NATIONAL QUALITY FORUM

Moderator: Benita Kornegay Henry
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2:43 pm CT

Woman: And (Unintelligible), are you on the line?

Gretchen Napier: Yes, this is Gretchen. I'm here.

Woman: Good morning, Gretchen. I just joined.

Woman: Oh great. And are you able to also do the Web streaming?

Woman: I'm on. Yes.

Woman: I - yes. I'm on the Web streaming, but I'm joining by phone audio because I don't have…

Woman: Okay.

Woman: …a good speaker.

Woman: Great.

So we're going to message you real quickly to get you into the sub-conference and we'll be - and we'll have a quick second then.

Woman: Okay.

Gretchen Napier: And this is Gretchen. I wanted to let you know I'm also on the phone for audio.

Woman: Wonderful. And so we're just sending a quick message to get - via the Web platform to get into the sub-conference.

Amber Decker: This is Amber Decker.

Woman: Hello.

Amber Decker: Hi.

Woman: Hi there. We're gathering people. We're going to get started in just, say, about ten minutes.

Amber Decker: Okay. I'm going to be on mute for now then.

Operator: The conference has been muted.

Woman: Am I in the sub-conference?

Man: Pound 1, 1, right?

((Crosstalk))

Woman: 1, pound, pound. 1, pound, pound.

Operator: Sub-conferencing is now active.

Kate Buchanan: And hi all. This is Kate Buchanan. We'll be beginning in just a couple of minutes.

Operator: The conference has been unmuted.

((Crosstalk))

Woman: We are getting a lot of feedback from all of our (unintelligible) those who are not (unintelligible) to have their lines muted. To mute your line, you hit star 6. To unmute your line, it's star 7. But we're asking everyone (to please) mute your lines because we're getting a lot of feedback.

Kate Buchanan: And this is Kate. And we'll begin in just a couple of minutes. Thank you all for joining us.

Woman: Hello everybody. Again, this is the Person Centered Planning and Practice Committee (Unintelligible). Please mute your lines if you're not speaking. Otherwise, we get a lot of echo. (Unintelligible). We'll get started…

((Crosstalk))

Woman: (Unintelligible). Thank you so much.

Debjani Mukherjee: Good afternoon and good morning everybody. My name is Debjani Mukherjee and I'm one of the senior directors on this project. Again, this is the Person Centered Planning and Practice Committee (Web meeting).

During this meeting, we're going to do a little bit of orientation as well as talk about the definition. And again, please mute (unintelligible) and/or your computer. Otherwise, we'll get a lot of echo. And that will sort of disjoint the audio. Thank you. It suddenly got very quiet.

And with that, I'm going to turn it over to this NQF staff to introduce themselves and then we'll turn it over to the co-chairs (unintelligible).

Sam Stolpe: Hello everybody and welcome. This is Sam Stolpe. I'm a pharmacist and epidemiologist, also serving as one of the other senior directors on this project. And I'm delighted to have the opportunity to work with each and every one of you.

Kate Buchanan: And hi all. I'm Kate Buchanan. I'm a senior project manager here. And I'm very looking forward to collaborating with everyone on this project.

Yvonne Kalumo-Banda: Hello. This is Yvonne Kalumo-Banda and I am the project manager. I'm glad that you could all join us today and I'm looking forward (unintelligible) the discussion.

Jordan Hirsch: Hi everyone. This is Jordan Hirsch. I function as the project analyst. And I'm looking forward to working with everyone.

Debjani Mukherjee: Gretchen and Cheryl?

Cheryl Phillips: Well hello, this is Cheryl Phillips. I am a geriatric physician by training and I'm the CEO and President of the Special Needs Plan Alliance. And I am so honored to serve as co-chair for this wide support work.

Gretchen Napier: This is Gretchen Napier and I am the Assistant Deputy Chief for Quality, Accountability and Innovation with LTSS TennCare in Tennessee. And I'm really excited to be working with you all today. I see a lot of people are saying they're still having a hard time hearing. Can - is there anything we can do, NQF staff, to try to help with that?

Woman: Hi…

((Crosstalk))

Woman: Well I do think the most important thing is that people are on mute if they're not speaking. I got on hold.

Gretchen Napier: Yes. So what we can do is we - the best way to hear is by calling in. Sometimes the computer audio can be a little challenging. And so what we do recommend is that people use dial-in number. That is a way of helping to make sure everyone can hear better. And the - jus to reiterate for those who are listening on the computer who want to dial in to get better audio, the number is 800-768-2983. Once again that is 800-768-2983. And the access code is 5599437. And we are going to write that in the chat box as well. But the access code is 5599437.

And so I think that as people dial in, they will get better audio. Sometimes the computer can sound a little soft. So that's what we recommend for folks. And then as Debjani mentioned and our co-chairs, muting both your computer microphone as well as your personal phones will really help everyone be able to hear better.

Debjani Mukherjee: Okay. And now we will turn it over to Elisa Munthali, our Senior VP for Quality Measurement here at NQF to read the disclosures of interest, as well as for our committee to introduce themselves.

Elisa Munthali: Good morning and good afternoon all my new (colleague). I'm the Vice President for Quality Measurement at the National Quality Forum. I just wanted to welcome and thank everyone for being on this committee.

Today, what we're going to do because this is an orientation call, we'll be combining our disclosures of interest with introduction. And just as a reminder, you received the disclosure of interests form from us before you were named in the committee. And in that form, we asked you a number of questions about your professional activities as they're related to the work that is in front of you today. What we're asking you to do is today is to orally disclose what you gave us in writing. We're interested in information only that is directly related to the work in front of you as a committee.

Just a couple of reminders. You sit on this committee as an individual. You do not represent the interest of anyone who may have nominated you for the committee or your employer. As I mentioned, we're interested in all of the activity that is related to the work in front of you. And that means paid and unpaid. And perhaps the most important reminder is just because you disclose does not mean you have a conflict of interest. We do this process in the interest of openness and transparency.

And so I'm going to start with your co-chairs. I'm going to call on them in alphabetical order and ask them to introduce themselves and tell us who they're with and let us know if they have anything to disclose. And then I'm going to go down the list of committee members in alphabetical order calling on you to do the same.

So we'll first start - I think we're starting with Gretchen?

Gretchen Napier: Yes hi. I'm Gretchen Napier and as I've mentioned, I am currently working for LTSS TennCare in Tennessee. Prior to that, I got started in the - helping the elderly by getting a license as the nursing home administrator but realized that that was not the way to really affect as much change as I had hoped and then ran independent assisted living facilities and published a resource guide for seniors for about ten years, and in the last ten years owned a private care management company that hired nurses, social workers and physical therapists to help aging individuals and individuals with disabilities in the Raleigh and Nashville to navigate their family systems and navigate the healthcare system.

So I am excited to be able to do this work with you all for person-centered planning and be able to share my experience as well as learn from all of you.

Elisa Munthali: Thank you so much, Gretchen. Gretchen, can you let us know if you have anything to disclose? It sounds like you don't.

Gretchen Napier: No, I don't.

Elisa Munthali: Okay. Okay. So, Cheryl?

Cheryl Phillips: Yes. I'm Cheryl Phillips. Again as I mentioned previously, I am the President and CEO of the Special Needs Plan Alliance. Prior to this, I served as a senior vice president for public policy for LeadingAge, which is a nonprofit aging services across the country. And I had extensive work with a home and community-based services and LTSS. I served on the Olmstead Committee Advisory Group in California and am very passionate about how we bring services to people, where they are and what they need, and most importantly that we start with their viewpoint on what they view as their needs.

So the value of this committee I can't speak more highly of. Thank you.

Elisa Munthali: Thank you so much, Cheryl.

Cheryl Phillips: And I have no conflicts.

Elisa Munthali: Thank you.

Cheryl Phillips: Well I'm very conflicted in personal life, but nothing to (unintelligible).

Elisa Munthali: I think we all might be.

So, Glenda Armstrong? Glenda, perhaps you're on mute.

Glenda Armstrong: Hi yes. You were right, I was. Thank you for reminding me of that.

Elisa Munthali: No problem.

((Crosstalk))

Glenda Armstrong: …Glenda Armstrong. I'm a nurse. And I'm older. And so I have a long, long history of working in both home and community-based services development, you know, primarily in the area of care management for older adults with complex health issues as well as people with disabilities. And also in the last couple of years I've had the privilege of being sort of an advisory member for a professor here at the University of Oklahoma, which is where

I'm currently working, to work on an NIH grant called "Aging In Place" and taking a look at why older adults refuse services that they need and certainly qualify for.

And finally, I'm just currently the manager of the Care Management Oklahoma Health Care Authority contract with us to do the care management for their Medicaid high-risk, complex, chronic care situations across Oklahoma and I'm manager of that program here for OU.

Elisa Munthali: Thank you so much, Pearl. Oh, sorry. Thank you, Glenda. Sorry.

Pearl, I was looking ahead. Sorry about that.

Pearl Barnett: No problem. Yes. I am Pearl Barnett. I think Glenda and I have worked together in my past life. I'm currently the Director of Operations at the National Association of States United for Aging and Disabilities. There I provide technical assistance to states in a plethora of areas, one being 1915(c) home and community-based Medicaid Waivers and States Plan Personal Care programs because in my former position in Oklahoma I was an administrator for the 1915(c) Waiver and Medicaid State Plan Personal Care Program for Aging and people with physical disabilities.

In that program we did quite a bit of work in moving toward person-centered planning, thinking and practices. We were one of the initial states that were approved in our statewide transition plan through CMS. And so since then I've done quite a bit of work in that area at NASUAD and previously with the state of Oklahoma. And I do not have any conflicts to disclose.

Elisa Munthali: Thank you so much, Pearl.

And before I continue with the rest of the committee, I did want to mention that there's been overwhelming interest in this Webinar and as a result, we're having some difficulty getting everyone to access the 500 capacity lines that are available. So please bear with us. We have some of the folks that are funding this work who aren't able to get on. But everyone else who's trying to get on because of the capacity issues, we're working with our vendor to make sure you do get on.

So we'll be sending something by - via the Web platform because we realized you probably can't hear this. But if anyone is connected to those that are trying to get on, if you can pass on the message, that will be very much appreciated.

So next we have Sally Burton.

Woman: She can't…

Elisa Munthali: I understand Sally is not joining us today. She is actually one of those that cannot speak. So we'll get to Sally later.

Amber Carey?

Amber Carey-Navarrete: Hi yes. My name is Amber Carey-Navarrete and I am the Director of Person Centered Services with the Easterseals Southern California. The primary purpose of my role with Easterseals is that I work with our many, many adult-based services, go into the services and I work with the people receiving those supports and services to support them in transforming their services to reach the outcomes that they want their services to provide for them.

And so in addition to that, I do work with - do some work with both the California and the National Adult Day Service Association just with training and providing (unintelligible), things like that when they have their conferences. What I disclosed on when asked was that some of the work that I do is grant-funded through organizations like this Allergan and Edwards Lifescience that they in a way really - they just kind of sponsor the work that I do. They in a way kind of direct it or make request or anything of that. They just believe in these services that we're providing them the person-centered transformations that our services are making and want to be a part of it in kind of sponsoring type of way.

