NATIONAL QUALITY FORUM

Person-Centered Planning and Practice Project

INTERIM REPORT

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Contents

Executive Summary

In 2019 the Department of Health and Human Services' (HHS) Administration for Community Living (ACL) and the Centers for Medicare and Medicaid Services (CMS) requested that the the National Quality Forum (NQF) convene a committee of experts with lived and professional experience in long-term services and supports (LTSS), and with the acute/primary/chronic care systems. This Committee aims to provide ACL, CMS, federal and state entities, and the general public with a consensus-based, multistakeholder view of multiple areas of person-centered planning.

The Committee addressed three key concerns related to designing practice standards and competencies for person-centered planning. First, the Committee proffered a functional, person-first definition of person-centered planning. Second, the Committee outlined a core set of competencies for persons facilitating the planning process, including details of foundational skills, relational and communication skills, philosophy, resource knowledge, and the policy and regulatory context of person-centered planning. Lastly, the Committee considered the systems characteristics that support person-centered planning such as system-level processes, infrastructure, data, and resources, along with guidance on how to maintain system-level person-centeredness.

This report represents an interim summary of the Committee's efforts to date. A future final report with Committee feedback will address the history of person-centered planning, a framework for quality measurement within person-centered planning, and a research agenda to advance and promote person-centered planning in long-term services and supports, which includes home and community-based services and institutional settings such as nursing homes, and the interface with the acute/primary/chronic care systems.

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 "ownership" of their health and healthcare services 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 notable, about 21 million Americans are expected to be living with multiple chronic conditions by 2040, and many will require long-term services and supports (LTSS) in community and institutional settings.[1]

In an effort to address LTSS needs that are predicated on individuals' needs, preferences, goals, and desires, the Department of Health and Human Services (HHS) is working with its partners and other federal agencies, states, consumers and advocates, providers, and other stakeholders to create a sustainable LTSS 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.

Background

The Affordable Care Act requires states that receive federal funds develop systems that support independence and self-direction of people receiving HCBS.[2] In January 2014, CMS published the HCBS "final rule" which included requirements on the person-centered planning process and components of the person-centered plan of an individualized person-centered service plan for Medicare beneficiaries who receive Medicaid funded HCBS under certain federal authorities.[3]

CMS and HHS have provided additional guidance regarding person-centered planning in several programs including the ACL "No Wrong Door" program, the Substance Abuse and Mental Health Services Administration (SAMHSA) Certified Community Behavioral Health Clinics, SAMHSA Mental Health Block Grant Program, CMS's Long Term Care Rule, and the Office of the National Coordinator (ONC) and CMS eLTSS data elements.[4]

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 operational definitions, systematic changes to support person-centered planning and service delivery, and how to select and implement structural, process, and outcome quality measures to evaluate the impact person-centered planning has in state systems.[5]

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 person-centered care and support community living. The final report identified PCP as an important domain described 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."[6] This project builds upon previous NQF work with the goal to provide 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 person-centered planning and practice (PCP) in LTSS systems. NQF solicited applications through a public 30-day nomination period and received a record high number of interested parties. The Committee members were subject to a public commenting period to obtain feedback on the multitude of stakeholders represented on the Committee.

Committee members represent a variety of stakeholders including self-advocates, caregivers, purchasers, providers, health professionals, plans, suppliers, and experts in community and public health and healthcare quality. The Committee includes experts in person-centered planning, relationship-centered care, shared decision making; self-advocacy, consumer engagement, HCBS; long-term care, community inclusion, and Medicaid. The diversity of people who receive LTSS required representation of self-advocates from the mental health, nursing home, dementia, and disability communities. The

Committee reflects the diversity of experience and insight, as well as the historical experience of being marginalized and underserved, and 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 will meet 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 person-centered planning in LTSS systems; develop a conceptual framework for PCP measurement; and create a research agenda for future PCP research.

This interim report focuses on the refined definition of PCP, core competencies of people performing PCP, and system characteristics that support person-centered thinking, planning, and practice.

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 those of consumer advocacy groups and other sources.

