

# **Meeting Summary**

# Person-Centered Planning and Practice Committee Web Meeting #3 Summary

The National Quality Forum (NQF) convened the Person-Centered Planning and Practice Committee for a web meeting on July 31, 2019. NQF introduced the Committee self-advocates as liaisons who will represent people living with intellectual and developmental disabilities (IDD), dementia, and mental health. Along with an updated environmental scan and literature review, NQF presented updated draft core competencies of people performing person-centered planning (PCP) facilitation. The Committee then provided input for further refinement of the PCP core competencies along with guidance on quality measure needs and resources for PCP.

# Welcome and Review of Meeting Objectives

Kate Buchanan, NQF Senior Project Manager, welcomed the Committee and reviewed the following meeting objectives:

- Introduce and welcome newly appointed Committee liaisons
- Obtain input on updated draft core competencies of people performing personcentered planning (PCP) facilitation
- Update on environmental scan and literature review

Co-chairs Gretchen Napier and Cheryl Phillips also introduced themselves and provided welcoming remarks to the Committee.

# **Liaisons Introduction**

Ms. Buchanan introduced the four liaisons to the Committee:

- Daniel Fisher, National Coalition for Mental Health Recovery
- Pam Montana, Alzheimer's Association
- Penny Shaw, Massachusetts Advocates for Nursing Home Reform and Disability Policy Consortium of Massachusetts
- Mathew McCollough, Office of Disability Rights, Government of the District of Columbia.

The role of the liaisons was defined as that of engaging and informing the Committee proceedings to assist the Committee in achieving the goals of the project, but they will not vote on the final report. The liaisons briefly introduced themselves.

# **Committee Feedback**

Following some Committee concerns expressed over the project operations, NQF Senior Director Debjani Mukherjee shared that moving forward there will be time set aside during web meetings to address Committee feedback and concerns with suggested solutions. Staff conducted outreach on Committee concerns. From this outreach, four re-occurring issues emerged. NQF project staff offered the following solutions:

- Considering the Committee members' interest in providing input on meeting materials (i.e., agendas, slides, and other reference materials), 10 minutes will be set aside at the beginning of each web meeting for the Committee and Committee liaisons to have their questions answered.
- Regarding the request to have reference documents cited in the meeting materials, NQF stated that staff will post all referenced documents on the Committee SharePoint site and provide links in the CenturyLink chat box during web meetings.
- For questions or comments about the project that are not covered in the agenda or meeting slides, Committee members and liaisons were advised to email the project box or set up a call to discuss their concerns.
- Two proposals were introduced to the Committee to help facilitate dialogue and alleviate the issue of individuals feeling as if they are not being heard. The first is to have NQF create some discussion questions that Committee members and liaisons can use to seek feedback from their respective stakeholder networks. The second option is to divide Committee members and liaisons into subgroups and allow for time during web meetings for each subgroup to react in real time to the meeting materials. The Committee members expressed interest in both approaches, and NQF stated that it would take into consideration both approaches to develop the best strategy.
- Regarding the concern about the ability of the project to engage with all stakeholders that will be impacted by the final outcomes of the project, two options were brought forth. The first is that during the interim draft report period October to November 2019, Committee members and liaisons will be encouraged to engage in listening sessions with their respective stakeholder advocacy groups. Committee members and liaisons will then summarize the feedback gathered and report back to other members and NQF staff during a web meeting. The second option presented is in addition to option one or instead of it, where Committee members and liaisons will send the draft report to their respective networks to solicit written feedback during the public comment period. The Committee members supported incorporation of both approaches to solicit feedback from their respective networks of stakeholders.

# **Refined Core Competencies for Person-Centered Planning Facilitation**

Following a summary and discussion of process additions/changes based on Committee feedback, NQF Senior Director Debjani Mukherjee informed the Committee of core competency updates based on additions and clarifications provided during the previous web meeting on June 24, 2019. Staff reminded the Committee that the development and refinement of the core competencies is an iterative process and that members will have an opportunity to provide additional feedback on the competencies during public commenting on the interim draft report.

