NATIONAL QUALITY FORUM

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HOME AND COMMUNITY-BASED SERVICES QUALITY COMMITTEE IN-PERSON MEETING

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ADDRESSING PERFORMANCE MEASURE GAPS IN HOME AND COMMUNITY-BASED SERVICES TO SUPPORT COMMUNITY LIVING

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THURSDAY
APRIL 30, 2015

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The Committee met at the National Quality Forum, 9th Floor Conference Room, 1030 15th Street, N.W., Washington, D.C., at 9:02 a.m., Joe Caldwell and H. Stephen Kaye, Co-Chairs, presiding.

PRESENT:
JOE CALDWELL, PhD, Co-Chair
H. STEPHEN KAYE, PhD, Co-Chair
ROBERT APPLEBAUM, MSW, PhD, Scripps Gerontology Center, Miami University
KIMBERLY AUSTIN-OSER, MS, SEIU Healthcare
SUZANNE CRISP, National Resource Center for Participant Directed Services
JONATHAN DELMAN, PhD, JD, MPH, University of Massachusetts Medical School
CAMILLE DOBSON, MPA, CPHQ, National Association of States United for Aging and Disabilities
SARA GALANTOWICZ, MPH, Abt Associates Inc.
ARI HOUSER, MA, AARP Public Policy Institute
JAMIE KENDALL, MPP, Administration of Community Living

PATTI KILLINGSWORTH, Bureau of TennCare
K. CHARLIE LAKIN, PhD, Retired, National Institute on Disability and Rehabilitation Research
CLARE LUZ, PhD, Michigan State University
SANDRA MARKWOOD, MA, National Association of Area Agencies on Aging
BARBARA McCANN, MA, Interim Health Care*
SARITA MOHANTY, MD, MPH, MBA, Kaiser Permanente Northern California
GERRY MORRISSEY, MEd, MPA, The MENTOR Network
ARI NE'EMAN, Autistic Self Advocacy Network
ANDREY OSTROVSKY, MD, Care at Hand
MIKE OXFORD, Topeka Independent Living Resource Center
LORRAINE PHILLIPS, PhD, RN, University of Missouri
MARY SMITH, PhD, Illinois Division of Mental Health
ANITA YUSKAUSKAS, PhD, Pennsylvania State University

NQF STAFF:

MARCIA WILSON, PhD, MBA, Senior Vice President, Quality Measurement
NADINE ALLEN, Project Analyst
ANDREW ANDERSON, Senior Project Manager
JULIET FELDMAN, Project Manager, Stakeholder Collaboration
SARAH LASH, Senior Director

ALSO PRESENT:
ELLEN BLACKWELL

D.E.B. POTTER

*** Present by teleconference**

T-A-B-L-E O-F C-O-N-T-E-N-T-S

P-R-O-C-E-E-D-I-N-G-S

9:02 a.m.

MS. LASH: Welcome back, everyone, and good morning. Hope you all got some rest last night. And we thank you for all the work that you've done so far.

Our Co-Chairs deserve a special round of applause for staying late with the NQF staff to really hammer out a lot of details and trying to understand what we heard in yesterday's conversation. So I think we'll do a little bit of recapping and summarizing that to re-ground today's discussion. And we've got a really nice down payment on measurement domains that we were able to accomplish during that conversation about characteristics of high-quality HCBS. And so, we'll have some revisions to today's agenda, but I'll sort of preview those for you as I go.

Could I have the next slide, please? So HCBS quality, our raison d'etre. The high quality HCBS system is needed to support older adults, people with multiple chronic conditions

and people with all types of disabilities of all ages. And we know that established frameworks and quality domains for evaluating LTSS and HCBS exist. This project is seeking to build upon that.

We had suggestions of look at this framework, look at that framework that sort of bubbled up when we were dialoguing yesterday. And one thing that we'll do this morning is crosswalk what we have found in the literature from existing frameworks and efforts to yesterday's conversation. And we can see, I think, a good deal of synergy in where the thinking of this group is and some existing work and quality.

But this project is setting a direction for enhancing what we have right now, because I think most of us agree it's not adequate for what we really need to be confident in the quality of HCBS and make the case for why it's so important, and we're really trying to do that through quality measurement.

So we know that states are going to be important players in quality measurement and that they've already invested quite a bit in certain modes of measuring and ensuring quality. And I don't want to send the message that we want to do away with any of that foundational work, but rather to sort of raise the bar and set a path forward for the next generation of quality and performance measurement.

Next slide. So measurement, this sort of arose yesterday as well, is designed to drive quality improvement, inform choice -- whether that's a consumer's choice or other people making decisions about things like contracting -- and potentially influencing payment. And measurement is most meaningful when you can detect meaningful differences in performance. And that gets to something that was discussed yesterday, that we really have a continuum of quality in HCBS just like we have in everything else. And measurement is most effective when there are meaningful differences that are revealed through the act of

conducting the measurement.

One example that we use here at NQF is if you looked out your window at a thermometer every day and it was always 73 degrees, would you still waste your time checking the thermometer every day to find out that it was still 73 degrees? So if we have fluctuation --

(Laughter)

MS. LASH: And it would be a lovely day, wouldn't it? So that we want to think in our work about the measures that will help us find those differences so that low performance can be addressed.

And I also want to say that measurement isn't the only way to change quality. Sometimes when we're in a committee like this every -- when you're the hammer, everything looks like a nail, that sort of cliche. Some aspects of quality care are going to be much better addressed by things like training, accreditation, payment and policy changes, peer review teams, consumer input into program design. So I really

encourage us to think critically about what are quality-improvement opportunities that can be influenced through performance measurement and what we might want to put in another bucket for other quality improvement initiatives.

Yesterday there was such good dialogue. I wanted to share a few things that I heard that we should carry forward today. First and foremost, that consumer outcomes are primary and the system only exists to serve those people and to maximize their inclusion and participation in the community, among other things, and that there is a continuum of quality present in the current system now, that coordination and integration of HCBS with health services is important, but at the same time we need to guard against over-medicalizing home- and community-based services.

And there were several conversations about high-level concepts like affordability and safety versus risk that we know are going to be defined differently based on what perspective a

stakeholder group is coming from. So, that consumers and different consumers and providers and different types of providers, various states will have different views on what constitutes affordable or efficient care, or sufficiently safe care or unsafe, or informed by choice.

And so, there will be room to measure any one topic from multiple angles and so that we don't have to decide just one way to deal with a concept like affordability or risk versus safety, that we in fact probably have an imperative to hold some conflicting philosophies in our heads at the same time so that the measurement framework can adequately meet the different needs of the diverse HCBS consumer population.

And we also talked a lot about certain concepts operating at a systems level, like the triple aim, and it really kind of only works if you're thinking macro and big picture. And other things are only meaningful when you're getting close to individuals and how they are living on a daily basis.

So when we think about these levels of analysis, measurement can operate at any or all of these different levels and certain topics go in one place. They might go in multiple places. And we'll tease out where certain measurement ideas best fit in who's accountable for each of these different types of processes, structures and outcomes.

The last thing we wanted to recap for you this morning are the results of the prioritization exercise on the high-quality HCBS system characteristics. There was, you know, in our long debrief after yesterday's meeting, a thought that we might want to collapse the bottom three categories here into something along the lines of well-being, and we can have a later discussion about what we want to call that, for two reasons: first, that there important concepts here about consumers' judgment of safety, physical and emotional health and well-being and freedom from abuse, neglect, exploitation or avoidable harm. And they do sort of relate.

And we thought that putting them together also makes a bullet that's relatively the same level of magnitude or size as some of the other ideas on this list that lump a few things together like the many concepts after that follow choice. There's a lot of nuances to that. So we'll get back to our domain discussion on these characteristics in just a minute.

Today's agenda in a new and improved way is we're going to try to do the following things: we just had a recap. We are about to begin a large group discussion of measurement domains that build on what we heard from you yesterday and what the staff had found in our literature review prior to today's meeting. We'll take a quick period for public comment and a break in the morning. And then we are going to break you into small groups to add further specificity to the measurement domains in the form of sub-domains. We'll probably break for lunch after that point.

And then after lunch we will tackle

your input on a sketch of a conceptual framework that we came up with last evening to see what enhancements you might be able to offer. We will review the methodology for the next step in the project, which is environmental scan and synthesis of evidence, and we'll close with a round robin of the full Committee. And we're trying very hard to end the meeting on time at 3:30 because we know many of you will have travel plans built around that.

Are there any quick clarifying questions before we begin the domain discussion?

(No response)

MS. LASH: Okay. To Steve and Drew then.

CO-CHAIR KAYE: I just wanted to first of all thank everybody for sitting in the same seats that you were sitting in yesterday, which makes it easier for the two Co-Chairs to call on you when we need to. And to acknowledge Barbara McCann joined us yesterday. Turns out she was on the phone all day yesterday, but her line was

muted and we didn't know that.

So I mean, I think you deserve extra credit for managing to remain silent and calm. So could you introduce yourself?

MEMBER McCANN: Yes, thank you. I can't say I remained silent or calm, but several people in the Atlanta area know my opinion.

(Laughter)

MEMBER McCANN: Thank you. I am a medical social worker by training and I work now with a large provider group, Interim Health Care, and 50 percent of our revenue is from home- and community-based services, and has been. We will be 50 years old next year as an organization in many, many states. I've worked with the Joint Commission on measurement. I've worked on PACE measurement and home health measurement. So this is dear to my heart and I am so pleased to be with you because in this country we need this so desperately right now. So, thank you.

I know you all by your voices, though.

(Laughter)

CO-CHAIR KAYE: Thank you, and welcome. Drew, you want to --

MR. ANDERSON: Yes. So we're going to move into the domain work. I'm just going to go through kind of how the sources were selected for the kind of frequency chart that we put together, if I can bring your attention to that. We handed it out yesterday. So we reviewed more than 200 sources, as you guys have seen. From those sources 38 were found to contain domains and sub-domains of quality measurement for HCBS or LTSS. And then we actually have the source selection criteria included and it kind of breaks down what these terms mean as far as relevance, breadths of scope, evidence type, source type and currency.

Those 38 sources were evaluated based on these criteria. Essentially breadths of scope was making sure that the source was broad enough to be inclusive since we are taking a very broad approach here. So it wasn't as granular as like looking at specific programs, but it more looked at like a system-level perspective. And evidence

type. We favored like systematic reviews, things that were more comprehensive. Source type, we favored things that were maybe a government report or something that was published in a research journal or that was peer-reviewed. And then since the body of evidence in this area is constantly changing, we favored the sources that were more current, something within the last 10 years. But we also recognize that there are seminal pieces that are important to the work as well, that are older, right.

So from that extraction of domains and sub-domains of quality we pulled the most cited and the most often cited. And as you can see from this list they were seven most cited, and then there I think eight, yes, eight often cited ones. And these are really collapsed up into very high-level buckets. I think I'll just point out that the first two, the consumer and caregiver experience is more about -- from a subjective standpoint. It's more about like person-reported experience. And the access to

supports and services bucket really comprises those five facets of access: affordability, accessibility, accommodation, availability of services. And I think the rest are pretty self-explanatory. And there are those huge buckets like quality of care and quality of life.

