

Public Chat Comments

Sender	Message
Amber Decker	This whole process has been unfair and rushed
Amber Decker	We cannot even see each other's chat comments
Amber Decker	This would have been better on Zoom. CenturyLink's connection
Sally Burton-Hoyle	Here Here Zoom would work much better!
Amber Decker	Century Link is a waste of money this whole process has been unfair and rushed and what we have created is not helpful.
Amber Decker	Terrible Feedback NQF should invest in a better platform we have not been able to engage meaningfully due to the egregious failure to use a software meeting platform that would allow for an actual discussion.
Alan Rozen	I want to begin by congratulating all of you for pursuing this critical topic that can impact every individual?if not directly, then most definitely someone they know. The subject and scope addressed by this report is truly admirable.
Jim Karpe	Please note that there were 139 comments. Nine of my ten did not make it to the committee until today, due to a technical glitch.
Alan Rozen	During this call, would someone please explain why this report completely lacks any reference to PCPP guidelines and expectations in the context of public emergencies and national disasters as I had encouraged within my previously submitted comments?
Alan Rozen	Current events highlight a critical issue I previously brought to your attention regarding emergencies and crises?about which this report still remains silent.
Alan Rozen	In previously submitted comments, I specifically recommended that this report should account for preparing, incorporating and utilizing these Person-Centered Care Plans (PCPs) during a disaster or emergency. My input reflects my experiences and challenges encountered with Hurricane Katrina, Hurricane Sandy, Hurricane Irma?unfortunately, now COVID-19, too?and the lingering sequelae and discoveries yet to be recognized.

Alan Rozen	While the process for developing these PCPs is extremely worthwhile to advance awareness and expand insight, should those results remain unrealized or unknown when they could be needed most, then that multiplies our collective error ? These situations WILL continue to happen and the associated suffering WILL be compounded?
Nicole LeBlanc	THIS PANDEMIC is making the case stronger and stronger as to why we need to close segregated settings and move to a more person centered system
Amber Decker	Never discussed access to assistive technology, access to internet, access to advocacy, access to support, access to training,
Nicole LeBlanc	Anyone offering case management, and doing HCBS Intake should work for an agency separate from the one providing the actual services
Amber Decker	The Person Facilitating your planning process should not be from a for-profit managed care plan-organization either.
Nicole LeBlanc	Spelling up Conflict of Interest is a must given that it can get in the way of PWD achieving their goals- Providers who do case management and all other services often can talk you out of switching agencies, or going from shared living to supportive living for example based on experience in the system
Nicole LeBlanc	I love how you say avoid conflict of interest
Nicole LeBlanc	This is a big issue in the I/DD World
Sally Burton-Hoyle	There should be no conflict of any other agencies. Simplify
Alan Rozen	Critical to assessing utilization and impact from this PCPP Report will be tracking the extent to which PCPs are shared, accessed, utilized and updated. Can the Committee or NQF staff please explain why this was not deemed relevant enough to include as a standard or even identify as a topic for future clarification?
Laura Demeuse	What is the meaning of "develop" in develop the person-centered service plan? Facilitating a meeting and writing a plan are very different types of development and will change requirements based on what CMS meant by this.
Nicole LeBlanc	IT NEEDS TO be written more in plain english
Nicole LeBlanc	NQF Should make a plain language version of the NQF PCP Report