The Committee provided the feedback on the proposed core competencies.

- Foundational Skills:
  - A Committee member suggested to amend "supported decision making based on individual's needs" to include individual's needs and desires.
  - Given the importance of self-determination when considering person-centered planning, Committee members suggested that consumer control be changed to consumer driven.
  - Committee members also noted that consumers need to initiate the concept of self-directed choice and control.
- Relational and Communication Skills:
  - The Committee requested the addition of independent facilitation and motivational interviewing as two new relational and communication skills.
  - Committee members requested the removal of the word weakness and replaced it with support needs when considering an individual's personal strengths and needs.
- Philosophy:
  - The Committee requested the addition of "technological solutions and considerations" to this section.
- Resource Knowledge:
  - The Committee recommended changing "case load" to "service load" to acknowledge and highlight the importance of individual to staff ratio management.
  - The Committee recommended adding "mandatory and/or required" to training and support for staff.
- Policy and Regulatory Context:
  - The Committee suggested expanding "human rights" to include responsibilities as well.
  - Other additions included: the CMS Home and Community-Based Services Final Rule, Individuals with Disabilities Education Act (IDEA), the Older Americans Act, the final rule of 45 CFR Parts 1321 and 1324 State Long-Term Care Ombudsman, Medicare and Medicaid Programs; Reform of Requirements for Long-Term Care Facilities, and 42 CFR 483.21 – Comprehensive person-centered care planning

#### Update on Environmental Scan and Literature Review

Following the discussion of core competencies, Ms. Mukherjee provided an update on the environmental scan and literature review for PCP-related measures. Ms. Mukherjee provided an overview of the measure scan process including search terms and databases utilized. She noted that both NQF-endorsed and nonendorsed measures would be considered for the environmental scan. Of the 366 performance measures identified by the scan, 206 were directly relevant.

Following this presentation, the Committee provided these clarifications and recommendations:

• Members recommended the following terminology changes: "patient" to be replaced with "individual,"; "geriatrics" to be replaced with "older adults"; and "chronic care" to be with replaced with "multiple chronic conditions."

• Committee members noted that when considering performance measurement, all individuals should be considered including older adults, and all caregivers should be considered allies and active participants.

The Committee provided the following list of resources to consider:

- CAHPS Home and Community-Based Services Survey (HCBS CAHPS), National Core Indicators subdomain of choice, Empowerment Scales used in psychiatry, Health Resources and Services Administration (HRSA) Maternal and Child Health Bureau (MCHB) measures, State Department of Health-related PCP measures.
- Types of measures recommended included:
  - Quality of plan, quality of life, quality of supports, quality of support caregiversrelated measures
  - o Implementation of plan measures
  - Peer mentoring measures
  - o Utilization measures
  - o Operational measures of PCP
  - o Survey measures and tools

### History of Person-Centered Planning in Long-Term Support Services (LTSS)

Person-centered planning was developed through multiple co-occurring movements which has resulted in different approaches and philosophies in PCP, with a lack of standardization. An understanding of the origins and current landscape of PCP could be helpful in recognizing and sharing best practices in PCP as well as encouraging standardization and adoption of best practices. Staff requested feedback from the Committee on the best way to approach the multipronged history of PCP within LTSS. Committee members recommended a holistic view of historical development and considering concurrent parallel tracks of development. Further, they recommended using National Center on Advancing Person-Centered Practices and Systems as a resource for timeline development along with key informant interviews.

#### **Public Comments**

NQF received numerous public comments. The comments fell into the following categories and recommendations:

- A member of the public supported NQF's proposal for creating discussion questions that request feedback from different stakeholder groups (i.e., from a health plan perspective on how core competencies can be incorporated? Do they resonate with health plan goals?). The individual thought it was a good idea to request feedback from individuals with lived experience and advocates. The commenter called attention to self-advocates working in small groups as a good way to gather feedback, stating that meetings are often split up into small groups with one person taking notes to report back to the larger group to drive discussion.
- Avoid the term "case management." Case management has an implication that it is someone's job to manage a person with a disability. Use terms such as "service

coordination management," or the use of consumer records terminology is seen as more appropriate language.

