



Person-Centered Planning and Practice Committee Web Meeting 5

The National Quality Forum (NQF) convened the Person-Centered Planning and Practice Committee for a web meeting on December 13, 2019.

Welcome and Review of Web Meeting Objectives

Co-chairs Gretchen Napier and Cheryl Phillips introduced themselves and welcomed the Committee members, liaisons, and general public.

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

- Review and adjudicate public comments on the interim report.

Overview of Interim Report

Samuel Stolpe, NQF Senior Director, provided additional direction for the meeting's activities, followed by an overview of the interim report. Within the interim report, the Committee addressed three key concerns related to designing practice standards and competencies for person-centered planning. The Committee had developed a functional, person-first definition of person-centered planning. Next, the Committee had 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 put forward in the report considerations for 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.

Dr. Stolpe emphasized that the report represents an interim summary of the Committee's efforts to date. The final report will address the history of person-centered planning, a framework for quality measurement within person-centered planning, and a research agenda to promote person-centered planning in long-term services and supports (LTSS). LTSS includes home and community-based services and institutional settings such as nursing homes, and the interface with other areas of the healthcare system.

Interim Report Feedback—Listening Sessions

Dr. Stolpe introduced the listening sessions that were hosted by Committee members with stakeholders who had reviewed the Committee's interim report and offered feedback on how to align the content with their experience and understanding of person-centered planning. Dr. Philips facilitated Committee members reporting of feedback from their respective listening sessions and moderated the ensuing discussion between Committee members on how to incorporate listening session feedback into the interim report.

Listening sessions were held by:

- Pat Nobbie and Mathew McCollough—Anthem Inc. and DC Office of Disability Rights
- Bevin Croft—The National Center on Advancing Person-Centered Practices and Systems (NCAPPS)
- Melissa Nelson—TMG by Magellan Health Inc.
- Amber Carey-Navarrete—Easterseals Southern California
- Sara Link—Virginia Department for Aging and Rehabilitative Services
- Pearl Barrnet—National Association of States United for Aging and Disabilities
- Susan Fegan—Centene Corporation

Common themes that emerged from the listening sessions related to recommendations that the Committee consider the length of the definition of person centered planning, use simpler language throughout the report, reduce the total number of competencies, and reframe the competencies to focus not on personal characteristics but on measurable and teachable knowledge and skills related to person-centered planning.

Interim Report Feedback—Written Comments

The public also provided extensive written comments to NQF staff related to the Committee’s interim report. Dr. Stolpe reviewed the nature and disposition of the comments received and grouped them generally into themes for the Committee to address. Dr. Stolpe presented summary statistics related to written comments, noting that the Committee received 139 comments submitted through the commenting tool from 38 organizations and 10 individuals. After the review of the comments, Ms. Napier led the Committee in a discussion of how to incorporate feedback received into the interim report.

Commenters generally supported the definition of person-centered planning and found it readable, though some criticized the complexity of its wording. Some others thought the definition should emphasize focusing the plan on the person’s life and place less emphasis on organizing a person’s supports and services. Some commenters also pointed out that with the insistence on focusing on “empowerment,” there isn’t sufficient consideration for persons with limited intellectual competency who are not capable of making certain decisions.

Dr. Stolpe also reviewed comments related to the core competencies. Commenters urged the Committee to consider competencies related to including peer support for people facilitating person-centered planning, to discriminate between cultural versus linguistic competence, to revisit the definition of dignity of risk, to separate competencies from strengths, roles, and attributes, and to pay special attention to the facilitation needs of people with intellectual disabilities. Several commenters pointed out that the list of competencies is long and aspirational. It was also noted that persons with disabilities serving as PCP facilitators may serve as role models to others by inspiring them to lead their own planning.