Amber Decker	PCP Facilitator should ideally have financial independence from any organization that will benefit from increases or decreases in services
Kate Norby	I appreciate and agree with the recommendation brought forth by Janis.
Amber Carey-Navarrete	I agree with Janis's comment of a preface
Nicole LeBlanc	PERSON Centered Planning needs to be generalized, It applies, to Employment, Residential services, Community Support, Respite etc
Alan Rozen	Please be aware that interpretations and expansion on ?conflicts of interest? regarding ?Facilitators? can have severely counter-productive and unintended consequences! ^For example, hospitals and hospices perform these functions at CRITICAL and emergent times.
Nicole LeBlanc	needs to be written in plain language-Nicole
Alan Rozen	^Some may feel that hospitals, contracted Palliative Care providers and hospices could be unduly restrained from critical PCP activities?
Sally Burton-Hoyle	Right Not plain language!!
Nicole LeBlanc	I 2ND THAT Its Nicole, All material should be written at a 4-8th grade level
Nicole LeBlanc	anything 9+ is too complex
Pam Montana	language needs to be easier to understand - especially for those living with Alzheimer's and other dementias. they / we would need help trying to understand this
Melissa Nelson	Thank you. I think the discussion has moved on from the plain language comment that Dorie mentioned. I just wanted to agree with the need to simplify the language and that I would be happy to help provide some examples of plain language changes to the NQF team if it would be helpful. Thanks for listening!
Mia Phifer	I support the recommendation to include a reference to these measures and have no recommendations for additional measures.
Nicole LeBlanc	Access to plain language material is a must
Nicole LeBlanc	Peer Mentoring done by other people with disabilities should be an option

Glenda Armstrong	I won't take us back to the previous issue but would like to offer that I had concerns about accountability when a conflict existed.
Alan Rozen	Please see above comments on metrics for PCPs being shared and accessed as a "glaring omission" as per the speaker's terminology and request for input...
Amber Decker	So do we mean Facilitation in the verb sense
Alan Rozen	The standards for ?Plan Creation and Implementation Subdomain? (Page 29) do NOT detail any necessity to document updates in terms of the time, date, section, acuity, participants and dissemination of these updates?
Pearl Barnett	I agree with the addition.
Pat Nobbie	I also agree with the addition. Pat N
Adeline Dorough	Great job navigating all of this, facilitators.
Alan Rozen	Subsequent evaluation of these metrics to assess quality of care and overall outcomes following this Report may be significantly hindered by disparate and non-standardized data elements--as per my prior comment submitted within this "Chat Q&A" at 1:54pm.
Angela Martin	I would agree with Pat Nobbie
Nicole LeBlanc	Where does Freely Given Relationship fall into play?
Angela Martin	I would agree with Pat Nobbie's comments about paid facilitators. Pwd (self-facilitation) should not be held to account for these measures. [I am sorry for the prior, partial comment. I inadvertently hit the "send" button before completing my comment.]
Susan Fegen	I applaud how you are handling this. Thank you!
Amber Decker	Not clear on what outside of accountability applications means please follow up on definition of Accountability Applications is no where in this Person-Centered Planning and Practice DRAFT FINAL REPORT FOR COMMENT April 9, 2020
Nicole LeBlanc	Makes sense, using respectful language like NOT using term MR and USE I/DD for instance
Jim Karpe	Slide 21: The meaning of the change is good, but the altered sentence is awkwardly constructed, with the final clause hanging out there: "and the person's preferred name."

Kate Norby	I agree with the addition "when appropriate." Thank you.
Nicole LeBlanc	Reframe from using words like HIGH/ LOW FUNCTIONING something I see many providers/case managers use based on experience in the system
Susan Fegen	I support it.
Nicole LeBlanc	makes sence
Alan Rozen	<p>To assess a provider of PCPP within a ?Process Subdomain? (Page 31) under their development and adherence to meeting these PCPP goals, confirming the appropriate dissemination of PCP?s?consistent with an individual?s wishes?will be important:</p> <ul style="list-style-type: none"> + Followed the individual?s wishes + Documentation that the individual has reviewed and approved of the developed PCP + Acted in a timely manner + Has the necessary systems and processes in place to share and disseminate theses PCPs accordingly + To what extent or frequency entities are seeking, reviewing and incorporating these PCP?s
Pam Montana	as someone living with AD I would definitely want to be involved and be able to share my wishes - and be part of the plan
Amber Decker	The Term accountability applications is not in the Person-Centered Planning and Practice DRAFT FINAL REPORT FOR COMMENT April 9, 2020 and I do not know what the term mean.
Pam Montana	and would also want help with it so that it's complete and accurate
Nicole LeBlanc	Make An Accessible Plain Langague PCP 1010 TRAINING TOOLKIT
Angela Martin	The Person Centered Plan is not the same as the Individual Service Plan. A Person Centered Plan discusses the persons' whole life. The Individual Service Plan is written by the service agency outlining what service(s) will be provided to support the PCP. The Faciliator assists the individual to write the PCP while identifying what services will be needed to implement the PCP. The identified services (amount, scope, duration) will be written by the case manager/supports coordinator not the Facilitator. In other words a Person Centered Planning and Individual Service Plan are NOT the