So from this yesterday we pulled together what you guys had come up with and we crosswalked it with what we found in the literature. And I think the only ones that we would want to pull out that we didn't find -- that didn't match up per se, were the equity, which we thought was very important, and then also the participant engagement in planning their program and designing their programs.

CO-CHAIR KAYE: Let me point out to you that you have a copy of this.

MR. ANDERSON: Yes, it's on --

(Simultaneous speaking)

CO-CHAIR KAYE: So you don't have to struggle to read it on the screen.

MR. ANDERSON: Yes. So we're going to

open it up to -- we're going to move right into discussion and kind of allow you guys to react to this. You can take a moment or so to look at how these things matched up and then we can talk about it.

And also if you need any clarification on what those buckets mean, please feel free to raise your hand.

MEMBER YUSKAUSKAS: Yes, I do. I'm curious what performance -- how you interpret that.

MR. ANDERSON: So the performance looked at performance of the system, performance at the intermediate entity level, like the health plan or the provider. It really is those levels of analysis and measuring performance at those different levels.

MEMBER YUSKAUSKAS: So like that would be change from one time to another.

MR. ANDERSON: Time to another, yes.

COURT REPORTER: I'm sorry. Can I ask who was speaking?

MEMBER YUSKAUSKAS: Anita Yuskauskas.

COURT REPORTER: Thank you.

CO-CHAIR KAYE: Could I just ask for a quick clarification as to why performance applied to efficient, well-aligned, well-allocated and not to equitable system fairness?

MEMBER YUSKAUSKAS: If you're looking it as change, it could almost apply to everything.

MR. ANDERSON: Yes, it is a pretty big bucket. If you look at the domain frequency chart, you can kind of see how that bucket was broken down and what would be included in it.

CO-CHAIR KAYE: And so that would be this chart, this thing. You should have copies of this.

MR. ANDERSON: It's from yesterday. And we have some extra copies.

CO-CHAIR KAYE: So the sub-domains for performance were program performance, system performance, performance outcomes, sustainability, descriptive statistics, shared

accountability and transparency. So you could put equity in that if you wanted to. I mean, It doesn't -- getting the correspondence right is less important than just our understanding of -- I mean, the object of this is, I think, twofold. We're trying to translate what we came up with yesterday as characteristics of the system into domains of quality. And it would be nice if the titles of those domains were shorter than our -- some of these lists are kind of laundry lists.

And also it would be nice for us to review what are we missing that Drew found in the literature. And perhaps maybe there are some things that we don't think are that important because they're not in the literature, although I don't feel that way. But I would like us to at least consider are the things that -- for example, I'm looking at this now, I'm saying, wait a minute, care coordination? Somehow we're not explicitly mentioning that? And maybe we are, but I mean, I do think care coordination is an important thing. And there is this sort of

system being integrated, but that may not -- I don't know if that's enough.

MEMBER MOHANTY: I think we were thinking of care coordination maybe under -- as part of coordinated, which was part of integrated. I'm trying to --

CO-CHAIR KAYE: Right, as a system thing.

MEMBER MOHANTY: Yes.

CO-CHAIR KAYE: Right? So then do we need a separate thing from the consumer that their care is coordinated? I don't know. I'm a little confused.

MEMBER MOHANTY: Yes, I think it's important domain to call out.

CO-CHAIR KAYE: Right. Yes.

MEMBER MOHANTY: I would make the recommendation to call it out more specifically.

MEMBER McCANN: Or could we perhaps consider the same definition of performance? It's at several different levels. So there's care coordination and integration of the system,

but it goes all the way down to the individual level.

CO-CHAIR KAYE: Right, although -- yes, that's a possibility. Kimberly?

MEMBER AUSTIN-OSER: The other thing about the care coordination is it kind of begs the question for me, is that really the job of the HCBS system to coordinate and integrate everything, or is that just the very nature of HCBS: that it's holistic, it looks at the person, all aspects of the person and it is a connector, or it is maybe something that helps drive the connection. But it seems to me if we have a domain about coordination, then it kind of puts the onus on the HCBS system to be the coordinator, which may be something that we think makes sense. But it seems like a different kind of conversation.

CO-CHAIR KAYE: Yes, I think you're making some good points there.

Charlie?

MEMBER LAKIN: I'd just like to know

what were your search terms? How did you delimit this? It just seems like 200 references in 100 journals all dealing with home and community in some way seems to be relatively few. And I'm just curious what did it take to get into your analysis?

MR. ANDERSON: Well, it first had to contain -- the source had to contain domains of quality for LTSS or HCBS specifically. So that's how we got down to those 38 sources.

MEMBER LAKIN: It had to mention home- and community-based services or long-term services and supports in the --

MR. ANDERSON: Right, to get into that 38, the top 38 sources. I think the other thing that was helpful to me is there's another thing that was in the packet that lays out the different frameworks that were looked at. So like the NCI and the AHRQ, and DREDF for Steve Kaye is in that. So I think this was helpful to me in terms of what they actually looked at, the different frameworks, and then calculated the

frequency that you see on this chart, which ones were highly cited and which ones were often cited.

CO-CHAIR KAYE: So to clarify, you say you looked at a lot more than this list of 10 or whatever? Right?

MR. ANDERSON: Oh, yes. Right.

CO-CHAIR KAYE: So these are sort of the main --

MR. ANDERSON: Right. So those 10 were narrowed down from that 38. So there's actually a much longer document, maybe like a 30-page, a long document that breaks out all of the domains and sub-domains for each of the 38 sources. And then from that document we found these 10 to be the most relevant based on the source selection criteria that we provided.

MS. LASH: And If I could just add one quick thought to sort of respond to Charlie's thought that maybe this isn't as comprehensive as we need it to be, that this was a first cut and the 200 or so sources that we thought were really

critical to begin with were suggested by a subgroup of this Committee that we checked in with early in the process as advisors, including the Co-Chairs, the HHS team and some of our own knowledge about the documents that have been particularly influential.

And so, it's not everything, but there will be a second iteration of the literature review and evidence synthesis guided by the domains and the sub-domains that result from today that will then become search terms for something more systematic. And we'll talk more about that methodology later this afternoon. But this isn't sort of the end-all-be-all, but we thought it was enough to get the patterns of what is sort of coming up over and over and the way people are conceptualizing quality.

CO-CHAIR KAYE: And I think it's actually -- it's surprising to me the extent to which there is almost a one-to-one correspondence between the stuff that we were talking about yesterday and this list here. I mean, there are

some omitted ones on each side and there's a little bit of duplication, but without explicitly using Drew's list of domains as source material, we pretty much came up with the same thing, which I think is kind of a reality check.

I want to take first Lorraine and then Andrey and then Bob.

MEMBER PHILLIPS: I would recommend an X be added to functional status in the last row. Physical health seems to be subsumed under well-being, but functional status is a key driver of need for each individual in the program, and to hide it under a well-being umbrella seems to minimize its importance.

CO-CHAIR KAYE: But I thought you wanted us to put that in there. Didn't you start off by saying you wanted an X for --

MEMBER PHILLIPS: There's no X under the functional status in the green row.

CO-CHAIR KAYE: Right. But you want it in the bottom row?

MEMBER PHILLIPS: I think if you're

going to --

CO-CHAIR KAYE: Or do you want a separate --

MEMBER PHILLIPS: Well, I would love to see it in its own row, but --

CO-CHAIR KAYE: You think you're not going to get that?

MEMBER PHILLIPS: -- in the absence of that --

CO-CHAIR KAYE: Yes.

(Laughter)

MEMBER PHILLIPS: In the absence of that, I want an X in the functional status column to line up with the well-being row.

CO-CHAIR KAYE: Yes. Okay. I added that on mine, anyway. So everybody add that, please.

Andrey?

MEMBER OSTROVSKY: Thank you. I want to make a quick comment and maybe a question to the group around the definition of integrated and the definition of care coordination and at which

level they operate. My understanding is when we refer to integrated, we refer to systems being integrated, including the medical side of healthcare, the functional side of healthcare, those being integrated. And oftentimes that can happen under the umbrella of whomever is paying for care, for example.

Care coordination, on the other hand, is I think at a more granular level, at the level of where services are actually delivered. And I think we could group them into one bucket, but as long as we clearly address that there may be differences between the two, I don't think we necessarily have to have separate domains.

And I think an interesting point from the kind of literature review documentation, under the section around care coordination the sub-domain that's referenced here is transitions of care, and that's it. Now, I do think care transitions are actually one of the most burgeoning areas where home- and community-based services are going to play a critical role, but I

think there's so much more beyond care transitions.

And so, I don't know how we should handle that, but I do think there's a distinction between integrated care, which is kind of a higher level concept. Effective care coordination, also very important, and I would argue maybe even more important because it's closer to the patient level. So I don't know what the group thinks about how we address that, but I think we could kind of keep it in the domain as long as it's called out.

CO-CHAIR KAYE: Yes, Bob and then Clare.

MEMBER APPLEBAUM: I don't know how this comments fits with yours, Andrey, but I was going to suggest that the line that says services are accessible, appropriate, sufficient, dependable, timely -- I was going to suggest adding coordinated to that line as a way to get at the coordination issue, because we want these services to be all those things plus coordinated.

And so that seemed like one way to deal with it.

And then I don't know if --

CO-CHAIR KAYE: Wait, before you move on, let -- I kind of like that. Is that a -- I see a lot of nods. Okay. Let's do that.

So, services. The third from the bottom. Services are accessible, appropriate, sufficient, dependable, timely and coordinated.

And, I mean, I heard what Kimberly had to say and that resonated with me, but I still think that it is an element of the quality of the services that they are kind of coordinated or integrated or something, or are aligned with acute services. So I think it doesn't quite imply that it's the burden of the HCBS system to do this. It's just are they or are they not? Are you okay with that?

MEMBER AUSTIN-OSER: I'm okay with that.

CO-CHAIR KAYE: Good. Okay. Now go on.

MEMBER APPLEBAUM: And then I don't

know if we're ready to do this yet, but certainly some of the items, particularly in the often cited category -- like, I'm looking at respect and dignity, which is often examined in the consumer and caregiver experience. I don't know if we're ready to try and collapse categories at this point, but there are several that are collapsible. I don't know if that's premature or if we want to try to do some of that yet.

CO-CHAIR KAYE: You're going to collapse the columns. Is that what you're saying?

MEMBER APPLEBAUM: Yes.

CO-CHAIR KAYE: Okay.

MEMBER APPLEBAUM: Correct.

CO-CHAIR KAYE: Right. I'm not sure we need to do that unless -- I mean, I'm not sure. I would rather stick with the rows as the domains, if that's what we want to do, and then maybe use the columns to give us titles for those or something. I don't know. That's how I see the process.

Clare doesn't have her card up. I saw Camille first and then Mike.

MEMBER DOBSON: I was heading in the same direction as Bob. I mean, I think that a number of the elements that we flagged can be identified through consumer and caregiver experience. So I was actually starting to go through and put Xs in extra places next to the list that we gave, because I think a lot of those domains about consumer-directed control and dignity can come out of consumer-experience domain. The same thing with community engagement and inclusion. So I started to go through and add more Xs on my page of things that I think the domains across the top could address. I think this is a good start, but it's sparse.

CO-CHAIR KAYE: You mean sparse in terms of Xs? Yes.

