Moderator: Kim Patterson December 13, 2019 1:00 pm ET

Operator: The conference has been unmuted.

Woman: Hi all. We've just unmuted the line. So we're going to ask everyone, because

we're already starting to get some feedback, if you are currently not speaking,

please, if you could mute your line, star 6. It just makes it easier for all able to

participate without having to mute all the lines.

So asking everyone, please hit star 6 if you are not speaking right now. We

are getting some feedback. So would greatly appreciate cooperation.

And just like before, on headsets or using their computer speakers, I'm

noticing we're getting some background from that. So we're asking everyone

to mute.

So (Cheryl) and (Gretchen), do we have you? Are we able to hear you. If you

guys just don't mind saying hi so we can do a quick test.

Woman: This is (Gretchen).

Woman: This is (Cheryl Phillips). And I'm here and unmute.

NATIONAL QUALITY FORUM Moderator: Kim Patterson 12-13-19/1:00 pm ET Confirmation # 21938555 Page 2

Woman:

Great. So I think that we are ready to begin. So, I'm actually going to turn it over to my colleague (Sam), to welcome us all.

Man:

Hello and welcome everyone. This is (Sam Stolpe) with NQF. And thanks (Kate) for our lead in. Delighted to be hosting this, our fifth Web meeting with the Person-Centered Planning and Practice Committee.

Thanks to all of you for joining us here to. As you know we just issued our interim report for this committee. And wanted to thank you all for the hard work in putting that together for the conversations that we've had over the past few months.

And we certainly learned a lot in exploring this together with you. And we now have that report out for feedback. And we're going to spend today going over some of the feedback that we've received. And of course, adjudicating comments and trying to improve our interim report to better fit the understanding of Person-Centered Planning and Practice definition, the core competencies and systems characteristics. And the way that we're reflecting the goals and desires of the community at large.

So many of you took the extra effort to reach out to those communities to gather input and have prepared some remarks for the committee to consider from those broader networks generally. And we thank you again for all the hard work associated with that outreach. Recognize that it's an effort on your part. It truly means a lot so thank you for doing that.

So let me hand it over to our co-chairs to say a brief word of welcome. And then we'll go ahead and get started with some housekeeping items.

NATIONAL QUALITY FORUM Moderator: Kim Patterson 12-13-19/1:00 pm ET Confirmation # 21938555 Page 3

Woman:

Well thank you (Sam). And yes, I do echo - both (Gretchen) and I. I know the staff have, but (Gretchen) and I as co-chairs, have gone through all of the comments.

I'm going to summarize some real briefly. But I also know that part of the purpose of this call is going to be hearing the input from the listening session.

So as I read through - and if I missed anybody's specific comments, I've tried to categorize them. Some of the gaps that were identified is addressing transitions. Addressing specific timing. Reference to already established person-centered plans.

There were recurrent statements about the role of the family, particularly for persons with intellectual disabilities and cognitive impairments. Multiple people mentioned as I read, that the language was far too complex and needed further simplification. And that there's multiple terms that need clarifying. Then we need to talk more about alternative communication methods.

There were some broad comments. And I personally liked the idea of dividing the thinking, planning, and practice. However, it may mean that we actually evolve to other tools other than just this one.

There was some broad discussion that this whole thing was far too complex. That person-centered planning is not neat and tidy and, very messy. And I think all of us who have participated, both as advocates working with them as individuals or working with loved ones or other people we care for, as well as providers, all appreciate the messiness of all of this.

Moderator: Kim Patterson 12-13-19/1:00 pm ET

Confirmation # 21938555 Page 4

I'm not sure how we can frame a document or a structure that really

encompasses that full breadth of messiness, for lack of a better word. But

perhaps that will be something that we're going to talk about.

And then several people mentioned limits to benefits to support individuals

who have additional needs. And while we truly concur with that, the lack of

resources and the lack of workforce are huge issues that would require their

own issue statement. And I think can have reference in this report. But

certainly this report is not going to resolve it.

So that's kind of a big picture of what I took. And I think the challenge for us

today is, how do we incorporate thoughts, still keep on track, still have a

product that adds value.

While it may not be the final purpose, that it adds value to the process and

continues us on this journey. And (Gretchen), I've talked already too much.

I'll turn it over to you.

Woman: Okay. Well, you know, and of course I agree with the summary that you put

together there, as we have talked earlier. And so I fully support that. And

want to reiterate, even though it's already been said, how grateful I am for

everyone's willingness to participate and engage and share their perspective.

We will not have the best product possible without considering all of the

different opinions and experiences that you all are sharing. So thank you for

that.

I also thank you for presenting a challenging conversation for me to facilitate

this afternoon. I love a good challenge. And I think when we get to talking

about the written comments in the next hour, that that is going to be a good

Moderator: Kim Patterson 12-13-19/1:00 pm ET Confirmation # 21938555

Page 5

opportunity for us to really think through some complex things. So I look

forward to doing that with you later.

Man: All right, thank you very much. As always we really appreciate your

leadership (Gretchen) and (Cheryl). And we're anticipating a great

facilitation of a discussion so, appreciate you both.

Let me hand it over to our own (Kate Buchanan) to walk us through a couple

of housekeeping items and to review our meeting objectives.

Woman: Thank you so much (Sam). So as we've mentioned throughout, Google

Chrome is the preferred browser for this platform. We also have the dial-in

information on the line.

We are asking all of our colleagues, both members of the public, as well as,

our committee members and liaisons who are participating, to please mute

your line if you are not talking.

Staff can do that on our end. So especially some of our committee members

or the liaisons that are participating with headsets, you may note that you were

actually put on mute. Because headsets tend to give a lot of, lot of

background.

So we're asking that when we - especially when we conduce the roll call, to

hit star 7. That way you can be unmuted. But we're asking everyone who is

not talking to please hit star 6. And then star 7 to unmute yourself. And just

as a reminder, we have had to mute some of committee members and liaisons,

just for the time being, because of some background noise. So to unmute

yourself, star 7.

NATIONAL QUALITY FORUM Moderator: Kim Patterson 12-13-19/1:00 pm ET Confirmation # 21938555 Page 6

Here you can see we have this team. It's (Sam Stolpe), myself, Yvonne Kalumo-Banda, Project Manager, as well as, Jordan Hirsch, a Project Analyst working on this work.

And I'm going to go through and conduct a quick roll call. So I know we have (Cheryl) and (Gretchen) on the line. Do we have (Glenda Armstrong)?

Woman: I'm here.

Woman: Great. Thank you. (Pearl Barnett)?

Woman: I'm here. Can you hear me?

Woman: Yes, we can. Thank you. (Sally Burton-Hoyle)?

Woman: Yes, I'm here.

Woman: Thank you. (Amber Carey-Navarrete)?

Woman: I'm here.

Woman: Thanks. Do we have (Bruce Chernof)? (Bevin) let us know that she was

unable to attend. Do we have (Amber Decker)? (Gail Fanjoy)?

Woman: I'm here.

Woman: Thank you (Gail). (Susan Fegen)?

Woman: I'm here.

Woman: Great. (Sara Link)?

Woman: I'm here. Thank you.

Woman: Thank you. Do we have (Joseph Macbeth)?

Man: I am here.

Woman: Thank you. (Denise Myler)? (Denise) may be on mute. If you hit star 7. So

(Denise), I see you on our list of people here on audio participants. So can't

hear you right now but, star 7 is how to unmute yourself.

(Melissa Nelson), I see that you are on. You are muted. Please hit star 7 to

unmute yourself.

Woman: (Melissa Nelson) is here.

Woman: Wonderful. Thank you. Do we have (Pat) Nobbie)?

Woman: Yes, I'm here.

Woman: Thank you. (Kate Norby)?

Woman: I'm here. Thanks.

Woman: Great. Do we have (Ann O'Hare)? (Leolinda Parlin)? (Richard Petty)?

Man: Good afternoon. I am present.

Woman: Thank you (Richard). Do we have (Mia Phifer)?

NATIONAL QUALITY FORUM Moderator: Kim Patterson 12-13-19/1:00 pm ET Confirmation # 21938555 Page 8

Woman: Hi. I'm here.

Woman: Great. (Michael Smull)?

Man: I'm here.

Woman: Thank you. (Dori Tempio)?

Woman: I'm here.

Woman: Thank you (Dori). Great. Do we have (Janis Tondora)?

Woman: Yes, I'm here.

Woman: Perfect. (Maggie Winston)? And then for our liaisons do we have (Daniel

Fisher)?

((Crosstalk))

Woman: Sorry, we're getting some background noise. Again, please star 6 to mute

yourself. (Matt McCullough)?

Man: Here.

Woman: Thank you. (Pam Montana)? (Penny Shaw)?

Woman: Yes, I'm on the call. Can you hear me?

Woman: Wonderful. I can. Yes, thank you.

NATIONAL QUALITY FORUM Moderator: Kim Patterson 12-13-19/1:00 pm ET Confirmation # 21938555 Page 9

Woman:

This is (Denise Myler). Evidently you couldn't hear me through my - I was on the computer and audio on the computer. But I am here.

Woman:

Thank you (Denise). We can hear you. That's great. Appreciate it. And so quickly to review the meeting objectives, we're going to review feedback from the listening sessions conducted by committee members and liaisons. And we're also going to review and adjudicate public comments on the interim report.

So I am actually going to turn it back over to (Sam) to introduce the interim report feedback on listening sessions.

Man:

All right very good. Thank you so much (Kate). And thanks once again to all of you who conducted the listening sessions.

So our next few - next hour, we're going to hear go through just a fairly simple process whereby we will invite the community -- excuse me -- the committee member or liaison to present an overall summary of the listening session. And we'll ask you to be brief, and to get to your - the main salient points of your engagement. Just because we don't have as much time as we would like to spend on each one of these.

So we're counting on you to just drill it down to the core feedback points.

And then we'll hand it back to the committee to discuss, immediately afterwards. So that we can start thinking about how to address those feedback points together.

NATIONAL QUALITY FORUM Moderator: Kim Patterson

12-13-19/1:00 pm ET Confirmation # 21938555

Page 10

That's the main order of operation but, I think it's pretty straightforward. So

without - unless there's any questions from the committee on how we're going

to be conducting the next...

Woman:

(Sam) this is (Cheryl). If I can just add one more thing. In addition to being

focused on the summary, if you can extract for us, if there were specific

recommendations from your listening sessions, that will be helpful.

Again, we want to try to keep these within five minutes. So you know, a

clear, crisp summary of the discussion, key points, and then if you can call out

specific recommendations.

Man:

Yes, perfect. Yes, thank you so much for the - I would go ahead and invite

our - we proposed an order for the presentation. So I'll go ahead and invite

our first participant. I think it's (Matt McCullough) and (Pat) Nobbie), who

were going to give us an overview of the AECD Annual Conference

Engagement. (Pat) and (Matthew) you are up.

Woman:

(Matt), I think you were going to go ahead first and then I'll follow.

Man:

Sure (unintelligible). So (Pat) and I went to the AEC Annual Conference,

before Thanksgiving. We had approximately 80 people in the room. They

were all across the U.S. so, it was a wide, very diverse group of folks in the

room.