	<p>same. So there should not be a concern about the Facilitator collecting, documenting, etc. content for the Person Centered Plan.</p>
Nicole LeBlanc	Any training created Should Involve self advocates with lived expereicen
Nicole LeBlanc	THANK YOU FOR INCLUDING NOTHING ABOUT US WITHOUT US
Nicole LeBlanc	<p>June 15th there will be a webinar on PAE-The PAE Attention Framework: Understanding the Ingredients for Successful Stakeholder Engagement</p> <p>Monday, June 15, 2020, 1:00 - 2:30pm EST</p> <p>To register, visit https://zoom.us/webinar/register/WN_SHeHfZxxTuev1kelPuNepw</p> <p>Stakeholder engagement is essential for successful transformation to more person-centered practices. Stakeholders?including people with lived experience and their informal support networks, providers, and broader communities?all have invaluable insights that can inform redesign, ensure buy-in, and support implementation. Even so, stakeholder engagement is a stumbling block for many program administrators who are spearheading systems change efforts. This webinar will: 1) examine the common benefits and obstacles to meaningful stakeholder engagement, 2) review a simple framework to guide engagement activities, and 3) provide real-life examples of how this framework can build stakeholder trust and sustainable engagement strategies for success.</p> <p>Meet the presenters</p> <p>Erin McGaffigan Dr. Erin McGaffigan has 22 years of experience in long-term services and supports for older adults and people with diverse disabilities. Her PAE Attention framework, developed as a result of her 2011 dissertation, informs her work with program administrators, researchers, advocates, health plan administrators, and people with lived experience to design and improve stakeholder engagement activities.</p> <p>Anne Fracht Anne Fracht has been advocating for herself and others for years and has</p>

	<p>received multiple awards for this work. She has worked at Advocates, Inc. as a Self-Advocacy Coordinator since 2009. Ms. Fracht also has sat on many advisory groups to inform program design and improvements, including Boards, Strategic Planning Workgroups, Human Rights committees, and more.</p> <p>Keith Jones Keith Jones President of SoulTouchin? Experiences is an African American activist and entrepreneur with cerebral palsy. As a strong advocate for independent quality living in the community, Mr. Jones has participated actively in addressing various issues that people with disabilities face. These areas include housing, education, and voting access.</p> <p>Bob Weir Bob Weir is currently the Home and Community-Based Policy Analyst for the State of Oregon Department of Human Services Aging and People with Disabilities program. Mr. Weir's experience includes work for people with developmental disabilities, adolescents in the Oregon State Hospital, and 31 years focused on seniors and people with physical disabilities.</p>
Amber Decker	Requiring paid facilitators to reach out to Family, community and Friends.
Nicole LeBlanc	Be good to have it written in plain language, shorter, larger print
Melissa Nelson	I agree with the one sentence addition.
Amber Decker	Should not only be applicable to dementia.
Pearl Barnett	I agree with the deterioration related to physical disabilities as well.
Amber Decker	Developmental Disabilities (which Dementia falls under)
Pearl Barnett	The language should be broader and include dementia, and other diseases as examples.
Nicole LeBlanc	People with Autism are under-served in system
Amber Decker	Due to the "Individuals Needs" might be better
Alan Rozen	Regarding Slides 23-24, please see my submitted comments on this Q&A Chat at 1:54pm:

