation and monitoring.

Organizational mission, vision, and values should connect directly to a set of standards that reflect person-centered practices in administrative functions as well as in service delivery, including how providers are licensed and certified and how administrative oversight is conducted. Progress should be measured through these standards, which will also be used to identify areas for improvement for the full system. For these purposes, quality measurement used should adhere to evidence-based standards, if available, that focus on outcomes as identified by the person (e.g., through meeting goals in the person-centered plan). The quality of the planning process should be monitored through the development and implementation of fidelity scales and other mechanisms as needed. Data collection should be standardized to create uniform data sets that may be used for comparison across accountable entities.

Gaps in amount, duration, and scope of services and supports that are identified though the PCP process should be documented and used as a basis for planning to meet unidentified needs.

The entire system should employ service user and family/caregiver engagement data to drive quality; routinely identify opportunities for improvement; and share learning across all system components through an annual quality improvement plan. PCP competencies, such as active and reflective listening and dispute resolution, should be employed in customer service interactions. Quality councils should be established to hold the system accountable for progress each year. Organizations should have transparent internal performance excellence systems including demonstrations of person-centered practices. Results of these performance systems should be both publicly reported and easily accessible.

Barriers and Opportunities

Information on systems characteristics was solicited from PCP experts through key informant interviews. In addition to systems characteristics, these interviews identified some barriers and opportunities for successful adoption of systems characteristics.

State-level barriers were specifically flagged, since LTSS, including HCBS program implementation, happens at that level. Key informants suggested that success depends on states embracing the systems' characteristics and values of PCP along with a willingness to assess and evolve through continuous quality improvement practices. Program evolution needs to be partnered with education and training for all individuals within the systems including persons, caregivers, staff, and providers. A suggestion was made to move away from clinical terminology and diagnosis toward a focus on what the person wants in their life. Interviewees also emphasized that PCP should be preceded by some form of objective assessment that supports open-ended feedback during eligibility assessment and/or planning processes.

Opportunities were also identified such as establishment of state/federal regulations related to PCP fostering administrative champions, building program resiliency, along with federal program oversight across states. Principles of PCP should be standardized, mandated, and enforced through oversight and assessment. Administrative champions should also be cultivated and retained to promote PCP principles and successfully manage LTSS programs that use those principles.

Person-Centered Planning and Practices Measure Framework

Background and Purpose

Measurement frameworks provide a structure for organizing currently available measures, identifying measure gaps and prioritizing measures for future development.[8] A measure framework comprises domains, groups/categories of high-level ideas; subdomains, a smaller grouping/categorization of ideas within a domain; and, measure concepts, descriptions of potential assessment.[8]

The PCP Committee developed a framework for PCP and practice measure development. The Committee considered existing measures in the field, gaps in measurement, and the complexity and entities responsible for PCP from the person to the facilitator to government system.

Table 3: Summary of Person-Centered Planning and Practice Measure Scan Results

Search Term	Database			
	QPS	CMIT	QCRDs	Total
Caregiver Experience	9	28	0	37
Clinical and Capacity	0	63	0	63
Home- and Community-Based Services	1	3	0	4
Hospital and Capacity	0	49	0	49
Long-term Support and Services	3	0	0	3
Person Experience	36	215	14	265
Person-centered Decision Making	1	0	0	1
Person-centered Planning	19	12	0	31
Person-centered Practices	30	12	0	42
Person-centered Thinking	0	1	0	1
Personnel and Capacity	0	4	0	4
Services Needs	24	0	0	24
Shared Decision Making	4	29	5	38
Social Work	0	13	0	13
System and Capacity	0	73	0	73

As a foundation for the framework, staff conducted a scan of current PCP and practice measures. Staff identified 15 search terms that it ran through three databases: Quality Positioning System (QPS), the clearinghouse for NQF-endorsed measures; CMS Measures Inventory Tool (CMIT), a repository for

quality metrics used by CMS; and Qualified Clinical Data Registries (QCDR), measures collected and reported to CMS. Table 3 illustrates the summary of the [Environmental Scan Search Results](#).