Elisa Munthali: Thank you so much, Amber. Bruch Chernof? Bruch, are you on?

Woman: Did you say (Gail)?

Elisa Munthali: I'm sorry?

Woman: Who you calling on next?

Elisa Munthali: Bruch. He may be having technical difficulties as well.

Bevin Croft?

Bevin Croft: Hi everyone, this is Bevin Croft. I am with the Human Services Research Institute in Cambridge, Massachusetts. And I am the co-director of the National Center on Advancing Person-Centered Practices and Systems. That is a newly established center, funded by the Administration for Community Living and the Centers for Medicare and Medicaid Services. And the focus of our center is supporting states, tribes and territories in engaging in systems change efforts to enhance person-centered thinking planning and process and practice for people who use long-term services and support system, all payors, all population center.

We just got off the ground this year and we're just beginning to roll out targeted technical assistance to states, peer-to-peer living collaboratives and a number of other features. And I do not have any conflicts of interest to disclose.

Elisa Munthali: Thank you so much.

Amber Decker? Amber?

Okay. Gail Fanjoy?

Gail Fanjoy: Hello everyone. I'm Gail Fanjoy. I'm currently the CEO of a provider agency situated in northern Maine. This agency was a very traditional agency founded in 1961 with all of the usual trappings of a facility-based agency supporting folks with intellectual and development disabilities. I was - I've worked here for 42 years and have had many different careers under the hood of KFI. And we transformed our services beginning in the mid 80s. We were the first agency in the state to shut down our sheltered workshop which was in 1987. And all services were transformed to be 100% community-based by the mid to late 90.

So our agency provides supports for folks to live in homes of their own. We have no one's property. We hold no one (belief). We provide supports for people to be employed competitively in community businesses or to own their own businesses. And we support people to engage as typical citizens in their communities of choice.

So I have - I also had a little stint being a subject matter expert for the Office of Disability Employment Policy's (Unintelligible) First State Leadership Mentoring Program. I've been doing a lot of work actually, Gretchen, in Tennessee and that's been very satisfying as well. I am also the grandmother of a darling 12-year-old grandson who is on the autism spectrum.

Elisa Munthali: Thank you so much, Susan. Oh sorry. I think we're - was that Gail? Sorry, I - my placing on my roster.

So, Susan Fegen?

Woman: You might want to run down (unintelligible).

Woman: Yes. (Susan)?

Woman: (Unintelligible).

Elisa Munthali: Okay. Sara Link?

Sara Link: Yes hi, my name is Sara Link. I'm the Director for No Wrong Door Virginia at Virginia Department for Aging and Rehabilitative Services. And I'm just delighted to be here with the amazing group. And No Wrong Door is a statewide initiative. It's also part of a federal system (unintelligible) a long-term services and support through person-centered planning and practices.

So we're really excited to be (unintelligible). I'm so excited. Bevin is part of this work too. And what we will be doing is we will be - as a part of some of our grant work through the ACL is we will have more person-centered thinking training, also are working a lot around trauma-informed care and I've done as part of my background a lot of work in home and community-based services and research on social isolations in older adults. And one of the things I'm probably most proud of with my work is I'm a returned Peace Corp volunteer having served in Guatemala for two years.

Elisa Munthali: Thank you so much, Sara.

Joseph Macbeth?

Amber Decker: Wait. Hi this is Amber. I'm able to get in. Can anyone hear me?

Elisa Munthali: Oh good, Amber. How are you?

Amber Decker: I can go after Joseph if that's okay. Sorry…

Elisa Munthali: Okay. So, Joseph, are you there?

Joseph Macbeth: Yes I am. Hi everybody.

Elisa Munthali: Hi.

Joseph Macbeth: My name is Joe Macbeth. I'm happy to be here. I am the President and CEO of the National Alliance for Direct Support Professionals. Our home offices are strangely enough located in Albany, New York and we are the representative voice of about 1.3 million direct support professionals, primarily working with people with intellectual and developmental disabilities.

The NADSP provides a variety of resources to provider organizations and training opportunities for direct support professionals, career ladders and credentialing programs for direct support professionals and an advocacy voice in public policy for the low-wage earners who do this really important job and are at the (fulcrum) of person-centered practically.

So I'm happy to be here. I have nothing to disclose. Thank you.

Elisa Munthali: Thanks, Joe.

And, Amber Decker?

Amber Decker: Oh. Sorry. I hear typing.

Elisa Munthali: If you're not speaking, could you - okay, Amber, I think you could go ahead.

Amber Decker: Okay. So I am parent of a child who is autistic. I am the daughter of an individual who utilizes long-term supports and services with a serious mental illness. I'm also a credentialed New York State Family Peer Advocate and an IEP parent member. And I'm currently on Disability Rights, PAIMI Advisory Council, as well as the Citywide Council on Special Education. And I live in Brooklyn with my dog and my son. I have nothing to disclose.

Elisa Munthali: Thank you so much.

((Crosstalk))

Amber Decker: Sure.

Elisa Munthali: Thank you. So we're going to go back to Susan Fegen. We understand you might be on the line right now. I know you're having (unintelligible) earlier.

Susan Fegen: Hi. Hi yes.

Elisa Munthali: Hi.

Susan Fegen: Yes it’s Susan. I’m here.

Elisa Munthali: Hi.

Susan Fegen: Let’s see. I’m with Centene Corporation. We’re the largest Medicaid provider right now in the United States. I’m a nurse. I’m also the person-centered thinking program manager for the company. Personally I’ve trained over 3500 people in the last two years. I live in Houston, Texas but actually I live on the airplane. So we’ve been all over the US, bringing person-centered efforts to all of our plans.

I’m certified through the Learning Community for person-centered practices and I have nothing to disclose.

Elisa Munthali: Thanks, Susan.

So we’ll go to Denise (Mayler).

Dennis Myler: Hi this is Dennis Myler. I’m in - I live in Idaho. I am very involved with the Independent Living Movement here in the state of Idaho. I am the board president of my local independent living center. I am also on the State Independent Living Council. I’m also involved with the Idaho Caregiver Alliance. I have a physical disability. And I was also my mother’s caregiver until things got to the point where due to my disability I could no longer take care of my mom at home.

And I have nothing to disclose.

Elisa Munthali: Thank you so much. Next we'll go to Melissa Nelson. Okay. Sounds like Melissa is not with us yet. Patricia Nobbie?

Melissa Nelson: Sorry. Can you hear me now?

Elisa Munthali: Hi, Melissa. How are you?

Melissa Nelson: Hi. Good afternoon.

((Crosstalk))

Elisa Munthali: Good afternoon.

Melissa Nelson: I'm Melissa Nelson. I'm Associate Director of Quality Services at TMG in Wisconsin. TMG operates Wisconsin's first certified IRIS consultant agency. We partner with thousands of adults with disabilities and older adults throughout Wisconsin who are in need of long-term supports and services through a self-directed fee-for-services home and community-based waiver program. And we support people to be living in their homes, fulfilling their outcomes and living their best lives.

I too bring a passion for person-centered planning and have no conflicts of interest to disclose.

Elisa Munthali: Thank you so much, Melissa.

Patricia Nobbie?

Woman: Thank you.

Woman: You’re welcome.

Patricia Nobbie: Hi, this is Pat Nobbie. I am the Disability Policy Engagement Director at Anthem, which is also nationwide managed care entity. I’m also the parent of a young woman with Down Syndrome, (Mia) who is 34 and lives in Athens, Georgia and has - is fully employed and has an actually fabulous life. For 12 years, I was the policy and then deputy director of the Georgia Council for Developmental Disabilities in Georgia and did a lot of programming and - program development for people with intellectual disabilities in person-centered planning, college programs, employment, et cetera.

I was then the recipient - a very happy and lucky recipient of the Kennedy Fellowship and worked for Senator Rockefeller in 2013 and was actually one of the staff that helped set up the Commission on Long Term Care. And then I went to ACL and worked with (Sean) and (Vicki) and some of the great folks at ACL, the Home and Community-based Settings rule and then moved to Anthem. There I do a lot of work in the field, educating families on what managed care is and social services we can provide to them to support them in the community.

I’ve done a lot of person-centered planning with my daughter in lots of different models. So I’m really thrilled to be on this committee. And I think the only thing that I disclosed is that I’m currently a board member of Council for Quality and Leadership.

Elisa Munthali: Kate Norby? Kate?

Kate Norby: Good afternoon. Good afternoon. My name is Kate Norby. And I am the Executive Director of Member Experience at Inclusa. Inclusa is a long-term care, managed care organization providing support and services to adults with intellectual disabilities, physical disabilities and older adults who need support.

We have a strong commitment and have been trying to grow community centric model of support centered on growing citizenship. And we have a lot of commitment to self-direction, self-determination that are (grounded) in person-centered practices. I'm very happy to be here. And I have no conflicts to disclose.

Elisa Munthali: Thank you so much, Kate. Next we'll go to Ann O'Hare.

Ann O'Hare: Yes hi. I am a nephrologist. I work in the VA hospital in Seattle. I'm also a professor of medicine at the University of Washington and (unintelligible) I'm involved in research, teaching and clinical care. And I would say that the focus of all of those is on, you know, person-centered approach. I've written quite a bit about person-centered care and done research in this area.

In terms of conflicts, obviously my employer in the University of Washington, the VA; I also receive grants from the Centers for Disease Control, NIH and VA. And other conflicts include some personal honoraria and travel support from DCI, which is the dialysis provider and Fresenius to give talks on my research. I also receive honoraria from - up-to-date for some contributions that I make there. And I also participate in something called the Pathways Project, which is actually sponsored by the Gordon and Betty Moore Foundation. It's a project to promote person-centered care for people with advanced kidney disease.

Elisa Munthali: Thank you so much, Ann.

Leolinda Parlin? Okay. She may not be with us yet.

Richard Petty?

Richard Petty: Good afternoon everyone.

Elisa Munthali: Good afternoon.

Richard Petty: It's good to be with you. And I am Richard Petty. I co-direct with my colleague, Lex Frieden, I co-direct ILRU, Independent Living Research Utilization at the Institute for Rehabilitation Research in Houston. I am the Director of the National Center for Aging and Disability. I am on the faculty of the University of Texas Medical School in the Department of Physical Rehabilitation Medicine Department.

And one point of interest is that I - and possibly a matter to disclose is that I am pleased that several of our team here at ILRU are part of the technical assistance team that will be working with the national center on advancing person-centered - excuse me, for this person-centered planning and practice with our colleagues at the - I'm sorry I just lost the name. I apologize.

Elisa Munthali: The Human Services Research Institute?

Richard Petty: Thank you very much. The Human Services Research Institute in Boston, our longtime colleagues, too long for me to have momentarily had a lapse on their name. But nevertheless, I've also been pleased to read the comments over the past several days about the definition and about some of the other points. And I appreciated that they have been very thoughtful and worthwhile and I do hope in the work that we do here that I can bring some of what has been learned in the Independent Living Movement.