- Public commenters provided potential new competencies including:
  - Motivational interviewing (relational and communication skills)
  - Training for the individual to know how to lead their own meetings (foundational skills)
  - Include Older Americans Act, CMS HCBS Final Rule of 2014, and Final Rule: 45 CFR Parts 1321 and 1324 State Long-Term Care Ombudsman (policy and regulatory context)
  - o Create a culture of high expectations (foundational skills)
  - Recognition of the person within the context of family and the community (foundational skills).
- Members of public recommended the following changes to language used within the core competencies:
  - The term consumer control (foundational skills) should be changed to consumer driven.
  - The term customer service (relational and communication skills) should be changed to person-centered service in regard to individuals and consumers.
- Commenters stated that NQF should avoid the term "care plan." In the person-centered community, a care plan is seen as a medical term. Use terms such as "independent living plan," "individual plan," or "person-centered plan." One commenter cautioned that to be truly called a person-centered plan the individual needs to have complete control over the plan. If the plan contains requirements for service eligibility or anything else the individual cannot control, it cannot be considered "person-centered."

# **Next Steps**

Yvonne Kalumo-Banda, NQF Project Manager, shared that Committee recommendations and public comment would be used to refine the list of core competencies of persons performing person-centered planning and expand the environmental scan for person-centered planning measures and its history in LTSS.

The Committee, Committee liaisons, and the public were requested to send all resources that NQF PCP project staff should review during their environmental scan to the project mail box <u>pcplanning@qualityforum.org</u>.

The next Committee meeting was announced as September 6, 2019 from 1:00 to 3:30 pm ET, during which the NQF PCP project staff will present the final list of core competencies of people performing person-centered planning facilitation and gather Committee, Committee liaison and public input on the draft recommendations for systems characteristics that support person-centered thinking, planning, and practice.

The public was encouraged to <u>subscribe to project alerts</u> to keep track of meeting dates and meeting resources as they are posted onto the project page.

# Appendix

Sender	Message
Bevin Croft	I like proposed solution #1 and recommend that feedback from people with lived experience is frequently sought.
Nicole Leblanc	I like the idea of discussion questions
Nicole Leblanc	Conversation questions and prompting questions are good for helping self-advocates give input.
Susan O'Nell	Can you make explicit on the committee who lives with intersectionality of lived experiences either as a person with support needs and/or family member and also members of other marginalized groups? (Persons of color, immigrants and/or people from a variety of cultural, linguistic, religions, and ethnic groups, LGBTQ+, military/veteran concerns, rural communities, etc.?) Obviously, people should not have to disclose anything they don't want to but I am concerned that there doesn't seem to be clear efforts to have representation of communities that have cultural and life experiences that are not well served in current services. Also, intersectionality has an exponential impact on people that being one thing or other does not bring (for example, being a POC or a person with disability alone is not representative of having a both disability and being a POC). If people identify with one or more of these lived experiences and bring that transparently to the committee, can that be made clear to the public? Many people do not glean to evidence-base because there is not good representation of their lived experience and members of their community in it. I think to have validity with all communities there needs to be clear attempts to incorporate those.
Nicole Leblanc	Also working in small groups are a good way to get feedback on documents. In the self-advocacy world when we do project meetings we often will split up into groups and have one person take notes and report back to big group, make questions plain English
Denise Myler	Denise: I like both but I also really like a discussion email board of all members, staff and liasions.
Nicole Leblanc	Do listening session with SABE, ASAN, and state self advocacy organizations, just an idea.
Nicole Leblanc	SABE conferance is Oct 1-3, good place to get self advocate input
Susan Fegen	I agree with both solutions.
Nicole Leblanc	Glad to see dignity of risk, I have done training, keynotes on that topic
Nicole Leblanc	WIOA defination of CIE-Competitive Integrated employment,
Nicole Leblanc	SERVICE COORDINATION MANAGEMENT