In developing the definition for person-centered planning, the Committee reviewed multiple iterations developed by NQF staff and drew upon previous definitions (definitions developed in the 2016 NQF HCBS Committee final report),CMS's final HCBS rule, and language from other relevant federal programs. 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:

> Person-centered planning is an approach to organizing your supports and services so that you can live the kind of life you want for yourself. This type of planning usually happens in a meeting or a series of meetings, and there are some important things to make sure the planning process stays focused on you:
>
> - You should be supported in taking whatever leadership role you prefer in this meeting, up to, and including, running the meeting yourself. There may also be someone else called a facilitator there to help guide the process and make sure it 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.
> - The conversation in the meeting, and the plan that comes out of it, should be about your goals, dreams, needs, wants, things you like and don't like, and what is important to you in your life.

- You may not know these things on your own, especially if you have not been able to experience much or have not been given many choices in your life. Other members of your person-centered planning team are there to help you think through the kind of life you want for yourself.

A good person-centered planning process will involve conversations that help you get control over decisions that impact your life and your experience receiving services. To do this, your team will want to learn more about many areas of your life, including things like:

- 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
- Special types of help that you might need
- People and resources in your community that can help you
- Things that are important for your health, safety, and overall quality of life

As you work to create your person-centered plan with your provider or team, there are some important rights you should be aware of:

- Person-centered planning is based on the core belief that you have the right to make choices and to take some risks in trying new things.
- In some situations, there might be limits placed on decision making (e.g., if you have a legal guardian), or your plan may be modified, or changed, to make sure you are safe from certain risks. Even in these situations, there are rules in place to protect your rights, and these should be explained to you in your meeting.
- The person(s) helping you to make your person-centered plan should discuss with you a range of professional (paid) services and natural (unpaid) supports so 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 Set Competencies of People Performing PCP Facilitation

Person-centered planning facilitation requires a set of skills and competencies leading to the creation of a unique plan that takes into account the assessment, planning, and coordination of services and supports focused on the individual's goals, needs, preferences, and values. 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 a plan around necessary paid and unpaid services and supports to ensure coordination and execution across providers, settings, and systems, as well as to ensure fidelity with the person's expressed goals, needs, preferences, and values.

The facilitator role encompasses responsibilities including providing information and guidance to people receiving or seeking services and supports, facilitating the planning meetings as requested by the individual, suggesting creative strategies to address the needs and desires of the individual, and monitoring the effectiveness of the person-centered planning process and service implementation.

Several 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, resource knowledge, and policy and regulatory context. Person-centered planning 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.

The assessment process needs to be separate from the planning process, and the two should not be conflated. 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 an executable plan for advancing the person's goals and meeting needs the person deems important.

Foundational Skills

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

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 individual's choices include choosing meeting participants, participant roles (e.g., who will facilitate), location, schedule, and meeting agenda. Facilitators must be sufficiently skilled to help the person to identify the site and time of meetings, which should be designed to accommodate the individual and key identified persons. The facilitator must have the skills to support the person to drive the agenda, which should include issues that the individual wants to discuss, excluding any the individual does not want to discuss. The facilitator must have strong interpersonal skills including reflective listening, high levels of empathy, and team building.

Facilitator Personal Attributes

- **Self-awareness**—Self-awareness is a key component of person-centered planning; 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.
- **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 person-centered planning 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**—Person-centered planning takes into account the whole person, including the complexity of his or her world view. 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 world view and a positive attitude toward cultural differences.
- **Openness to learning**—Willingness to learn is an important skill in facilitating person-centered planning. 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 individual.
- **Critical and creative thinking**—Problem solving ability and critical and creative thinking in particular are important in identifying resources and solutions. Person-centered planning requires the facilitator to exhibit self-guided, self-disciplined thinking which reasons at the highest level of quality in a fair-minded way.
- **Personal integrity**—In the context of person-centered planning, personal integrity means having minimal conflicts, clear values of caring for the person, acting in accordance with those values, and acting consistently over time.

Understanding the Individual

- **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.
- **Contextual understanding**—Appropriate planning occurs with a full recognition of the person within the context of family, friends, and community.
- **Actualizing effective freedom**—Understanding the factors that effectuate the successful implementation of the person's freedoms and choices.
- **Group power dynamics**—Person-centered planning optimizes the person's autonomy and control, which in many instances may be limited by the people around the consumer, even ones who care deeply for the person. The facilitator understands limitations to the person's ability to actualize their plan, including the power dynamics between the person and their family, caregivers, systems, and broader social and cultural dynamics.
- **Understanding disparities**—The facilitator considers the influence of the person's race, gender, sexual orientation, culture, and other factors in creation and maintenance of the plan.