The Committee also received comments related to the systems characteristics for fostering person-centered planning. Commenters pointed out that there should be a clear distinction between a service plan and a person-centered plan, that there should be adequate funding and support for programs and staff, that teamwork is a key feature of healthy systems, and that there is often a disconnect between system funding structures, regulations, and day-to-day case management.

General comments expressed concerns related to the report’s structure and layout, the language, the tone, and the audience. Some commenters expressed concerns related to how the report would be used and its potential to lead to program evaluation. The report was also criticized as too idealistic and aspirational.

Public Comment

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

Comments Regarding the Draft Report:

- The report should be accessible to all by being written at a sixth- to eighth-grade level
- A large-print version of the report would aid accessibility
- Add to the definition that person-centered planning is a “collaborative” approach

Comments on Dignity of Risk:

- Dignity of risk does not have to be a major undertaking. It can be simple tasks like riding the bus alone or living by oneself.
- The culture needs to change from one of protection to one that facilitates dignity of risk. This will increase/foster more independence which will provide individuals the ability to achieve their goals and dreams.
- Balancing different generational expectations: the generation that has grown up with the Americans with Disabilities Act has high expectations, dignity of risk, and presumed competence, while older generations hold onto institutional thinking due to the perceived notion that sheltered settings are best because they overprotect. Growth and equity in society come from getting out of one’s comfort zone and increasing self-determination.

Miscellaneous Comments:

- Use “peer mentoring” or “hiring peers” (both using individuals with lived experience) to assist individuals with person-centered planning.
- Agencies should hire persons with disabilities which would help make the system more person-centered. This would also show presumed competence.
- Document when specific sections of a person-centered plan are updated
- Review one’s plan whenever there is a significant change to one’s location, setting, health status, treatment, provider(s), family member(s), personal preferences, and needs, concerns, or desires.
- For the final report, consider adding in emergency preparedness. Best practices would include: consideration, documentation, and dissemination of a developed plan to all parties potentially involved in the person-centered planning process.

Next Steps

Yvonne Kalumo-Banda, NQF Project Manager, shared that the final draft report will present the Committee recommendations and public comments. The final draft report will be open for public comment for 30 days from April 8 to May 8, 2020.

The Committee, liaisons, and the public were advised to send all project-related correspondence, inquiries, and resources to pcplanning@qualityforum.org or call 202-783-1300.

The next Committee meeting was announced for January 6, 2020 from 1:00-3:30 pm ET. During this meeting, NQF PCP project staff will introduce a person-centered planning framework approach, a development process, and a draft measurement framework. The Committee will review and provide input on the draft measurement framework.

The public was encouraged to [subscribe to project alerts](#) to keep track of meeting dates and meeting resources as they are posted on the project webpage.

Appendix: Public Comments Received via Chat

Sender	Message
Kate Buchanan	All - the listening session feedback is on the website http://www.qualityforum.org/WorkArea/linkit.aspx?LinkIdentifier=id&ItemID=91668
Nicole Leblanc	Maybe contracting someone to make the report in accessible report would be good
Nicole Leblanc	It was nice to see that you made an effort capture dignity of risk in the report
Nicole Leblanc	https://readable.com/features/
Nicole Leblanc	TOOL To make report more plain english
Nicole Leblanc	FYI NCAPPS will be doing a webinar on Dignity of Risk tuesday
Nicole Leblanc	<p>December 2019 Webinar:</p> <p>Finding the Balance: Person-Centered Supports that Honor Safety and Dignity of Risk</p> <p>Tuesday, December 17th, 2:30pm to 4:00pm Eastern Time</p> <p>To register, visit https://zoom.us/webinar/register/WN_Zkaw7MQQQiyzdJlzyNdoaw</p> <p>Person-centered supports must ensure that people have opportunities to make informed choices and to be supported in managing the risks that come with some decisions. Support providers have a direct role in helping people to live lives of their choosing and often face the challenge of balancing the individual's choice and what is their duty of care?. Participants in this webinar will 1) hear from people with disabilities about their experience in planning, navigating concerns about well-being, and seeking the dignity of risk?, 2) learn from providers of supports about requirements, challenges, and successes in the delivery of quality person-centered supports that considers health and safety while honoring a person's right to make decisions that may not always be in their best interest, 3) learn about training available for direct support providers that will equip them with the skills and strategies to help manage health and safety concerns in a person-centered way.</p> <p>Meet the presenters</p> <p>John Raffaele</p> <p>John Raffaele is the Director of Educational Services at the National Alliance for Direct Support Professionals. John has Master of Social Work Degree, and is a highly experienced professional adult educator, group worker and facilitator. John's education is from Yeshiva University in New York City and The State University of New York at New Paltz.</p> <p>Marian Frattarola-Saulino</p> <p>Marian Frattarola-Saulino is the Co-Founder and CEO of Values Into Action (VIA). The VIA family of organizations includes the first Supports Brokerage in Pennsylvania and one of the original Support Coordination Agencies in New Jersey. She presents internationally on co-production as a fundamental right,</p>