Alan Rozen	?The standards for ?Plan Creation and Implementation Subdomain? (Page 29) do NOT detail any necessity to document updates in terms of the time, date, section, acuity, participants and dissemination of these updates??
Pearl Barnett	I would remove "unpaid" and "providers" from the recommended changes on page 23.
Nicole LeBlanc	The issue of parents being paid is a tensious issue in the self advocacy movement
Laura Demeuse	increased caregiver dependence can be ANY diagnosis... I would argue someone with a mental illness, TBI or even sub abuse may have caregiver or support issues due to increased symptoms - make this caregiver statement about dementia more broad it will be fine.
Alan Rozen	Personally AGREE with concerns stated on slide 25!!!
Nicole LeBlanc	MAKE IT SIMPLIER
Alan Rozen	Keep in mind relevant disciplines (such as Social Workers, Case Managers, etc.) directly can have professional responsibility care coordination as well as communication (Slide 25)
Nicole LeBlanc	CASE MANAGEMENT IMPLIES MY JOB IS TO MANAGE YOU
Nicole LeBlanc	SERVICE COORDINATOR SOUNDS NICER AND More respectful
Alan Rozen	^AGREE with Amber Decker's current points
Amber Carey-Navarrete	I agree with the suggestion of a paragraph clarifying that the facilitator may or may not include other responsibilities such as coordination.
Pat Nobbie	I think Sam's approach is reasonable. It is a good distinction - and I do agree with Janis' point is well taken. without follow-through, it's just paper.
Nicole LeBlanc	Agree
Amber Decker	agree with MS
Nicole LeBlanc	COORDINATION IMPLIES ARRANGING SERVICES AND FOLLOW THROUGH
Alan Rozen	As a reminder, this Report does NOT seem to measure nor account for measuring the "transitions" currently being discussed
Nicole LeBlanc	FACILTATION means faciltating someone PCP mtg
Amber Decker	coordination should adhere to Facilitation Role

Amber Decker	coordination should adhere to facilitation PCP Practices when applicable
Alan Rozen	"Transitions" do happen: once a PCP is developed or updated, it must be disseminated, confirmed by the individual, shared with providers, residences, etc.
Pearl Barnett	I recommend including the committee review on the developed paragraph regarding facilitation versus coordination.
Amber Decker	again this was something that I said was an issue multiple time. The Term Care is Vital in the sense that individuals have a right to continuity of care.
Barbra McLendon	Alzheimer's Los Angeles is very pleased the committee has recognized the importance of meaningfully engaging family caregivers in the planning process as well as the need to include caregiver needs as an integral component of the care plan. We are pleased with the proposed new language. We also support the comment made regarding paid vs unpaid on slide #23. Many family members are paid through California's In Home Supportive Services program to provide care.
Pam Montana	need to make sure we consider and mention those of us with degenerative diseases. the plan will need to change as our cognition declines
Pearl Barnett	I agree with Janis. I would also add that the identification of services that are reviewed and authorized are a part of the overall person-centered plan.
Sally Burton-Hoyle	yes
Nicole LeBlanc	AGREE
Amber Carey-Navarrete	agreed
Sally Burton-Hoyle	This process is insulting to me
Melissa Nelson	I support the phrase the person directing the plan
Pat Nobbie	support removing "focus person"
Sally Burton-Hoyle	I have gotten off and back on a few times and no improvement.
Pearl Barnett	Request to include language stating, The person-centered plan is used to identify services and supports, and should include the ability to authorize payment of paid services as well as document unpaid supports.

Nicole LeBlanc	Attitudes play a BIG ROLE in Whether or NOT A setting feels like " TRUE COMMUNITY
Melissa Nelson	Yes, I agree with adding "person's perceptions of desired comm inclusion, choice, and control.
Nicole LeBlanc	https://autisticadvocacy.org/wp-content/uploads/2012/02/KeepingthePromise-SelfAdvocatesDefiningtheMeaningofCommunity.pdf
Nicole LeBlanc	link the KEEPING THE PROMISE OF COMMUNITY as a resource
Susan Fegen	I agree with the slide
Alan Rozen	With regard to Slide 29 today, please consider my prior comments to assess and track the extent to which individuals have actually reviewed and approved their PCPs
Pat Nobbie	yes, agree!
Amber Carey-Navarrete	agree to take out studied
Alan Rozen	^I AGREE with removing the words "studied" as listed on Slide 29
Pat Nobbie	sorry, agree with the research edits slide 29
Nicole LeBlanc	LIVING A SUCCESSFUL LIFE TRULY INCLUDED
Nicole LeBlanc	Making sure Goals are NOT chosen by parents or influenced by providers
Nicole LeBlanc	Sometimes Families or Staff pick folks goals
Alan Rozen	AGAIN, why not including "minimal" expectation on the extent that PCPs are reviewed by that individual, approved and shared with desired entities involved??? (Page 34 of Report and Slide 29+)
Nicole LeBlanc	Easy access to services