MEMBER DOBSON: Yes.

CO-CHAIR KAYE: Yes. Okay. Right. Mike?

MEMBER OXFORD: It's back on kind of

the care coordination, but also the difference or the definition of that including the difference between that and case management, which I don't like that term either, but it seems like that's really -- it occurs to me that that's something that is really important because HCBS is often really a tool. It's not an end. It's a means to an end. So, and then of course in terms of quality, a lot of the programs, it is the end. So it's just ADL stuff. Transfer, get out of bed, get dressed. That's the end of your life. Whereas, you got to do that stuff right to be able then to pursue your individual goals and get a job or live your dream and so on.

So I don't know exactly where that really fits in, but -- I'm sorry the way my brain works, but we really didn't get into that a whole lot and it just seems to me like that's real important. And it occurred to me when we talked about coordination, like how limited is care coordination and what is that compared to, like, making sure that people get all the assistance

and support they need between all sorts of things? Transportation has to line up. Where you live. Other kinds of training and supports that may not probably be part of HCBS, but there needs to be a connection to it elsewhere.

CO-CHAIR KAYE: Okay. Thanks, Mike.

So are people generally onboard with the idea of using these characteristics to identify our domains of quality, or at least as a starting point for that?

(No response)

CO-CHAIR KAYE: I'm seeing nods. So if we do that, how about if we go through the list and come up with a phrase or a word for each one of them, if we can? Or maybe we'll decide that we need to divide some into two, or join them or something like that. And maybe we could use the column headers as helpful hints for that.

Andrey?

MEMBER OSTROVSKY: Maybe a note on process so we don't lose some of the rich granularity we've already established. As we try

to distill a one-liner brief statement, could we maybe have bulleted sub-domains, if you will?

CO-CHAIR KAYE: Right. And that's where we're going next, is to have groups where we make sub-domains. And, yes, that's exactly what we're thinking of is that a lot of these are really -- sound like to me, lists of sub-domains. So what we're going to do, I think, is break into groups and then each group will be assigned a certain group of these domains and asked to identify possible sub-domains for that.

Okay. So, Mike, you already spoke. Camille, do you want to speak again, or you got -- okay.

So, workforce. We already have workforce, which seems to me a good name. I don't know how to label participant engagement in the design, implementation, evaluation of the programming. I mean, it's not engagement because engagement could mean community engagement.

Go ahead, Barbara.

MEMBER McCANN: Perhaps under person-

centered?

CO-CHAIR KAYE: Well, but we have other person -- so this is engagement in the design, implementation, evaluation of the program.

MEMBER McCANN: Right.

CO-CHAIR KAYE: So it's like do you have consumers on your advisory board? That kind of thing.

MEMBER McCANN: So it's broader than evaluation of their individual program of services?

CO-CHAIR KAYE: Yes.

MEMBER McCANN: Okay.

CO-CHAIR KAYE: That would be a separate one. We've got that in a separate one.

Mary?

MEMBER SMITH: I think it's usually referred to as participation.

CO-CHAIR KAYE: Well, in our circles of disability sort of stuff, participation means community participation as opposed to this one,

which means participation in the system, system participation.

MEMBER McCANN: Okay.

CO-CHAIR KAYE: System participation? I don't know. That's not very good.

MEMBER McCANN: Well, in our world it's really the consumer participation.

CO-CHAIR KAYE: Yes. Let me call on Patti first because she had a -- and then Kimberly.

MEMBER KILLINGSWORTH: Just a quick thought about that one and also the previous one. So is there an opportunity to make this participant engagement a part of consumer direction, person-driven and understanding in the sub-domain area that it applies at both the systems level and also at the individual level? Just something to think about in terms of collapsing things.

CO-CHAIR KAYE: What do people think about that?

(No response)

CO-CHAIR KAYE: I see one person nodding and a lot of people -- a couple people nodding and a few people looking unsure.

MEMBER OXFORD: Well, I mean, I guess it could be okay, but my fear would be that it would be lost kind of somewhere along the way with the kind of same old, oh, yes, that means that you involved the person in the planning circle when you -- I mean, and we would lose the sort of --

CO-CHAIR KAYE: I kind of -- I see them as --

MEMBER OXFORD: -- system level.

CO-CHAIR KAYE: -- kind of -- yes, I see them as both important and kind of distinct.

MEMBER OXFORD: Yes.

CO-CHAIR KAYE: Suzanne, did you have a comment on that specific thing?

MEMBER CRISP: I did. When I first suggested that, everybody was going, oh, but person-centered planning -- and that shows that there should be a distinction.

CO-CHAIR KAYE: I kind of think so.

MEMBER CRISP: Because even we didn't understand what we were referring to, and others won't either.

CO-CHAIR KAYE: Yes, and we keep on trying to conflate them and then we --

MEMBER CRISP: Yes, it's a very new concept, too.

CO-CHAIR KAYE: Right.

MEMBER CRISP: I mean, it's an old concept in that we've always said, yes, yes, yes, but now we're really -- we have to demonstrate that we're doing it. And so, that is a new concept within itself.

CO-CHAIR KAYE: Yes. Patti, you're frowning.

MEMBER KILLINGSWORTH: No, I'm fine with that. The other thing I wanted to mention is with respect to workforce, whether we want to make that provider, slash, workforce, right, so that we're looking at both the provider as a provider and also the workforce as the people who

are actually in the home and providing supports.

CO-CHAIR KAYE: What do you think? Gerry?

MEMBER MORRISSEY: Not on that point. I was still back on this system issue, which maybe the word ownership -- only because I think there's a differentiation between -- this one is really talking about systems and how individuals can participate and advise about the system of care that he or she is in, right? So I'm just trying to think of the word. It can't be -- since it's really not about individual engagement, it's about their authority, the individual's authority to have advice or input or direction about the overall system. So I just thought of a word like ownership. That's probably not the best word, but it's --

CO-CHAIR KAYE: Yes, I think you're going in an interesting direction.

Kimberly?

MEMBER AUSTIN-OSER: So a couple of comments. One, the way I keep seeing it, and I

feel like I keep hearing this as well from other folks, is whether they're the same domains or not, and probably they are, I feel like they have different faces, one on the system side and one on the consumer side. So if I think about this in terms of like system evaluation, I'm looking at it as how is the system performing on the quality metrics, and how are we doing on the individual level? And so, I do think that the participant engagement side is on the system side. And then you have a whole participant-engagement domain on the individual side. And I see these as having -- here's the domain and underneath it we may have six sub-domains that all have to be addressed so they don't disappear, get folded into something.

CO-CHAIR KAYE: Right.

MEMBER AUSTIN-OSER: The other thing is I just want to understand a little better, Patti, your comment about provider and the person in the home. I guess I'm not sure I understand the distinction and can't really comment on it

unless you --

MEMBER KILLINGSWORTH: So I think a part of the value of this exercise is to step back and look through the lens of the work that's been done before us and to think about what did we miss or maybe not consider that we should consider? So the domain that I think is most often cited in the literature -- it says is provider capacity and capabilities. And so we hear a lot about networks, but also about the capacity of providers and how they are operated, if you will, the quality management systems that providers have in place, which is really, really important.

But that's very different from the workforce. And is the workforce well-trained? And is the workforce consistently assigned, and those sorts of things? And so, I think there's value in looking at that from both levels. And we didn't really talk about providers much. We talked about workforce, which I think needs to be there. I think it's a part of the paradigm

that's really changing that we really need to be sure that we're measuring. But I'm not sure that providers shouldn't be there, too.

CO-CHAIR KAYE: Suzanne, are you going to comment on the worker/provider thing, or you're going to comment on the ownership, the engagement?

(No response)

CO-CHAIR KAYE: So, let's park that for a moment.

And, Kimberly, did you want to say something more?

MEMBER AUSTIN-OSER: Thank you, Patti. That's really helpful, and I would agree with you.

CO-CHAIR KAYE: So what if we were to say workforce, slash, providers? Would that satisfy people? Does anybody object to that strenuously? Sandy?

MEMBER MARKWOOD: Well, I'm not sure I object, but I just wanted further clarification. So, Patti, when you're talking

about providers, how does that relate to the listing under services? Accessible, appropriate, sufficient, dependable and coordinated. I guess, are we talking about that from a provider system standpoint? And then we have one on efficiency. So I'm trying to figure out how those all meld together, or not.

MEMBER KILLINGSWORTH: Well, I think looking first of all at whether there is a sufficient number of providers, but then also how those providers actually operate is critically important. The training systems that they have in place, the supports that they have in place for workers, again how they do their quality management systems. I think it's important to look at provider performance as a whole and then also to recognize that, from the person's perspective, the greatest impact is that person who's actually in the home delivering their support, or with them in community delivering their support.

And so, I think both of those are

important. And I don't think that we capture the importance of provider capacity and capabilities within making sure that there is an efficient system or that services are accessible and dependable. I think those are good measures, but I think there's more about provider capacity than that.

I mean, our DD system just became the first system in the country to be accredited for person-center excellence. Those providers have additional capabilities now in terms of how they actually interact with and support people and train staff. And that's above and beyond work force capacity.

CO-CHAIR KAYE: Okay. This seems to make sense to me.

I'm going to call on Sarita because she hasn't said anything yet this morning.

MEMBER MOHANTY: Yes, I understand what you're saying. I guess I'm just a little concerned that when we talk about provider, there's going to be some confusion about the

definition of what a provider is. So I think unless that's really specified and clarified somewhere in the definition there -- because I guess coming from the healthcare side, I think provider, I could think about it as a physician, a nurse, but then I think about community providers as well. And I also think about the home care providers. So I guess I'm still struggling a little bit about how to make that distinction or call out provider versus those that are work force in the home.

CO-CHAIR KAYE: Okay. Andrey, Ari Ne'eman and Mike.

MEMBER OSTROVSKY: I think this is sort of related to that point. Since we're talking about the context of HCBS, I think we kind of default to HCBS providers and kind of keep it -- we can maybe oversimplify it that way. Because I think we may be able to address the issue of the other types of more medical providers when we speak to integration or maybe when we speak to care coordination in whatever

vein we do it. But I think since this is in the context of HCBS, that just might already constrain how we define that.

CO-CHAIR KAYE: Okay. Ari?

MEMBER NE'EMAN: I definitely agree with the idea of looking at provider quality in the context of an adequate network of providers or rates or timeliness, but with respect to training, I want to suggest that we differentiate between the availability of training and financial support for training to be made available for workers and workers being paid to go through training and looking at levels of worker training as themselves a measure of quality. Particularly in self-directed systems I think the latter would be of concern given the significant number (A) of family caregivers being paid in self-directed systems, and certainly I think we would probably largely be in agreement that we don't want to be imposing minimum training requirements on people to take care of their own relatives.

But second, also given the significant number of consumers who even when they're being supported by people who are not family members have distinct preferences to train their workers themselves and not have them subject to an external entity that tells them how to provide support prior to them being able to be on the job or as a metric of quality for their work.

So again, I'm totally in agreement with the idea of provider quality as a measure, and even the availability and funding for training as a measure, but I just strongly caution us against utilizing the existence of the percentage of personnel who have been trained as a measure.