Sender	Message
Eileen Burk	Under relational and communication skills (slide 30), would you want to include motivational interviewing? It is a skill that we teach to our staff.(I am neither a member or liaison; is it appropriate for me to interject?)
Nicole Leblanc	Case management implies that my job is to manage the person with a disability
Denise Myler	Denise: in independent living we use consumer records term instead of case load management
Eileen Burk	Also, slide 31: Is Dignity of Risk mean allowing the consumer the option to fail?
Tammy Evrard	In consumer control, there needs to be awareness and training for the individual to know how to lead their own meetings, etc.
Nicole Leblanc	Operate in a strengths based approach
Pearl Barnett	Policy Regulations to consider adding - Older Americans Act, CMS HCBS Final Rule of 2014, and Final Rule: 45 CFR Parts 1321 and 1324 State Long-Term Care Ombudsman
Nicole Leblanc	They are abstract concepts - rights and responsibilties
Nicole Leblanc	self determination to page 30
Nicole Leblanc	Create a Culture of High Expectations
Nicole Leblanc	Too many of us suffer from Low Expectation Syndrome
Emily Price	Recognition of the person in the context of family and community is a competency
Nicole Leblanc	Training on models of disability, presuming competance
Denise Myler	Denise: slide 29 consumer control in independent living we use consumer driven
Sally Burtron-Hoyle	Independent Facilitation must be addressed as an option for choice and control
Sally Burtron-Hoyle	Why not person driven as opposed to consumer!!!
Nicole Leblanc	We need to break the power struggle between staff and PWD
Sally Burtron-Hoyle	"Consumer" is not a term used by many
Daniel Fisher	Training should be carried out by persons with lived experience of the disability served. The imbuing of principles of recovery is best carried out by persons with lived experience.
Glenda Armstrong	I too believe we need to be specific about training elements - for sure to include skills that are typically not trained well like motivational Interviewing, trauma and cultural competencies.
Nicole Leblanc	Service Coordination separate from provider of services
Nicole Leblanc	In VT The Providers of dd services do all the case management and provide services while also being the rep payee in many cases on top of that
Cheryl Phillips	need to add older americans act on policy slide. And need to remember we are also reporesenting older adults who may have different expectations of agency and self-direction

Sender	Message
Amber Decker	Customer service should be replaced with person centered service :)
Amber Decker	Slide 30
Leolinda (Parlin) Iokepa	Was the HCBS CAHPS individual measures in the document or will be provided later?
Kate Buchanan	Hi Leolinda we did not provide the individual hcbs cahps measures but can go back and pull them out; thank you for the suggestion.
Nicole Leblanc	It would be good to have measures on Peer Mentoring, for both I/DD and Mental Health
Nicole Leblanc	Awesome point, geratics is a difficult term to understand
Ellen Blackwell	Yes, let's please change "geriatrics" to older adults. Signed, Ellen Blackwell, MSW (geriatric social worker)
Nicole Leblanc	Older Adults, seniors is more plain english
Emily Price	Many states are looking at Social Determinants of Health as an indirect measure
Nicole Leblanc	http://www.aucd.org/docs/add/sa_summits/Language%20Doc.pdf
Sally Burtron-Hoyle	Person centered plans should be independent of the care plan
Denise Myler	Denise; in independent living we use independent living plans
Sally Burtron-Hoyle	Care plan is never a term that is a part of the PCP!
Nicole Leblanc	In Maryland we call it individual plan
Leolinda (Parlin) lokepa	Consider looking at the Family Voices Family Centered-Care Assessment Tool for adaptation and generalization http://familyvoices.org/fcca-usage-request-form/
Denise Myler	Denise; independent living plans are fluid and changes as the person needs to make changes,
Sally Burtron-Hoyle	Care plan is a medical term!
Sally Burtron-Hoyle	PCP is about a persons life not care!
Nicole Leblanc	language matters how you use it, it can lift a person up or tear a person down. Language influences the attitudes of others in the way they see people with disabilties
Amber Decker	Person Centered Service Plan
Cheryl Phillips	Recovery is not a reasonable term for those with progressive disabilities
Amber Decker	I mentioned POC Plans of Care because of it's legal authority vs. PCP person centered plan
Sally Burtron-Hoyle	YES!! Just a person centered plan!
Patricia Nobbie	I agree with person-centered plan if we have to 'name' something now