We have been informed by Independent Living philosophy which has to do with individuals making their decisions about their choices about the services and supports that they use to remain independent in their community and making other decisions about their lives as part of what’s called “consumer direction” or - and the organizations with which they are involved are led by people with disabilities. That means the boards of directors and the staff of those organizations to - in an effort to try to affect consumer - control and consumer direction as completely as possible.

I’ve also been involved in participant-directed services, another valuable concept and approach. I hope we can bring some of that thinking into the work that we’re going to be doing and that when - before we are done that we can make sure that this is as simple and straightforward a process for the individual and that we’re not creating hurdles and hoops for individuals to have to negotiate and navigate to receive the supports that are going to be valuable for them in their daily lives and their community.

So I’m very much looking forward to working with the group…

((Crosstalk))

Richard Petty: …and with the folks that are here. Thank you.

Elisa Munthali: Thank you so much, Richard. Mia Phifer?

Woman: (EOP) teams were fabulous and by the way…

Elisa Munthali: Mia?

Woman: …(unintelligible).

Mia Phifer: Good afternoon everyone. This is Mia Phifer with the National PACE Association, located in…

Elisa Munthali: Mia?

((Crosstalk))

Mia Phifer: … - can you hear me?

Elisa Munthali: Yes I can. But I'm just going to ask everyone else if you're not speaking, if you could please put your phone on mute. We can hear your conversation.

Thank you. Mia, I think you can proceed.

Mia Phifer: Thank you. Again this is Mia Phifer with the National PACE Association located in Alexandria, Virginia. The National PACE Association works to advance the effort of Program of All-inclusive Care for the Elderly so that older individuals can continue to live in their community. Our model is based on the center and belief that it is better for the well-being of seniors with chronic care needs and their families to be served in a community whenever possible.

Here at the Association I am the Vice President of Quality and I work closely with our members to advance the quality of care provided to those that are being served by the PACE community. I'm extremely excited to be a part of this community. I have extensive experience working with individuals in the community not only through the PACE model of care but having the opportunity to have worked in long-term care with hospice as well as other community-based settings.

I have nothing specific to disclose to the community.

Elisa Munthali: Thank you so much, Mia. Michael Smull?

Michael Smull: Thank you.

Elisa Munthali: Michael? Hi.

Michael Smull: This is Michael. And I'm the Chair of The Learning Community for Person Centered Practices, a not-for-profit that holds the intellectual property rights to person-centered thinking and person-centered planning in a particular approach, and a senior partner with Support Development Associates, which is a small consulting firm.

I've worked with people with disability labels for 47 years across 48 states and eight countries. And by the way I'm also a returned Peace Corp. volunteer who led the team that developed Essential Lifestyle Planning in late 80s and early 90s, person-centered thinking in the early 2000s, working on helping people become person-centered organization in mid 2000s and (unintelligible) worked with the team that developed the No Wrong Door Person Centered Planning approach and have worked across the groups of people who are described as in need of long-term supports and services.

Everything I do is about either teaching or consulting within the realm of person-centered planning, person-centered thinking, person-centered practices. So that would be the disclosure. And I'm very much looking forward to working with such a varied and gifted group.

Elisa Munthali: Thank you so much, Michael. Dori Tempio? Dori? Janis Tondora?

Janis Tondora: Hi everyone. This is Janis Tondora. It's great to be here. I have long been (unintelligible) folks on the phone. So it's good to be here.

I have a longstanding personal and professional - for person (unintelligible) first introduced through the experience of having (unintelligible) traumatic brain injury and through that relationship I experienced person-centered planning and how it changed his life dramatically. And that (unintelligible) about it like a tool to really help people who are disempowered to really reclaim their lives in the community.

So early in my career, I actually worked more in a school-based setting as an inclusive education consultant and kind of grew up within the person-centered planning models of (unintelligible) essential lifestyle planning and so forth. And I carried that with me when I went back to graduate school for clinical psychology and (unintelligible) in the community mental health and nearly threw in the towel because of those quite disillusioned, the field of (unintelligible) need to be really so far behind. There has been in the broader disability advocacy (unintelligible).

But fortunately I landed at a place called the Yale Programs for Recovery and Community of Health, which is the Department of Psychiatry Program at the Yale Med School. And our programs have been very heavily involved for over 20 years now in the national recovery business where we do a lot of work, research, policy development, writing, teaching, consultation, material development to really support the (unintelligible) and then community inclusion among people living with a range of behavioral health conditions.

And I do not believe - I just got back two weeks straight of traveling. I do not believe that I disclosed any conflicts of interest in the online form (unintelligible) NQF. But obviously as a grant academically-based program, we do receive grant funding from a number of credible partners including National Institute of Health. We've had CMS funding, SAMHSA funding through the range of the type of work that I was just describing. And the training and consultation work that we've done is typically funded either through honoraria or training and consultation agreements both with states, with universities and with behavioral health provider, each.

So again it's great to be here and I look forward to working with the group.

Elisa Munthali: Thank you so much, Janis. And I'm going to go back because I understand Dori has joined us online and via the telephone. So, Dori, are you there? Dori, by any chance, are you on mute? Okay. We do know you're present. So thank you for joining us.

And, Maggie Winston?

Maggie Winston: Hi everyone. My name is Maggie Winston and I live in Kenai, Alaska. First of all, I'm an individual with a disability. I utilize long-term services and supports in my own home. I'm also a systems advocate and transition specialist at our (research) for independent living. And another position, I'm adjunct faculty for Alaska's LEND Program which is an interdisciplinary program for graduate students, teaching them to be better advocates for individuals with disabilities. And I am also the chair of Alaska's DD Council. So I have quite a bit of experience in person-centered planning and practice.

And I don't believe I have anything to disclose. But I'm very happy to be here with all of you.

Elisa Munthali: Thank you everyone and thank you, Maggie. We are very happy to have you all with us. And I just wanted to remind you before I hand it over to the project team that at any time if you remember that you have a conflict (unintelligible) speak up. You may do so in real-time or you may send a message via the chat function on the Web platform to anyone on the NQF staff or to your co-chairs. Likewise, if you believe that one of your colleagues is acting in a biased manner, we want you to speak up.

So with that, I just wanted to thank you again. I hope you have a good meeting. I'm going to turn it over to my colleague, (unintelligible).

Sam Stolpe: Thanks very much, Elisa. And just a word…

Dori Tempio: It's Dori again. Can you hear me now?

Sam Stolpe: Hey, Dori.

Elisa Munthali: Yes we can, Dori.

((Crosstalk))

Dori Tempio: I called back in to see if it would work if I call back in and it seems to have worked. Hi everybody.

Elisa Munthali: Hi.

Dori Tempio: This is Dori. I am so excited to be on this committee. It is such an honor and I'm thrilled. I come to this work from a variety of angles. I am a proud woman with both a developmental disability and a physical disability and then

I also serve in a professional capacity, working with person-centered planning and people with disabilities.

I've worked at Able South Carolina Center for Independent Living. I am the director of community outreach and consumer rights. I am a certified trainer with the Southeast ADA Center. I work with our local UCEDD and LEND programs on empowering professionals who work with people on person-centered planning. I sit on our statewide DHHS committee on working on person-centered planning. I, in addition to that, I am the chairperson of the Person-Centered Planning Training Subcommittee. Going along with that…

Sam Stolpe: Okay.

Dori Tempio: …I work directly with individuals, empowering them to utilize person-centered planning in their everyday life as well as teaching them independent living skills and I am a graduate of the Georgetown University Leadership Academy, increasing leadership for cultural diversity and cultural and linguistic confidence and network supporting individuals of intellectual and developmental disabilities and I was one of their instructors at last year's programs.

I could go on, but that's a lot of information for everybody to know. But I am thrilled to be here and I am so glad to be a part of this program because I think there's so much we all bring to the table that can advance people with disabilities and being a part of the process for any medical decisions or other aspects of their life decisions about them and putting them at the core.

Elisa Munthali: Thank you so much, Dori. We're very happy that you could finally join us and we're happy to have you on the committee and we're very pleased that everyone is on the committee. And again, I'll turn it over to Sam.

Sam Stolpe: Dori, I think you might be my new favorite person. We love that introduction. You did sound so cheerful. We're delighted to have you and everyone else. Thank you so much.

I wanted to briefly describe the process by which this committee was formed and just really highlight what you undoubtedly have already noticed. This is a multi-stakeholder group. We have a wide variety of perspectives represented on this committee and I'm delighted that we have care recipients, trainers, academics, health plans, practitioners, behavioral health experts and I just want to reemphasize direct recipients of care inside of the HCBS setting.

And when we were putting this committee together, we were delighted to have as much interest as we've received. We had over 130 people apply for this committee, which is actually a record for NQF. So there's tremendous amount of interest. It's tremendous response from the community and a lot of passion held by this group and others that are not necessarily directly on the committee but who applied - maybe even those who did not apply that are going to be following this work moving forward.

When we are putting the committee together, we were striving for balance. We were striving for depth as well as breadth of representation of voices that are both providing and receiving care inside of this particular setting. We had requirements that were stipulated by our contract that were in front of mind as we were reviewing those 130-plus applicants. So when we started populating the roster, we looked at those requirements first. Each of the stakeholders that applied, these are the individuals who applied, we categorized them according to those requirements as well as some other characteristics that were desirable for balance. Then those individuals that we selected initially for those requirements, once we got to that first round, we as a team went through for literally dozens of hours of employee time committed to carefully reviewing biographies, CVs and statements of interest to ensure that we were capturing the sorts of perspectives that were going to be able to inform this work and advance it.

Now of course we're with only 25 people being able to sit around this table for this committee and over 130 applicants. Not everybody that applied was able to join and we had a bunch of high-caliber individuals that we just simply weren't able to see. And it's simply a numbers game. We hope that we didn't disenfranchise anyone in that process but we've also kept this open. This whole process that we're going through is in the public domain. All of our calls are - have a public comment period and there's numerous opportunities for the public to comment throughout our process.

You'll notice as we go through and review over the course of this call that we have a number of things that we're looking to accomplish but each one of those is done in a measured deliberate and iterative process through which we'll receive feedback from the community including interviews with key stakeholders which we'll be outlining a little bit further on.

But just wanted to shed some light on how we've conducted this process of populating this committee and hopefully you got some idea to the degree or care that we've taken as an organization. We take this really seriously and ensuring that we're getting the right voices around the table and thanks very much to each of you for joining.

Kate Buchanan: Thank you so much, Sam. So my name is Kate Buchanan. As I said, I'm senior project manager here and I just want to take a couple of minutes to provide some overview on NQF as well as the scope and deliverables of this project. I know many of you are familiar with NQF but some of you are not. So we want to just provide some brief background.

So NQF was created in 1999. We're currently celebrating our 20th anniversary by a coalition of public and private sector leaders after the president's advisory commission on consumer protection and quality in healthcare industries which concluded that an organization like NQF was needed to promote and ensure patient protection and healthcare quality through measurement and public reporting. And here you can see our mission, vision and values and we want to be the trusted voice in driving measurable health improvement.

So if we move on to the next slide, you can see that we engage in many different types of work. We have over 600-plus NQF endorsed performance centers. We also advise HHS on selecting measures for 20-plus value-based payment programs in the federal government. We have many different areas in which we engage in healthcare quality work and this is one of the excellent projects that we get to do under our measurement science of convening private and public sector leaders to reach consensus on complex healthcare issues and performance measurement.