The scan resulted in a total of 366 measures identified by NQF staff. Staff determined that there were no measures identified within the measure repositories specific to person-centered planning. However, 206 were considered by staff to be relevant to PCP and practice in the sense that they could inform a measurement framework and measurement gaps; the other 160 were deemed not relevant. Staff analyzed the relevant measures and noted that the measures fell into six broad categories: experience of care, frequency of interaction, complex care, care transitions, communication, and shared decision making. Staff identified gaps in measurement for persons with intellectual and development disabilities, older adults, persons with chronic care needs, and persons with mental or behavioral health conditions in the measurement domains of patient/consumer experience, communication, shared decision making, and self-directed services.

The Committee supplemented the staff environmental scan search results by identifying PCP measures and measure concepts found outside of QPS, CMIT, and the QCDRs. These included:

- **Functional Assessment Standardized Items—**These measures are a set of functional status assessment tools for persons in HCBS settings. The Functional Assessment Standardized Items (FASI) align with other LTSS measurement tools and include the following domains:
  - Self-care
  - Mobility, including ambulation and motorized wheelchair use
  - Instrumental activities of daily living, living arrangements and caregiver availability[9]
- **National Core Indicators**—The National Core Indicators (NCI) is a collaborative, voluntary quality indicator tracking and improvement effort by public developmental disabilities agencies. These standardized quality indicators are used across states to assess the outcomes of services provided to persons and families, with domains focused on service planning, employment, rights, choice, community inclusion, and health and safety.[10] NCI includes a domain on Information and Planning with several indicators that are relevant to PCP:
  - The percentage of family respondents who report they are informed about the array of existing and potential resources (including information about their family member's disability, services and supports, and public benefits) and information received is easy to understand
  - The percentage of family respondents who report they have enough information about public services available.
  - The percentage of family respondents who report that the case manager/service coordinator is respectful of family's choices and opinions
  - The percentage of family respondents who report their family member has a service plan.
  - The percentage of family respondents who report their family member has a service plan that the family respondents and/ or family member helped create

- o The percentage of family respondents who report their family member has a service plan and that the plan meets the needs of the family member
- o The percentage of family respondents who need help planning for their family member's future with respect to various aspects of life (such as employment, financial, housing, legal, medical, social, transition from school, recreation, etc.)
- o The percentage of family respondents who report feeling prepared to handle the needs of their family member in an emergency (such as a medical emergency or natural disaster)
- o Of family respondents who reported that their family member moved outside of the family home for the first time in the past year, the percentage that report that their family member received enough information about supports and services available to support him/her, and the family respondents had enough choices of services providers to support the family member
- o Of family respondents in which the family member left school during the past year, the percentage of family respondents reporting that their family member had a transition plan
- o Of family respondents in which the child is of transition age, the percentage of family respondents reporting that their family member has a transition plan
- o Of family respondents reporting that their (child) family member is of transition age, the percentage of family respondents reporting that their family member has a transition plan and the family respondent helped make the transition plan
- o Of family respondents in which the family member left school during the past year and had a transition plan, the percentage of family respondents reporting that their family member's transition plan included getting or continuing work in a community job
- o Additional domains include Work, Community Inclusion, Choice and Decision-making, Self-Direction, Relationships, Satisfaction, Service Coordination, Access, Safety, Health, Medications, Wellness, Respect/Rights, Choice and Control, Access and Support Delivery, Community Connections, Family Involvement, Satisfaction, and Family Outcomes
- **2019-2020 NCI Aging and Disabilities Indicators**—The domains of the survey include an optional module for PCP that includes nine indicators[11]:
  - o Percentage of people who remember their last service planning meeting
  - o Percentage of people who are involved in making decisions about their service plan
  - o Percentage of people whose service planning meeting took place at a convenient time
  - o Percentage of people whose service planning meeting took place at a convenient location
  - o Percentage of people whose service planning meeting included the people they wanted to be there
  - o Percentage of people who discussed their preferences and needs in the service planning meeting

- o Percentage of people who received a copy of their service plan after the service planning meeting
- o Percentage of people whose service plan reflects what was discussed in the service plan meeting
- o Percentage of people whose service plan includes their preferences and choices