Sender	Message
Susan O'Nell	One issue with calling it a "person-centered plan" is that there really is a difference between a plan that you control completely and a plan that meets requirements for service eligibility. Truth is if the person doesn't completely control it, it's not a person-centered plan. It's a tension. You can't "do" a person-centered plan to someone.
Nicole Leblanc	Do they actually pick their goals, freely chosen without influence from staff, families
Patricia Nobbie	and also agree with Bruce that caregivers or participants or allies of the individual are also important to be considered in the measures
Nicole Leblanc	Do people feel comfortable with their staff, are they listened to by their agency, when they have issues with staff are they free to express that withiout fear of backlash, intimindation etc.
Sally Burtron-Hoyle	Michael Smull is focusing on the critical ideas on why you cannot develop a scientific measurement for the use of PCP's across systems.
Sally Burtron-Hoyle	There are operational measures based on how and when the person is involved in the community as defined by them.
Paula Acosta	Public input: Did the environmental scan distinguish between PCP staff competency performance measures from PCP service quality outcomes? if not, should it. Is that a gap? Ensuring professional PCP staff skills would seem to be at the core of delivering PCP quality.
Nicole Leblanc	WE NEED Training on supported typing
Nicole Leblanc	Presume competence
Nicole Leblanc	Who is their favorite support person, who knows everything on how best to support them etc
Patricia Nobbie	This reminds me I wanted to comment on some terminology that keeps creeping up - "Shared decision-making." To me this implies always, a professional is involved and often can overshadow the individual. We should be saying "informed decision-making and "supported decision-making"
Daniel Fisher	Need a way to determine if the goals are stated in the person's own words. Often funders require a language in the goals that are unfamiliar to the person engaged in the service
Leolinda (Parlin) lokepa	Another measurement tool to review would be the Pediatric Integrated Care Survey <u>http://www.childrenshospital.org/integrated-care-</u> program/patient-and-family-experience-outcome
Nicole Leblanc	AGREE, Change elderly to seniors or older adults
Nicole Leblanc	Talk about how the system has gone from being medical, moral model to the civil rights model of disability we use today

Sender	Message
Tammy Evrard	Just some thoughts. What is a meaningful life to the person? How is the voice of the person being heard on an on-going basis? How is the person leading the everyday activities? How is the person choosing the supports, services and people they want in their life?
Sally Burtron-Hoyle	In Michigan we put PCP in Mental Health Code for ALL recipients of mental health services in community mental health system, DD, MI, Substance Abuse
Denise Myler	Denise; it would be helpful to look at subdomians in decade time- frame
Tammy Evrard	Resources: SARTAC - Self Advocacy Resource and Technical Assistance Center <u>https://selfadvocacyinfo.org/resource/</u>
Nicole Leblanc	Showcase various civil rights movement. aging, disability and self advocacy movement
Patricia Nobbie	The principles of person-centered thinking are really universal at their core
Nicole Leblanc	Talk about how all movements intersect with each other
Amber Decker	Human and Patient Rights in New York or in the individuals state
Amber Decker	Slide: 46 I would say "DECADES since 1960s" is the best historical timeline
Tammy Evrard	Hope that we can continue to ensure the philosophy of Nothing About Us Without Us remains throughout the work.