So with that, I just want to take an opportunity to provide some background on the project itself. So the American Taxpayer Relief Act of 2012 authorized the Commission on Long-Term Care report to Congress. The findings had that $130 billion per year for long-term services support is expected. We expect a dramatic LTSS growth in the next 20 years.

The report provided several relevant recommendations which is to improve focus on quality in LTSS and to pay particular attention to home and community based services.

And…

Operator: The conference has been muted.

Kate Buchanan: So in 2014, HHS awarded NQF a task quarter to convene a multi-stakeholder committee to identify home and community-based services measurement gap as well as to prioritize measurement opportunities. The 2014 committee identified 11 domains for measure development including person-centered planning and practice.

So if we look at the current person-centered planning and practice landscape, we've heard that many states still struggle to implement person-centered planning. The federal and government request assistance from states in the following areas: Operational definition, how to reconfigure a system to support person-centered planning, how to structure payment for person-centered planning and how to select and implement quality measure to effectively evaluate the impact of person-centered planning.

If we look at the future need, 21 million Americans are expected to require long-term services and support in person-centered planning. And in 2012, Kaiser Family Foundation estimated that of Americans who are 65 and older, 70% will use LTSS and Americans who are 85 and older are four times as likely to need LTSS from those ages 65 to 84.

So this context brings us to the current committee charge. And I want to reiterate what Sam said that this is an iterative process. There are many deliberate components of this that will - the committee as well public comments will help impact over the course of the project.

So over the course of eight Web meetings, the committee will refine the current definition for person-centered planning, develop a set of core competencies for performing person-centered planning facilitation, make recommendations to HHS on system characteristics that support person-centered planning, develop a contextual framework for person-centered planning measurement and to create a research agenda for future person-centered planning research.

And so this committee will meet until July 2020. Over the course of that, we will have eight Web meetings. The committee will also release two reports. The interim report, which is due to be released in October of 2019, summarized the committee's work to date. This will be released for a 30-day public comment period. And so we will be able to receive a lot of wonderful feedback on it. We will then go through and finalize our recommendations for a final report that will be released in July and that report will also at a 30-day public commenting period where we will request the community to review the work to date and to make any suggestions or recommendations that the committee will consider.

So as we mentioned, the culmination of this project is a comprehensive report providing recommendations to Health and Human Services and we do want to emphasize that when we're thinking about person-centered planning in this project, we're thinking about person-centered planning in the context of home and community-based services. So we're really looking at this in HCBS setting.

And so as you can see, these are the five goals of the project and that we will have two 30-day public comment periods. But that this project is complex and there are many different facets including, you know, definitions, recommendations for system, a research agenda recommendation for person-centered planning. So there are a lot of really complicated, really comprehensive things that we'll be working on in an iterative fashion throughout the duration. So we'll be constantly - the committee will be constantly revising and it'll be an evolving body of work. So we really appreciate that.

And I will turn it over to Cheryl to handle any questions that members of the committee have and we're going to quickly unmute the lines. We just have to mute them for a second for some of the background noise.

Operator: The conference has been unmuted.

Cheryl Phillips: Thank you, Kate. And so this is a good time for us to clarify questions. We will go into the definition next. So if you're questioning the definition of person-centered planning, we're going to go through slides and Gretchen will lead that discussion.

Right now, this is a call for - do you have questions related to our charge, the scope of our work, the timing and the deliverables? So things that Kate just reviewed with us. And I'll pause and see if there are any questions from the (unintelligible).

I'm not hearing any. We certainly appreciate the feedback that has already come in because I think it has helped to clarify some things moving forward. So again, I will pause one more time and see if there's any questions on the scope of work and what was outlined for the committee charge and then turn it over to the folks who will then go through our definition.

Debjani Mukherjee: Thanks. This is Debjani. So for the committee members, if you have any questions and you would like to raise your hand, please feel free to do that using the Web platform. For everybody else in the public -- we’ve had many public members who have dialed in today and are on the Web -- we will address your raised hand or your question during public commenting. So if you’re from the public and have a question or a comment, please hold on to them, it will come up shortly after the next segment, and then we will allow you to present your comments.

Amber, your hand is raised.

Amber: Sorry. Yes. So I'm just hoping that sometime in the future we can be provided with a working link for Slide 14, just because that seems to be a very important slide, and I just want to verify the data, where it came from. Thank you.

Debjani Mukherjee: We will do that. We will send the link to the whole committee so that they have a working link. Sure. Thank you, Amber.

Any other committee questions from the members? Okay. Hearing none, again this is Debjani, and what I will do in the next segment is kick off the draft definition on the slide, and then I will hand it over to my colleague Sam to sort of take us through, and then we'll have a discussion.

So, as Kate mentioned, this project (unintelligible) different aspects (and parts). And the first one is the draft definition of person-centric planning. Again, this is (unintelligible) process, the definition in various forms (unintelligible) the next many months, and you will be provided lots of opportunities to edit it and provide comments, et cetera.

Next slide. So, basically, to come up with the definition that you will see later (unintelligible) undertook a research agenda. And it's in two parts (unintelligible) looking at current definitions of person-centric planning, and for that we looked at the 2014 NQF HCBS (unintelligible). We looked at the final HCBS rule, as well as federal (unintelligible). We also conducted a (list search) of peer-reviewed articles, (grade) literature, as well as state Medicaid programs, to see what kind of definition (unintelligible) using.

Operator: The conference has been muted.

Debjani Mukherjee: So in the next slide you will see a definition of the HCBS final. You will have that for your reference; I will not read it aloud. But some of the words that sort of pop out are community systems that deliver HCBS, goal of person-centeredness, appropriate quality monitoring, substantial feedback, etcetera.

Next slide. We have the NQF HCBS committee definition. Again, some words that sort of pop out -- assessment planning coordination of services and support, individual goals, needs, preferences and values, and (unintelligible) community, providers and systems to carry out the plan, etcetera.

Next slide. Again this is the administration community living definition. Again, some of the words that pop out are options, preferences, values and financial resources, person (unintelligible) preferences, needs and desired outcomes, paid and unpaid services. And these are just some words that we're calling out now that you will see later enumerated in our definition.

So the next slide starts off the state definitions. We've provided with you a couple of definitions. The first one is Minnesota. Next slide please. The next slide shows you the definition from California. And these are just for reference and as well as if later on you wanted to refer to them and/or use them in any of your comments.

And then finally, the next slide gets us to a list search result. And this sort of talks about what we found when we looked at peer-reviewed literature. We had 31 articles that were related directly to person-centric planning. We also looked at eight different Medicaid programs, and those are mentioned right below. We looked at resources provided to us by ACL and CMS. We looked at the (grade) literature that included articles from AARP, the Scan Foundation, Commonwealth, Justice and Aging, that provided us with a rich evidence related to PCP and sort of information that went into defining the definition that you will see later.

Sam?

Sam Stolpe: Thanks, Debjani. Hi guys. This is Sam once again.

What I'm going to do now is describe the process by which NQF developed a - what we're calling a strawman definition for you all to react to. We wanted to strip down the core components of the definitions that we found of person-centered planning, and characterize them in a way that you all could digest. To look through those individual components and to those individual categories, and get a check from all of you if - to make sure that these sorts of components are capturing what we as a committee feel is a manageable working definition of person-centered planning that we can have - point to as a standard for people to adopt across the industry.

So as we're going through each of these definitions, we pulled out key words and then characterized them into what we had as six components. Now the first was around the purpose of person-centered planning. That purpose is often mentioned inside the definitions, as well as the plan itself, what the components of that person-centered plan should be.

We have something here called "Factors." And what we mean by that is person-centeredness factors, like what does it mean to be person-centered. And those are often operative inside of the definition itself.

Things that also got mentioned inside of these definitions quite frequently were notes around what sort of providers and professionals end up being engaged in the provision of person-centered planning services, as well as things around financial resources and how recipients, persons in the community, need to have that be part of their plan when they're thinking about the financial limitations, and how they can appropriately use the resources available outside of strictly health and safety-based services provided over - through their insurance coverage, but to resources that might also be available in the community.

Then lastly, we had a series of keywords that emerged around access. So let's go ahead and go to the next slide. We'll go straight into that first category which is the purpose, the purpose of person-centered planning.

What we saw emerge quite frequently from these definitions were characterizations of the desires of the individual, of the person. And the definitions that often used words such as individual or consumer or person. I'm going to use person moving forward as that tends to be a term that's broadly accepted in the community, and I apologize if you prefer something else. But person is what we're going to be operating with inside of the committee generally speaking.

So, person-focused decision, determining legal needs for - as far as protection is concerned. There's often mentioned of guardians or family courts. And also the determined advocacy (unintelligible) and availability.

For the person-centered plan itself, quite frequently, the things that we would see emerge inside of the definitions were things such as the assessment of needs, likes and dislikes by the person receiving care -- functional, financial, health, mobility, and social needs. The creation of a plan that's suitable specific to the person's needs and desires. Coordination of care and services necessary to promote living inside of their individual community.

Another characteristic that often emerged is that such person-centered plans aren't fully actualized until the plan itself has been written and shared. (We saw) that numerous times (unintelligible) operating definitions.

There were themes around informed consent, backup plans, as well as the need to include the individual's strengths and weaknesses as they perceive it, as part of the person-centered plan itself.

On our next slide, we listed out some of the person-centeredness factors that we saw often inside of those definitions as well. And those person-centeredness factors included the inclusion of values, a strong sense of a need for cultural competency and perspective and the approach to person-centeredness.

And then we have some individual, like, person-level preferences, needs and desires that often emerged. And some interesting needs that we feel like the committee would be particularly focused on were needs around social and companionship, spiritual and financial needs, included as the person-centeredness aspect of it.

Another aspect that often came up inside of operating definitions is that these sorts of person-centered plans need to be person-directed, that the operative for person-centeredness necessarily requires that the person is the one that is guiding and directing the process by which the plan is developed, and a special consideration needs to be made on the part of the facilitators of person-centered planning to ensure that the person is able to direct the formation of the plan.

So we have some other hallmarks that emerged in many of the definitions, some of which are listed on the slide -- themes around empowerment, that they should be interactive and collaborative, that the honor and dignity of the person needs to be maintained throughout the process, that self-determination needs to be a key focus of the plan, that they should be relationship focused. Again, as noted, person-directed, that the desired language of the person should be the operative language of their plan. There's also some focus on employment opportunities, personal resource control, as well as personality dynamic basis for the plan.

All right, moving on to the next area. Person-centered providers. This is for both paid and unpaid services. You'll see a number of them listed on the slide, which I'll briefly read through. So, excuse me, family guardians and legal authorities, clinical providers, non-clinical providers, safety net providers, support service staff, companions, person representatives, and community workers, were all represented in many of these definitions.

So next we have a slide on person-centered planning resource allocation. And what we meant by that or what we saw inside of the definitions around this were an emphasis on ensuring that patients were able to do an assessment of their - of all of their financial resources as well as physical, housing and community assets that were available to them, and making sure that those needs were met and the resources that were available to the patients were highlighted as part of the plan.