Sender	Message
	<p>based on experience from her current operational work. Marian is also a co-founder of The Alliance for Citizen Directed Supports.</p> <p>Michelle Murphy</p> <p>Michelle Murphy is a Staff Development Specialist with the Arc Mid-Hudson in Kingston, NY. She is a credentialed direct support professional (DSP) with 15 years of experience in various roles. Michelle currently oversees the NADSP E-Badge Academy at the Arc Mid-Hudson. Michelle is known for her vibrant personality, her passion for employee self-care, and empowering DSPs to be their best selves while providing quality supports.</p> <p>Nicole LeBlanc</p> <p>Nicole LeBlanc has 12 years of experience in disability policy field. Dignity of risk is her passion, and she has created a booklet on disability employment policy through a public policy internship. She currently works as the Person-Centered Advisory and Leadership Group (PAL) coordinator for the NCAPPS. Her Motto is ?Control Your Own Destiny, or Someone Else Will.?</p> <p>Chester Finn</p> <p>Chester Finn is currently employed by the New York State Office for People with Developmental Disabilities (NYS OPWDD). He has served three terms as National President for Self-Advocates Becoming Empowered (SABE) and is also an advisor and former president for the Self-Advocacy Association of New York State (SANYS).</p>
Nicole Leblanc	https://ncapps.acl.gov/webinars.html
Rose Warman	there may be a need to negotiate if there is a health and safety issue
Nicole Leblanc	Dignity of risk can be things as simple as taking a bus alone, trying something new like moving into their own apartment
Nicole Leblanc	it doesnt have to big like moving from a rural state to a big city
Nicole Leblanc	The agency culture of providers needs to change to facilitate dignity of risk, more independence, supporting folks to achieve their goals and dreams.
Nicole Leblanc	Informed choice is very important when it comes to decision making
Nicole Leblanc	We need people to learn how to support folks to be true equals in society, develop freely given relationships, part of dignity of risk is getting outside of ones comfort zone. Change = Growth
Nicole Leblanc	Amen, I love that comment its a person centered plan not a guardian one
Nicole Leblanc	People are people before anything else. Everyone has an opportunity to the same dignity and opportunities as those w/o disabilities.
Nicole Leblanc	report should be written at a 6-8th grade level at the very least