Additional domains address several core principles that the Committee has identified as central to PCP: Community Participation, Choice and Control, Relationships, Satisfaction, Service Coordination, Care Coordination, Access to Community, Access to Needed Equipment, Safety, Health Care, Wellness, Medications, Rights and Respect, Self-Direction, Work, Everyday Living, and Affordability
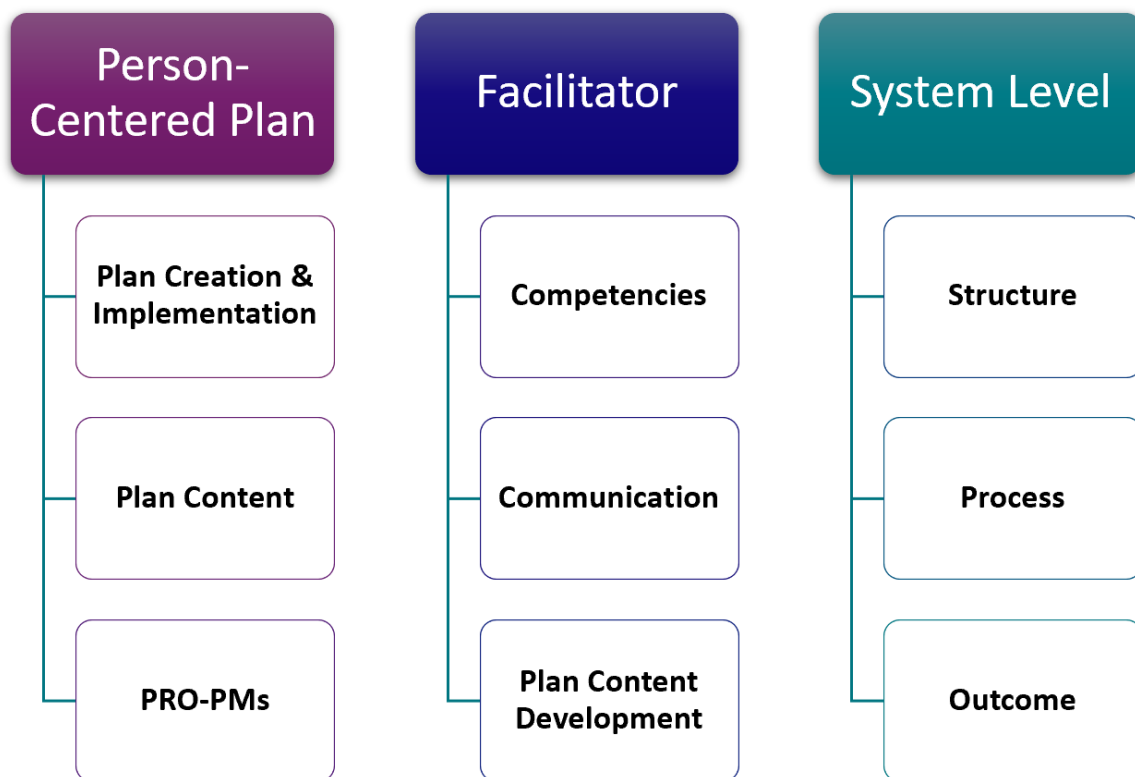
- **Personal Outcome Measures from the Council for Quality and Leadership**—The Council on Quality and Leadership's (CQL) Personal Outcomes Measures (POM) include measures of quality of life and are used for support planning and gathering information related to goals and outcomes. CQL uses the measures to improve the quality of life for persons with disabilities and the service organizations that support them. The POMs include 21 indicators organized into five factors to address quality of life topics such as health, safety, social roles, rights, relationships, community integration, and employment, among others. The indicators align with measurement concepts central to PCP.[12]
- Goal attainment measures developed by NCQA through funding by the SCAN Foundation.[13]
- **National Center on Advancing Person-Centered Practices and Systems (NCAPPS) Indicators**— NCAPPS conducted an environmental scan of indicators that was released in December 2019.[14] It contains many useful indicators (such as the following) that relate directly to PCP, not just for the person but also related to support workers' skills, knowledge, and training.
    - o People are active members in planning services
    - o People take part in setting and refining goals
    - o Services and supports reflect the individual wishes and desires of people
    - o People who are important in the lives of people receiving services are supported to be a part of their lives
    - o People who support people receiving services are knowledgeable about the strengths and abilities of the people receiving services
    - o People are involved in making decisions about their services and supports
    - o People are involved in making decisions about the people who help them
    - o People are involved in making choices in their everyday lives
    - o People take part in community activities
    - o People do not experience barriers to taking part in activities in their community
    - o People are treated equally and with respect in their communities
    - o People have access to needed services
    - o People are provided information about services and natural supports that are available
    - o People receive enough information to make informed choices about their services and supports