They did actually (Unintelligible) definition of person-centered thinking and

principles. They did have some concerns about trying to be so formal. Trying

to put it into a plan that life itself doesn't necessarily fit into a plan.

Moderator: Kim Patterson 12-13-19/1:00 pm ET

12-13-19/1:00 pm ET Confirmation # 21938555

Page 11

So whoever is supporting these folks, they need to be flexible. And they need

to adapt to the person's needs. They need to understand that the - when it

comes to supporting people, they should be fully aware of what the resources

that are around that person. They can either be (unintelligible) support or

formal support. But they should have a very good (unintelligible)

understanding of how is that person coming - interacting with the community?

And how are they actually contributing to the community? Not only are they

receiving services but, there's a flip side to that.

How are the people receiving services actually giving back into the

community? And that aspect of the plan really needs to be focused on that.

Finding ways to getting folks with (unintelligible), people with disabilities

more engaged in the community. And finding the appropriate resources in

order to do that.

And in terms of the folks supporting the community living with

(unintelligible), they need to understand that there should be a fine balance

between (unintelligible) taking risks, allowing people to (unintelligible) and

lean from them. And help them learn (unintelligible) being made along the

way.

So, and of course there was some emphasis on cultural competency and

understanding that the United States (unintelligible) own diverse

(unintelligible) from linguistic backgrounds and stuff like that.

So are we identifying the appropriate steps to understand this cultural and

linguistic background and so forth. Are there other concepts that need to be

emphasized (Pat), that were mentioned during our session?

Moderator: Kim Patterson 12-13-19/1:00 pm ET Confirmation # 21938555

Page 12

Woman:

No, I think you covered, you know, the things that people really emphasized.

Certainly getting the whole document into a more plain language or easy

reader was mentioned several times. And I know it's been mentioned in a lot

of the other comments as well.

And the other thing that I've seen in some of the other feedback, and that

we've talked about since is, separating the whole idea of person-centered

thinking from the actual process of writing a plan.

And that the thinking part is more about the person's life and their

connections to community and relationships. And the activities and things

that, you know, make them happy and fulfill them. And then what actually is

the service plan process, which is something that is derived from the system.

And I know that a number of us on the committee are kind of concerned about

making that clear when we get to a final document.

So otherwise I think - one of the other issues we had was, we had somebody

who had a visual, who was blind. And they had a really difficult time reading

the report. And had to go through, you know, some major iterations to get to

a place where they could get a screen reader that could actually read it.

So that - you know, when this goes out again to the general public, that's still

going to be a challenge, I think. Making sure that it's accessible to people is

going to be important.

Woman:

Excellent. Any other comments. Wonderful succinct review and yes, really

appropriate recommendations and comments. (Bevin)?

Woman:

And I think...

NATIONAL QUALITY FORUM Moderator: Kim Patterson 12-13-19/1:00 pm ET Confirmation # 21938555 Page 13

Woman: Oh yes, go ahead.

Woman: Yes, just quickly again, just one more thing. And I think this has also come

up among several committee members is that there's too many qualifications

kind of all put together and nobody can meet them all.

So just trying to sort through how we describe that a little better, is something

I know several of us are concerned about. That's it. Thank you.

Woman: Yes, it falls under, better the enemy of good. We wanted to have an extensive

list of qualifications but, we may have created something that's daunting and

not realistic. So yes, thank you (Pat).

Woman: Thank you.

Woman: (Bevin) from NCAP?

Man: So (Bevin) wasn't able to join today. This is (Sam).

Woman: Okay.

Man: But she was kind enough to type up NCAP's listening session in a way that I

could communicate it to the committee.

Is there any - before we do that though, is there any feedback from the

committee around the presentation that (Matt) and (Pat) have given? Any sort

of adjudication of their comments that you feel like we should address now?

Moderator: Kim Patterson 12-13-19/1:00 pm ET

12-13-19/1:00 pm E1 Confirmation # 21938555

Page 14

Some of them were general comments also, that were captured broadly in the

written comments. So if we want to hold off on that, we can do that as well.

Okay, so hearing none for now, we'll table some of the discussion around how

we can potentially incorporate that into the report for a little bit later as we

aggregate some of the feedback. Because I suspect that a lot of these things

will repeat themselves.

So just to give a brief description of the NCAP's one hour listening session to

solicit feedback on this report, they had over 80 people attend the feedback

session via videoconference. So it's an overview of the effort. And then each

of the sections in the report -- there were three -- were discussed for 15 to 20

minutes.

And so as I went through the write-up that (Bevin) was kind enough to put

together, I identified six key points that I'd like to share with you.

So first, NCAP, along the same theme, identified the consistent use of clear

and plain language accessible to anyone using the person-centered planning

process is an important approach.

Second, they identified within the definition, that person-centered planning is

an approach to organizing your supports and services. And they have that in

quotes. They wanted to stress that person-centered planning was originally

developed to organize and shape the way that communities support and

include people with disabilities. Not as a tool for service planning.

So they were concerned that it's not necessarily the right tool to organize paid

support. And that does not honor the history and reflect the lived experience

of those who developed early person-centered planning approaches.

Moderator: Kim Patterson 12-13-19/1:00 pm ET

12-13-19/1:00 pm E1 Confirmation # 21938555

Page 15

The next key point was along the lines of a clear recommendation. And

mainly that the description of the person-centered planning team include

references to important relationships that occur outside of service settings.

Specifically, non-traditional members of a disciplinary team, which would in

this context include friends and family members as well. So that we should

stress that a little bit more in the way that we describe that in our definition.

Transitioning to core competencies. So NCAP also identified that there were

quite a few distinct skills in the five categories, and multiple sub-categories.

And that while this is both comprehensive and powerful, that it's also a little

too aspirational in their view.

They found it difficult to imagine that any one person would possess all of

these skills, values, knowledge, and experience. So that's something for us to

keep in mind and potentially think about how we can address that within our

report.

Next, the competencies of the facilitator have an underlying assumption that

the facilitator is a staff person or other paid professional. So the suggestion

was that we could modify the language in a way that the detailed description

of the desired skills, while it's comprehensive, that the daunting list could

have some unreasonable or undesirable outcomes.

So they suggested we should consider how a person would be seen as capable

of leading their own planning session. And make sure we front-load that.

And that friends and family members should not defer to professional voices

leading the planning session.

Moderator: Kim Patterson 12-13-19/1:00 pm ET

12-13-19/1:00 pm E1 Confirmation # 21938555

Page 16

So we should emphasize that this is not to preclude the option of the person

leading their own planning meeting. Or that a family member or friend could

assume the readership role upon request.

Lastly, they put forward this idea related to core competency, that we make a

distinction among items that are clearly personal values and attributes versus

skills that could be taught. There's a big difference in their mind between

whether the core competency, and what is a value and attribute and/or

experiences.

So there's a note for us to consider what it truly means to have a core

competency. The competencies could be trained. And that it's more

challenging to train values and attributes and to measure those.

So the suggestion that we should separate these and draw clear distinctions on

what can be done through training to develop those core competencies.

Those were the main points that were identified. They have a much more

comprehensive written submission that's available for the committee if you

would like peruse that at your leisure.

Woman:

Thank you (Sam). Any feedback from the group? This is (Cheryl).

Man:

Hi, this is (Richard Petty).

Woman:

Hi (Patrick).

Woman:

No. Sorry, this is (Pat Nobbie). So one of the things that I saw in the

verbatim comments that I just, you know, wanted to see what the committee

Moderator: Kim Patterson 12-13-19/1:00 pm ET

Confirmation # 21938555 Page 17

thought was that someone mentioned that using the second person felt

patronizing.

And I know we talked a lot about that before we issued the draft. And we

thought that actually might be more personable. So I just wonder what other

folks think about that. Because I'm not really sure what I think. But I just

wanted to see what other people's reactions were.

Man: This is (Richard Petty) and I do have a reaction to that. And the comment that

you're referring to, caused me to go back and look at that language again.

And instead of really supporting the definition, as I read it, it's now seeming

to me to be almost promotional in its tone. And I wonder if that may be why

that it's - why there is the reaction to it that there is.

Yes, using that language could and of itself do that, although I don't

necessarily think that's the case. I think it's the tone of the other language

around it that seems to be an attempt to promote the process to others who

may not know about it. And I'm not sure that's a good place for that.

It might be for someone's brochure about it, to cause someone to be interested

in it. But this may not be the place.

Woman: Hi, this is (Susan Fegen). Can you hear me?

Woman: Yes.

Woman: Yes, I agree with that very much so. And the comments that we had kind of

had brought back to us was, it almost sounded in a sense, demeaning.

NATIONAL QUALITY FORUM Moderator: Kim Patterson 12-13-19/1:00 pm ET

Confirmation # 21938555 Page 18

And one of the suggestions that was offered up to us was, maybe we should

go back to writing it in, you know, a higher version. And then contract with

someone to create a manual or guide that can be written in, you know,

different formats for different reading levels per se. So that, you know, it

doesn't come off as much for - you know, one of the comments was that the

(unintelligible).

But by providing this additional support for, you know, people who need the

support (unintelligible), may be an option to us. So that we can have filter,

you know, this amongst all of the different levels of peoples with disabilities.

Man: This is (Richard Petty). Just a couple of other points. Still a little concerned

about our discussion about, in the document, about risk. Risk is not

something that someone should have to negotiate. Someone who's well

informed may make decisions that we wouldn't agree with. But all of us take

a level of risk every day, whether someone agrees with us or not.

And there is that right to fail which we're not addressing very fully. And in

fact there was a reference to paragraph on Page 9, about someone negotiating

when it seems like there was an intent that we were saying that someone

would be negotiating with the team of folks who were assisting them.

And that's an over-step of what the role of the team is. Because the idea of

someone having to negotiate about their services and supports that allow them

to be in the community, is it appropriate? And that causes great concern.

Woman: Hi, this is (Pearl). And I also have a listening session but, I wanted to just, out

of what Richard, what you just stated, that was one of the comments that came

out of the listening session that I had with our Advancing (unintelligible)

members is, the reference on Page 6.

wian

Moderator: Kim Patterson 12-13-19/1:00 pm ET

12-13-19/1:00 pm ET Confirmation # 21938555

Page 19

I think you pointed to Page 9, as well as, Page 10. There's assumption that

the person-centered planner - sorry, the person-centered facilitator would help

keep the individual safe from risk or, the person safe from risk. And what was

offered in one of - from one of the participants in our listening session was

really like you said, it's their choice, the amount of risk that that person wants

to take.

And maybe the facilitator is a more so focusing on identifying like the

potential consequences of those risks, so that the choice is an informed choice

to take the risk.

But I was just speaking with one of our Board members and they were saying,

you know - and this happens all across the country. If a person really wants a

risk - to take a risk, it shouldn't be something that they have to fight their

planning team to do. It's really their choice of whether they live there and

they just need to know the - have a reason and be informed. And then accept

that responsibility of taking the risk.