CO-CHAIR KAYE: All right. I want to propose two things here: I was thinking since Ari raised this yesterday, I was wondering whether instead of trained we could put appropriately skilled? Does that sound good to people? Is anybody going to object to taking out the word training or trained?

(No response)

CO-CHAIR KAYE: All right. So let's change that to --

MEMBER AUSTIN-OSER: Actually I do.

MEMBER KILLINGSWORTH: I do.

CO-CHAIR KAYE: You do? So two people object. All right.

MEMBER KILLINGSWORTH: Part of the reason why I do is because in -- I mean, recently we did 18 visits in nine cities across the State of Tennessee and asked people what was most important to them from that person's perspective, their experience of care. How do you measure quality? And can I just tell you training hit the top of the list a lot and it was always near the top of the list. People talked a lot about I don't want someone coming into my home who -- and doesn't mean that I can't train them on my specific needs, but they ought to be well trained when they walk in the door.

They ought to know a lot about providing supports, a lot about person-

centeredness. There's a lot of things that are very -- and I'm not talking so much about consumer direction, although I do think that everybody who does consumer direction ought to have some basic life support skills so that you know how to do first-aid and CPR. But beyond that I think for a general work force you want them to be well trained. I do think that's important.

CO-CHAIR KAYE: All right. I think there's enough objection. I think you're going to have to address this when we get to sub-domains and actual measures rather than the actual content of the domain.

MEMBER OXFORD: I think, Steve, I mean, I've seen this going on for years and I really -- I worry about that they -- really is a divergence between the self-directed, consumer-controlled programs and those that aren't. And furthermore, there's been a whole lot of emphasis I think federally on self-directed means. You learn to be an employer, which when you talk to

people, they're not interested in taxes and record keeping and that kind of stuff. So, there's that piece of it.

But I'm really afraid about developing some of this stuff that actually not only may not apply, but that are going to be barriers in the self-directed world. And at the same time if we try to put self-directed in there too much, it really doesn't fit in with general work force and --

CO-CHAIR KAYE: Right.

MEMBER OXFORD: -- those kind of liability issues and all sorts of stuff going on in a different thing.

And so, I don't know if the sub-groupings is going to cover it or not, but it really seems like we may really at some point need to kind of diverge the two or we're going to be trying to pound a square peg in a round hole the whole time we try to do this.

CO-CHAIR KAYE: Okay. Let's stick to the question which was raised, which is should we

add providers to the work force? What if we were to just change the title of this to HCBS Providers? Would that satisfy people?

MEMBER OXFORD: It could be individuals or agencies.

CO-CHAIR KAYE: Okay.

MEMBER OXFORD: I mean, I'm confused about that all the time. I mean, if we could just define what that is.

CO-CHAIR KAYE: Clair?

MEMBER LUZ: I want to speak to Patti's comment, because I agree that -- but I want clarification. I think you're referring to the organizational providers when you say providers. In the context of what you were just saying you were talking about an organizational level?

MEMBER KILLINGSWORTH: I think when traditional provider agencies are delivering services, they have an absolute obligation to provide training. And honestly, I think state programs have an obligation if they're state-

funded or Medicaid-funded programs to define what those minimum training requirements are.

MEMBER LUZ: Well, and I know some people bristle at the word agency, but maybe if we used the word organization, or organizational. Provider organizations and work force.

CO-CHAIR KAYE: How about if we just settled on work force/providers? And we'll have to clarify it in the description.

I'm afraid we're spending too much time on the top of this and we're not going to get through. So let's address this question of -- so for the second one Gerry suggested ownership. I kind of like that. Is there a better suggestion for people participating in the design and implementation and evaluation of the program?

(No response)

CO-CHAIR KAYE: Let's leave it and then we'll come up with something better, unless Suzanne wants to address that.

MEMBER CRISP: I just wanted to say

are we trying to say participant input in operations?

MEMBER MORRISSEY: I thought the premise was that at a systems level we wanted individuals who are the consumers of the services to have a voice, a control, advice and direction.

CO-CHAIR KAYE: What about consumer voice?

MEMBER CRISP: Yes.

CO-CHAIR KAYE: Consumer voice?

MEMBER CRISP: Do people bristle at the notion of stakeholder --

(Simultaneous speaking)

CO-CHAIR KAYE: Stakeholder engagement.

(Simultaneous speaking)

CO-CHAIR KAYE: No, somebody bristled. Okay. Consumer -- what? Go ahead.

MEMBER MORRISSEY: How about individual engagement?

MEMBER CRISP: What was that?

MEMBER MORRISSEY: Individual. Well,

as long as we don't lose the point, which is I don't want to kind of -- I'll use the word respectfully, modulize that. You either believe this or you don't believe this. The people that are the consumers of the services have a right to kind of discuss, engage, mediate, negotiate their service system.

CO-CHAIR KAYE: Sarita?

MEMBER MOHANTY: Yes, I like the stakeholder engagement piece, and I think because I think that it would include the consumer and it could also include -- I mean, and a lot of times you have community based organizations that represent the consumer that should also be partaking in the design. I don't know. Maybe would stakeholder engagement -- I'm just kind of curious as to why maybe folks are not --

(Simultaneous speaking)

CO-CHAIR KAYE: Because Mike wants to make sure it's the consumers that are engaged.

MEMBER MOHANTY: Well, yes. Well, no, and I --

CO-CHAIR KAYE: Consumer/stakeholder engagement.

MEMBER MOHANTY: Yes, I mean, I definitely think consumer. To me consumer falls under the stakeholder.

MR. NE'EMAN: I think the issue is that very frequently we see states consult substantially with provider organizations, or sometimes even parent organizations without meaningful consultation with consumer or self-advocate organizations.

MEMBER MOHANTY: Then maybe we could call it, like you said, consumer/stakeholder.

MR. NE'EMAN: I'm fine with consumer and stakeholder engagement. What do others think?

CO-CHAIR KAYE: Consumer and stakeholder engagement.

MEMBER OSTROVSKY: Can we cut; it's a small word, but and other stakeholder just so we don't make it sound like consumer is not a stakeholder?

(Laughter)

CO-CHAIR KAYE: Or something like that. Okay. We can wordsmith these. But at least we have a shorter phrase than that entire long 10-word thing.

Moving on to choice. Person-driven focused on achieving individual goals, consumer-directed, controlled dignity of risk. And that one is called person-centeredness.

MEMBER DELMAN: Can I comment on the last one?

CO-CHAIR KAYE: Sure.

MEMBER DELMAN: I'm not going to formally object to anything, but I just wanted to explain why -- I'm in another committee where the issue has come up. And of course I feel that consumers should have themselves a category to be involved. And one is -- and this can be consumers or delegates, but one of the reasons services have been so terrible is because consumers have been left out of the discussion. It's been very provider-driven or administrative-

driven and the outcomes of consumers have been ignored.

And until you get to what the consumers outcomes want, then you can get back to processes with consumers. Consumers, at least in mental health, and I think in all disabilities, have been the catalysts for change in any service system. I consider that for certain in mental health. So you need to clearly place a role for consumers.

Other stakeholders I'm not so worried about, frankly. They've been there. They typically want more of a traditional thing. You're going to see less change with other stakeholders. Consumers are going to argue for something different, which I think is what we're looking for.

Secondarily, consumers are the end users. And that's the problem with the health system overall. And that's why we have something called person-centered care in the Affordable Care Act. And they place a tremendous amount of

emphasis on participants or patient engagement.

So what I'm suggesting is that I would want to be consistent with the ACA when we do these domains. And that's an emphasis not on stakeholder, but on consumer/patient.

CO-CHAIR KAYE: Good. Thank you, Jon.

All right. So back to this big bucket of choice and everything. Is there one thing we can call this? Two things, maybe?

MEMBER DELMAN: Self-determination?

CO-CHAIR KAYE: Self-determination is proposed. Go ahead, Suzanne.

MEMBER CRISP: I mean, in the self-directed world we always say choice and control. And then everything else is assumed and would be in a sub-domain.

CO-CHAIR KAYE: I like choice and control. You okay with that, Jon? Choice and control?

DR. MORRISSEY: Yea.

CO-CHAIR KAYE: Okay. So then the next one is privacy, dignity, respect,

freedom/independence and legal rights. I always have trouble bucketing this one. Of course I always like independence, but that seems broader.

MEMBER APPLEBAUM: How about choice and control?

CO-CHAIR KAYE: You want to move that into --

MEMBER APPLEBAUM: Well, people could talk to me about what the difference is, because I don't see it.

CO-CHAIR KAYE: You want to collapse these two?

(No response)

CO-CHAIR KAYE: No objection to collapsing these?

MEMBER OXFORD: The only thing that's going to get left out is going to be the legal rights piece. Otherwise, I think that they are collapsible under choice and control. But that's different, because to me, when I saw that in there, I mean, that was like moving from, oh, it's a program policy, it's a permission that

you're given to actually having a formal right over it. And that's something that we want to move towards and have been moving towards. And they're actually different. So the legal rights piece wouldn't fit under the typical choice and control. I don't know what everyone things about doing with that.

CO-CHAIR KAYE: Let me first get Ari Houser, who's had his hand raised.

MEMBER HOUSER: Yes, I think this is a different -- I think we lose a lot of what's in the privacy/dignity/respect if we slide it under choice and control, because I think there's more that -- even if you're not in a self-directed program and perhaps you don't have a choice of provider but you need services, and so you're getting services from someone. Whether or not that was your provider of choice or your provider of convenience or the only provider who's there who can do it, that provider should respect you, uphold your dignity, respect your privacy. That's something that's important whether or not

that service is -- you chose it or you got it because you needed it.

MEMBER APPLEBAUM: But that's what choice and control means. I mean, it doesn't mean just that you choose a provider -- control over every aspect of your delivery of your service. And so, yes, it's respect, it's dignity. I mean, all those things. I mean, obviously we can quibble about definitions, but that is what control over the service system is about.

MEMBER HOUSER: I understand that, but I kind of think this is kind of on the other side. The choice is you should have the choice of all these things and then no matter what you chose, the provider should respect privacy/dignity. And it's not your choice that the provider respects your privacy and dignity. It's the provider's responsibility. And I think that's more than just your choice.

CO-CHAIR KAYE: Clare?

MEMBER LUZ: So the language of choice

and control is very individual-oriented.

CO-CHAIR KAYE: Yes.

MEMBER LUZ: Somebody who is competent. Privacy, dignity, respect, freedom, that all applies to people with dementia, who have cognitive difficulties, who have severe mental illness, who don't have the ability to exercise choice and control.

CO-CHAIR KAYE: Yes.

MEMBER LUZ: So we have to include them. They deserve dignity, respect, privacy. I'm afraid we lose that if we put it under choice and control.

CO-CHAIR KAYE: I think given that there's -- I mean, we did separate these and we did vote on them separately, so since there's some objection, I think we should not collapse them. But I think we do need a title for this. And I don't know what that would be.

MR. NE'EMAN: I would just refer to them as legal rights. I mean, at the end of the day that's what we're getting at here. As I see

it, the privacy/dignity/respect section roughly correlates to the provider on residential requirements and settings rule.

CO-CHAIR KAYE: Jon is not happy.

MEMBER DELMAN: I'm just wondering if you can say human rights, because it's a broader term.