Empowering the Individual

- **Yielding control**—The ability to have planning driven by the person through self-direction and self-determination, including supporting consumers to initiate planning.
- **Training the person to lead the process**—Facilitator may encourage and teach individuals how to lead their own meetings.
- **Creating a culture of high expectations**—Persons creating their plan need a nurturing environment where they feel secure about expressing their desires for their life, where the goal is success, and where persons are confident that they will receive encouragement and support.

- **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 be prepared to help navigate choices in the planning process, helping the person feel secure in a manageable process.
- **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.

Relational and Communication Skills

The ability to build relationships and maintain positive communication are central to facilitating person-centered planning. Through strong relational and communication skills, the facilitator keeps the focus continually on individual aspects, not standardized or available approaches or services and supports. 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. If the individual uses alternative communication, the facilitator ensures that the process accommodates the person.

Relational Skills

- **Negotiation skills**—Facilitators have negotiation skills to elicit and negotiate goals effectively—the ability to establish trust, to listen, and to identify and recommend solutions to potential barriers and understand an individual's history, context and values. Facilitators elicit all challenges and barriers including those not transparent such as an unsafe living environment, abusive caregiver(s), mental disorders including substance use disorders, and mitigation of problems.
- **Dispute resolution**—The individual's goals drive the plan. People pursue the goals they define and own over those selected by others. In the course of planning, some disputes may arise, such as what is in the best interest of the person. Facilitators pull the conversation back from negative feelings, keeping the desires of the person at the forefront.
- **Engagement skills**—When negotiating goals—or interventions to address goals—facilitators engage with the person and those helping them plan. They assist the person in controlling the meeting and provide information about the risks and benefits of options.
- **Team building**—Building the plan is a collaborative task, and the facilitator fosters a team environment. 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.

Communication Skills

- **Active and reflective listening**—Facilitators use active listening throughout the planning process, giving their full attention, 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 individuals targeting a change in their lives. In the context of person-centered planning, motivational interviewing is an important tool to encourage the exploration of the person's needs and desires. The facilitators listen and reflect back the person's thoughts so that the person can hear their reasons and motivations expressed back to them.
- **Alternative communication methods**—No two people communicate precisely the same way, and facilitators account for the preferred communication methods of the person, including addressing communication barriers. Individuals 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.

Philosophy

Person-centered planning is based on the premise that everyone has preferences that form the foundation for how they want to live their lives and their dreams, goals, and desires. The focus is on these preferences, not an individual's conditions or cognitive level. The person facilitating the plan has competencies in the philosophical underpinnings of person-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 individual is foundational to the approach.

Generating Purpose and Meaning

- **Effective Freedom**—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 optimized decision making. The freedom of articulating the plan must accompany access to resources and the power to use them.
- **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 person-centered planning 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 persons have the right to take.
- **Presumption of Competence**—Presuming competence means assuming that the person has the capacity to understand, think, and learn.
- **Supported Decision Making**—A series of relationships, practices, arrangements, and agreements designed to assist an individual with a disability to make and communicate to others decisions about their life, often around alternatives to guardianship, and other legally sanctioned restrictions to freedom for people with disabilities.

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 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 reaching targeted levels of growth, leading to taking actions that help the person discover and hone their interests, talents, and passions. The facilitator supports the person to articulate what his or her best life looks like, and to tailor their plan to fit their ideal.
- **Recovery**—The recovery model is centered on looking beyond the immediate distress of survival and existence, to a future state of better physical and mental health. People can recover from certain mental and physical conditions to lead full and satisfying lives. This is only applied when appropriate, such as for conditions where it is reasonable to consider recovery.
- **Understanding of ableism**—Ableism is discrimination in favor of people of able mind and body. It consists of a set of views that devalue people with developmental, intellectual, psychiatric, and physical disabilities. Ableism defines people in terms of their disabilities or health status as inferior to the nondisabled. Facilitators understand the challenges faced by persons who encounter this form of discrimination, and operate under the assumption that persons with disabilities function as co-equal members of the team and in society.