Woman:

This is (Dori Tempio). And I had some comments that came into me

regarding those same exact (unintelligible) and comments, very similar to

what you all have shared. That people were very upset by how that looks like.

They were talking about individuals with disabilities, having them negotiate.

And then (unintelligible) living in a culture where people feel they need to be

taken care of. And how do we differentiate between that. Because then you

also read the layers from people that are talking about people with different

needs, different wants, different types of disabilities.

Moderator: Kim Patterson 12-13-19/1:00 pm ET

Confirmation # 21938555

Page 20

Then also I think a lot of people, when I've been reading all the comments.

And then, as well as the feedback I've got in is different. Where is the

mainstream of education for all of the people facilitating this process, where

it's all done on a very - I want to say this in a very cordial way, but an

unbiased level. In a way that everybody sitting the same thing nationwide.

That one person isn't doing it this way, another person isn't doing it this way.

Somebody else is doing it this way. And I'm not talking about

accommodations for people with disabilities. I'm talking about the way we

carry out the process. Because you have some people that are very much less

hands on and let a person make decision. You have other people that want to

run the process.

So how do - the concerns I have that came up from people I talked with is,

how are we going to make this a mainstream thing that is the same across the

board, nationwide. So every single person who is going through this process,

is getting it done in a way that is equal to everybody else.

And that there aren't some people doing one thing and someone else doing

another, in the way they're providing and facilitating the process.

Woman: Thank you (Dori), good point. So I would summarize that as its consistency.

Woman: Yes, thank you.

Woman: Any other comments? I want to make sure we have time for all of our

listening sessions.

Woman: This is (Gail).

NATIONAL QUALITY FORUM Moderator: Kim Patterson 12-13-19/1:00 pm ET Confirmation # 21938555

Page 21

Woman:

Hi (Gail).

Woman:

Hello. Regarding the last comment. I mean it's, you know, standardization flies in the face of authentic person-centered planning. And so I think that we need to really be careful about mandating a particular process of whatever. Maybe we will need to discuss that further today or another time.

But I did want to go back to the comment about risks and just tell you about some experiences that I have witnessed in other states. And (Gretchen) you can probably relate to (unintelligible) kind of risk aversive state.

That if somebody who is receiving support wants to take a risk - and I'm telling you folks, I mean we would not even identify some of these activities as risky at all.

But if there is a paid person -- usually it's a direct support person -- who is helping out, supporting that person or comping that person and something goes wrong, even something minor goes wrong, that direct support person is at great risk for being fired. And not only being fired but, their name being put on a list - a blacklist. To never be hired anywhere again.

And so I think, you know, it's not necessarily - we can't look at the risk of a person in isolation from how our systems are organized around support for people. Thank you.

Woman:

This is (Glenda). I'd like to respond to that one too. And I think you made some really thoughtful comments there. Just as a sort of a flip to that coin, and I think we need to consider all of it, including what you just said.

NATIONAL QUALITY FORUM Moderator: Kim Patterson 12-13-19/1:00 pm ET Confirmation # 21938555

Page 22

But I also have experience where, you know, people who make decisions that those paid professionals don't like, they are getting threatened with, well then

we'll withdraw the services. So it's a very slippery slope.

Woman:

This is (Pearl). I just want to point out that there are ways that the paid professional, the paid providers can work with their state. And as well as, the person to make sure that, that communication and the ability for that person having the choice of taking those risks is documented in a way that doesn't come back and impact negatively the paid professional. It's just a process that needs to be put in place in either the provider agency at the state level or both to ensure there's documentation that supports the decisions made.

Man:

This is (Richard Petty). Absolutely.

((Crosstalk))

Man:

And that is absolutely the case. Centers for Independent Living have been in a position to allow people to take risks. Not, allow, is not even the right word.

Woman:

Right.

Man:

It's just that people do take risks. And in addition it's clear in the arrangement, the written arrangements that centers make with individuals that they assist. That the individuals have that - certainly have that authority in their own lives. And may do it. And it is the work and the role of the centers to make sure that they are informed and that their decisions are informed. And that's the role of the organization.

Moderator: Kim Patterson 12-13-19/1:00 pm ET

Confirmation # 21938555

Page 23

And I'm concerned that we simply ask that organizations and we wring our

hands about the danger to professionals should drive this process. I think

there are ways to address this.

It starts with the documentation when an organization begins to work with an

individual. The organization for where that person works. Or the professional

organizations in which individuals - which employees or individuals are

individual contractors in which they are affiliated. And there are solutions to

this.

((Crosstalk))

Woman:

I would - this is (Penny Shaw). I would just like to make a comment at some

point along the way here, too.

((Crosstalk))

Man:

As would I. This is (Joe Macbeth).

Woman:

This is (Sally Burton-Hoyle). I want to - I'm going to say that every single

person's person-centered plan is going to be different. The only thing we can

make uniform is the parameters in that, number one is that the person is at the

center of the process, that we listen to them. And when at all possible, we do

every single thing.

Every person-center have barriers. Because we're talking about, like in

Michigan we do it for people with mental illness. We do it for people with

intellectual and developmental disabilities. And everybody' are different.

Moderator: Kim Patterson 12-13-19/1:00 pm ET Confirmation # 21938555

Page 24

The outcomes are all going to be different, as they should be, across the whole

country for each person. But they have barriers. And I think that's the point

that, at the person-centered plan, that's the job of the team is to help that

person overcome the barriers if we're going to help them have life in the

community.

Woman: This is (Dori) aga

This is (Dori) again. And I just - you know it wasn't I was saying oh,

everybody has to do it the same way. I just wanted to note that you have a lot

of people that don't buy into this.

I talk to citizens who go through this every single day. And one of you

brought up, they feel like they're sometimes a prisoner to that person.

Because that person has an oversight of their services.

And if they don't agree that this person should be at the center of it; if they

don't agree with the person's choices. If they don't agree with how they want

to carry out those choices, then they're not able to do that. Because they'll tell

them, we'll deny you services.

So what I'm saying is, then there has to be some sort of oversight of that.

Where everybody is getting opportunities where they do not feel like, well if I

don't do it your way I'm out. Because that's not okay.

If we let other people make choices, we let other people take risks, then there

needs to be somebody regulating how this is carried out. And if it's not

regulated then why should people who are trying to do - make their lives the

way they want to be, they're the ones punished. Because they're trying to do

the right thing. Go through a system that is supposed to support them in

making their choices.

Moderator: Kim Patterson 12-13-19/1:00 pm ET Confirmation # 21938555

Page 25

And they're supposed to - they said to me, how come it's called, person-

centered, when I'm not at the center of the plan, the thought, or the process.

Woman: And I think that the role of guardian comes in right here. And I've often said,

this is not a guardian-centered plan. It's a person-centered plan. And what

you're describing does happen in horrible situations where the guardian steps

in and says no, they're not going to make these choices. But it's always a

person-centered plan.

Woman:

This is (Penny).

((Crosstalk))

Woman:

I think it's just that we - I know we're talking about guardians.

((Crosstalk))

Woman:

(Unintelligible) talking about risks, but we may be getting into the management of risk which is a little bit different task. What we're trying to do right now is facilitate the conversation.

And I don't want to have our whole time consumed with the management of risk. As important as it is, we may miss some of the other opportunities. So, if we can get back to the comments that (Bevin) provided. And then let's put as a parking lot, the management of risks, which I concur, is absolutely critical

critical.

Woman:

This is (Penny) Shaw. Can you hear me?

Woman:

Yes, thank you (Penny).

NATIONAL QUALITY FORUM Moderator: Kim Patterson 12-13-19/1:00 pm ET Confirmation # 21938555 Page 26

Woman:

I would like to say that I represent nursing home residents in this country. They are among the least empowered and constantly threatened. Many of my roommates are constantly threatened. If they don't do something they like the (unintelligible) assistance of, they're told they'll be put in a locked unit. All kinds of threats occur.

So I would like to say they're among the least empowered and the least likely to have their rights (unintelligible) in institution settings.

Woman:

(Penny), I concur wholeheartedly. Institutional settings create such a perverse incentive.

Woman:

Yes, yes, terrible.

Woman:

The surplus of safety as we nicely call it, which is really taking away people's right to assume any personal risk or independence. Very good point. Thank you.

Man:

This is (Joe Macbeth). And I just wanted to circle back real quickly. The fact that most of the direct support professionals receive inadequate training to understand risks in informed decision-making.

And I think there needs to be a concerted effort to provide an adequate training resource to help direct support professionals balance that risk in informed decision-making. And it simply does not exist.

Woman:

Yes, I wholeheartedly concur. In fact, we could have a whole report just on autonomy, risk management, you know, personal assumption of risk and how the system and providers often, deleteriously mitigate risk.

Moderator: Kim Patterson 12-13-19/1:00 pm ET Confirmation # 21938555

Page 27

All the way from signing out AMA, which is like a punishment to people so,

well pointed out. Any other comments on the NCAP Report? Because I do

want to make sure we get to (Melissa) and (Amber). So (Melissa), let's hear

from you, please.

Woman: Okay, this is (Melissa Nelson). Can you hear me?

Woman: Yes, thank you.

Woman: All right. So, we conducted listening sessions with two citizen advisory

councils. And the members include both individuals who have lived

experience with disabilities, and some family members or guardians.

And here are some of the key themes that they asked me to share. What they

liked about the definition was that it was strong, it was strength based, and

that it was written in plain language.

Specific remarks included, "This could be a game-changer." And, "If this is

implemented well, it could change how people with disabilities are perceived,

and lead to positive change."

Ways that they thought that the definition could be improved is, to make sure

it's crystal clear that the person chooses who is involved and who supports

them.

And they also thought (unintelligible) so hard to have their voices heard that, if

healthcare staff don't internalize this, it's not going to succeed.

Moderator: Kim Patterson 12-13-19/1:00 pm ET

12-13-19/1:00 pm ET Confirmation # 21938555

Page 28

So, some how they wanted that captured in there somehow. We, too, had quite

a lively discussion on the dignity of risk versus health and safety and there were

various perspectives on that I will defer until a later time.

What people liked about the core competencies is they really felt like active

listening was key and needed to be emphasized and that the work – the group

needs to explore differing perspectives to work through disagreement while

keeping the person at the center.

Ways that they thought this section could be improved is they really feel like

it's important that claim language is used throughout the entire report. Other

people have mentioned that, too.

They wanted to make sure that it emphasizes understanding and respecting

personal choice and emphasizing that the person is the expert on their own lives

and wondering how we can better support people to develop their skills so they

can more fully participate.

What people like about the system characteristics is that the person is at the

center and that they emphasize that everyone needs to be trained on person

centered thinking and practice regardless of the role people play in the health

care system and that even how someone is greeted can be so important on

whether or not they feel they're being treated with respect and dignity.

And it's important to teach people in the system, how what I want - what I want

someone I love to be - I'm sorry, let me say that again. It's important to teach

people in the system, what I want someone I love to be treated the way you're

treating me?

Moderator: Kim Patterson 12-13-19/1:00 pm ET

Confirmation # 21938555

Page 29

And, again, they thought that this section needed to be written more in plain

language and emphasize it's not enough to talk the talk. Healthcare

professionals need to walk the walk.