CO-CHAIR KAYE: Human rights. I like that.

MR. NE'EMAN: Yes, I like that, too.

CO-CHAIR KAYE: Human rights?

MEMBER OXFORD: How about human and legal rights?

CO-CHAIR KAYE: Human and legal rights. No, human rights.

MEMBER OXFORD: Well, no, because I mean I always differentiate. Legal rights are embodied in law, whereas human rights can be more general and maybe there isn't a law. Like I think that there's a human right to having adequate housing. Well, there's no law, there's no legal right to that. But I think it is a

general human right. And so, some of these things are legal.

CO-CHAIR KAYE: Okay. Human/legal rights. Okay?

Efficient, well-aligned, well-allocated, integrated. And we also have data integrity on this. Is this efficiency? I don't know what it is.

MEMBER OXFORD: I'll just point -- we put it under the domain of performance, so that could be a word.

CO-CHAIR KAYE: System performance? Gerry, you like that?

MEMBER MORRISSEY: Yes, or organizational performance. Organizational is good.

CO-CHAIR KAYE: Organizational is good. I think system is where it belongs.

MEMBER MORRISSEY: System performance.

CO-CHAIR KAYE: Is that okay? Yes?

(No response)

CO-CHAIR KAYE: Okay. System

performance for that.

Okay. Community engagement, inclusion to the same degree as people not receiving HCBS, participation, employment and productivity, having fun, social connectiveness. Is there an umbrella term for this?

DR. MORRISSEY: Inclusion. How about real lives?

CO-CHAIR KAYE: Real lives.

MEMBER SMITH: I think those things usually fall under the umbrella of quality of life. Even though we have it at the top, when I see those things, that's what I think of.

CO-CHAIR KAYE: Could be, but it's just kind of a minefield term. So we'd have to be mindful of the fact that we might cause controversy if we use quality of life. And if we don't, we'll be somewhat safer. But that doesn't mean we shouldn't use it.

Sara, you've had your hand up for a while.

MEMBER GALANTOWICZ: Sure, just

similar to what Gerry's saying. Something about maybe like full community inclusion so we get the notion that it's community inclusion, but it's full or equitable so that we have this notion that it's the same level as people without disabilities?

CO-CHAIR KAYE: Full inclusion is a phrase from the Americans with Disabilities Act. We could use that.

Ari is not happy.

(Off mic comments)

(Laughter)

CO-CHAIR KAYE: Oh, you were shooting me a look like you --

MEMBER HOUSER: I was just going to agree.

CO-CHAIR KAYE: Oh.

MEMBER HOUSER: Community inclusion.

CO-CHAIR KAYE: Full community inclusion or full inclusion? Full community inclusion. Okay.

MEMBER OSTROVSKY: Can I ask a quick

question?

CO-CHAIR KAYE: Sure.

MEMBER OSTROVSKY: Would full community inclusion suffice -- encapsulate having fun? Honestly, I think like if there was a quality measure for having fun, that -- there maybe should be one, but I feel like it's one thing to be included in the community, it's another thing to have other domains of quantity of life. So I'm thinking maybe quality of life may a nice umbrella term with very clear sub-domains for all of these individual points, each one being quite important I think.

MR. NE'EMAN: I would push back on the use of the term quality of life because of its other implications. But what about full community inclusion and participation?

CO-CHAIR KAYE: Michael?

MEMBER OXFORD: I was actually before the full inclusion came up going to throw out participation. So that might work. Full inclusion and community inclusion and

participation.

MEMBER SMITH: I don't think it covers the employment piece, personally.

CO-CHAIR KAYE: Well, I think participation includes -- as I said yesterday, I think participation is economic participation as well as social participation.

MEMBER SMITH: I don't think you'd get it out of that.

CO-CHAIR KAYE: Charlie, are you nodding to that or are you --

MEMBER LAKIN: Sub-domain.

CO-CHAIR KAYE: Sub-domain.

MEMBER LAKIN: I think full community inclusion is --

CO-CHAIR KAYE: Can you use your microphone, please, Charlie?

(Off mic comments)

CO-CHAIR KAYE: Ari Houser?

MEMBER HOUSER: I mean, I think most of us, all of us have -- each of these: engagement participation, inclusion really have

precise meanings to us, but to the general public they're all approximately synonyms. I think we need to just pick one and then with sub-domains we can clarify. Otherwise, we're just listing things that to most people mean the same thing.

CO-CHAIR KAYE: Yes, I kind of wondered about that, too. If you had to pick between inclusion and participation, Ari Ne'eman and Mike, which would you pick?

MR. NE'EMAN: Inclusion.

CO-CHAIR KAYE: Are you okay with inclusion, Mike?

MEMBER OXFORD: Yes.

CO-CHAIR KAYE: Okay. Could you turn off your microphone now?

(Laughter)

CO-CHAIR KAYE: Thanks. Okay. So we're back to full community inclusion. Mike and I make fun of each other all the time.

All right. So the next one is family caregivers are supported, so should it just be family caregivers? Should it be caregivers?

Clare?

MEMBER LUZ: Can I back up just a second, because I'm okay with full inclusion, but I think there's more to quality of life than inclusion in a community. I mean, there are other aspects of quality of life that are very individually-based. And you can have fun by yourself.

CO-CHAIR KAYE: Yes.

MEMBER LUZ: I mean, there are many ways to have fun by yourself. So I'm advocating for a separate category that does cover other things related to quality of life and having fun besides social integration into a community.

CO-CHAIR KAYE: Is there a term that is less fraught than quality of life and yet broader than community inclusion that could apply to this whole thing?

MEMBER OSTROVSKY: I mean, not to get too like psychology-literature-based, but like actualized? Like I don't know. It's sort of like really getting too broad, but I don't know.

Self-actualization is really what we're all trying to get at, but that's kind of broad.

CO-CHAIR KAYE: You agree with that?

MEMBER OXFORD: Well, I mean, I like the --

(Laughter)

MEMBER OXFORD: No, I like the concept, but I'm afraid we're getting away from the plain language sort of directive that we're supposed to be doing. But I mean the concept is on track.

MR. NE'EMAN: I would argue that if we do do some kind of self-actualization or whatever we end up calling it, it should be distinct and in addition to full community inclusion. I think we've got at least two distinct concepts here and inclusion needs to be called out in its own right.

CO-CHAIR KAYE: Let's revisit this later, if that's okay. I mean, this doesn't have to be the absolute final list. I mean, yesterday we went and blended two things together to make

this thing, and how we're talking about un-blending them. It seems like a step backward at this point.

So the next one, family caregivers are supported. Should we call it family caregivers? Should we call it caregivers? Barbara?

MEMBER McCANN: I'd recommend caregiver support since there a variety of caregivers who are not family members.

CO-CHAIR KAYE: Caregiver support. How about that?

(No response)

CO-CHAIR KAYE: Yes? Okay. Good.

The next one is effectiveness of services, quality of care. What do we want to call that? Effectiveness? Suzanne?

MEMBER CRISP: I like quality of care better, because services can be effective, but yet not be high quality. I mean, you can give a person a bath, but maybe not an enjoyable bath. I don't know. I like quality of care better.

CO-CHAIR KAYE: Is there agreement on

that?

MEMBER OXFORD: Well, I just wondered -- or performance. I mean, those to me are sort of like -- I think quality has other things besides those things.

CO-CHAIR KAYE: Quality of care?

MEMBER OXFORD: Yes.

CO-CHAIR KAYE: Except we put quality of care in as a sub-domain of this.

MEMBER OXFORD: Right.

MEMBER SMITH: Yes, I agree with Mike. I think that effectiveness in -- I think effective performance piece I think is more distinct than just quality of care.

CO-CHAIR KAYE: And yet performance we had -- we have another one that said system performance. Efficient, well-aligned, well-allocated integrated. Should we blend that with the other one? But isn't quality of care about the care that is received and not -- the other one is a system -- yes, I see. The other one is a system performance, and maybe this some other

kind of performance?

Go ahead, Sandy.

MEMBER MARKWOOD: Well, that's why when Patti raised her issue that I circled back, because to me this seems like this isn't the system performance. This is the performance that's happening in somebody's home. So I see this as more the individual service level.

CO-CHAIR KAYE: How do you put that in a two-word or three-word phrase?

MEMBER MARKWOOD: I guess I see it as quality of care, but I see it as quality of care at the individual level versus the systems level.

CO-CHAIR KAYE: Let's see. Mary, do you still want to say something?

MEMBER SMITH: Yes, I think I would prefer to leave it as effectiveness/quality of care. I mean, I don't think it's too long.

CO-CHAIR KAYE: Okay.

MEMBER SMITH: I think effectiveness says something different.

CO-CHAIR KAYE: Is that all right?

Effectiveness/quality of care as a domain?

MEMBER OXFORD: Well, I just have to throw out that I think care is a marketing term and it sort of means a whole lot. So I don't know. People probably throw things, but I just wonder if quality of service and support wouldn't be better.

CO-CHAIR KAYE: Now, it's gotten to be longer than four words though.

MEMBER KILLINGSWORTH: Or just quality and effectiveness.

CO-CHAIR KAYE: Quality of what?

MEMBER KILLINGSWORTH: Quality and effectiveness.

CO-CHAIR KAYE: Quality/effectiveness?

MEMBER KILLINGSWORTH: Yes.

CO-CHAIR KAYE: Well, but then now we have -- but the whole thing is about HCBS quality. So then it's -- if you don't say quality of what, then you don't -- quality of service. How about quality of services? And supports? No, how about effectiveness/quality of

services or just quality of services? Quality of services.

MEMBER SMITH: I would go with effectiveness/quality of service. I still think you're losing something by dropping the effectiveness.

CO-CHAIR KAYE: Okay. Effectiveness/quality of services.

Okay. The next one is services are accessible, appropriate, sufficient, dependable, timely and coordinated. And this was -- it got X'ed for consumer and caregiver experience and access to supports and services. Is this what we mean by consumer experience? Bob first and then Andrey.

MEMBER APPLEBAUM: What's the difference between effectiveness of services quality and services are accessible, et cetera?

CO-CHAIR KAYE: Should we be collapsing these two domains? Yes? I hear yes.

MEMBER OXFORD: I think the --

CO-CHAIR KAYE: Who wants to say no?

MEMBER SMITH: I do.

MEMBER OXFORD: I think the only caveat would be if we lose coordination as a very -- and if it has to be a sub-domain, I think that's fine.

CO-CHAIR KAYE: Right.

MEMBER OXFORD: But as long as it's very clearly called out and measured -- because if we don't measure the coordination of services, it may very -- actually it probably -- it does fall under quality. If it would be --

CO-CHAIR KAYE: I think so.

MEMBER OXFORD: -- low-quality services if they're not --

(Simultaneous speaking)

CO-CHAIR KAYE: Is not coordinated?

MEMBER OXFORD: -- that would be a great sub-domain. So that's fine if we --

(Simultaneous speaking)

CO-CHAIR KAYE: Okay. Hold on Clare. First Kimberly.

MEMBER AUSTIN-OSER: So, it feels like

we're conflating again system and individual, and I feel like that it does need to be separate. Yesterday we had this whole conversation around service effectiveness in the home versus is the HCBS system delivering what it said it was going to deliver and do what it said it was going to do? To me services are accessible, appropriate, sufficient, dependable has both a system side to it and an individual side to it. Effectiveness of services and quality of care has a system side and an individual side.