Next up we have access. So the access considerations and person-centered planning definitions that emerged were often around access to transportation, access to social events and community engagement, ensuring that the person has access to groceries and food-related needs, and then access to a variety of supports and services both paid and unpaid, are considerations in the plan.

So, next up, there's some additional considerations for person-centered planning definition that we wanted you to be aware of, that we didn't include inside of those six domains. There's also staff - our staff identified two important considerations for person-centered planning around the 1915 (I) and (C waiver) programs and inside (unintelligible) state (LTSF) programs. These were services covered and provided by the state. So we can get into those if we don't feel like we're making enough progress on some of these other items.

So with that, this is a bit of a slow reveal to a draft definition that we were able to (devise as a staff). Now, just keep in mind that this is intended for you to react to and as a refinement point. We'll spend a lot of time revising this definition, and by no means is this anything close to definitive. What we wanted to do is make it as simple as possible and have it contain each of those six areas, some language around that, for you to flesh out, for you to build out the strawman so that it fits what needs to be a standardized operating definition of person-centered planning specific to home and community-based services. So I'll go ahead and read this and then I'll turn over to our co-chairs for committee discussion.

Okay. So, our person-centered planning is an approach to facilitating the assessment, planning and coordination of an individual's services and supports that is focused on the individual's goals, needs, preferences and values.

The goal of person-centered planning is to optimize the individual's quality of life through consideration of personal preferences (unintelligible) safety needs, as well as resource allocation including access to services that facilitate home and community-based services. Within person-centered planning, the individual must be empowered to make informed choices that lead to the development, implementation and maintenance of written service plan for both paid and unpaid services and support.

Okay. So we've gone and teed it up, and we're happy to answer any questions about how arrived at the definition or our process. But once we've completed that, we'll go ahead and try to advance the first goal of this committee, which is to make this definition refined.

So, Gretchen (unintelligible) I'll hand it over to you.

Operator: The conference has been unmuted.

Gretchen Napier: This is Gretchen, and I'm going to help facilitate this portion of the call today. And just in terms of helping us understand how much time we have and to give us some structure for this, there are six sections and we have about 55 minutes to cover that. And so there are 25 people on the committee and I want to be sure that everybody gets the opportunity to be heard. At the same time, we don't really have time for everybody to share every thought they have. But I just wanted to sort of set that expectation, that is, to keep it brief and concise. And we're going to go section by section, the plan, and then person-centeredness, etcetera, and try to look at it in that kind of way.

Again, if you're not speaking, if you can please mute your microphone or your phone, that would be great, so we don't hear conversations and dogs barking, we'll be able to get through here a lot more quickly.

So, starting off with the plan section, which are the items that are in red here, what other things, concerns, what suggestions you all have regarding the plan part of the definition.

Amber: This is Amber, I actually raised my hand, so I'm just trying to follow some process. I don't know if I can ask a question or not.

Gretchen Napier: Yes, go ahead. I can't see…

Amber: Okay.

Gretchen Napier: …who's raising the hand, so…

Amber: Oh, I'm sorry.

Gretchen Napier: …can see that and you all want to call on somebody, that would be fine. But I can't, I'm not seeing that on my side. So, go ahead, Amber.

Amber: So you're asking us if we have any questions about what's in red, is that correct?

Gretchen Napier: Right. As we're talking about the definition, the red is the plan part, the plan factor. So, specifically about that. And then we'll move on to the other sections.

Amber: Okay. Thank you for clarifying. So my question is in terms of the assessment. I think that assessment is a word that can be confusing and not always evidence-based. So I'm not really so sure if I have a question versus just a comment. I don't know if anyone has anything else to add up to that. Thank you.

Gretchen Napier: Thank you, Amber for that. We appreciate that.

Anyone else have thoughts either about Amber's comment or other comments about the information in red, or just planning in general?

((Crosstalk))

Gretchen Napier: Yes, I can hear you.

Woman: Okay. You could tell me if I'm (unintelligible) because again we're all new to this.

I wanted, just looking at the definition and the core part that you're talking about right now in red, even the definition itself, it's an approach, right there, it is not individual focused, if you're talking about this like it's a medical option. And if you're talking of people, it should be focused on individuals and it isn't optional. It's integrating the person as a core part of this process.

And I did agree with Amber on the assessment because I think that is a very vague word and what does that look like. But I have concern that we just say it's an approach. No, it should be a core - the individual should be at the core of this, talking about a (unintelligible) (that we're) driving somebody else that's driving that person's wants. And that person, it isn't something where we say, oh, I feel like doing this, or, I don't feel like doing this. It's (unintelligible) and people with disabilities are the best experts on their own lives. And it should be consumer-driven, it should be that individuals are the core at what you're doing.

So if it's just phrased it's an approach, that doesn't…

Gretchen Napier: Okay.

Woman: …to me sound like it's person-centered…

((Crosstalk))

Gretchen Napier: I hear what you're saying.

Woman: Did I…

((Crosstalk))

Gretchen Napier: Yes. I hear what you're saying. You have a suggestion for how we (unintelligible) we didn't say person-centered planning is an approach, how would we sort of start the definition.

Woman: Yes. Thanks. I didn't want to (unintelligible) and as somebody who's been on both sides of the process, I can tell you, to me, that as an individual with a disability who has been a part of this process, that does not make me feel like I'm a core part of this. It makes it sound like it's a medical approach that we're going to possibly take.

Glenda Armstrong: This is Glenda. If I could just add, I absolutely agree that it's not about focus, it's about the person directing, it's about the person is the absolute core of the process. So perhaps, and I love NQF HCBS committee definition that essentially says the person directs the development of the plan, which describes the life they want to live in the community. So it's not about the, you know, the preferences and health and safety needs and consideration of culture. I mean, not that those aren't important.

So what it really comes down to is that it is a plan that is totally directed by the person and describes the way they want to live, and the providers' responsibilities are simply to carry out that plan, according to what the person has said that they want. And I think it just needs to be that strong.

Amber: This is Amber. I'm sorry, I just wanted to add something very quickly.

I think, you know, if you did want to start somewhere, it would be, you know, facilitating an individualized, evidence-based assessment and the individualized part is sort of key because there are so many different individuals involved from different siloes that have different needs and that participate in different types of evaluations and assessments. But the word assessment is difficult to digest in the first place. And so, changing that I think might be helpful.

Gretchen Napier: Okay. You said individualized and evidence-based assessment?

Amber: Correct. Correct.

Gretchen Napier: Okay. Just making sure of the words.

Amber: Personally, all I have seen is surveys - things that were once surveys sort of converted into assessments that don't really have any evidence of being person-centered or producing outcomes that are successful, in my opinion. But maybe I don't know enough about it, so.

Woman: This is (unintelligible). I think - I had some feedback to the committee, the organizers just this morning actually. I think it's related to what Amber and others are saying. And my feeling was that the definition, it was more about person-centered planning as a practice, relationally and talking about the plans. But in my experience, to talk about it relationally about the plan without first starting with a really strong statement about the purpose and the philosophy underneath puts it on (unintelligible) grounds.

So my feeling is that the definition should really start with something that recognizes that this is not just the right thing to do or nice thing to do. It's a person's fundamental human right to self-determine around plans that have an impact on their life and their care. And so my feeling as I was playing around with the opening, possibly make a stronger statement around that, something about it's an approach that respects an individual's fundamental human right to self-determination by (unintelligible) coordination, etcetera.

So I have other thoughts about the definition as a whole, but I think I'm agreeing with what others are saying, that I would like it to start with a strong statement that this - I prefer to think about this as somebody's rights, not just a best practice or the right thing to do, is that this is (unintelligible).

Richard Petty: This is Richard Petty. And there is a distinction that does need to be made and understood is - there is a discussion about the individual directing the plan. And that's different from the individual deciding, and that's an important distinction. And I think that's certainly something that we should consider. And in addition to that, we talk about an assessment and what part of that is the individual making his or her own assessment, it can be certainly guided with instruments and help and support. But what I'm seeing there now seems to be of something that's very externally directed at this point. Is that correct?

Gretchen Napier: Yes, I hear what you're saying and I think a lot of the suggestions that have come up have really felt to direct us more toward focusing on the person and instead of the approach. And somebody early on said, suggested that we start back with something like what the Administration for Community Living definition was, right, with person-centered planning allows individuals to be engaged. So, instead of jumping right into the approach, it really focuses on the individual. And then of course, the recommendation to talk about, you know, to be stronger and to be more of a right, I think would help it be more focused on the individual instead of on corporate.

((Crosstalk))

Richard Petty: This is (Richard) again. I did just send out a note, and I'm not - my purpose is not to make this consumer control and consumer direction, which I think is a wonderful approach, but I did send some descriptive information about consumer control which I thought might inform us.

Patricia Nobbie: This is Patricia Nobbie and…

((Crosstalk))

Woman: I just want to reiterate essentially what (Richard) is saying, I just want to go back and talk about the words in black, because I don't think that it is an approach. I think it's really a family of approaches. And the word assessment is incredibly problematic to me. It's really the person's definition. It's the person's definition, which again we could get to (by) a series of questions and knowing of the person and having that person's friends and allies present versus just the system's impression. And assessing, it seems like it's this external thing that we're going to, you know, these patients, they're going to put you through, and it's going to be somebody else's determination and definition of how you define and pursue a desirable future.

I don't think that there's an assessment. There's a hundred that's going to give you that information. It's the person that's going to give you that information.

Woman: Right.

Man: This is…

Patricia Nobbie: This is Pat…

Michael Smull: I'm sorry, Pat.

((Crosstalk))

Michael Smull: I replaced the word assessment with the word discovery, that person-centered planning is a person-directed process of discovery and planning to assist people in determining, coordinating and receiving the services and supports needed to maintain, to achieve its self-defined quality of life.

Patricia Nobbie: Yes. This is Pat. And I was thinking along those same lines. I think one of the elements that I saw missing throughout the entire document is communication, and that no good planning can start without getting to know the person. And so it's a commitment to, you know, the process of getting to know the person, and that also relates to the person who just commented on the assessment being the individual's assessment of what their situation is and what they would like to do.

So I, you know, the words I was thinking of was experience, and then I think Michael said discovery. I think we have to start back a little bit with who is the person, and then, what do they need?

Gretchen Napier: Yes. I think they're all very helpful, and I like the idea of communication and listening, so that when it talks, it's actually something in black, but we talk about individual services and support that is focused on the individual. So it's really focused on listening and communicating to understand the individual goals, something more along those lines, is what I'm hearing everyone saying. Right?

Pearl Barnett: This is Pearl. I agree with that. One thing that I wanted to mention is, in the beginning of the definition, assessment, which I think everyone has determined we don't like that word. But what we're not listening is the actual delivery of services. I think at the end of the definition it talks about implementation, but that's not very clear to me. So I think it will be important to make sure that it doesn't just stop at the written plan but is actually that delivery of the written plan as well.

Gretchen Napier: Thank you.

((Crosstalk))

Cheryl Phillips: And, (Colleen), this is Cheryl. Were you able to get your question answered? I see you've had your hand raised.