They also wanted to emphasize the importance of supporting people to work

and making sure that flexibility, instead of rigid thinking, be added to the list.

In the last comment they had was someone who has participated on other NQF

committees, specifically ask me to recommend that NQF consider

implementing Zoom with the video feature because it could allow people to

better participate by being both seen and heard.

And they helped that that would help level the playing field. And that's the end

of my prepared remarks.

Woman: Well, thank you very much, and I do like the idea of, would you want a loved

one to be treated the way you are treating me right now, and you are being

treated. Yes, you know, that concept of personalizing it.

Any comments to the group to (Melissa)'s suggestions? And, again, the

recurrent discussion of the dignity of risk, which I think we will touch on this

absolutely. But it probably needs its own set of work to fully elucidate.

I'll hold any more comments. If not, we will move to (Amber), the client

advisory committee of Easter Seals and the (Frantee Ladderman) Regional

Center. (Amber), are you there?

Woman: Hi. I'm here. Can you hear me?

Woman: We sure can. Thank you.

vv Olliali.

Moderator: Kim Patterson 12-13-19/1:00 pm ET Confirmation # 21938555

Page 30

Woman:

Okay, great. All right, so, yes, as you mentioned, I held two listening sessions

with advisory committees, with people with lived experience. And as far as

specifics into readability and all of that, those were all added in the comments

and I will go into all those specifics.

And just speak about kind of the overall feedback and conversations that was

taking place at both of the listening sessions.

So, overall, the readability in certain areas, they felt was really good. Certain

areas, not so much, and needed more clarification on some things. But as

echoing I many of the (unintelligible), it was felt that overall, it was too much.

And that...

Woman:

You know what, (Amber), I apologize. I don't mean to interrupt, but somebody

is talking on another line or maybe talking on your cell phone. Can other people.

Please mute because we are having a hard time hearing (Amber).

The person who just finished talking, can you mute your line? Thank you. Well,

I don't - maybe somebody from staff can block it. (Amber), go ahead. I'm so

sorry.

Woman:

Oh, yes. No problem. All right, so the overall - it was felt that it would helpful

to go ahead and, you know, plain language, of echoing a lot of other comments

as well as kind of honing in on the key aspects and all the different areas.

As far as what the individuals and these listening sessions felt were kind of

those key aspects, one, especially in the definition and then throughout the

entire document, the idea of empowerment versus that power over that so many

people experience in their LTSS.

Moderator: Kim Patterson 12-13-19/1:00 pm ET

12-13-19/1:00 pm E1 Confirmation # 21938555

Page 31

And they felt that that was really encompassed well throughout much of the

document but there were a few areas where they felt that that could be

incorporated even more.

I think that kind of lends to some of this discussion we were just having with

dignity of risk and informed choice, making all of those different aspects.

A lot of the conversation was revolving around that. When it comes to facilitator

core competencies, they really honed in and thought the most important parts

were respect and felt that a lot of the other competencies fell under that as well

as the strength-based thinking that, if the facilitator is respectful and comes with

strength-based thinking that they really kind of honed then on the most

important parts for them.

And then when it comes to services and support, really simplifying it down to

what is really needed, which is specifically exploring and supporting people to

explore and figure out what is most important, what they want out of life and

then finding those supports and services to actualize that and really bring those

things into fruition.

And of that encompassed, they felt like that kind of really hones in on the most

important pieces.

Man: This is (Richard Petty). I think just to echo I believe it was (Melissa)'s comment

earlier, and reflecting comments that she had heard. And that is in QF, it would

be an excellent idea for you to adopt Zoom.

It's a modern platform. We're headed to the third decade of the 21st century.

We really need a platform that will support good communication.

Woman:

Yes, good suggestions and accessible by most. Indeed. Any other comments for (Amber)? And thank you for the great consistent summary. We've been quickly and furiously jotting notes as we're going along.

Any other thoughts? If not, I think it's time we go back to the written comments. So, I'll take one more chance for any feedback and then return it back to (Sam) and (Gretchen).

Woman:

Hi, (Cheryl). This is (Katie). Actually, ((Pearl Barnett)) also conducted a listening session. So just wanted to get...

((Crosstalk))

Woman: Oh, I don't have it on the agenda. I am so sorry.

((Crosstalk))

Woman: Late breaking news. Late breaking news. My apologies. Yes, absolutely. (Pearl), please.

Woman: Oh, no. Thank you. I do apologize. I thought I sent it out. I'd have been having some issues with...

((Crosstalk))

Woman: You know what, you may well have and I didn't get it. So I will accept the responsibility here.

Moderator: Kim Patterson 12-13-19/1:00 pm ET

12-13-19/1:00 pm E1 Confirmation # 21938555

Page 33

Woman:

No, no, no. No worries. So, I conducted a listening session with advancing state

members on November 20. Some of the things that we discussed have already

been brought out. So I'm going to try not to repeat a lot.

Also I'll recognize that some of the people who were at the listening session on

November 20 are also on the (Ecap) listening session conducted with (Bevin)

and (Alex).

So, I'm going to try to be concise in my comments. With regard to the definition

and the question of what's missing from the definition, some of the comments

that we received, it appears that the definition doesn't really incorporate older

adults in this aspect of keeping the control and the decision-making authority

that they already have had throughout their lives.

So, it seems like a lot of the definition is about gaining control or adding new

skills, that many older adults just want to keep what they already have their

person centered planning process.

They want to make sure that the planning process is scalable. So, everything

doesn't have - everyone's scans should not look the same. Just like everyone's

planning process, I think, (Earl) said earlier on this call, doesn't have to look

the same.

So, it might be a different experience that, when you have someone who either

has had services for 20 years, they might have a different experience in their

purchase and they're planning process than someone who is just now starting

with their first (unintelligible) center plan which leads to another point that the

- it didn't seem to really highlight the service delivery aspect and identification

of modification of the person centered plan.

Moderator: Kim Patterson 12-13-19/1:00 pm ET

Confirmation # 21938555

Page 34

So, it seems to be very focused on kind of their initial plan development phase

by knowing that, as you're receiving services and they're a service delivery -

like, the people who are part of that service delivery process, many times are

part of that discussion where they say, oh, your plan said this but, based on

feedback from you, this may need to be revisited and their plan needs to be

updated.

And it doesn't seem like the report really mentioned how that process is circular

throughout a person centered planning lifecycle.

Other things – was the definition was so long that it's overwhelming and not

very digestible. And I think that that comment have been made several times.

And then I think the comment was made in (Devon)'s comment about the

amount of competency being, one, too much, creating what comment was a

superhero that really, like, how would - and I represent the state, so how would

a state say you have to have all of these fields and characteristics.

What does that look like? What does that look like in identifying people who

are part of the process? And then, the next thing is, like (Devon) said, like that

deal versus value and separating, like, what is the deal versus what is the value

of that plan - of that person centered plan facilitator that we're discussing?

And then, couple of things that were mentioned regarding the laws that were

applicable. We have a couple of them come up. It looks like the DES isn't listed

here, as well as the Vocational Rehabilitation Act was not listed there.

So those – or the Rehabilitation Act - so those are (unintelligible) they really

are part of the discussion and guide the discussion. One comment was about

elevating the discussion and supported decision-making.

Moderator: Kim Patterson 12-13-19/1:00 pm ET

Confirmation # 21938555 Page 35

It is mentioned, but maybe elevating what that is and what that means in the

report. And then there's a comment about the beginning of the report says that

it's written in people first language, but on Page 14, in the description social

model with disability, it moved to identity first language.

So just verifying whether or not the reports should be consistently in people

first language would be important. And if we are using both people first and

identity first language, that just being laid out so that it's just not such a surprise

when you get almost to the end of the report and you see the language shift.

Woman: So, great comments. Thank you, (Pearl). Any comments on the report? And

then we do have one more from (Sarah Link), as well. So any responses to

(Pearl)'s summary?

Woman: This is (Pat). I just want to say I really support and thank her for reminding us

that older adults who have been in control and so that needs to be

acknowledged. So thank you for reminding us of that.

Woman: This is (Salish Myler).

Woman: Yes.

Woman: I didn't really do a listening session. I emailed a few people around the state of

Idaho. I - my comments came back - the big concern is that right now in Idaho,

we have the Idaho Parents Unlimited and the Idaho Council on Developmental

Disabilities currently working with our state Medicaid administration on

(people) centered planning.

Moderator: Kim Patterson 12-13-19/1:00 pm ET

Confirmation # 21938555

Page 36

And they kind of want to know, you know, what are we really going to end up

with because they're feeling like they are starting one process and one NQF

comes out with this, it could blindside what we're already accomplished - trying

to accomplish in the state.

Woman: Yes, that is an important point and balancing with what (the state works). But I

still think that, as we create this report, states may look to it, and perhaps modify

their processes. They may stick to their own processes, but at least we have the

support (unintelligible) to build on. But it is an important point without a doubt.

And, (Sarah), I want to make sure that we have time for you as well. Was

somebody going to say something else? I didn't mean to interrupt. So, if not

(unintelligible).

Woman: Hi. This is (Sally). I want to support what was just said about what this is going

to do to states like Michigan that we've had in our mental health code since '95.

So, like, what is going to be the impact of this if, in fact, there's less consensus

on people and supported decision-making and kind of their dreams and desires?

Could it have a bad impact on it?

Woman: Other thoughts?

Woman: (Sally), this is (Pat Nobbie). I think this is why we've had some real concerns

about making recommendations that don't support people in the community,

having a life versus making recommendations about what service planning

should look like.

And that it needs to be clear about, you know, if this paper is going to address

both things, that we are very clear about what is one thing and what's the other

Moderator: Kim Patterson 12-13-19/1:00 pm ET Confirmation # 21938555

Page 37

thing and there some kind of division or sections in the paper that point that out

because I think that is a real concern of a lot of us.

Woman: Any other thoughts or comments?

Woman: Sorry, this is (Amber Decker). Where are we in the agenda?

Woman: Well, we are still I'm listening sessions. And I have one final one. We had

(Pearl), which was a late add and also (Sarah Link), which is a late add. And

then were going to move to the written comments.

Woman: Okay.

Woman: Hey, it's (Susan Fegan). Do you have are listening session in as a written

comment?

Woman: I have to defer to staff. (Susan Fegan)'s written comments, are they listed as a

listening session or underwritten comments?

Woman: They were – this is (Kate). Sorry. Apologies. They're probably listed under the

written comments, but (unintelligible) take the time to conduct a listening

session. Of course, I want to give you an opportunity, so we'll try to – we'll fit

it in and then we'll get onto the written comments. So, my apologies.

Man: This is (Janice Condora). Can I just ask a question and just follow up on a recent

discussion about kind of the distinctions between the person centered thinking

and practices and person centered planning?