And then the efficient, well-aligned, well-allocated, integrated data, integrity, that feels like it also has probably mostly a system side and a little bit of a -- so I feel like I'm not sure why we have to -- is it one system or service quality domain and then it falls out system versus individual? I don't understand why we have to collapse or get rid of things or whatever, because I feel like these have merit. I don't care how we roll it up. I want to make sure they get addressed.

CO-CHAIR KAYE: But the question is are they conceptually distinct?

MEMBER AUSTIN-OSER: I think they are.

CO-CHAIR KAYE: Okay. And Mary thinks they are. And Clare was going to comment.

MEMBER LUZ: Well, I certainly think that accessibility is a distinct concept --

CO-CHAIR KAYE: True.

MEMBER LUZ: -- different from quality.

CO-CHAIR KAYE: Are there some of the items that are under this current one: services are accessible, et cetera, that need to be moved up into quality of care? I mean, can we modify this to make it more conceptually distinct somehow?

Ari Houser?

MEMBER HOUSER: So, I have an answer to that question, but also I'll took about 10 second to digest the family caregivers and we moved on. And I want to push back strongly that we say family caregivers and not caregiver

support. I think it's pretty well -- that when we say family caregivers, most people understand that that means also non-family members, friends, neighbors, even though that group is probably about 90 percent family.

We also know that when we say caregivers, most people think paid providers. And I think we run a much larger risk of having people think that we're ignoring family caregivers if we leave it out. Then we run a risk of having people think we are ignoring neighbor caregivers if we say family.

I want to say that, but then we can finish the discussion that we're in now. I think the, services are accessible, appropriate, sufficient, dependable, timely really speaks to the what of the services that you're getting, that you're getting the services that you need.

The effectiveness of services kind of gets to those services that are actually being performed well and they're having the desired outcome. And I might move coordination up into

effectiveness. I'm not certain about that, but I think that coordination is more of a how services are being performed than sort of that they -- it's the right checklist.

CO-CHAIR KAYE: So, if we were call this something like appropriateness of services, is that -- that's sort of a different concept than effectiveness. So would that satisfy the two different -- I mean, we'll get back to your family caregiver thing, but I want to try to resolve this. Is that going in a reasonable direction? Effectiveness versus appropriateness?

MEMBER OXFORD: Yes.

CO-CHAIR KAYE: Okay. One nod. Mary?

MEMBER SMITH: Are you suggesting leaving effectiveness as it is and then calling the next category appropriateness?

CO-CHAIR KAYE: Yes.

MEMBER SMITH: I don't think that appropriate means that the services are timely or that they're accessible.

CO-CHAIR KAYE: Do you have another

way of phrasing what is in that bucket?

MEMBER SMITH: In this bucket?

CO-CHAIR KAYE: Yes.

MEMBER SMITH: I don't have one word for it, no.

CO-CHAIR KAYE: Mike does?

MEMBER OXFORD: Well, no, I mean, I guess I would say that the more I think about it, I think to be effective they'd have to be accessible, appropriate, sufficient, dependable, timely on an individual and a systems level. I mean, I don't --

CO-CHAIR KAYE: So you're arguing for merging the two, right?

MEMBER OXFORD: Well, yes.

CO-CHAIR KAYE: Okay. Clare?

MEMBER LUZ: So I see appropriate, sufficient, dependable, timely as part of the quality measures. I see them under quality.

CO-CHAIR KAYE: Of care?

MEMBER LUZ: Of care or services. But accessibility is a much different concept. It

includes affordability and just do the service even exist, whether they're poor quality or not?

CO-CHAIR KAYE: Right. So we could move the -- all right. What about sufficiency? That's different from quality of services, right? Accessibility and sufficiency are kind of similar sorts of concepts, right?

MEMBER LUZ: But it doesn't address -- what are -- Drew, you mentioned the five points under access/accessibility?

MR. ANDERSON: Right, the five facets of access to care, which is availability, affordability, accommodation, accessibility and --

MEMBER LUZ: So I was suggesting moving everything up under quality except accessibility and figuring out something else to do with that --

(Simultaneous speaking)

CO-CHAIR KAYE: What about sufficiency? Is sufficiency an aspect of

effectiveness and quality of services?

MEMBER LUZ: Efficiency is part of quality? I would say so.

CO-CHAIR KAYE: No, sufficiency. Yes. Yes? Kimberly? And then Camille. Sorry. And hold on. Sandy, you still want to say something, right?

MEMBER MARKWOOD: Well, yes.

CO-CHAIR KAYE: Yes, wait a minute. I just want to see -- do all of you who have your things up want to say things?

(No response)

CO-CHAIR KAYE: Okay. We'll move in that direction after Kimberly.

MEMBER AUSTIN-OSER: I'm just not sure why we're doing this. I'm really not.

CO-CHAIR KAYE: Because there was a motion to collapse the categories and we don't seem to be able to come up with a single concept that captures --

MEMBER AUSTIN-OSER: Okay. If that seems to be something that some people need to

do; I don't, but if other people do, then that's fine. I guess I'm just wondering, like we had a really long, I thought really good conversation about this one. I mean, we had a lot of them, but on this one in particular this is where we addressed right time, right place, right service without saying it that way. We actually tried to get to the essence of why that's important. And I feel like we're just kind of deconstructing all of that now, maybe even destroying it. And is there a problem with just saying -- let's come up with a domain and then list these out separately underneath it, or is that -- I don't know. I feel like we're destroying something that I thought was really important --

(Simultaneous speaking)

CO-CHAIR KAYE: And Camille is nodding in agreement. Okay.

MEMBER DOBSON: Can I just jump in for a second?

CO-CHAIR KAYE: Please.

MEMBER DOBSON: Point of order to the

staff. I want to understand where we're moving next, because we're having a lot of conversations about the measurement is individual or it's a system level. Isn't that what we're going to talk about when we break down? Right?

CO-CHAIR KAYE: When we break up we're going to talk about --

MEMBER DOBSON: But some of these are --

CO-CHAIR KAYE: -- sub-domains.

MEMBER DOBSON: -- individual.

CO-CHAIR KAYE: We're not going to specifically talk about -- well, we could.

MEMBER DOBSON: Well, it does. I mean, our charts back here show system --

CO-CHAIR KAYE: Right, but we're thinking of not --

MEMBER DOBSON: -- individual --

CO-CHAIR KAYE: But I think we decided yesterday we would not go into that.

MEMBER DOBSON: Not going to do that? Okay. Because the struggle is -- I agree

completely with Kim. I'm not quite sure I understand this exercise either, because all these elements could in fact be sub-domains under the title, and I worry that we're losing it by pulling it up in a category title that we don't miss some of these. These all could be sub-domains. Some at the system level, measure at the system level. Some get measured at the individual level. I'm struggling.

MS. LASH: I would sort offer that part of the objective for this conversation now is to get the group to have a common understanding of what is in each domain and to make sure that they are conceptually distinct so that when we break into small groups and capture the sub-domains based on this and other discussion that you're not overlapping again at that more nuanced level of detail. And there would be room for sub-domains that operate at a system level of measurement. An intermediate accountable entity like a health plan or at a consumer and family level.

CO-CHAIR KAYE: Right. I want to say that I don't think we're going to right now reach consensus on this. So this doesn't have to be the final list. But I want to go back up to Ari Houser's comment that he proposed that instead of caregiver support that it just be family caregivers. Is there an objection to that?

MEMBER OXFORD: Well, I think it begs the question, so what about support for non-family caregivers?

CO-CHAIR KAYE: Barbara is agreeing with that.

MEMBER OXFORD: And again it's being more of a mix. I mean, again my experience is of a self-directed world, but it's an in and out and family are paid. They're also volunteering. The same family member is paid and a volunteer. It just depends on day of the week or something. And so, I'd argue that it needs to be broader.

MR. NE'EMAN: I would share that concern and add to that host homes and life share as arrangements in which you have similar

intimate relationships with non-family support providers.

CO-CHAIR KAYE: Barbara?

MEMBER McCANN: As a social worker and somebody out in the house, we have fought so hard against the legal definition of family, and that with the variety of caregivers it just allows us to say that support can be greater than just legal family.

CO-CHAIR KAYE: Anita?

MEMBER YUSKAUSKAS: I think our focus in the last few years has really been to try and develop natural supports in the community and relationships, and I think by restricting it to family, it becomes too narrow.

CO-CHAIR KAYE: Right. We can clarify it in the description. I think, Ari, you're being shot down here.

All right. So the next to last one is equitable system/fairness and distribution of services that eliminate health disparities. Do we want to say something about equitable or

something like equity? Service equity or something like that?

MR. NE'EMAN: Is the emphasis of this on equity or health disparities?

CO-CHAIR KAYE: Two concepts we tried to put together. Well, we certainly can't call it health disparities, because it sounds like we're supporting health disparities as a domain.

MR. NE'EMAN: Well, we could conceivably combine the equity component with efficiency, and then just call this closing health disparities.

CO-CHAIR KAYE: Fairness. What about fairness? Fairness goes with equity, right? Clare?

MEMBER LUZ: My understanding was that the emphasis was on equity and that would in turn lead to reduced health disparities.

MR. NE'EMAN: I'm fine with that. Equity and fairness then?

CO-CHAIR KAYE: Equity and fairness?

(No response)

CO-CHAIR KAYE: Okay. All right. So then the last one -- so we haven't yet had a discussion of whether it's appropriate. So what we did last night after you guys left was combine the last three that had the fewest votes because we felt like we didn't want to lose those concepts. And we combined them and then arbitrarily labeled them as well-being, which I suspect is not going to make everybody happy. And under that physical/emotional health, safety from the part of the consumer, freedom from abuse, exploitation, neglect. Is that well-being to people? Physical well-being, but we have emotional health in it.

MEMBER APPLEBAUM: how about physical and emotional well-being?

CO-CHAIR KAYE: Yes? Physical and emotional well-being.

(No response)

CO-CHAIR KAYE: So are we relatively happy with these as domains? I mean, we haven't completely finished the work and not everybody

got what they wanted, but, Gerry, are you relatively happy?

MEMBER MORRISSEY: I'm more than relatively happy, but just with one point. I don't mean to wordsmith this, but I'm trying to think about if these are the characteristics of our system for the next 5 to 10 years, because these things don't -- back to participant engagement of the system, I think a more powerful word is ownership. It's loaded intentionally so that the individuals actually have a real voice. And you can take stakeholder engagement I guess and make it a sub-domain, but I think you want words that have some power and meaning behind them. And sometimes fewer words have that effect than a lot of words.

CO-CHAIR KAYE: Who has a computer open that they can look to see what the synonyms of ownership are?

Oh, I know. Because I spilled tea on my computer yesterday I'm afraid of putting it on the table while I'm doing this. Go ahead, Drew.

MR. ANDERSON: The synonyms are possession, right of possession, freehold, proprietorship, proprietor rights, title.

CO-CHAIR KAYE: That's not helpful.

MR. ANDERSON: That's not where we're going. Yes, I know.

CO-CHAIR KAYE: See, I'm on your side with that, Gerry. We're kind of introducing a kind of new concept. I actually kind of like it.