(Colleen Starklove): Are you talking to (Colleen Starklove)?

Cheryl Phillips: Yes. I'm sorry.

(Colleen Starklove): Yes. I'm actually writing a lot of things that I hope that you guys would think about. I come out of the Independent Living Disability Rights Movement, and I agree with the people who are talking about this being a right to have, planning that takes - really focuses on what individuals need to be independent.

And, you know, we can suggest, I'm sitting here kind of working with the definition trying to work in things that take out assessment and put in - I think you talked about the word allows an individual to participate. I think it has to be requires an individual's participation in making decisions and making choices from a framework of options that exist in the community. That's where the independent living model goes. And I suggest that and I'm going to keep writing.

((Crosstalk))

Woman: …not saying allow or require, and talk about empowering. Because really it shouldn't be an allowance or requirement of the individual but it's - the process is empowering the individual to participate throughout.

Woman: The reason that I…

Sam Stolpe: Hi, this is Sam. Just one moment. I'm sorry. This is just a reminder for folks who are not on the committee, to please hold your comments until the public comment portion, and allow the committee to deliberate during the course of this discussion. Thank you.

(Anne O'Hare): This is (Anne O'Hare).

Woman: Hello?

(Anne O'Hare): Could I add one? Sorry.

Woman: Sure.

(Anne O'Hare): This is (Anne O'Hare). Could I add one thought?

Gretchen Napier: Sure.

(Anne O'Hare): Okay. And I think this is in keeping with some of the most recent statements, is I do think this is more than just trying to help people get the care they want. I think it is about upholding personhood. It is about upholding the essence of who people are.

And we probably also need to think about people who can't express their preferences. There are whole groups like, you know, in that category. We also need to give some thought to that.

Glenda Armstrong: Hi, this is Glenda. I think that's a great comment too. It kind of leads me to just one other thought I've had. And that is, if we could make our discussions and definitions look like our hearts do. I mean, instead of - this has a lot of language that social workers or nurses or doctors or, you know, institutions would use, and maybe we could use just plain language that everybody would understand and relate to.

You know, when we say things like allow or require and use phrases like, you know, implementation and maintenance and those kinds of things, I think that aren't really everyday language, it kind of sets up a, I don't know, a power differential. And I don't think we want - we don't want to be perceived that way, I'm sure.

Gretchen Napier: Sure. Yes, that's very helpful. That's very helpful.

Woman: I agree.

Gretchen Napier: Okay. I'm going to stop our conversation about planning now, the red part, and just get us moving onto the person-centered factor. So (unintelligible) things that are in light-blue, and some people have already started talking about that a little bit, but we could turn our focus more toward person-centered factors and giving your feedback on the light-blue items, that would be helpful.

(Denise): This is (Denise). I do not understand what safety needs is meaning. Is that safety of the person, is that safety of the home, is that safety in their community as they're trying to access transit? It's confusing to me.

Gretchen Napier: I'm sorry, which word was confusing?

(Denise): Safety needs.

Gretchen Napier: Oh, right. Okay.

Amber: This is Amber. I think I provided my written statement already, but I'll just reiterate because it's coming up, that planning and coordination of an individual services and supports that is focused on individual's goals. I think a lot of the disabled and individuals that are currently in some sort of person-centered planning process in their state, I think there's a lot of pressure, and that the original guidance definition didn't start with individual's goals because people are just sort of living their lives and they're not always - they don't always have goals for everything. So I think that that can be troubling and very - and a lot of pressure.

Gretchen Napier: Well, another word that I have heard people talking about recently are wishes, instead of talking about goals, to talk about what are your wishes. How do you feel about that instead?

(Susan): This is (Susan) (unintelligible). I think that, instead of goals, maybe we should focus really on their desired outcomes. What is it they truly want for their lives? Because from desired outcomes we can create goals.

((Crosstalk))

Woman: …desires.

(Susan): Sorry. I also think that goals and desires are already you're assuming that individuals have, you know, and we're talking about ages, you know, zero to 150. I mean, I think that it's a lot to - I think wishes is better, or hopes, or, you know, desires is better. But I also think it shouldn't - I think goals is a problem, obviously.

Woman: I think…

Bevin Croft: This is - I just want to offer…

Woman: I think outcomes is one of those…

Woman: Yes.

Bevin Croft: One phrase that we found helpful, this is Bevin, is vision for a good life.

Man: Yes.

Woman: I like that.

Maggie Winston: This is Maggie Winston. I was going to say the same. All of these - all of these words in blue could really be concise to just to an individual's pursuit of a meaningful life. And I think that…

((Crosstalk))

Maggie Winston: …talking about person-centeredness and direction, then something about a meaningful life needs to be added.

Amber Carey-Navarrete: Hi, this is Amber Carey-Navarrete. And I concur with everything that we've been talking about in this light-blue section, but I also want to make sure that we call attention to the word "consideration" in light-blue, because when we're talking about person-centered planning, we're not just considering, you know, this vision or pursuit of a meaningful life. (Unintelligible) pursuit of their meaningful life, their vision, their wishes, whichever words we find are the right ones for this definition aren't considered. That is what's directing and at the core of what we're doing here.

Woman: Right, I agree.

((Crosstalk))

Woman: Thank you for pointing that out.

Melissa Nelson: This is - can you hear me?

Woman: I can hear you, Melissa.

Melissa Nelson: Okay. To follow up, I was thinking about the blue word in (unintelligible) because it almost makes it sound like the end-goal is to develop a service plan. And I believe that the end of - or what we're hoping to accomplish is helping people live the lives that they want and the way that they want to live them. So I'd be concerned with seeing the service plan as the end-goal.

Woman: That's a great point.

((Crosstalk))

Woman: I'd just second that. That was my comment as well.

Woman: Yes. This is (unintelligible). I agree with that as well. I do want to point out, and I submitted this in my written statement too, the lack of addressing abilities. We're talking about the needs multiple places throughout the definition, but we never talk about what the person's actual abilities are. And I think that that's amiss.

Also, I think that, to the comment of the consideration, we already in the previous area talked about preferences, and that should be the individual preferences. So there really shouldn't be a repeat of personal preferences after consideration because the - it focuses on the individual's preferences, if that's what we're saying there.

Gretchen Napier: Yes. Thank you, that's very helpful.

(Amber Docker): Consideration -- this is (Amber Docker) -- consideration is used as a singular, which seems like it's just a one-time-only deal and it's kind of an ongoing thing. So I just had a problem with that. And it also serves as a guidance. You know, HHS's guidance emphasized that it should be implemented in a manner that supports the person and makes him or her central to the process.

Woman: Yes. No, I was agreeing with you.

(Amber Docker): Oh, okay.

Dori Tempio: This is Dori. Just to add, I think in the blue, some other words that should be in there are choices and self-determination. I think that's important. It's not just your preference, it's your choice.

Gretchen Napier: Right. Thank you, Dori.

Dori Tempio: And you get to that choice with person-centeredness factor, because we're also promoting self-determination and letting people use that.

Gretchen Napier: Excellent. Okay, for the sake of time, going to move us onto providers, which is in the green section. It's really the very last part of the last sentence, paid and unpaid services and support. Is there any other way that you - or any other thoughts you all have about providers on how we would need to address that?

Patricia Nobbie: This is Pat. So I just - I think just providers or just services that facilitate HCBS is too limiting. And I think we can - we should think about getting out of the mindset that you can only access a quality life through services. There's a lot more that goes into like my daughter's plan, that it's not paid for, it's not paid staff. It's the relationships in the community that we try to build that really expand her world, so.

Gretchen Napier: Yes. So, just to clarify, the brown - I'm sorry to interrupt - but the brown and the green sort of look alike. And so the provider section is really the very last five or six words of the whole definition there.

Patricia Nobbie: Oh, both - okay.

Gretchen Napier: Paid and unpaid services…

Patricia Nobbie: Paid and unpaid. Okay. Sorry, it was the same.

Gretchen Napier: Does that sound better?

Woman: Yes.

Gretchen Napier: Does it sound better?

Patricia Nobbie: Yes.

Pearl Barnett: So this is Pearl, and I just want to reiterate that I don't want us to take away from the person's own ability and their own things that they are bringing to the table and living their life. And then also, I know unpaid support tends to include family caregivers, but it might not be as understood as we would like it to be. So, maybe highlighting family support that also supports the person.

Gretchen Napier: Yes. So you're talking about including the individual's abilities as well as specifically calling out families. I hear that.

Pearl Barnett: Right.

Gretchen Napier: That's great.

Amber: This is Amber…

Woman: And I'm wondering if we could add - if we could add like community resources and relationships. I'd really like to see something about, you know, and this goes back to what Pearl's saying about the person's ability to make their own relationships. So, paid and unpaid services and supports and other community resources and relationships.

Woman: Okay, great. Amber, you said you wanted to say something?

Amber: I was going to say paid and unpaid services and supports, including those that are, you know, self-determined. I mean I think that there are a lot of times when individuals, you know, like, let's say, want something for a higher - better quality of life, like braces, you know, and they might decide to pay for that themselves but it's still something that they decided and captures their decision-making somehow, would be nice.

Gretchen Napier: Yes. Anything else about the provider section?

Dori Tempio: Can I add one last thing in the providers? Because I think people were saying great things -- this is Dori. Either support system, circles of support. Because I think, I'm going to (unintelligible) out there for you all, not everybody has a family, not everybody has a strong support system that's within that family dynamic. I started out my life in a state institution for people with profound intellectual and developmental disabilities. I didn't have a family till I was seven years old. So, some of my support system came directly from other resources.

So, really I want people to be careful of that. Because don't assume that everybody's family is their direct support.

Woman: What if you put opportunities, paid and unpaid support services and opportunities. Because I think that would facilitate, you know, more options at least for people who might be able to find more support if the opportunities were central…

Bevin Croft: This is Bevin. I think Pearl already said it but I want to reiterate and make sure it doesn't get lost, there are so many good comments going around, that in addition to paid and unpaid services and supports and community, sort of community factors, it's I think another really critical piece here, is people's own abilities, strengths and inner resources. So that the plan just doesn't include things that are external to the person that happened to the person but they really include the person maximizing their own gifts and abilities.

Gretchen Napier: Yes, I've got that down. Thank you for emphasizing that.

Woman: I would prefer to use the words formal and informal versus paid and unpaid.

Woman: Yes, I think that's great too.

Woman: Really in relationship - I mean the person - you don't plan for people in a vacuum. So, you know, this is about the person's connections to community, and really talk about unpaid services and supports is really kind of a human services lingo. You know, maybe talk about the person's friends and allies. But I think formal and informal is more respectful.

Woman: Well, and I wonder too though, I mean, how many people really know what we mean when we say formal and informal resources. So if we, again, you know, take it down to the language we use every day and how we - how will we describe formal and informal resources in everyday plain language? And what I've heard from some of the great comments is, you know, circle of support, community relationships, words that everybody will recognize and know what they actually mean.

Woman: Right, right.

((Crosstalk))

Woman: Another term we use is…

Woman: I was wondering, you know, if we could just take out the words paid and unpaid. I mean, do we really need to make the distinction? Really if the person is being, you know, at the driver's seat, I think it should just be the services and support that they deem relevant and essential.