Because I've really been grappling with this the last few weeks reading the

different comments, and my concern is that, at least in the context of the

Moderator: Kim Patterson 12-13-19/1:00 pm ET

12-13-19/1:00 pm ET Confirmation # 21938555

Page 38

behavioral health system, a lot of times what we've seen happen in many states

is that there are really beautiful, organic, or even a (satellite) person centered

planning model that are, you know, helping people create the kinds of lives that

they want in the community, you know, with a level of self-direction that's

important to them, their daily routine.

That can include anything from (wrap) planning to creating your own self-

directed life. We've seen some people using maps and tasks.

But what has happened at times is that vision of person centered planning and

creating the life I want for myself in the community happens independent and

outside of the person's interface with the treatment system that is supporting

them.

So, at the same time that they have that person centered plan that presents a

vision of the life they want for themselves, they also have a service plan that

they're required to have within their treatment system.

And that service plan, if there is not some kind of interface between a vision

and a person center, that service plan often defaults to being (internalistic),

coercive, fully driven by diagnostic categories and professional assessments

and regiments about what a person needs and risk aversion and the whole thing.

So, I think it's a question for the people who are talking about how do we kind

of see that we make distinct person centered thinking and practice from a person

centered (unintelligible).

How do we do that with not - my feeling has always been, if the beautiful stuff

that's helping people create the kinds of lives they want for their community is

happening, but it's happening outside the context of their service plan, their

Moderator: Kim Patterson 12-13-19/1:00 pm ET

Confirmation # 21938555

Page 39

service plan still has a huge impact on their experience of care in their life, how

do we make that certain that that service plan maintains the same integrity and

the same person centered value?

Woman:

This is (Amber Decker). I just want to add to that by saying that a few calls

back, I had said, you know, are we talking about person centered planning as a

service, or not?

And that's still the thing that I don't know and that we should consider because

how can you maintain the integrity of any kind of person centered service plan

or person centered plan without acknowledging that it is a service, that person

centered planning is a service that needs to be kind of provided and encouraged?

Woman:

This is (Pat). So, I think, you know, some of the conversations that we've had

off-line with our advocate friends and actually (Devon)'s paper mentioned this

as well, that person centered planning was not - the genesis of that, was not to

be a service.

It was to be a process that people would be supported to develop a life for

themselves in the community. And so I think this is - I mean, what (Janis) just

expressed, is the essential question.

And I agree that if - it's all well and good to sit down and have great plans in

the community in practice and really construct what the person wants. But of

that's completely divorced from what they will get financial support to do, then

you know, then what does that mean?

At the same time, I don't know that we're going to ever get the system to do the

things that we really want it to do and to be really organic and supportive of

people in their lives.

Moderator: Kim Patterson 12-13-19/1:00 pm ET Confirmation # 21938555

Page 40

So, I think this is an essential question and I'm not sure I have the answer,

except that I do think in the report, we can write to those distinctions.

Woman:

Yes.

Woman:

And as (it applies). In any state with any person, that's just - those decisions

are made with the person from the ground up, depending on whatever context

they are in because some states are better at this than others.

I mean, they have a longer history, have better infrastructure and more money.

You know, it depends. But I think we can rise to the distinction so people can

make their own decisions.

Woman:

This is (Gail). I can attest. Maine has a long history of person centered planning.

It is morphed and changed over the years, but it still, at the end of the day,

produces a document that is really your passport for funding.

And so, because the way services (unintelligible) to be designed to serve people

as the (unintelligible) reports that on the margins of society, if you share a label

and you share a zip code, the odds are really certain, almost certain they are

going to share the same kind of life.

So there are people that are in day custody that have had person centered

planning and they're day looks just like the day of the person sitting at the table

beside them or in the bed beside them (unintelligible) or in the shelter

workshop.

And so, unless, you know, there's really another whole set of people concerned

with people having a really good life and not concerned about checkboxes and

Moderator: Kim Patterson 12-13-19/1:00 pm ET

12-13-19/1:00 pm E1 Confirmation # 21938555

Page 41

ways to get services paid for, but actually ways to help people have a good life

in the community, then, you know, we really need to keep on struggling with

how we're going to codify that in a way that's going to produce change in the

system.

And I think it's a really big burden to put that on the backs of people with

disabilities, and so, what can we do to ensure that those two thoughts come

closer together?

Woman: Thank you. And all good comments for the discussion. I do want to keep the

focused on the listening session comments. Because I want to make sure we

get through written comments next.

So I'll give one last shot at (Sara). (Sara Link), do you want to briefly do your

listening session and then we'll wrap up and move to written?

Woman: Yes, thank you so much for making space. So Virginia's Department for Aging

and Rehabilitative Services, we did a listening session. It was virtual and it

included 32 attendees.

And some overall comments, the folks that participated with us, they really

liked the definition as it was directed towards the person who owns the plan.

They also liked the very (unintelligible).

We also saw some areas for improvement and one of them was the

consideration of using the words, receiving services - using services, instead.

They thought that the term, receiving, was a little bit more passive whereas,

using services, as a bit more active.

Moderator: Kim Patterson 12-13-19/1:00 pm ET

12-13-19/1:00 pm ET Confirmation # 21938555

Page 42

A couple of other thigs that were mentioned were they just have - as have other

comments that have been said on the call about so many qualifications under

the core competencies. And there was just a concern about people being able

to acquire all these skills.

And one other area that was under core competencies that was the consideration

about the term, motivational interviewing. There was just a couple of areas

where folks thought maybe what they could be is a sentence or two that would

explain that, within that area.

And we heard some very positive feedback about, you know, all of the planning

that has gone into this work. I think a lot of people were excited to see such a

document and, such hard that has happened.

One of - a few individuals on the call as well, mentioned that they would love

to start weaving some of these descriptions about core competencies into job

descriptions. Specifically around care coordinators.

A few things about the edits, which I know have been addressed. I think that

(Bevin) Croft and a few other committee members had mentioned the

differentiation between the terms person-centered planning and person-

centered practices. And I - just offer up, there's some of those definitions that

(Bevin) provided.

And then the last area was under PC culture. There was a few folks that did not

like the term, case study. They felt that that - these are people in term

(unintelligible).

And so that's a quick summary of Virginia's comments. And I also submitted

them to via email message. Thank you.

NATIONAL QUALITY FORUM Moderator: Kim Patterson 12-13-19/1:00 pm ET Confirmation # 21938555 Page 43

Woman:

Thank you. Any other comments? I am conscious of the time and we still have written comments to review. So any other thoughts that we haven't already mentioned. Because I think we're start to have some overlapping themes.

Woman:

Yes (Cheryl), this is (Kate) from NQF. My apologies. We forgot to include (Susan Fegen). We wanted to give her just an opportunity to present some feedback on her listening session. Our apologies.

Woman:

Okay, thank you. So quickly on (Sara). And t hen if not, let's move to (Susan Fegen) please. So (Susan), go ahead. You may be on mute still, (Susan). Start 7 will unmute you.

Woman:

Can you hear me?

Woman:

Yes we can. Thank you.

Woman:

Okay, very good. So I have two actually, listening sessions with (unintelligible) and National Disability Advisory Council, which is made up of people with disabilities from all different levels across the nation.

And so some of the general statements again was that the definition is too long. That's kind of repetitive. I think we've gone through all of that. One of the things they were quite surprised to hear was how facilitators, when we are working with people who are involved with the MCO, they did not realize that the state mandates who can be a facilitator and what their requirements are.

And so I think maybe we need to educate in some fashion, that you know, each individual state kind of lays out their program for person-centered in their regulations. And MCOs kind of have to abide by what their requirements are.

Moderator: Kim Patterson 12-13-19/1:00 pm ET

12-13-19/1:00 pm ET Confirmation # 21938555

Page 44

We need to have stronger language around the individual being in control and

planning. And again the verbiage about them being able to choose who is part

of it.

One of the big concerns of our Disability Council was that there's very little

written in this about persons with disabilities being encouraged and prepared

for and considered for and hired as, roles as facilitators. That their experience,

their peer experiences, and that really brings depth to the facilitation in some

fashion.

That you know, can't be taught. It's a lived experience that we really need to

focus on. Any by doing this, also offers opportunity for people with disabilities

to advance.

The word, caregivers, really rang throughout. That was something they didn't

particularly care for. They wanted to find a different type of verbiage to use for

it.

And then one of the other concerns was the definition of ableism. And with

that they did advise that maybe we need to change it to more of what is from

the Center of Disability writes maybe, out of New York. Or what we have on

Wikipedia where it talks about the stereotypes, you know, that people have to

(unintelligible) justifications for ableist practices. And so really to make that

clear.

And then I held a listening session of course, with our own corporation with our

case managers, our Quality Department, Finance Department. And overall

again, same kind of verbiage. That we have to be very careful in how many

core competencies we lay out.

Moderator: Kim Patterson 12-13-19/1:00 pm ET

Confirmation # 21938555

Page 45

Maybe even to define the difference between what an MCO does as a facilitator

and what a provider does as a person who's actually hands on, providing these

services and you know, enforcing or initiating their person's desired plan.

And also that we need to have verbiage in here that really defines the limitations

as to what type of financing and resources is available. You know, we do realize

that we need to help support people in really, anything they want. But I think

there needs to be verbiage that says, there has to be, you know, a line in there

somewhere that says, we can only provide, you know, what is allowed to be

provided by the MCO.

And then lastly, at our workforce and (unintelligible) capacities (unintelligible)

bring language in here. One that you know, we have to comply by HIPAA.

And so that, you know, we have to have permission in writing from people to

share the plan with others.

And then also to make sure that whoever we are choosing and training,

understands that the best way to do a plan is actually ask the person that we're

doing it with.

(Unintelligible) any evidence-based standards, it's almost impossible. But

maybe we also need to also then work on, how do we gather measures to see

how person-centeredness is actually working, valid and reliable information.

So that's it in a nutshell. I think I submitted both of those proposals if anybody

wants to read the whole thing.

Woman:

Excellent.

Moderator: Kim Patterson 12-13-19/1:00 pm ET Confirmation # 21938555

Page 46

Woman:

Thank you.

Woman:

Thank you Susan. Fantastic. Any comments, responses? And I think we may pick up some of these recurrent themes under the written comments as well. Well given the time, I think I'll - yes, someone was going to say something?

Woman:

Yes, I just wanted to point out that the person-centered plan should be comprehensive and not based on what the facilitator, what services or support they have at their hand. Or they have the ability to present. But rather the entire goals and objectives of the person, no matter the payer source. Or either whether there has been a identified provider or assistance for that goal, it still should be included.

Woman:

Yes. So it should be from the perspective of the person, not the facilitator and the service provider.

Woman:

Exactly.

Woman:

Okay, thank you. Any other comments? Good point. Well I'm going to turn it over now to (Sam) and (Gretchen). And we'll do the written comments. Thank you all.

And thank you. These listening sessions are sometimes kind of daunting to do. Greatly appreciated and represent a huge amount of work and the value is phenomenal. So when we think of the hundreds of voices that we were able to amplify these comments through, it makes it so much more powerful. Thank you. So, (Sam) and (Gretchen) all yours.