MEMBER OXFORD: By ownership are you thinking more like buy-in?

CO-CHAIR KAYE: Buy-in, yes.

MEMBER OXFORD: So, it's less than control. We're not saying that -- I mean, yet -- that the people that use the services get to control at the system level, but to have buy-in and actually -- because engagement, right, the problem is, oh, well, the state did a meeting where they did a slide show and there were 500 people in the meeting and there was two minutes for questions.

CO-CHAIR KAYE: Yes. No, I mean, I'm

appalled at the stakeholder engagement in California --

(Simultaneous speaking)

MEMBER OXFORD: Right. So, but buy-in I think to me means that actually at the system level you said, okay, we're okay with this.

CO-CHAIR KAYE: All right. Jon, Clare, Bob and Suzanne.

MEMBER DELMAN: I don't think buy-in is sufficient. When writing about this I've talked about active participation or meaningful participation in this process, meaning given an opportunity to participate in a key decision making process in a way that you have impact. So that's my working technical words, active participation or meaningful participation. Buy-in is, all right, we'll do it. Okay. I agree. I can't --

CO-CHAIR KAYE: How do you feel about ownership?

MEMBER DELMAN: Well, what does ownership mean? I'm a little confused. I like

control better, but I'm not sure it's necessary.

CO-CHAIR KAYE: Gerry, keep thinking.

(Laughter)

CO-CHAIR KAYE: Clare?

MEMBER LUZ: I'm okay with ownership. I'm not okay with buy-in because I do think the situation can exist where somebody decides everything and then gets you to agree to it and then calls it buy-in.

CO-CHAIR KAYE: Okay. Bob?

MEMBER APPLEBAUM: I just would agree with Jon. I really like something like meaningful involvement in the design, or something like that. I think the thing I don't like about ownership is we live in a world where 75 percent of nursing homes are for-profit, 60 percent of home health agencies are for-profit, and I think ownership can connote something that I think we don't want to communicate here in this particular --

CO-CHAIR KAYE: Suzanne and Anita and Sarita.

MEMBER CRISP: I like a forceful statement like participant voice matters. I think that kind of captures it all, that they're part of the process, that they have input, that -- I don't know.

CO-CHAIR KAYE: I mean, I did propose consumer voice earlier, but that didn't get much traction.

MEMBER CRISP: Yes, I know. And I like matters, because participant voice -- that's a little --

CO-CHAIR KAYE: It matters? In other words, it's not just yelling and screaming. It's that it really --

MEMBER CRISP: It's not just, hi, we're putting this publication in the newspaper and --

CO-CHAIR KAYE: Right.

MEMBER CRISP: -- you need to read it and react to it. Yes.

CO-CHAIR KAYE: Anita?

MEMBER YUSKAUSKAS: I think the terms

like meaningful participation are good, but I don't think they go far enough, because I think it's the old conception of person-centered planning. You slap the label on it and you invite the person to the meeting and then you have a person-centered planning meeting. And we all know that those failed miserably. And I think a word like ownership is really important. If we can find a synonym that denotes control and that somehow can fit with the system, I think we need to be much more assertive about how we label this.

CO-CHAIR KAYE: Sarita?

MEMBER MOHANTY: Yes, actually I was looking up the definition of ownership just so I could kind of understand. And obviously I get the point of kind of the legal aspects and concerns about for-profit, but the other that kind of resonated with me is that if you talk about the formal definition, it's actually accepting responsibility, accountability and obligation, which I think those are important

components of ownership, too. I mean, so I think I like the word ownership, I guess is what I'm saying, because it also has those aspects of it included in the definition.

CO-CHAIR KAYE: Well, okay. So could we could flip it and say the system is accountable to consumers?

MEMBER MOHANTY: Yes, and that consumers in that sense have accountability for the system at hand, too. I think it's both.

CO-CHAIR KAYE: Right.

MEMBER SMITH: Or accountable to consumer voice.

MEMBER MOHANTY: Or you can say accountable to consumer voice. That's another one, too.

CO-CHAIR KAYE: Sandy?

MEMBER MARKWOOD: We can just say consumer voice/ownership.

CO-CHAIR KAYE: Consumer voice/ownership, Sandy is saying.

MEMBER MARKWOOD: Yes.

CO-CHAIR KAYE: Consumer voice/ownership. I'm seeing some nods. How many objections are there?

(No response)

CO-CHAIR KAYE: Consumer voice/ownership wins.

(Laughter)

CO-CHAIR KAYE: Okay. What should we do now? Is there public comment?

(No response)

CO-CHAIR KAYE: Thanks, everybody.

MR. ANDERSON: So, we're going to open up the lien for public comment, but first we're going to take comment within the room.

MS. BLACKWELL: Steve, could you read back the last one about ownership again? This is Ellen Blackwell. I'm just speaking as a consumer right now. Okay?

CO-CHAIR KAYE: So Consumer Voice/Ownership is the title.'

MS. BLACKWELL: I'm not crazy about that. And what I would just throw out to the

Committee is consumer -- to me it's consumer/self-determination.

CO-CHAIR KAYE: But this is not the service thing. This is the system thing. So it's consumer voice in how the system is organized or not.

MS. BLACKWELL: But I guess what worries me a little bit is that I'm hearing a lot of talk about systems, but when I think about this project, it goes much beyond state systems into just a person who might be getting services in their own home. And this work crosses payers, so, I mean, I'm just thinking there was a lot of focus on the systems when it could be at the individual level.

CO-CHAIR KAYE: We already have a choice and control bucket right under that that has a lot of --

MS. BLACKWELL: Okay.

CO-CHAIR KAYE: -- stuff like this where the --

MS. BLACKWELL: Okay.

CO-CHAIR KAYE: -- consumer gets to control.

MS. LASH: Okay. Before we take a break I wanted to read some comments from the Web chat since we didn't emphasize those as much as we would have liked to yesterday.

Jennifer Rosenbaum asked or commented that she's interested in understanding the domains from the meta-analysis and if they were comprehensive and mutually exclusive. The short answer to that is no. She was wondering about the broader domain identities to capture comprehensively and in a mutually exclusive way; and you all might want to consider these in the sub-domain discussion, family roles, community roles, work force roles, financial independence, physical and emotional health and vital communities. She suggests the domains might be organized together with some of those concepts.

Mary Lee Fay also commented there's University of Minnesota data that of the 1.14 million people with IDD served by state IDD

agencies, at a date in June 2012, 600,000 or so, which is 56 percent, lived in the home of a family member, 10 percent lived in a home they owned or leased, and 5 percent lived with a host family or in a family foster home. The remaining 28 percent lived in a group home or facility. And so, individuals providing support to people with IDD is not a small number.

There were other comments in support of a broad interpretation of caregivers beyond the term family.

As an alternative to the term ownership, responsibility.

And finally, a comment that the term equitable had some concern unless it is well-defined so that we are sure whether we're communicating equitable distribution of services such that everyone with the same level of disability receives the same mix of services, or are we talking about equitable outcomes? Focusing on outcomes would require us to recognize that people come to the table with

different levels of resources and some would require more paid support while others would have greater access to family, friends and community resources.

Thank you all for those comments. We'll reconvene at 11:00.

(Whereupon, the above-entitled matter went off the record at 10:43 a.m. and resumed at 11:03 a.m.)

MS. LASH: All right, everyone, we'd like to give you some instructions for starting the small group work on sub-domains. Drew will take it away.

MR. ANDERSON: So, we're going to break off into four groups of five to six committee members. Each group is going to be comprised of committee members, one NQF staff member and an HHS observer, if they choose.

This is really going to be the opportunity to look back at the list of characteristics again along with the domains that you've kind of rolled up into bigger buckets and

look at them across the different levels of analysis as you can see here and I'll show you this slide.

We'll also need you guys to pick somebody to be a facilitator and try to keep notes of the discussion that you guys have so when we come back as a larger group you can share, you know, how you arrived at these domains -- these sub-domains.

And we're going to ask that you guys try to limit it to about five. You can have more, but try to work within getting around five sub-domains for each one of these categories.

As you can see from this chart, the domains are listed. Each group is going to have two to three domains. It's going to be listed on the left hand side and you're going to be looking at it across the system, intermediate, accountability level and individual level as we've, you know, been discussing.

So, with that, here are the group assignments.

So, take a look at this list. We're going to have group one, is going to be in the far left hand corner here to me. Then group two will be the far right. Group three will be over here where I am sitting. And group four will be closer to Sarah on that side.

And we have flip charts on each side of the room.

And each of you will be -- each group will be looking at these two to three domains that's listed on this slide here.

Any questions?

CO-CHAIR CALDWELL: Just before we break, during the break, there was some other discussion about one of the domains. So, I wanted to bring back a proposal and just get people's reactions and if people aren't okay with it, then we can sort of put it in the parking lot.

But there was still some disagreement about the one domain that says caregiver support. And I think, you know, what Ari Houser raised is

sometimes when the general public sees that just the word caregiver, they don't think of the unpaid caregiver or the family caregiver.

So, one potential way to get around that is to say, family and unpaid caregivers. And I wanted to see if that might be okay with people that had issues with that.

It would broaden it beyond family but it would still put the emphasis that it's primarily, you know, this is the unpaid caregivers because we have a domain on the workforce and the direct care.

MEMBER CRISP: So, we're differentiating between paid and nonpaid? So, we're saying that nonpaid family members and other nonpaid caregivers? So, I'm not sure what we're saying here.

CO-CHAIR CALDWELL: Yes, I mean it would be family and unpaid caregivers. The issue of paid family caregivers and where that would go, it could go within this domain, you know, if you see that as a family support mechanism.

MEMBER CRISP: What about the family members who are being paid, though?

CO-CHAIR CALDWELL: That's what I'm saying.

MEMBER CRISP: Yes, I mean I don't get it.

CO-CHAIR CALDWELL: Gerry?

MEMBER MORRISSEY: Back to Ari's point, I do think we should put family in there because family's have a dominate role in all of this work.

I thought from yesterday, the whole point of -- we understood some family members do paid and unpaid, and we are recognizing that by putting the word supported. I thought that's the logic of how that occurred yesterday.

CO-CHAIR KAYE: So, I thought we were saying -- so, I think we're trying to fudge things a bit by saying family which could, potentially, which presumably includes all family members and unpaid and anybody else who's unpaid.

So, in other words, not a paid worker

who is a stranger. So, that's what I would see this bucket as.

MEMBER MORRISSEY: Neighbor, natural supports?

CO-CHAIR KAYE: Yes. Right, what do you think, Mike?

MEMBER OXFORD: Well, I guess my concern is that whether they're paid or not, family, defined broadly including sort of social family ideas, it's just a little bit different dynamic than just hiring someone from an agency or something like that.

So, I don't want to just lose that by saying, oh, we're only talking about family if they're unpaid because I think family has a different dynamic including when it's paid compared to some stranger.

MEMBER MORRISSEY: So, to that point, why couldn't we, in the sub-domain differentiate that?

CO-CHAIR KAYE: But what is the title of the domain then?

MEMBER MORRISSEY: Family caregivers.

CO-CHAIR KAYE: But that got rejected by a lot of people last time.