Amber Decker	<p>Page 34 Person-reported outcomes should minimally include:</p> <p>Goal attainment and quality of life</p> <p>Actual perceptions of "person centeredness," or the extent to which the individual feels that they are the focus person of the planning process</p> <p>Satisfaction with the planning process, including a qualitative analysis of the critical elements to person satisfaction with PCP process</p>
Bevin Croft	Hi, I am concerned about the grouping of treatment adherence and recovery - I can't unmute for some reason but would like clarification
Amber Decker	Please add access to Services to Person-reported outcomes will vary by population, but may include: Access to Services and PCP
Nicole LeBlanc	Self Direction can often lead to better outcomes
Chairperson	we send the comments to the Committee directly and post to the website
Nicole LeBlanc	Self Direction can help people to increase their independence
Nicole LeBlanc	We need to promote and support self direction now more than ever as we fight to move away from SEGREGATED SETTINGS as a result of COVID19
Nicole LeBlanc	We need support groups for self direction
Nicole LeBlanc	provider agencies should NOT steer FOLKS AWAY from Self Direction
Amber Decker	<p>Please add to page 34</p> <p>access to Services to Person-reported outcomes will vary by population, but may include:</p> <p>Access to HCBS Services, and Self Directed Care and PCP</p>
Nicole LeBlanc	All people entering services need access to OPTIONS COUNSELING done in a VALUES NEUTRAL manner, Non-Bias
Kate Norby	Agree with making self-direction more prominent.
Alan Rozen	As with my prior input throughout this PCPPP Project, I am more than willing to provide any clarifications regarding my comments to the NQF Staff offline (e.g., after this Web Meeting #9), if desired...
Amber Decker	Treatment adherence and recovery should not be listed in this section at all in the frame of PCP
Melissa Nelson	I agree with Janis's feedback

Pearl Barnett	I would suggest replacing the term "health care" and replace with more broad terms "services and supports".
Amber Decker	Page 14 should also include "Duty of Care"
Amber Decker	Please read my comment or add it "Duty of Care" is very. important
Nicole LeBlanc	This PANDEMIC is a PERFECT opportunity to make The HCBS system for Person Centered, SMALL living arrangements
Alan Rozen	AGREE with need for more time for additional input!!!
Nicole LeBlanc	https://youtu.be/T3dDb-V5v6c check out this video on PCP
Amber Decker	agree with Jim Karpe !!!
Pat Nobbie	I agree with documented disclosure of conflict of interest
Amber Decker	agree with a definitions page
Pat Nobbie	There are issues with the outcomes section. I think we can reconsider this section.....page 34
Laura Demeuse	make sure you have a definition of "person directing plan" if you choose to use this. People who don't know PCP will misunderstand this to mean a facilitator or someone other than the person.
Nicole LeBlanc	Being truly person centered leads to BETTER HEALTH OUTCOMES'
Nicole LeBlanc	MORE SELF DETERMINATION THE BETTER HEALTH OUTCOMES'
Amber Decker	MOLST should and End of Life issues can and should be discussed or revisited
Laura Demeuse	Still concerned that this document does not have strong language that really upholds the PARTNERSHIP the system needs to have to make PCP work. Please keep this at the forefront otherwise ALL the work about calling person centered plans - person centered plans will be meaningless and there will be a system plan and a person plan
Jim Karpe	Want to again urge that this process slow down. Would like to get confirmation that the comments I submitted