(Sam)

Very good. Thanks very much. All right now moving on to our written public comments. So as you know, we solicited public comments through two

Moderator: Kim Patterson 12-13-19/1:00 pm ET

12-13-19/1:00 pm ET Confirmation # 21938555

Page 47

formats, both the listening sessions and the written comments. So just to

summarize, for the 139 comments we received through the commenting tool.

Amongst those we had 38 organizations and 10 individuals who submitted and

amongst those 139, we had 85 general comments about the report, 32 comments

about the core competencies and 22 around the system characteristics. Now we

also received email comments from six individuals and 11 organizations and

they all fell into the general - the categories around general comments, the

definition, core competencies, and systems characteristics.

I guess in the next few minutes going through the general themes that emerged

from these and once I've walked through these our co-chair (Gretchen) will help

us to navigate exactly what the committee would like to do to try to resolve

some of these issues and ways that we can concretely adjust our report so that

it takes these comments into account.

So first, related to the definition. We've covered a lot of these, but I'll just go

through them quickly. And there was comments around the readability so that

the content is still a bit complex. Citations were around some multiple clauses

and some of the length of the sentences.

We also received comments around whether or not the plan is about the person's

life or just their services and support and that concern was expressed also inside

of the listening session. And it was also pointed out that there wasn't

consideration for persons with limited intellectual competency, meaning that

they may be incapable of making certain decisions and that, that consideration

needs to be baked into the way that we talk about the definition of person

centered planning.

Moderator: Kim Patterson 12-13-19/1:00 pm ET

12-13-19/1:00 pm ET Confirmation # 21938555

Page 48

Lastly, there was a comment around the presence of natural or unpaid support,

and that should not reduce entitlements professional or paid it supports. The

concern around this, we need to consider the committee is very important, but

also we want to think through whether this is a policy issue or a definition issue.

So next up, we had themes around the core competencies as well. First, peer

support for people facilitating person centered planning. That's a theme that

came up quite a bit as a core competency, should that be built into what's

expected of someone to facilitate?

It was also pointed out that there's a cultural versus linguistic competence that

the expectation should lean towards - more towards the former. Some people

didn't like exactly how we framed up dignity of risk and we've discussed this a

little bit, but perhaps we can come up with a bit more concrete, how we can

approach that within the report. Facilitators' strengths, role and attributes of

how we actually tease those out. Core competencies as was mentioned. Some

of them came across as aspirational, but there's too many of them that this

person who would - has all of those would likely walk on water. The need for

people with intellectual disabilities and facilitation methods for that was also

pointed out is that could be addressed a little bit more strongly.

There is also, continuing on to the next slide, there's addressing the issue of

power that often consumers are not entirely in a power position to make

decisions. So our report was suggested would benefit from more emphasis on

that point. And, lastly, related to core competencies, that role modeling -

persons with disabilities serving as PCP facilitators.

So we didn't call this out specifically that this is something that could be stressed

as an important thing that maybe people like the person for whom the plan is

being facilitated, that they would benefit from being able to see how someone

Moderator: Kim Patterson 12-13-19/1:00 pm ET

12-13-19/1:00 pm ET Confirmation # 21938555

Page 49

else with comparable disabilities or in a comfortable position might actually

develop a plan and help them guide it.

And moving on to our last area of the week, this one's around system

characteristics. Now, we were asked to differentiate between service plan and

person centered plan. It was pointed out that adequate funding and support for

programs is fast, is a critical element of a healthy system. The teamwork needs

to also be emphasized as inside of the system and it was also pointed out at the

emission or disconnect between systems, such as funding structures and

regulations, case management, retention, etc. also play a critical role.

General themes. We noted that there's a need to incorporate multiple

perspectives both personas from the elderly community with cognitive

impairments, dementia, Alzheimer's, etc., need assistance and then person

centered plans cover a very wide range of individuals that are taking it or

utilizing it long term supports and services in both the community and

institutional setting.

Also needs to address degenerative and cognitive conditions and not just

physical disabilities, to address trauma informed care as part of PCP, and also

pointing it out that states struggle with maintaining and growing their home and

community based service systems.

There were a couple of other general things that I'll point out but many of these

came up in our discussions. So just very briefly. Structure and layout was

brought up. Language voice and audience used of - how the report would be

used, evaluation and implementation of the characteristics etc. needs to be

considered, that the report is idealistic and aspirational.

Moderator: Kim Patterson 12-13-19/1:00 pm ET

12-13-19/1:00 pm ET Confirmation # 21938555

Page 50

Core competencies and system characteristics, audience focus on facing

programs and that the report should not present the individual as too

independent, but as part of the social network which inevitably influences

decisions. And then there's also suggestions as that some of the some of the

jargon that was used could be removed. Okay. So let's go ahead and hand it

over to (Gretchen) to lead us through a discussion on how we could potentially

address some of these issues.

Woman: Thank you (Sam) and this is (Gretchen). I am most excited that it's clear we're

all working towards a thoughtful consideration of a whole person's purposes,

their will and their preferences and working toward individualized support for

a good community life. Sometimes we're differing on how we want to get

there. And so you've been provided the comments and the Excel spreadsheet

that has the highlighted rows, as well as a PDF document that has a summary

of the written comments.

And so we want to focus this portion of our call on talking about the changes to

the report that we want to make, based on comments - the written comments,

and, you know, keeping in mind, obviously, what's going to be most

transformational for individuals.

So we would, because we have limited time we'd rather not rehash the issues

that have already been addressed to specifically talk about - what your based on

the comments what recommendations you have for making changes to the

report.

So I will open up the floor to whoever would like to share their input about

changes to the report.

Moderator: Kim Patterson 12-13-19/1:00 pm ET

12-13-19/1:00 pm E1 Confirmation # 21938555

Page 51

Woman:

So, a few things. I think in terms of this report, I think we need to emphasize

that if we find a donation, a basic donation of what the states work upon. You

can watch a more detailed you now process and strategies. So we are

(unintelligible) with this this whole process so much go on. Okay. I have an

understanding that, that so many stages, so many approaches that during taking

part and planning would seem more developed.

So I don't really separate the two because the two don't interact with each other

per say. So with that said I know that from an initial standpoint there needs to

be some for a lack of a better term a (unintelligible) standard of what they

should be working from. And from there they can build upon what they think

should be the best approaches and strategies.

So for example, a lot of people spend a lot of time dealing with those risk factors

that (unintelligible) is dealing with the operational control that the service

providers have over the community members with disabilities.

So it's a very (unintelligible) in my mind it's a very big team when you are

talking about risk factors of trying to allow a person to express risk and changes

of risk and putting in some - putting in some standards for the service provider

team to consider.

For example, it won't be a great idea for a person that has access to a credit card

to throw out their credit card when they are on limited income. That's - so there

is a lot of education factors that need to be given to talk to them.

So in terms of the report I would try to communicate that we are not trying to

really be really strict and (unintelligible) by all the competencies and the skill

sets that the service providers or the system should have that are based on the

diverse comments that we receive at CIC a very broad summary or background

Moderator: Kim Patterson 12-13-19/1:00 pm ET

12-13-19/1:00 pm ET Confirmation # 21938555

Page 52

of where we are coming from based on what we receive from X number of folks

that gave us the comments.

So I think if (unintelligible) Housing and Human Services I know that there is

a (unintelligible) going on within the federal government in terms of Housing

and Human Services not necessarily focusing on all the numbers.

That there (unintelligible) dealing with their qualitative approach of how are we

serving our folks? And so I think the report can really emphasize that we're

trying to really focus on the qualitative approaches and how do we improve the

quality for our citizens towards (unintelligible) in general.

And so with that in mind, I regress. Thank you.

Woman:

Thank you very much for sharing that. It was good to hear your perspective on

planning and thinking being more integrated in. But also opportunities for

utilizing value based payments to focus on a qualitative approach. So thank you

for sharing that.

What other suggestions to the report do members of the committee have?

Woman:

So this is (Pat). And I think, you know, what several of us have thought about

and what we've heard from the comments is to just be very clear about the

difference between person centered thinking which may use various models and

types of conversations and approaches none of which is prescriptive. It's really

what the person themselves want and he's comfortable with.

So defining that and being distinct about that versus when you get into a

planning process which is with the service system and may have a paid

facilitator to support that and what the standard for that process should be.

Moderator: Kim Patterson 12-13-19/1:00 pm ET

Confirmation # 21938555

Page 53

And I know - I mean, I heard (Janice) loud and clear about, you know, if they

are not somehow linked then people tend to default to what the system is going

to pay for. But if we stick with that then that's all anybody will get.

And so I know that there are folks out there in the community, you know, my

daughter among them, you know, just for example, we meet for an hour with

the service coordinator. He is from then system and her budget and we check

the boxes that the system needs to provide me its support. And then she leaves

with that plan that gets put in the system in the state where she lives.

And then the rest of us who have been at the meeting to Dallas with me talk

about her life and what she wants to do and it might be just for the next month

or two but it's a constantly evolving thing which is something I know has been

in a number of comments that the plan changes. The plan is adaptable. The plan

can be revisited.

But I think it would serve us well to lay out that distinction in the very beginning

and then describe each part of that.

Woman: This is (Amber Decker). I just want to know what if someone is going to ask

again like how we are moving into written comments.

Woman: We are in written comments now and so we are asking for your comments about

how - what changes you want to make to the report based on written comment.

Woman: Because it seems to me like the whole use of the word plan versus planning is

quite confusing. And this is something again that I had mentioned in the

beginning in saying, when we are talking about a person centered plan are we

talking about an actual plan or are we talking about the planning process --

Moderator: Kim Patterson 12-13-19/1:00 pm ET

Confirmation # 21938555

Page 54

because if we are talking about a physical plan it could be helpful to include

and specify that that's what we are saying versus a planning process.

I also wanted to bring up some of the executive summary portion of the interim

report and making sure that we include a managed care system as well --

because I do think that there are people living with and dealing with managed

care systems. And while it does seem like it's not a place but it is something

that we are all - that a lot of people are dealing with and so I'm not sure why

that was left out.

Woman:

Okay. Thank you (Amber) and (Gail). Go ahead.

Woman:

No. So this is (Pat) again and I just wanted to say (Amber), that's exactly what

I'm saying. Let's be distinct about the definition of plan, planning, practice,

process. Let's be really distinct about that in the beginning (unintelligible).

Woman:

So this is (unintelligible). So plan versus planning it all depends on where -

what's going on in that person's life. Sol for example, we see planning is

important for a state so of course the comprehensive services and administration

that serves our community members to find and creating employment for

(unintelligible) processes or plans.

But these processes and plans are in many cases for a limited period of time

until that person obtains their integrated comparative employment. But some

may take longer than others but the hope is that the plan will not be ongoing.

However with folks with (unintelligible) where we are always servicing - we

are offering different services or injecting on a constant basis or that's on

ongoing planning that you have to be very, very intentional about how will you

continue providing ongoing support for a person (unintelligible).

Moderator: Kim Patterson 12-13-19/1:00 pm ET

12-13-19/1:00 pm ET Confirmation # 21938555

Page 55

So in my mind a plan is only for a short period of time and it will only serve a

certain element in a person's life. However planning in general I think that's a

very long ongoing process. So in my mind I think from a very (unintelligible)

standpoint and maybe my approach of those two terms is very different from

yours but that's where I'm coming from.