Resource Knowledge

The focus must continually be on the individual with whom the plan is developed and not on inserting that person 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 professional decision making, or displaced by service providers. The general strategy for avoiding these consequences is to presume competence and capacity by the individual, allies, and the community, to provide assistance when the current situation involves unmet needs, and to ensure that the individual has the ability to identify available resources.

The facilitator must have an understanding of long-term services and supports and the larger healthcare system, how to handle legal issues, and a myriad of other solutions for the person for whom they are helping to develop the plan.

Information on community resources must be available to all individuals participating in the person-centered planning process. The person must have access to people who can map out general community resources and options for community involvement. The goal is to identify resources to meet unmet needs and develop collaborative agreements to resolve barriers and ensure effective resource use. At the individual's plan level, the person determines the best ways to investigate and become engaged in their community.

System Resource Knowledge

- **LTSS and the medical health care system**—People will need resources and support identifying what care is needed, where to receive care, 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 care 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, services may become saturated and impede the person's access. Facilitators must know how to stay up-to-date on current service loads, and how to locate desired services and/or 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 Resource Knowledge

- Community assets and resources—In order to support the person's vision for their engagement with their community, the facilitator must have a working knowledge of the assets and resources available, including housing supports, employment resources, safety net providers such as food pantries and clothing donations, transportation, culturally specific resources, libraries, volunteer programs, and myriad other community resources. Connecting the person to community resources leads to greater inclusion as valued members of community and society.
- **Populations and subgroups**—The facilitator understands the dynamics of the person's community, including the populations and subgroups.
- **Local advocacy groups and key individuals**—The facilitator is aware of local advocacy groups and the key individuals within those groups who can both assist the person to reach their goals, as well as to empower the person's self-advocacy according to the desires and interests of the individual.

Planning Specific Resource Knowledge

- **Identifying process elements and experts to support PCP**—Facilitators are process experts in how to conduct person-centered planning 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.
- **Identifying content elements and experts to support PCP**—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, as well as to provide solutions in implementing the person's plan.

Policy and Regulatory Context

In addition to knowledge of how to actually conduct the planning process, an individual facilitating person-centered planning needs to understand the broader systems environment. This includes a good understanding of laws, federal and state regulations, local policies, and court decisions.

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.
- **The Older Americans Act**—This act was created to provide comprehensive services for older adults. Familiarity with the rights afforded through the Older Americans Act is critical to advancing plans for older adults.

Regulations

- **CMS Home and Community-Based Services Final Rule**—This final rule outlines new requirements for several Medicaid authorities under which states may provide home and community-based long-term services and supports. The regulations enhance the quality of HCBS and provide additional protections to individuals that receive services under Medicaid.
- **State Long-Term Care Ombudsman Final Rule**—This rule described in 45 CFR Parts 1321 and 1324 requires states' Long-Term Care Ombudsman to 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 long-term care (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 at 42 CFR 483.21 require facilities to develop a baseline care plan within 48 hours of 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.

Court Decisions

- **Olmstead v. L.C.**—This U.S. Supreme Court case focused on the rights of people with mental disabilities to shield them from discrimination. Persons with mental disabilities have the right to

live in the community rather than in institutions if determined that community placement is appropriate.

Advocacy

- **Self, individual, and systems advocacy**—Facilitators should have good familiarity for how persons can advocate at the self, individual, and systems level for changes that benefit them. Self-advocacy means speaking up for rights of access. Individual advocacy means speaking out against unfair treatment. System advocacy refers to changes in polices, rules, or laws that determine how services are provided.
- **Human rights and responsibilities**—Facilitators must have an understanding of basic human rights and responsibilities, such as the right 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.
- **Social model of disability**—The social model of disability puts forward the proposition that perception of disability is more heavily influenced by societal notions than by a person's actual impairment or difference. 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 person-centered planning because the traditional medical model does not fully explore the personal experience of disability or help to develop more inclusive ways of living.

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

As healthcare systems across clinical and long-term services and supports (LTSS) settings (home and community services and institutional care) embrace person- and patient-centered planning, programs need to use universal elements of person-centered thinking, planning, and practices. For example, state Medicaid agencies are reconfiguring systems to support person-centered planning 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, eligibility and service access, person-centered service planning and monitoring, finance, workforce capacity and capabilities, collaboration and partnership, and quality and innovation*. 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 person-centered planning 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 person-centered planning 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

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. 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 systems of care including justice, education, healthcare, and social service agencies. Leaders should participate in person-centered training and direct the application of person-centered principles to intake, assessment, planning, and monitoring activities.