- o Information is presented in a way people understand (using people's preferred language and using words people understand)
- o Support workers speak in a way people understand
- o Support workers treat people with respect
- o Support workers have the right knowledge and training to meet people's unique needs
- o Support workers are responsive
- o Services are provided in a way that is respectful to the person's culture
- o Staff believe that the person can grow and learn new things
- o Staff support the person to grow and learn new things

Domains

Building upon the environmental scan results as well as its development of core competencies for people engaging in PCP and practice, the Committee identified three domains for the measurement framework: person-centered plan, facilitator, and system-level measures. Each domain is broken down by three subdomains. The Committee emphasized that the focus of measurement should be on the outcomes of the persons. Figure 2 illustrates the Person-Centered Planning and Practice measure framework.

Figure 2. Person-Centered Planning Measurement Framework

Person-Centered Plan	Facilitator	System Level
Plan Creation & Implementation	Competencies	Structure
Plan Content	Communication	Process
PRO-PMs	Plan Content Development	Outcome

Person-Centered Plan Measures Domain

This domain captures what processes and outcomes need to be performed to ensure that the plan is done right. Within this domain, the Committee identified three subdomains: plan creation and implementation, plan content, and person-reported outcome performance measures (PRO-PMs).

Plan Creation and Implementation Subdomain

- Preplanning—To prepare for the planning phase, this specifically identifies what processes need to be implemented prior to development to ensure persons are prepared to plan. This should include the person's preference for timing, location, and participants in the planning sessions.
- Documentation of a plan—The plan is written down, a copy of the plan is provided to the person, and a copy is retained within the person's record. It is important to recognize that forms are viewed as tools to support effective person-centered processes but do not drive it.
- Updating of a plan—Most people will have plans that change over time; the plans must evolve with the person. It is crucial to remember that the plan itself is not the goal, but rather its implementation.

Plan Content Subdomain

- Person-centered plan meets the person's expressed needs and desired outcomes. The HCBS Setting Final Rule § 441.725 states that "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."
- The plan should identify goals to support and address the person's needs and desired outcomes ("goals" refer to a variety of different attainment measures including maintenance). Goals should be expressed as desired by the person, and must not be dictated by the facilitator, service providers, or others involved in the planning process. In addition to goal documentation, barriers to the person's goals must be identified and mitigated.
- The plan is written in the person's own words, using first-person language when it is appropriate to do so and the person's preferred name. There are three circumstances to consider if it is appropriate to write in the first-person:[15]
    - When the person actually wrote the plan or when you are quoting the person and comfortable the person meant what they said.
    - When the person actively edited the plan with the plan writer and clearly approved and understood what was said and how it was said.
        - When the person primarily communicates with her or his behavior (and not with words) only if – The people who know and care about the person are certain this is what the person would say if they could tell you
        - The plan writer is comfortable that these are people who are close enough to the person and spend enough time with the person to truly know
        - What is written will be tested (and changed) by ongoing listening to the person's behavior.

- The plan should identify and highlight the strengths of that person.

- The plan includes both paid and unpaid supports.
- The plan has community inclusion components reflecting natural community relationships.

PRO-PM SUBDOMAIN

- The person expresses knowledge of their rights.
- The person is able to access their own plan.
- The person assesses their planning experience focusing on the following:
  - Perception of leadership role, empowerment
  - Perception of informed decision making
  - Strengths
  - Addressed goals and preferences, things important to person
  - Correct people were in the room
  - Overall satisfaction with the facilitator

PCP Facilitation Measures Domain

Facilitators of PCP will not always be paid professionals and may be individuals who are close to the person—or may be the person. Because of this, many measures included in this domain may not be applicable to every facilitator; many of the measurement concepts for facilitation are especially practical in accountability applications for paid professionals.

An anchoring principle for measurement within this domain should be the facilitator as advocate for the person. Measures should be designed such that an improvement in performance results in a deeper ability for the facilitator to be an advocate for the person. Within the facilitator measures domain, the Committee identified three subdomains: facilitator competency, communication, and plan content development.