Woman: I agree with you actually and that's part of the reason - this is (Amber Decker).

And that's part of the reason why I bring it up is because I keep hearing

comments and language around a physical plan versus the planning process.

And that's the other reason why I thought in the executive summary it's

important to include, you know, where people live. Right. And where people

are.

And I was kind of surprised that we sort of, you know, left that out and said

includes homes and community based services and institutional settings such as

nursing homes. And then it's like, well, there is way more institutional settings

other than nursing homes. Right.

So we left out a bunch of other institutional settings but we also left out in the

community, I mean, like people that are not living in any institutional setting

who might also be obviously in receipt of person centered planning and person

centered services and homemade community based services and long term

supports and services too.

So I also think it's important to include the aspect of the fact that they are also

now dealing with managed care systems and social services systems as well

because we - I didn't even put that in my comment but I'm saying it now

because it's important to note.

Moderator: Kim Patterson 12-13-19/1:00 pm ET Confirmation # 21938555

Page 56

Woman:

Okay. Thank you. Those are really helpful comments about the plan versus

planning and short term versus ongoing, the physical document as well as

(Amber) I take note to you about your comments about the settings and the

different places where people are living. So thank you for that.

Who else has comments about - written comments and what changes they

recommend to the report based on a written comment?

Woman: This is (Denise Maylor). I know there has been some concern from some of the

written comments with regards to care giving or caregivers and if they are not

likely net term. But that's the best term they have got. Those families are

providing care not only to a disabled child who has severe disabilities that

require a lot of extra time and attention.

But we also need to look at caregivers in this plan and person centered planning

with regards to our older or younger people who are becoming involved with

the dementia and Alzheimer's because when those diseases are early that's

when the caregiver and the person can discuss some of the planning needs for

when that person later becomes too involved in this Alzheimer's or the

dementia that they can no longer be an active participant.

Then the caregiver has a planning process that they can use because of what's

been developed earlier in those diseases. And family caregivers are critical to

us in helping us to accomplish a lot of things as individuals with disabilities that

we may not otherwise be able to do.

Woman:

Thank you for that perspective on the word caregiver. I appreciate that. What

other suggestions to the report do people have based on the written comments?

Moderator: Kim Patterson 12-13-19/1:00 pm ET

Confirmation # 21938555

Page 57

Woman:

This is (Glenda Armstrong). I would just like to sort of further some comments

from earlier about the facilitators and I loved comments about how folks really

wanted the chance for the person to not only chose that person but maybe

assume that role themselves but I think we absolutely need to add that option.

And I also would say and I think I heard a little bit about this earlier that when

we are talking about paying facilitators we really I think need to consider that

that paid facilitator cannot come from a payer or a service provider -- because

what I have seen time and time again and I'm sure others as well is that when

that happens is when it goes south.

It's when it becomes that the facilitator is actually working for the agency or

the entity - the payer entity instead of the person. So I think it's really important

that we consider separating a paid facilitator from those corrupting ranks of

payer sources and service providers. Or at least talk about that.

The other thing and this may sound a little strange but I know this and we are

in complete agreement that we have some to be one language and I think we've

made great strides but, you know, we have some ways to go and that's great.

What I would like for us to consider too the way that we are using the word

empower. Empower by definition says to give the authority or power to do

something which implies that we had the power that we were giving to someone

else when in fact that person comes with the power.

And I think we can shift the thinking that it's not us giving anybody any power

but it's us recognizing and supporting the power of that person that they innately

have just like everybody else. That's it.

Woman:

I agree. I agree with that.

Moderator: Kim Patterson 12-13-19/1:00 pm ET Confirmation # 21938555

Page 58

Woman:

And I do too.

Woman:

Okay. Wonderful.

Woman:

This is (Pat) again. I want to react to something that (Mat) said that I think is

important and kind of brought that up in the email that (Gail) and I sent to the

committee earlier this week.

About the different perspectives within the disability community and the fact

that for some folks from some particular backgrounds or history or experience

a plan is the one and done and that's fine. And for other folks it needs to be this

ongoing support and there can't be an assumption that at any point they are

going to not need that support anymore.

And so we had, you know, (Gail) and I had thrown out to the group that maybe

we think about describing some of the distinctions in the paper because there is

different histories, there is different experiences and there are also different

rules and regulations and laws and some historical documents that follow

different populations. And I think I saw this in some of the comments that the

NQF staff also presented regarding people with chronic illness, people with

Alzheimer's and dementia. There is different things.

And so we can't expect a facilitator or the person conducting personal centered

planning with anybody to know all of that but they should be aware of the things

that are poignant to the person they are working with. And if we somehow

describe that I think that might be helpful.

Woman:

Absolutely. Thank you (Pat).

Moderator: Kim Patterson 12-13-19/1:00 pm ET

Confirmation # 21938555 Page 59

Woman:

This is (Gail). And I think that that would really require us to take a look at

what can we really kind of generalize in this report that is true across disability,

that pertains to lots of different situations that people may find themselves in

that require long term services and support.

And then how can we horn in on those particular kind of subgroups and how

can we make this really relevant to people with intellectual and developmental

disabilities versus people who are living with Alzheimer's and - for folks with

intellectual and developmental disabilities I mean truly the word caregiver is

not something that we would ever want to say.

I mean, really kind of, you know, paints the picture of someone who is not - so

anyway, let's hope that, you know, maybe we can even say, well, and if that's

the language that you use over there then go ahead and use it, you know, but we

don't want to - we want to make sure that that is not kind of mixed in with some

of the other groups who would not necessarily find that to be appropriate.

Woman:

Thank you (Gail).

Woman:

This is (Amber Decker). I just want to say that I thought that the absence of

children in this report was kind of shocking. They are medically fragile

children. They are persons of all ages that require long term care and supports

and services. And, you know, since we are relying on the Department of

Education as the support system for children in that respect is kind of

unrealistic.

So I wanted to just note that as well.

Woman:

Thank you (Amber). What other comments about recommendations to the

report based on the written comments do you all have?

Moderator: Kim Patterson 12-13-19/1:00 pm ET Confirmation # 21938555

1 # 21938555 Page 60

Woman:

This is (Dana). Just an exceptional perspective on and I think you knew this as

we were addressing it. I think structurally the definition is one or two sentences.

That's it. And I think what we struggled with is that there were so many

important things that people wanted reflected but I think they need to be

reflected in other parts of the document.

But I think we need a very brief one or two sentence definition. (Daven) has

offered one. I think there is one that's actually embedded in the current

definition. And I think a lot of the body of what follows and what's currently in

the definition could be extracted out to a page immediately following that that

is, you know, key components or values or something of that nature.

Then I think before we get into anything about competencies we have to answer

the question what is a facilitator and who can be one? It needs to make a very

clear statement that first and foremost if a person desires to direct and facilitate

their own planning process we start with that assumption. But make it very clear

that as many people have said that it could be a friend, another national

supporter et cetera. And then in some cases it may be a professional and I think

we have to get clear on that before we move into competencies.

And I think we need to have some sort of process statement where we really

tackle plan versus planning. And then we have to be thinking about, you know,

really the rest of the document which follows because that could have a

significant impact on what's ultimately included with those sorts of

competencies and system characteristics.

So I think we need some - just my thoughts in terms of restructuring.

Moderator: Kim Patterson 12-13-19/1:00 pm ET

Confirmation # 21938555

Page 61

Woman:

Well, I think that's really helpful and specific. One of the things that seems

challenging is making a document that's broad enough that it encompasses

everybody and while all the time speaking about how we want it to be

individualized and person centered and we don't want it to be unuseful because

we've generalized too much.

So I think those are some really helpful suggestions about, you know, tearing

down the definition possibly to be more succinct and then throughout the

document being able to emphasize that there are a lot of different ways to do it

as long as its correctly centered.

So thank you for those specific recommendations.

What other recommendations do you all have?

Woman:

I was - this is (Amber Decker). I was a little bit frustrated by the eligibility and

service access section because of the - just like I didn't think that we really

discussed eligibility prior to this document and in what context we are referring

to.

So I thought it was important to emphasize that a person who should be able

and entitled to use whatever data they have concerning themselves or whatever

opinions they have concerning themselves throughout any planning process or

plans especially one that determines eligibility -- because its very - like relying

on just one methodology is a little tricky. So things like that happen more and

more when it comes to a long-term service sector.

Woman:

Okay. Thank you. Who else has some recommended changes to the report?

NATIONAL QUALITY FORUM Moderator: Kim Patterson 12-13-19/1:00 pm ET Confirmation # 21938555

Page 62

Woman:

This is (Pat). I will just throw out a question. What does the committee think about moving the system characteristics after the definition and putting the facilitator qualifications or whatever after that with the thought that a foster system is capable of supporting a good person centered philosophy and practice. No amount of qualifications is going to help. Just a question.

Woman:

(Pat), this is (Susan). I totally support that.

Woman:

Who else has thoughts about (Pat))'s recommendation or question?

Man:

This is (Michael Small). I think planning without implementation is a form of abuse. So the better the plan, the higher the expectation. So I think arranging it in a way that makes it clear that if you are going to do it as a person centered plan that you have also have made a commitment to act on the learning. So I guess...

((Crosstalk))

Woman:

Thank you (Michael). That's helpful. Anybody else want to respond to (Pat)'s question or have another suggestion?

Woman:

This is (Janice). I mean, I would just agree. I think no matter what system we are talking about too often we try to change the system on the back since individual practitioners who are not in a position and don't have control over things that are - they are not able to actualize the skills that they have learned in person centered thinking and trainings.

So I think placing them earlier in the document would send that message and, you know, it's really is. It's an aspirational document about all the things that

Moderator: Kim Patterson 12-13-19/1:00 pm ET

12-13-19/1:00 pm E1 Confirmation # 21938555

Page 63

we hope that people can do in partnership with individuals and the system is

not currently set up in many ways to do that.

So I like that idea of restricting it and I think we should be transparent and

actually write a couple of sentences about why it is upfront and just be

transparent about our thinking in terms of how the document is organized.

Woman:

Yap. Absolutely. Okay. Are there any other comments?

Woman:

Yes. This is (Glenda). I was just thinking about that last comment. I really,

really like it. I think it's important that we include a recognition of the need for

system transformation and talk a bit about what's not working in the current

system and how we hope this approach will have a transformative effect. I do

think that's important.

Woman:

Yes. I like that.

Woman:

This is (Janice) again. I think that that general theme of how we decide to maybe

restructure or reorganize the document I think it should be transparent in our

thinking about that. Like before any core competencies are provided I think

that, you know, we need to make a statement as to the fact that this is not a job

description and we recognize that no single human being is ever going to

possess these characteristics.

First and foremost the one characteristic they should present is they should be

chosen by the individual.