Woman: Agree.

Woman: You could say paid and then say, you know, informal, natural relationships or whatever. I know when I was at ATL and we were working on a caregiver survey, we had a lot of discussion about paid, unpaid, formal, informal, and in order to be precise about what we meant. So I think that's a - that does need to be sort of vetted out a little.

Man: Yes.

Gretchen Napier: Thank you all very much for that input. I think that will be really helpful to us going forward. But I need to move us along. So we're going to switch to the next section which is about purpose. And the part of the definition that was proposed for purpose is "optimize the individual's quality of life." Do all feel like that's the best purpose or do you have comments or thoughts about how we can make that a better purpose?

Dori Tempio: This is Dori again. And because that goes back to something somebody said but it ties in to this. At the end of the day, if we're working with individuals and it's about them, you want it to be in language that they can understand…

Woman: Yes.

Dori Tempio: …plain language. Because if this is - we're working with them to make this happen, at the end of the day, when I read this whole thing, the typical person nationwide reads at a sixth grade level, is what statistical data says. So, half of the people out there wouldn't be able to read this if they didn't have a disability. And if you do have a disability and being a person with the developmental disability myself, if that's one of the populations served, I wouldn't understand this if I didn't have the ability to process at - it takes me a few minutes.

But the honest truth, I think when you put this together, somebody early on said it, and I agreed, put it in easy-to-understand language that gets right at the core or center of what you're trying to say. Optimize the individual's quality of life. Most typical people who you're serving through person-centered planning would have no idea of what that means. So, putting it straight, simple, to the point, that I want to know that, if this is for me and I'm the person that you're serving, together working with you through this process, I want to know exactly what it means, how this is going to help me, what is my role in receiving with you the services, and what do I have to offer out here to make this work together with the person who's a part of my plan?

Melissa Nelson: This is Melissa again. I was just thinking, to my earlier comment about, is the ultimate goal to be supporting people to live their best lives?

Amber: This is Amber. Yes, I just wanted to sort of emphasize that also, that, you know, it's a tremendous amount of pressure for somebody to be empowered, and then through empowerment they are making informed choices at least to development, implementation and maintenance. How does an individual know that the choices that they made are actually leading to that outcome, without some kind of due process or review process or, you know, opportunity to check if that's actually going forward, if they're empowered. It's just a bit unrealistic and pressurized for someone who might not feel empowered and yet they're sitting in a situation where they're supposed to be empowered.

Gretchen Napier: Sure. That makes a lot of sense.

What other thoughts do people have about purpose?

Pearl Barnett: This is Pearl. I suggested using the term right outcomes rather than quality of life. And it's, you know, back to that outcomes and allowing that to be, you know, based on the desires of that person.

Glenda Armstrong: Hi, this is Glenda again, and I'm wondering too if making maybe even a little bit simpler if, when I go back to the NQF HCBS committee definition, I loved the phrase, the life they want to live. It's very simple and it really kind of says it all, just the life they're - we support the life they want to live.

Woman: That's great.

Gretchen Napier: I like that a lot. Okay, I'm going to end the purpose on that note. I think that's a great way to end the purpose section on. We're going to move on to resource allocation, which the words they've used are resource allocation. So I know we've had a lot of conversations about trying to use plain language. Is this plain language enough or do you all have some suggestions for how we could make that clearer, more easily understood?

Amber: This is Amber. I just, you know, I put my comment in writing, but I feel that resource allocation is mentioned and it seems to dismiss, you know, that there's a conflict-free aspect here that, you know, maybe the term conflict-free should be in here. You know, I just - if it's going to be…

((Crosstalk))

Amber: …you know. Yes, it is complicated, but…

Woman: Yes, it's not plain language. Resource allocation is not plain language.

Amber: Right.

(Jenna): This is (Jenna). I agree with the comments about the more common language, and also with this component in particular, I would definitely like to see something a little bit stronger about community inclusion in there. So, building off of what others have said, the goal of PCP is to help the individual move towards the life they want to live in the community of their choice. So, kind of getting away from the word goal or desired outcomes or quality of life, but also at the same time, you know, highlighting the aspect around community inclusion, which seems to be relevant to this component.

Woman: This is (unintelligible). With resource allocation, we need to - I'm not sure if we're talking about me the individual who's trying to create my own person-centered plan or if it's resource allocations that are available in the community. Somehow we really do need to break those into two parts.

Gretchen Napier: Sure, because obviously you have to take into consideration all of the resources that are available, whether they're from the community or from the person. So, more clarifying that a little bit, I can see how that would make sense.

What other thoughts do you have about resource allocation?

Patricia Nobbie: I think how you just said it is -- this is Pat -- to say how all of the resources available to the person can be applied to help them live a life in the community. I mean, that's kind of wordy, but it's not just the service resources but the other resources that are available in the community that need to be available, you know, need to be applied.

Amber: Yes. This is Amber. I just want to say that I think the word negotiation, which I put in my comments, is really kind of important because there should be sort of a delineation between what's necessary and the work to highlight the work to highlight the importance of negotiating and figuring out. Discovery, somebody said, was a very good word. So I just wanted to emphasize that.

Woman: I'm having a hard time understanding the difference between resource allocation and providers in this context of this conversation. Is anyone else?

Woman: Yes, I do.

((Crosstalk))

Woman: Resource allocation has not been a part…

Woman: Who's speaking?

Woman: …process…

Bevin Croft: Sorry, this is Bevin.

Woman: I think, you know, what I would say is that resources are not only dollars but also the - maybe the insurance coverage that they have or like a resource from their church or worship community that provide support for them, that sometimes is the provider, you know, that is paid or unpaid support service, but it also is the actual resource being utilized, whether it's someone's time or money to…

Woman: What about personal resource allocations? I mean those are something that takes place, if you want to sort of specify what kind of resource allocation.

Woman: Right.

Richard Petty: Well, this is Richard Petty. The resource allocation, using the term allocation implies already - I don't know why that happened.

Woman: Okay.

Richard Petty: But that implies that you're splitting up resources. And I'm not sure it sounds like that's what we really mean.

Pearl Barnett: Yes. This is Pearl. I would like the word allocation to be removed. I don't know if anybody else (unintelligible).

Woman: So it has to do more, with what I hear you all saying, that it's more about the community and individuals, resources, and how they are utilized for the individual's best life, something like that.

Amber: No, I disagree. I'm sorry. This is Amber. I disagree. I think resource allocation means dollars, and there are personal resource allocations and then there's other resource allocations. So, you know, the problem is not the term, the problem is specifying it, if you're going to say it, and it should be specific.

Pearl Barnett: Well, I think this term is, I mean, questionable. I think - this is Pearl again. If we're talking about dollars or finances, then we say finances. If we're talking about community interactions or emotional support, then we say that. But the term allocation can mean so different things. And then it could also mean nothing to some people.

Woman: Can I ask you a question? Are you also talking about tools or equipment or assisted technology that someone may need as well?

((Crosstalk))

Gretchen Napier: Right, I think that's a great point. So in some ways we're being too generic and not specific enough.

Woman: Right.

Gretchen Napier: So we just need to kind of weigh out how specific we're going to be without a two-page document that is the definition. So we'll take all this under advisement and I'm sure that the NQF staff is going to be able to take all of our feedback and come back with something that has taken all this into consideration.

Because I want to be respectful of everyone's time, I'm going to move us on to the last section, which is access. Does anybody have - and this is the access to home and community-based service. Does anyone have some feedback about that?

Amber: This is Amber. I have a big statement on that because I think access, you know, it literally says, access to services that facilitate HCBS rather than access to HCBS services. So it implies that there's multiple tiers involved of engagement prior to even accessing home and community-based services.

Bevin Croft: Hundred percent agree. This Bevin.

((Crosstalk))

Woman: …HCBS's services, so.

Bevin Croft: Well, it could. Yes.

Gretchen Napier: What other thoughts do people have about the access portion?

Woman: It's only one line.

Woman: Could you put something…

Woman: I think you can add the word supports, it's not just services but services and supports.

Woman: Could you put something, and I'm just thinking off the cuff here, but I would like it to include something in there access, however we decide to say it, access to services that facilitate or help an individual to have, you know, or access home, community, you know, based services, because that's what I'm looking at. It's not pressing the individual, and I think that's what it is. It's aimed to help the individual to use the services within.

Woman: That's right.

Maggie Winston: This is Maggie Winston. I think it's important, maybe also put something in about removing barriers to access to services, or just putting a notion in there that barriers exist to access the services. And so, something like that.

Gretchen Napier: Okay, great. That's really helpful.

We're almost finished. I'm just going to open it up, in addition to continuing the comment about access, is there anything that others would like to share about this definition before we can move on and open it up to the public comment?

Bevin Croft: This is Bevin. Just really briefly, my suggestion would be to eliminate the use of acronyms in this definition, in keeping with the comments about making this more accessible in terms of language. People can feel really alienated by acronyms. I don't think we need them.

Gretchen Napier: That's a great reminder, thank you. What other feedback do we have before we - from the committee, before we open it up to public comments.

(Sarah): This is (Sarah). I agree with the simplification of the language. I think this definition is really robust and it's really hard to dissect. So I look forward to seeing the next iteration of this definition.

Maggie Winston: This is Maggie Winston. I would agree with that statement as well. And just reiterate that it sort of still sounds like a medical document in a lot of ways and that independent living movement and philosophy and, you know, even person-centered planning is more of a social model, and this document really does not reflect that 100% yet, I don't think.

Amber: This is Amber. I just am still confused as to why this - the current definition is not good enough and, you know, kind of a bigger question? But maybe somebody can tell me at another time why we're reviewing something that's already been defined. What was problematic with the first definition? Which I already put in my written comments. Thank you.

Gretchen Napier: Okay. Thank you. I think we're going to wrap up this session and open it up for public comment. Thank you, staff. This is our first call. I want to make sure I'm following along the protocol. Is there anything else we need to do before we open it up to public comment?

Woman: No, we're good. And also individuals can use the chat function as well to provide public comments. And we will give them a minute in case they're on mute. So if you're trying to make a public comment and we can't hear you, you're probably on mute, so please unmute yourself.

(Colleen Starklove): This is (Colleen Starklove) in Saint Louis. Can you all hear me?

Woman: Yes, we can.

(Colleen Starklove): Okay. Thank you for this opportunity to offer some public comment. I've been busily writing in the comments column, so I submitted a lot of things to your committee. But I would like to - I'd like to tell you that I think it's really important, first of all, to understand that the people who will use this definition to do planning with individuals who have disabilities, many times do not understand the model of people with disabilities using their voice to express what they want.

It's important that the definition really be very much of a guiding tool. That's why I suggested earlier the word "require," requires the strong input and direction from somebody with a disability. That doesn't mean you can't offer them suggestions and ideas, because many times they may not be aware of (what's out there) in the community.

But the word independence and living independently is not in this definition, and I think that's something that really needs to be there. So I sent a lot of -- I won't take up everybody else's time -- I'm sending a lot of comments, I'm very happy to help this committee. I do think that it's very important that you have more people with disabilities on this committee, because you're already seeing them speaking up and saying this doesn't really fit me.