FACILITATOR COMPETENCY SUBDOMAIN

- PCP training that includes knowledge of PCP principles and relevant program and policy.
- Facilitator possesses the foundational skills of PCP facilitation.
- Facilitator assessments include knowledge of the person, resources available to the person, policies, and regulations that impact the person, and health conditions and/or disabilities of the person with whom they are working.
- The facilitator should demonstrate appropriate cultural competency.
- The facilitator is an advocate for the person.

COMMUNICATION SUBDOMAIN

- The facilitator documents the person's preferred spoken language, and ensures that the person has language services available.
- The facilitator makes available and uses hearing and other communication tools.

PLAN CONTENT DEVELOPMENT SUBDOMAIN

- The facilitator engages in timely assessments, review, and updates of the plan.
- The plan is produced within the time frame required.
- The facilitator tracks what happens after a plan is in place.

System-Level Measures

The Committee considered the accountability of entities responsible for a person's plan, implementation, and maintenance. System-level measures are grouped into structural, process, and outcome subdomains.

STRUCTURAL SUBDOMAIN

- There are effective training programs in place to ensure plans are created, implemented, and updated. These trainings should have a ratio of facilitators to participants that supports an environment conducive to learning.
- There are enough resources allocated that those who work within the system are able to effectively provide person-centered planning, practices, and services.
- There is enough professional latitude for the facilitator to exercise the necessary flexibility to carry out effective planning.
- There should be processes in place to ensure that the plan continues without unnecessary interruption in the event of staff turnover or other losses.
- Persons have access to experts in person-centered planning and practices.
- There are structures in place for stakeholder engagement, such as formalized policies input and comment periods for policy and program changes, as well as ongoing stakeholder committees.

PROCESS SUBDOMAIN

- Entities should assess PCP completeness, staff training completeness, and quality improvement participation rates.
- Access to resources to ensure plans are created, implemented, and updated.
- Regular data collection and feedback on services.
- Mechanisms to gather input from family, involved others, and community partners on organizational performance.
- Stakeholder engagement policies are implemented and improved based on feedback.

OUTCOME SUBDOMAIN

- Person-reported outcome measures including quality of life and satisfaction with services and supports.
- Satisfaction with organizational performance and service delivery components.
- Person-reported outcome measures looking at PCP take into account the mediating factors associated with services and support quality, access, and delivery.

Environmental Scan Results and Research Agenda for PCP

In order to suggest additional areas for development of meaningful quality measures for PCP, as well as to further enrich the knowledge base related to the impact of PCP, the Committee proffered a research agenda to validate the core competencies for PCP facilitation and the systems characteristics that lend themselves to good implementation of PCP programs.

To identify gaps in PCP research, the staff conducted an environmental scan of the existing peer-reviewed and grey literature. For the purposes of the scan, the following questions guided research efforts and ensured that the information sources collected are relevant to the project objectives:

- What current or emerging quality of care measurements (e.g., metrics, indicators) exist regarding PCP?
- What are the major current and emerging concepts regarding PCP that can be used to evolve associated quality measurement?
- What directions should quality measurement science take to advance improvement in PCP, and where are the apparent and important gaps?
- What additional gaps remain in PCP research that represent the most important opportunities to advance the knowledge base of the field?

The scan also included the following databases using the search term "person-centered planning":

- APA PyschInfo
- CINAHL Plus
- Cochrane Library
- Google Scholar
- PubMed
- RehabData

An additional methodology was employed consisting of a snowballing approach, which involves using the reference list of a paper or the citations to the paper to identify additional sources. Criteria for inclusion included peer-reviewed journals in English. A search for keywords in the full text of the article was applied, with the exception of Google Scholar, which produced too many results (5,800+) without the use of a restricted title-only search. The focus of the review was not only on research outcomes associated with PCP, but also approaches to PCP and historical development.

Results of Environmental Scan

The scan resulted in 312 results, which were reviewed by staff. These are provided in a supplementary Environmental Scan Search Results document. The staff noted that the vast majority of articles identified did not have rigorous methodologies used or did not yield empirical outcomes. Many of the articles had only tangential or peripheral discussion of PCP. Those specific to PCP primarily consisted of descriptions of programs, PCP methodologies, and direct applications of PCP, with very few articles testing a scientific hypothesis.