Organizations should have a clear vision and strategy for delivering person-centered practices. Leadership should actively support this strategy and appropriate resources as necessary. 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.

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 case 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, caregivers, and service providers about person-centered practices. Communications should include and articulate a clear set of person-centered principles to guide the practices of all staff across the organization.

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.

Eligibility and Service Access

Organizations should implement the system-wide use of a person-centered assessment and coordinate with health providers to determine eligibility and make appropriate referrals to services. The focus of intake and 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 life. The assessment should be developed using survey research methodologies, including focus groups,

interviews, and discussion with people and their families/caregivers/friends/neighbors, and should employ psychometric testing uniformly applied by trained assessors. Assessment and person-centered-planning must not be conflated but integrated in an ongoing learning process.

A no-wrong-door model of service access should be employed with person-centered planning 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 Service Planning and Monitoring

Service planning should align with federal, state, and local person-centered planning policies found in statute, regulations, and guidance, and should be driven by stakeholder engagement. The process includes identifying strategies for the person to lead their own planning if desired, resolving disagreements, addressing what is important to the person and what is important for the person, and how the team will identify and plan for any known risks the individual 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; progress continues to be made; 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. 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 person-centered planning for all people receiving 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 taking new opportunities, and are accomplished in a timely fashion. Financing decisions around person-centered planning 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 person-centered planning process 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 person-centered facilitators and care coordinators demonstrate knowledge of person-centered assessment, planning, and monitoring. Care coordinators and facilitators

should maintain that knowledge by receiving support and mentoring from their supervisors and attending ongoing training sessions.

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 should be supported in a variety of ways, including respite, training, and inclusion in the person-centered planning process when the person finds value.

Direct care workers (DCW) should undergo training in person-centered practices relevant to their duties. They should be supported in implementing necessary person-centered skills as well, since they are routinely part of ongoing planning activities related to the persons they work with. These approaches help to reduce the traditionally high levels of DCW turnover, by supporting DCWs as valued members of the overall support team.

Collaboration and Partnership

Organizations should ensure that people who use services as well as 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 receiving 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 from planning to implementation and monitoring to people using services.

Organizations should cultivate ongoing partnerships with other systems and promote community integration for people needing supports. Other systems include the acute/primary/chronic care systems, housing, employment, education, transportation, Veterans Administration, safety net providers, etc. Conflicting policies across systems should be addressed through the lens of a person-centered perspective.

For instance, a Medicaid funded HCBS program may not be compatible with a congregate housing model funded through Department of Housing and Urban Development (HUD), and an understanding of the flexibilities if HUD financing is necessary to negotiate a person-centered approach to housing. Person-centered planning facilitators should engage and incorporate personnel and supports needed from these systems. Additionally, organizations at the state and community levels should cultivate a collaborative partnership with providers and work to determine what systemic factors may act as barriers to provider performance and work toward effective solutions.

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

Quality and Innovation

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 person-centered planning 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. Person-centered planning 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 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 person-centered planning 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 and persons within the systems including persons, caregivers, staff, and providers. A suggestion was made to move away from clinical terminology and diagnosis and toward a focus on what the person wants in their life. Interviewees also emphasized that person-centered planning should be preceded by some form of assessment that supports open ended feedback either during eligibility assessment and/or planning processes.

Opportunities were also identified such as establishment of state/federal regulations related to person-centered planning, fostering administrative champions, building program resiliency, along with federal program oversight across states. Principles of person-centered planning should be standardized and and 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 person-centered planning principles.

Next Steps

Following the 30-day public comment period, the Committee will reconvene to adjudicate input received. The Committee will then focus on the environmental scan that includes historical development of PCP in LTSS systems, the conceptual framework for PCP measurement, and the creation of a research agenda for future PCP research. These products will be incorporated into the comprehensive draft final report, which will be released for another 30-day public comment in April 2020. The Committee will review public comments on the comprehensive draft report and finalize recommendations in June 2020. The final report will be released in July 2020.

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