Woman: Thank you.

Woman: Yes. Do we have any other public comments? We're looking at the chat box as well. So if people are unable to submit a public comment via the phone, we are looking at our chat box to see if there are public comments.

(Marsha): This is (Marsha) (unintelligible) in Oregon. I'm (unintelligible) association and (unintelligible) but I'm speaking (unintelligible) my son as a consumer of in-home services. It might be as simple as asking (someone), what kind of things would you like to do or participate in that would make your life happier? I think that might be easier for some people to understand.

I even have trouble with the phrase person-centered care. It sounds to me like a medical treatment that somebody might arrive to give you. I think plan is a better term. And as for definition, I think these are essential elements of living. And as a person for - looking for their (facial) expression, their desires, and your role would be to actuate this. Thank you.

Woman: Thank you very much for providing your comment. Do we have any others?

We have one that was submitted via chat that we're going to read aloud.

Man: This comment comes from Michelle. I agree with the use of plain language (unintelligible) advocates can understand. I suggest a bulleted list rather than a lengthy paragraph. I also suggest the definition make it clear that person-centered planning is one piece of person-centered thinking and practice.

Woman: We have another comment?

Woman: Did you say yes or no?

Woman: We have another comment from Melissa, and she has asked. Does resource allocation also refer to eligibility for different services?

Woman: That's definitely something that we will go back and think about. I appreciate that provocative question, a very serious, thoughtful, inducing question.

Woman: And are there other public comments?

Man: Yes. From (Laura Demuse). We've been talking about the relationship of the journey of the person versus the needs of the system. I think this - sorry. I think this is the problem you've been talking about the entire time. We are considering (unintelligible) as directed at the person in philosophical level than making a plan of service and the person-centered planning process defined as being the two systems, pieces that make up person-centered planning.

And it goes on to say the key will be making sure that the definition of person-centered planning is the plan of service plus the person-centered planning process.

Woman: Thank you very much for that comment.

Woman: And another comment from (Kelly). Her question is, how will PCP accommodate the needs of those who cannot advocate without the assistance of another person?

Woman: And I think that's a really good comment, it was something that the committee discussed today about talking (unintelligible) and in making sure that's including the definition. So we appreciate that.

Woman: Yes.

Man: Another comment from (Amy). As someone who does person-centered planning regularly, the definition you've listed is way too complicated. A PCP is a living, breathing document that focuses on what is important to inform individuals to live a preferred life in their community.

Woman: Thank you very much.

Man: One more from (Susan Onell). Just want to say the flavor is still institutional and need-based, not strength-based, not (gift-based), not inclusion and valued social role based. Don't always lump family with guardian and/or legal authorities, implication that family is always monitoring or supervising. We offer companionship, we simply love the person, we have legitimate needs in this process too. Also family is one form of community support, and as Dori pointed out, not the only or always available. It makes no mention of neighbors or friends, partners, children, etcetera. I worry about lack of diversity and voices of people and family members who are in communities who are underserved.

Woman: Thank you very much for that comment, and we'll definitely take that into consideration.

Woman: (Alan) has written, I think there needs to be more emphasis on PCP as a process rather than event. I also think there needs to be an emphasis on providers being willing to change the way they do business and respond to PCP.

Woman: I appreciate that comment. It definitely reflects a lot of the things that we heard from the committee as well as other public commenters.

Man: Michelle has a follow-up comment. Related to the goal, isn't the plan intended to make it possible for the person to live a life like any other person? Live as they choose and as close as possible to the life they would live if not hindered by disability.

Woman: Yes, and I think that that was something that all of our committee members were talking about as person-centered planning being the process and an outcome to people living their ideal lives.

(Unintelligible) have any more via the chat. Do we have any more on the phone, before we move it over to next steps? Oh, Pat (unintelligible) you have your hand raised? So, Pat, did you have something that you wanted to mention?

Patricia Nobbie: No, I didn't realize that I had clicked that.

((Crosstalk))

Patricia Nobbie: I agree. I think the public - I think the public comments were spot-on and did agree with a lot of the things that were raised during the call. So that was good.

Woman: Okay, great. And we have one more public comment (unintelligible)?

Man: If I may, I would like to comment that the point about goals and wishes I found very true from my experience of developing outcomes for people with (ED/ID) receiving services. Many people do not have goals and (unintelligible) the people we serve, and we end up putting - I'm sorry, it's the end of the comment - words in people's mouths.

Woman: Okay. Good. Thank you for that.

Patricia Nobbie: Actually this is Pat, and I would like to just mention the comment that (Colleen Starklove) made in the beginning about independence. I get nervous about that because there are many people with intellectual disabilities who will not be independent. They can live successfully with support in the community, but they will not be independent. So I just want to be cautious about that.

(Colleen Starklove): (Colleen Starklove), can you hear me?

Woman: Yes.

(Colleen Starklove): Independent living - I'm sorry, I didn't get the name of the person who just made that comment. Independent living does not mean living without support. My husband was (unintelligible) to wheelchair, became one of the national and international leaders in the disability rights movement, and had - couldn't get out of bed every day, couldn't bathe and dress himself. But he had the right support that enabled him to be independent.

So we're really not excluding people who can't make their own decisions without some supports. Independence is very all-encompassing but it does not mean doing things by yourself.

Woman: Thanks for clarifying…

Woman: And it also means being a part of the process, that it's part of decision-making for your own life. So it doesn't mean you do everything by yourself, but you're included in the decisions made about you and what you want for yourself.

Woman: Great, thank you. And I believe, (Kris) (unintelligible) you have your hand raised?

(Kris): I do. Can you hear me?

Woman: Yes, we can.

(Kris): Okay, great, thank you. I submitted the chat box but it seems like maybe they're not coming through. I'm with the National Association of Social Workers, and really appreciate the opportunity to observe the Webinar and it's been really thought-provoking.

I'd just like to comment on some of the terms that were being discussed in relation to people in (unintelligible) and the supports and services they provide. You know, I can empathize with the challenge around paid and unpaid, which gets even blurrier now that some family caregivers get remuneration (unintelligible) formal and informal. You know, at NASW, we tend to avoid informal because we've gotten a lot of feedback, as had some of our partners, that focused their entire work on advocacy on behalf of (unintelligible) with family caregivers, that the term can feel minimizing to family caregivers. So I think I'd just, you know, mention perhaps some caution (unintelligible) that term.

And also the idea of family (unintelligible) can relate toward somebody who's saying about how we really need to be as inclusive in that term as possible. We tend to just say something like as defined by each individual. And so it's really kind of looking at redefining the term family rather than continuing to add on additional (unintelligible) may pose some feeling of some are more important than others (unintelligible) legally recognized family versus the friends or the neighbors or whatever.

And then finally, just a big shout-out, can't remember who it was that mentioned, abilities, that I was really glad to hear the need for that, and, you know, would agree, ability, strength, however you describe them, just that concept (unintelligible) would be great. Thank you.

Woman: Thank you so much, (Kris). And I believe we have another comment in the chat box.

Woman: Yes, we have a comment from Angela. And she asks, why are the terms care recipient being used? This term (doesn't) empower people. Person-centered planning is about a person and not about care. Person-centered planning support, the person could think about how they want to live their lives and what supports an individual may need to accomplish their life expectations. Care is about a medical need. This is critically important to truly honoring the individual and the principles and values of person-centered planning.

Woman: Thank you very much for that comment, Angela.

Man: We have one final comment, from (Aaron Levisten). Hi, thanks for - thanks very much for taking public comments. I agree with the recommendation for plain language, and would ask the (unintelligible) use the term person rather than individual, which is often used to indicate person in services, people with intellectual and development disabilities.

I also agree with an earlier comment by a committee member that goal of person-centered planning should be supporting the person to have good life as they define it. Finally, I would encourage the committee to review the work of the National Supporting Families, Community of Practice.

Woman: Thank you very much, (Aaron). We will take a look at the resources that you identified.

I think with that, we are going to close up all the commenting period. As always, people are free to email us if you have additional comments at PCPlanning@QualityForum.org. We will show that email address on the slide, so it's available on the slide deck. But if there are additional comments, please feel free to email us.

And we are moving on to my colleague (Ivan) to talk us through our next steps.

(Ivan): All right. So our next steps, just wanted to share information about accessing SharePoint for our committee members. I do believe a welcome email was sent out which gave details about your NWF SharePoint log-in details and where you will find the documents. Please feel free to reach out to us if at all you're having any problems accessing that Web site.

Then (unintelligible) documents will be posted on the SharePoint as well as to your calendar invitation which will be sent out prior to the meeting.

For the public, if you want to keep track of the meetings that we have, we ask that you go to the project page and subscribe to have these meetings on your calendar outlook. We also ask that you subscribe to the project alert so that way you will be informed of all the developments as they happen.

The committee roster and biographies have been posted on the project page. We'll soon be posting all the public comments that we received, as well as the responses that was provided by the project staff.

And on the calendar meetings, I already touched that, so we're good.

The next slide just shows a picture, a screenshot of what SharePoint will look like once you access it. It will have all the meeting materials according to the Web Meeting Number 1 up to I believe 8. That's where we load it as the materials are being developed.

And the next slide, that gives you an outline of what it will be looking like. You will just click on the Addition button for it to expand and (unintelligible) drop-down of where you can find those resources.

(Unintelligible) we have all the committee Web meeting schedule, the dates and times, Eastern Time, and the objectives of each and every meeting.

So the next steps. The project staff, which is the NQF staff, will incorporate the feedback that has been received through this discussion and whatever it is that we receive through the chat box. We will incorporate that feedback into the definition. So we'll continue in conducting (an environmental) scan of the core competencies for performing PCP facilitation. Feel free to send us our way any resources that you might want us to look at, to our project page which is PCPlanning@QualityForum.org.

The next committee meeting, which is Meeting 2, will be on June 22, from 2:00 to 4:30 - June 24, from 2:00 to 4:30 p.m. Eastern Standard Time. And during that meeting, we will present the initial scan of the environmental scan findings and requests that we obtained, input on the environmental scan, scope and approach. We ask that you log in early, mute your lines so that we can maximize all the time that is allocated for this meeting.

Woman: And with that, we want to give (Gretchen) and Cheryl opportunity to provide some closing comments.

Cheryl Phillips: Well, this is Cheryl, I will step in. First of all, thank you all. I think this has been a remarkably rich, diverse and important conversation, and I think it set a framework for what the rest of the work will be. Occasionally there are opinions where we may have some disagreements within the committee, and I think that we have balanced that well. And we will wait to see the staff's next version taking into account all of the committee's comments as well as comments from the public.

So again, thank you all for being attentive, participatory, respectful, and part of this most important conversation.

Man: This is (unintelligible). Just on behalf of NQF staff and our other co-chair who has already had to (dip out), I just want to offer our thanks as well. This has really been a great conversation. We're looking forward to continuing that conversation on June 24. And we'll be in touch via email in the interim. Thanks everybody. Have a great weekend.

Woman: Bye.

Man: Thank you.

Woman: Bye.

Woman: Thank you.

Man: Bye.

Woman: Thank you.

END