There were other limitations to the existing literature. The bulk of the studies occurred during the late 1990s through the 2000s. Much of the research had clear limitations in study design and funding with almost no controlled testing of hypotheses. There were also limitations in the populations studied in the articles specific to PCP—with much of the research focused on persons with intellectual and developmental disabilities and with many articles directed toward secondary school settings.

While there were several articles conducted among persons with intellectual and developmental disabilities that exhibited stronger results, these were relatively infrequent throughout the literature.[16] For example, one article identified 15 research papers reporting empirical findings regarding the effectiveness of PCP published between 1985 and 2009. In this review, PCP was found to result in the development of an improved social network, improved choice, better communication, and deeper parental involvement.[17] It was also demonstrated that people with severe intellectual disability, challenging behavior, or communication problems were often not included in the process. This suggests there still remain opportunities for further PCP research that better engages people with behavioral, intellectual, and developmental challenges.

Other researchers have shown that the PCP process may be confounded by too strong of an emphasis on optimistic outcomes or unrealistic goals.[18] To address these balancing issues related to PCP outcomes, acknowledging the quality, content, process, and life-style-related outcomes has been recommended.[19] Empirical studies demonstrating the connection between persons' outcomes and appropriate approaches to PCP and exhibition of the core competencies expected for PCP facilitation remain a significant gap in the literature.

In addition to the effectiveness of PCP, several other themes emerged from the literature review. Related to PCP outcomes, there were several articles that focused on preferences that were identified as well as the assessment of goal attainment. Programmatic themes for broad PCP implementation also were represented, with the impact of PCP training being the most frequently studied aspect. The impact of PCP on adherence to medical treatments is another outcome identified as a theme within the literature review. The staff also noted comparison or compatibility of PCP with other programs as another research theme. While additional articles were found related to barriers to PCP implementation at the systems level, these often lacked empirical data and analysis.

After reviewing the themes associated with the literature, the Committee offered several research priorities that would validate the PCP competencies and systems characteristics, and suggest measure concepts for development into measures, as well as general advancements in PCP understanding. These were grouped into domains. The domains and the research ideas contained within each represent the research agenda identified by the Committee. These consist of the effectiveness of PCP (including population specific research), facilitation of PCP, and PCP program improvement.

Effectiveness of PCP

Outcomes and Experiences from PCP

The Committee considered the continued evaluation of the impact of PCP a high priority. In particular, well-funded studies that evaluate the impact of PCP using empirical analysis in relation to key outcomes, both observed and person-reported, should be conducted. Such studies should also evaluate the person's perceptions of experience and satisfaction.

The observed outcomes will vary by population studied, but may include the following:

- Goal attainment as documented within the plan
- Impact on physical, behavioral, and mental health
- Treatment adherence and recovery

Person-reported outcomes will vary by population studied, but may include the following:

- Goal attainment and quality of life
- Person's achievement of desired community inclusion, choice, and control

Person-reported experience and satisfaction:

- Actual perceptions of "person centeredness," or the extent to which the person feels that they are at the center of the planning process
- Satisfaction with the planning process, including a qualitative analysis of the critical elements to person satisfaction with PCP process

Specific Program Evaluation

The Committee also considered the effectiveness of specific programs to be an important area for additional research. It noted that there are a variety of PCP approaches. While there are many similarities within the approaches, program-specific evaluation using standardized metrics that would allow for comparison of outcomes would help the field identify best practices and potentially lead to more a more consistent delivery of PCP related services. Comparative effectiveness of these programs using retrospective analyses, as well as evaluating other approaches such as interdisciplinary service planning or life care planning, are potential research areas that the Committee considered a priority. Outcomes should include those identified in the preceding section as well as analyses of cost effectiveness.

Impact of PCP on Managed Care Systems

With more and more planning services being delivered through managed care systems, the Committee also prioritized outcomes research for PCP specific to managed care systems. Studies in this area should include retrospective analyses of PCP services and include evaluative metrics identified in the Outcomes of PCP section above. Cost/benefit analyses should be performed to better understand the benefits of PCP from the plan perspective and the individual perspective when the person is enrolled in managed care.