Sender	Message
Amber Decker	It seems like our panel's feels that our mission is to create an algorithmic tool to digitize "person-centered planning" so it can be easily plugged into existing for-profit payer-led managed care plan IT and infrastructure, which currently processes medical claims. A medical claim consists of one or more diagnosis codes (ICD-10) and procedure codes (CPT). The fundamental incompatibility of PCP with corporate health insurance infrastructure is a major reason why this whole mission is problematic. PCP is hard to do but because health insurers will have little reason to lift a finger to accommodate the person.
Nicole Leblanc	One thing about VoC Rehab is that its the most self determined program, law because they have to prove you cant work, Jonathan Martinis talks about that when doing training on Supported Decision making
Nicole Leblanc	I prefer People first language
Nicole Leblanc	When it comes to Person Centered Planning, and values we have the ADA generation that expects high expectations, dignity of risk, presume competence, views disability with pride, vs older generations that still hold onto the institutions, sheltered settings are best cause they over-protect, This is a big challenge of our time
Nicole Leblanc	To better inform and create a truly inclusive definition it would be nice to see a national forum, listening session targeted at self advocates for all self advocacy organizations, an idea
Nicole Leblanc	Have a balance between paid supports and unpaid supports? This is where Social Role Valorization comes into play- developing unpaid relationships in the community?
Nicole Leblanc	The system would be more person centered if we brought back Goods line in waiver budgets -pay for stuff like college classes, gym membership etc
Alan Rozen	It may be beneficial to clarify whether this PCPP development process is expected to produce a Final Report that will serve as a fully realized "operations plan" VERSUS a strategic conceptual framework to improve our healthcare system for ALL.
Nicole Leblanc	Add stuff on Peer Mentoring-Hiring peers with lived experience to assist folks with PCP , conflict free case management
Nicole Leblanc	If agencies who provide services were to hire people with disabilities that could go along ways towards making a system more person centered! It is also a great way to showcase presuming competence. We are all smart in our own way.
Nicole Leblanc	Peer mentoring become a billable service under the waiver
Amber Decker	Plans should solicit HIPAA's via the person.
Nicole Leblanc	Strategies to train support staff on how to support folks as equals, rather than the power of you mindset
Amber Decker	Are there Person Centered Plans Already? Do we have samples?

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Nicole Leblanc	Here is a nice PPT on Dignity of risk- https://www2.health.vic.gov.au/~media/Health/Files/Collections/Presentations/S/Striving-For-Care-Excellence/Exploring-the-concept-of-Dignity-of-Risk
Nicole Leblanc	http://www.cpoynys.org/wp-content/uploads/2016/10/Dignity-of-Risk.pdf CQL PPT resoures on Dignity of Risk
Amber Decker	Yet we keep referring to them
Alan Rozen	I still want to emphasize the importance of being able to access and disseminate not only a plan but also documenting whenever a section has been updated: The best way to respect your wishes and to follow your plan would be to also review it every time there is a significant change in your location, setting, health status, treatment(s), caregiver(s), provider(s), family members, personal preferences, needs or concerns.?
Nicole Leblanc	Creating a large print version of the report would be good
Alan Rozen	FYI...NEW TOPIC: I observe NOTHING has been mentioned about planning and preparing for emergencies!!! As a medical leader who has previously served vulnerable populations during hurricanes in Florida, debilitating storms in the midwest and blizzards in the northeast, I highly recommend the Final Report highlight that best practices would include consideration, documentation and dissemination of a developed plan to all potentially involved entities.
Alan Rozen	Tx for ALL of your efforts and endeavors!!!
Alan Rozen	I support and summarize current speaker's feedback as a Mission Statement, Vision Statement, Values, Principles, etc.
Nicole Leblanc	Good idea Pat Nobie
Alan Rozen	Personally agree with suggested reordering and restructuring
Nicole Leblanc	Agree 110% cause we need to design a system without the attitudes of segregation, institutionalization, Based on experience even though we have closed segregated facilities the attitdues from large congregate settings still exist
Nicole Leblanc	Perfect example shared living
Alan Rozen	And, important for all entities to ensure plans can be appropriately accessed, shared and updated
Nicole Leblanc	Abuse prevention in duty of care?
Laura Demeuse	Please add "Person-centered planning is a COLLABORATIVE approach..." to the definition. All the comments about facilitation as a team and needing to involve family members, guardians, etc...collaboration is really the key to getting people good lives!
Amber Decker	Adding Freedom of Choice