Beyond that there are a representative set of important, you know, skills and

values and attributes that, you know, we hope are involved in the facilitation

process that recognize they can't exist in any one individual. It feels like

Moderator: Kim Patterson 12-13-19/1:00 pm ET

Confirmation # 21938555

Page 64

because we are never going to be able to pair it down to the extent that I think

that we want to. So I think that just being transparent that we recognize that but

we also don't want to exclude anything that's important.

Woman:

So this is (unintelligible). So in terms of (Emma)'s thoughts I think maybe a

good idea is to do as like another version of what people across the

(unintelligible) should attain. I think it's good to have a very (unintelligible)

version of how we should be treating our citizens and we should concentrate to

shoot for that.

And so if there is a way where we could kind of (unintelligible) piece of this

that ultimately when it comes to all these different systems particularly the

managed care systems that's what when citizens are at (unintelligible) with the

managed care system that they should see some relevance of the shared version

that we are talking about right now in respect of (unintelligible).

So I think it's great to see all these different (unintelligible) creates values and

stuff but seeing all those other versions of what the institution should strive for

going forward.

Woman:

This is (Melissa). I'm just sending out one of the draft definitions that we had

discussed earlier when we had a rich discussion back in October so just wanted

to throw that out there if it might have any nuggets that we would, like to

include. Thank you.

Woman:

This is (Amber Decker). I just want to add (unintelligible) versus a team. I

mean, can we maybe just do away with the term facilitator and say team versus

just one person because I think we are all kind of on the same page with saying

that there usually is not one person that participates in this.

Moderator: Kim Patterson 12-13-19/1:00 pm ET Confirmation # 21938555

Page 65

Woman:

So I think we should use the term team. A team that supports - team members that support something that encompasses that this person is (unintelligible) by - hopefully by people that care for him or her and that you're trying to do what's best for that person for them to (unintelligible).

Woman:

Yes. I agree.

Woman:

Okay. We are getting close to time for public comment so (Lucy) you can open it up for public comment. So what other recommendations does the committee have regarding the report?

Woman:

I just have a - this is (Pat), a question on, you know, what will happen now. Will the NQF staff take a stab at rewriting and reissuing or what's the process at this point?

Woman:

Hi, this is (Kate). So what we are going to do is NQF stuff is going to work on updating the interim report based on these public comments. It's actually something that the committee will review again but it will be closer to the February, March timeline because the next iteration of the report that will be reviewed will actually include a couple of other components.

So the report will be updated, staff will take a first crack at it but we will be of course relying heavily on committee input. So looking for something probably closer to February or March of 2020.

Woman:

Okay. Thank you (Kate). Okay. So last call before we move to open up the lines for public comments. What other feedback does the committee have with regard to recommended changes to the report?

Moderator: Kim Patterson 12-13-19/1:00 pm ET Confirmation # 21938555

Page 66

Woman:

This is (Amber Decker). I added duty of care under generating purpose and

needing because I do believe that there is - that there should be especially if

there is a medical provider or a part of the team or a parent that's a part of the

team or a guardian that's a part of the team. I think duty of care is an important

aspect.

While I respect taking risk tremendously I also think that a lot of the time people

that are making decisions are grappling with both duty of care and dignity of

risk. So I don't know if anyone else has anything to add about that but wanted

to get it in there.

Woman:

Does anybody want to comment on what (Amber) said or has a new

recommendation?

Woman:

Yes. This (Glenda Armstrong). The only other thing I kind of had in my notes

too was and there were several comments about this about something which

was described as it was bureaucratic, it was administrative, it was medicalized,

it was - showed like a linear process.

And I think it's tough because where this whole movement started from on

the people side and how we are trying to meet it - I mean it is a tough job but I

do agree that it does seem - it does seem more to lean toward the bureaucratic

or the administrative side in terms of description and process. First we have an

assessment and then we do a plan and not taking into account how really as

someone earlier said how really messy that can get. So I (unintelligible) I think

that's important.

Woman:

So this is (Matt). So we are doing in a different - I'm in total agreement that the

current (unintelligible) for lack of a better term is very academic and when the

things are working so does the other (unintelligible). But on the plus side to this

Moderator: Kim Patterson 12-13-19/1:00 pm ET

12-13-19/1:00 pm ET Confirmation # 21938555

Page 67

movement that we are talking about I think starts from the ground up. And the

fact that the federal government recognizes that this is the fair way to go is

(unintelligible) my role here today.

So creating the report may scream very, very bureaucratic and academic

(unintelligible) to you in terms of your (unintelligible) but there is a real

opportunity here because the federal government is (unintelligible) and

consumers and so forth.

There is a real opportunity to have a long term change for this mission terms

about healthcare and will happen within the next few years where we are trying

to establish during this year and going forward (unintelligible) seven year from

now. But I really see a great opportunity for every community to lead this

pathway and hope to in their role improve the quality of life for our citizens.

And so that's really why we are so engaged in this process because in my mind

the program has recognized that the process of planning and thinking is

worthwhile for everybody but they don't have a true grasp of what that is. And

so you need to take the time to have these conversations. It helps what we are

trying to achieve during these meetings or during sessions for many years to

come.

Woman:

I couldn't agree with you more. And you said it much better than I did. Thank

you.

Woman:

I agree. I was thinking this is a perfect comment and on. It was a great summary

that really I think demonstrates the direction we are all trying to go in. So thank

you for that.

Moderator: Kim Patterson 12-13-19/1:00 pm ET

12-13-19/1:00 pm ET Confirmation # 21938555

Page 68

I'm now turning it over to (Kate) to is going to open up the line for public

comment.

Woman: Great. Thank you so much (unintelligible). So we have as we have with all our

meetings several ways to provide public comments. So you can use the chat

using the chat box or you can say your comment aloud I just want to remind

people of (unintelligible).

So we've received many, many comments - public comments throughout this

meeting. And what we do is we want to make sure that everyone has an

opportunity to review them.

So while we may not be able to read each one of them aloud we do export them

into a file that we share both with the committee members and liaisons as well

as posted on our Web site that everyone has access to. So I do want to

acknowledge that we've received many, many public comments throughout the

duration of this web meeting and those will be shared. They will be shared

externally and they will be shared internally.

And so there are - there is at least one comment that we have in the chat box

that I'm going to read aloud and then I'm going to ask if there are any comments

on the phone.

Once again you may have been muted so its star 7 to unmute but I want to read

our first comment from (Laura (Denise)) that says, "Please ask persons under

planning for a collaborative approach to the definition. All the comments about

facilitation as a team and meetings who involve family members, guardians et

cetera collaboration is a really key to getting people good lives."

Moderator: Kim Patterson 12-13-19/1:00 pm ET

12-13-19/1:00 pm ET Confirmation # 21938555

Page 69

So that is one of the comments that we've received so far. If you have additional

comments please type them in and I also want to open up the lines to see if there

are any public comments that people wanted to share verbally.

And once again its star 7 to unmute. Most people should be unmuted. If we

heard some background on your phone we may have had to mute you but it is

star 7 to unmute.

I do also want to add that some people had a lot of extensive comments and

they may want to summarize them for the project team. So we always encourage

emails. Its pcplanning@qualityforum.org . I know that we've received many

emails from members of the public with additional feedback or guidance. So

we did want to offer that up as an opportunity. We don't close this publicly but

everyone in the project team does listen and they do inform our work.

And I'm going to give it just another couple seconds here to see if people are

chatting comments but I didn't know if there is anyone on the line who wanted

to say anything.

Woman: This is (Glenda) again real quickly. I thought I bring in what I was looking in

the Excel document that you sent there is a definition from the New Jersey

Department of Education that came from (Lauren Augoredis). I'm probably

mutilating that name. On November 26 and I think it may have some things that

we might want to consider.

Woman: Thanks (Glenda). Thank you for pointing that out and our staff has read all the

public comments and we will go back to that one and we will see how we can

inform the work. Thank you.

Woman: Sure.

Moderator: Kim Patterson 12-13-19/1:00 pm ET Confirmation # 21938555

Page 70

Woman:

And I'm not seeing any other public comments from the public. So I'm going

to turn it over to my colleague (Yvonne) for our next step.

Woman:

Thank you (Kate). So for our next steps we will be having a web meeting on

the 6th of January. That will be our web meeting number 6. We encourage

everyone who is not part of the committee or liaison to go to the project page

and subscribe to the project alerts that way you get a notification when the

meeting materials have been posted and just as a reminder to add it to your

calendar so that you can join us.

And then after that we will have a meeting in February. That will be our web

meeting 7. In between we will have a document that we posted out for public

commenting. That will be our draft final report where you can also add input.

And then that will be followed by finalizing all those comments that we've

received and putting it into our final report in July.

So as I mentioned our next meeting is on January 6, 2020 and it will be from

1:00 to 3:30 pm Eastern Standard Time. And during this meeting we will

introduce the personal centered planning framework approach, development

process and draft measurement framework. So once we present this information

we will be looking at the committee as well as the public to review and provide

input o this draft measurement framework.

And during web meeting 7 we aim to finalize the draft measurement frame work

prior to posting the report and then we are also going to gather committee input

on PCP research agenda and what other areas of focus that you would like us to

- you would like to see in the future in the field.

Moderator: Kim Patterson 12-13-19/1:00 pm ET

Confirmation # 21938555

Page 71

And on June 1 we will have a review of the public comments as we have done

today but this will be for the draft comprehensive report before it is finalized.

Again suggested on the screen are our contact email

pcpplanning@qualityforum.org. You have our phone number, the project page

has also been signed here and there. We have SharePoint that is available to the

committee members as well as liaisons where we would post some project

documents that are able to inform the progress of the project and for their

reading.

And then we also have the project (unintelligible) that I mentioned for you to

receive notification regarding some key developments in the project.

Okay. That's about it. I will hand it over to you (Kate).

Woman:

Great. And I just want to hand it over to our co-chairs and then my colleague

(Sam) after that to provide us some closing remarks. So (unintelligible)

(Cheryl).

Woman:

Just very briefly, great discussion. Everybody was focused on target, excellent

additions. I know that we will probably never have the perfect report but we

will certainly continue to have the better report and I'm again reminded how

important this work is so thank you all.

Woman:

And I couldn't agree more (Cheryl). The conversation that we have and the

back and forth and new perspectives that we get to hear from everyone

(unintelligible) to make it a much better product and I'm thankful for

everyone's commitment, participation to being fully engaged.

Moderator: Kim Patterson 12-13-19/1:00 pm ET Confirmation # 21938555

Page 72

Man:

Wonderful. Thanks so much. This is (Sam). So on behalf of the NQF staff that

really big thanks to everybody who participated on this call. I recognize a lot of

sincerity and honestness comes to the table and the hard work that you all are

putting in to helping us think through how best to try to advance things for a

really large amount of people that could potentially benefit from our work truly

means a lot.

So where I'll be reconvening in the New Year so until then at least in person or

on the phone we'll adjourn so thank you so much. And I also - sorry, before we

go I also need to just say thank you very much to our co-chairs for facilitating

and for their leadership truly has been very, very helpful in helping us to get

through the comments today. Thank you so much.

All right. With that we'll adjourn. Thanks everybody.

((Crosstalk))

**END**