Population-Specific Research

The Committee noted that outcomes research for PCP has largely been focused on certain populations, but there remain additional research gaps for a variety of groups. In each of the outcomes research fields outlined in this section, the Committee noted that subanalyses should be performed to identify disparities in PCP delivery and special consideration for certain groups, including:

- Children and adolescents

- Persons in foster care and incarcerated
- Persons with an intellectual and developmental disability
- Minority groups by ethnicity, gender identification, etc.
- Persons with multiple chronic conditions
- Older adults
- Parents and caregivers
- Persons with serious mental illness
- Persons with substance use disorder
- Persons with traumatic brain injuries

Facilitation Improvement

Training Effectiveness

The Committee also noted that the impact of facilitation training on outcomes related to PCP is an important research priority. This could be done through a prospective study conducting evaluations of facilitation before and after training, using both objective data points as well as subjective assessments performed by the facilitator and the person. Such a study should also include analyses of the effectiveness of initial training, retraining, and overall process improvement.

Overcoming Barriers to Individual Person-Level Goals

One of the most important aspects of PCP is identifying the goals, aspirations, desires, and values of the person, and supporting them also to articulate and address the barriers to living the life that they want to live. Given the importance of this part of the planning process, the Committee emphasized that research on improvements in the facilitation of PCP should also include differential analyses of methods to identify and address barriers to achieving individual person-level goals. One example of a study in this domain that assesses these methods would be a prospective, comparative effectiveness study of multiple approaches to overcoming barriers to achieving individual person-level goals.

Facilitation Preferences in PCP

The Committee considered that the effectiveness of PCP facilitation training and delivery of PCP services would ideally be well-balanced by considering the preferences of the person during planning sessions and provision of facilitation. Qualitative research on persons' facilitation preferences could be conducted in tandem with outcomes research on the effectiveness of PCP; namely, during the collection of person-reported outcomes data.

Program Improvement

Cost Effectiveness and Resource Utilization in PCP

One barrier to widespread implementation of PCP is simply the costs associated with administering it. While this barrier is well recognized, there have not been significant evaluations that detail the costs and resources required to implement PCP. The Committee called for such evaluations as well as research and analysis on building programmatic efficiencies to best implement PCP at the systems level.

Strategies to Encourage Participation

The Committee also called for case reports for strategies to encourage persons to participate in PCP. There has not been good research to date assessing participation rates in PCP, nor interventions that could potentially increase program participation. While the level of planning is determined by the person within PCP, there are a number of methods that could potentially encourage persons to elect to develop a plan. Studies to evaluate these strategies could follow traditional comparative effectiveness research methodologies, such as a retrospective analysis comparing one or more interventions and controlling for potential confounders that may limit individual participation rates, such as cultural considerations or type of disability.

Measure Development Research

The Committee noted that quality measures identified for the research priorities above also require research and testing. The Committee called for research and testing of measures related to PCP, including evidence generation for the measures, assessment of performance gaps among PCP service providers, the scientific acceptability of the measures including testing their reliability and validity, assessments of the feasibility of implementation of such measures especially regarding the burden of data collection associated with person-reported outcome measures, and analyses of the usability and actionability of the measures. The Committee suggested that measures used for programmatic evaluation go through the NQF measure endorsement process.

Community Comments Received and Conclusion

This final report was informed by comments submitted by the public on the interim report and draft final report. The Committee and NQF staff wish to acknowledge and thank the individuals and organizations who submitted comments to help align this report with the many communities it is intended to serve. The Committee received a total of nearly 300 public comments on the draft interim and final reports. These public comments were shared with the Committee, themed by NQF staff, and presented during two focused meetings to adjudicate the comments appropriately and incorporate suggested changes into this report.

The resulting final report describes the consensus-based multistakeholder views of the Person-Centered Planning and Practice Committee and public whom NQF convened over an 18-month period to develop a definition of PCP, an outline of a core set of competencies for persons facilitating the planning process, systems characteristics that support PCP, development of a framework for quality measurement within PCP, and a future research agenda to advance and promote PCP in LTSS.

The work of this Committee aims to support the development of the person-centered planning and practice field. The Committee recognizes that the individual owns and drives the planning and practice of their life and supports. The quality measurement framework was constructed to inform measurement areas that need to be developed and tested. The research agenda is intended as a guide to the continued advancement and promotion of person-centered planning and practice.

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