MEMBER MORRISSEY: Family caregivers, well, we actually compromised on whatever words -- you came to family caregivers as supported yesterday as a group, right?

CO-CHAIR KAYE: And today, we're calling it caregiver support.

And I guess Joe and I said if there was push back, we would just leave it the way it is. So, I guess that may be what we're going to do.

MEMBER OXFORD: It seems to me the broad general domain is caregivers and then you break it down family, non-family, paid, unpaid, et cetera. I mean that's my logic.

CO-CHAIR CALDWELL: Although, I think we had most the paid except for maybe family are going to fall into workforce bucket, right?

MEMBER AUSTIN-OSER: I actually am not sure if that's the right distinction. It sounds

logical but we've run into, and I think that there's some real merit here, that the paid and unpaid isn't the difference between the natural support and the workforce.

And so, I think that's what we're getting at here is that that's not the distinction that, you know, family caregivers and other natural supports, unpaid and everything else falls into workforce.

I actually think there's a middle ground that probably fits better under family and other natural supports kind of a category or whatever you want to call it.

CO-CHAIR KAYE: Well, we'll give Ari the last word.

MEMBER HOUSER: I guess I would -- this isn't perfect, but generally, where I might put the break is not whether you're paid or not, but whether you require payment to do the work or not.

I think a lot of family caregivers who are, again, and that's how you're faced and it's

not perfect, but probably most family caregivers who are paid would be caregivers anyway even if they weren't paid. It's a way of supporting them.

There's -- and often what they're paid is not what they would be paid if they were doing work for hire, but it sort of a support and it enables them to provide more care than they would otherwise be able to.

Again, I don't think that's perfect, but I think that's closer to what the dividing line would be.

CO-CHAIR CALDWELL: Yes, I think maybe we could just leave it as it as is now. Go to the sub-domains. It'd be interesting to see what comes out of the sub-domains and maybe that'll, you know, allow us to come back and readdress it.

Because, for example, I'm still not sure the paid family caregiver issue, does that go under this or does that go somewhere else like under workforce?

So, that might help us if we get the

sub-domains then maybe that'll help. So, go ahead.

MEMBER CRISP: Okay, okay. I think what we also have to struggle with within that smaller group is that even paid caregivers provide an enormous amount of unpaid also. So, it, you know, it's going to take some detailed thinking.

CO-CHAIR KAYE: Okay. Before you go off, I'm more interesting in a list of sub-domains than I am in the chart and what the level of analysis is.

So, if you get bogged down, please think conceptually first rather than how you're going to measure it. All right? So, please try to keep -- I would urge people to try to think more conceptually than anything else.

And, remember, we don't have to identify measures here, that's a long way off.

MS. LASH: Right. And, you could come up with a sub-domain for measurement that fits all three levels of analysis to one.

But, as Steve is suggesting, try to crystalize on the five or six sub-domains that are core to the domain maybe before you try to sort them across the levels of analysis.

In terms of timing, we wanted to give you until about noon to work within your small groups. I'll make an announcement when lunch is set up and you can all help yourselves to lunch and continue working, if you need to.

Otherwise, you can use between 12:00 and 12:30 to take a break, catch up on email, et cetera, et cetera.

Any other questions? Kimberly?

MEMBER AUSTIN-OSER: Yes, I have a question.

So, while I care about all of these domains, I'm not in the one that is probably the most important to me. Are we going to have some conversation about this when we come back --

MS. LASH: Yes.

MEMBER AUSTIN-OSER: -- and be able to weigh in on it?

MS. LASH: Yes.

MEMBER AUSTIN-OSER: Okay.

MS. LASH: We're going to spend --

MEMBER AUSTIN-OSER: More than just reporting out?

MS. LASH: -- about 45 minutes or so after lunch sharing our results with the larger committee so that we can have the opportunity for --

MEMBER AUSTIN-OSER: Feedback, okay, great.

MS. LASH: -- further dialogue and buy-in.

MEMBER AUSTIN-OSER: Thank you.

MS. LASH: We'll do some live editing of sub-domains if we need to.

And so, do keep that in mind as you're working together that you'll be sharing your progress at the end.

Okay, let's do it.

(Whereupon, the above-entitled matter went off the record at 11:15 a.m. and resumed at

1:05 p.m.)

During the break time, the following small groups met and upon resumption of the meeting, presented their reports:

Group 1 (Consumer Voice/Ownership, Chose and Control, Human and Legal Rights) with Juliet Feldman: Joe Caldwell, Kimberly Austin-Oser, Robert Applebaum, Andrey Ostrovsky and Ari Houser.

Group 2 (Workforce/Providers, System Performance, Equity and Fairness) with Andrew Anderson: Charlie Lakin, Jonathan Delman, Sarita Mohanty, Mary Smith, Anita Yuskauskas and Ari Ne'eman.

Group 3 (Physical and Emotional Well-being, Caregiver Support, Full Community Inclusion) with Sarah Lash: Stephen Kaye, Suzanne Crisp, Patti Killingsworth, Gerry Morrissey and Lorraine Phillips.

Group 4 (Effectiveness/Quality of Services, Services Are...) with Nadine Allen: Camille Dobson, Sara Galantowicz, Clare Luz,

Sandy Markwood, Barbara McCann and Mike Oxford.

MS. LASH: Okay, everybody, we have until about 1:45 to hear some debriefing from all of the small groups and have some short discussion about what sub-domains people came up with.

I want to reserve anything about the levels of analysis that you assigned to those sub-domains for an offline exercise that essentially we will put down everything from the small groups on paper along with a lot of other products of this meeting including draft definition, so that you can really see the components as a whole and we will give the committee the opportunity to review all of that via email in the next several weeks.

That way, you can have some more deliberate think time with everything and obtain any extra input that you might like.

In the interest of time, and I'm sorry to rush it because I know that there were such strong conversations in the small groups, we'll

have a representative from each relate the sub-domains that they established in each domain, they're typed up for you to work from and I will try to spend eight to ten minutes per group so that we can move on to the next section.

And Joe will be facilitating you if you run over.

CO-CHAIR CALDWELL: Yes, I think just to reiterate, on this part, you know, we don't have to reach consensus or anything today on these sub-domains. There'll be a lot more discussion, like Sarah said, there'll be like an electronic or email input and then we have another meeting in August.

So, really, today, keep in brief and then present, you know, what the workgroup came up with and then, you know, just peoples initial reactions if there was something controversial or if there's something missing or an important idea that didn't get mentioned.

So, I think that's a good way and we'll start with my workgroup which is led by

Bob.

MEMBER APPLEBAUM: Well, I wouldn't say anything was led by Bob, but Bob got pointed out to be the spokesperson. There was no leading.

Okay, so I guess I would say that this was pretty straightforward from what we had talked about yesterday. Probably one of the questions that we had was this -- in one of the documents, there was something about shared accountability and we weren't exactly sure what that was and assumed it had something to do with the responsibility of the consumer in all of this and we weren't sure exactly how to put that into the choice and control domain.

We did talk a lot about self-determination. And so, one of the proposals is to possibly even call this domain choice and control and self-determination which we thought Steve might axe because of the extra long words on it.

But there was a lot of discussion

about that self-determination cut across a number of these areas. And so, whether it makes it into the title or not, we still wanted to make sure that it got there as something that was really important.

And then, I think that everything else, I think was relatively straightforward.

Does anybody from the group want to add anything to this one?

Okay, so, can we go to the next one? Is that enough detail from your perspective, Joe?

CO-CHAIR CALDWELL: Yes, I think so.

MEMBER APPLEBAUM: Okay.

CO-CHAIR CALDWELL: Yes. Would you rather just kind of read through all of them? Maybe you should.

MEMBER APPLEBAUM: If there's somebody on the phone, we're screen sharing so they can read it. Okay, so that's not in the interest of time.

MEMBER DOBSON: Can I ask -- if we have questions about what the sub-domains mean?

Is this not the time to ask?

CO-CHAIR CALDWELL: Yes, I think this is the time. We probably should do them one by one, do you think, instead of coming back.

MEMBER DOBSON: It's up to you.

CO-CHAIR CALDWELL: So, I guess do we go back -- you had the question on the first one?

MEMBER DOBSON: Yes, I wanted to know what choice of delivery system model meant.

MEMBER APPLEBAUM: Okay, so --

MEMBER DOBSON: Program delivery models, what that meant.

MEMBER APPLEBAUM: Okay, so, in some ways, that was the idea about whether people had actually access to self-direction. But then, as we started talking about it, people thought self-direction was so important they wanted to include it out on its own line as well.

But that was sort of in the cases, can you choose to self-direct? And, again, it could have been put -- self-direction could have been put in that one but then somebody thought, well,

maybe there's some other things that might be choice of program and so we left self-direction on its own line.

MEMBER OXFORD: Well, just real quick. I mean, so, like at home, it's not only self-direct or agency direct but also kind of cutting across is if you want to be involved with like what we'll call this work program, if you're interested in like minimum employment and so on and so on.

And so, there are really for any one person may be able to pick across three different programs, sometimes more without regard necessarily just to self-direction is what I'm trying to say.

MEMBER HOUSER: I was just going to say that that's broader, sort of the same thing, that even if you're choosing between a handful of service delivery models, none of which are self-directing, that's still a choice that you would have relative to just being assigned one.

And the presence of actually having

multiple programs to make that choice because it's self-choice. Like you could be assigned one of three programs or there could be only one program. Either way is restricting choice.

CO-CHAIR CALDWELL: Okay. Can we move on to the next one?

MEMBER APPLEBAUM: Okay, so, this one was -- there was some overlap with the choice area, but again, we had decided as a larger group to keep them separate.

But probably the one thing that is different from this one than maybe we had started out thinking about was this first item about respectful delivery system also for the workforce.

And so, we didn't want to lose the fact that in addition to being respectful to the consumer for a system to be high quality, it also needed to respect the worker and that meant adequate wages, benefits, those kinds of things that have sometimes gotten lost in the system.

So, that was the only thing that was

really very different.

And then, we also included these sense of safety item, recognizing that it might overlap with someplace else, but we didn't want them to get lost since there was so much discussion about it.

But I think other than that, it's relatively straightforward in terms of the words on the page.

So, I don't know, group, anybody want to add anything?

MEMBER DOBSON: System responsiveness?

MEMBER APPLEBAUM: Is that yours? Okay, please.

MEMBER AUSTIN-OSER: I don't think it was mine per se, but it was a conversation that we had about that when there are maybe human and legal rights violations or there are things in the system that the system is sensitive to it and highly responsive.

And so, making sure that when we're looking at a quality system that it has

mechanisms in place to address when this goes south.

MEMBER APPLEBAUM: One of the examples that came up was the ombudsman program, which if you think about from a system perspective, we have added no resources to the ombudsman program but we've added tremendous responsibility for home and community based services. And so, that was an example of system unresponsiveness, if you will, to the system.

CO-CHAIR CALDWELL: Okay, any other questions on this one?

MEMBER LUZ: I had a question. I love that you have that first bullet and this might be picky, but just the wording when you say respectful workforce, to me, in my brain, it means we are requiring that the workforce be respectful. So, I don't know how you --

MEMBER AUSTIN-OSER: I had the same thought. If we could change the way that's written, that would be really helpful. Just put maybe parens include respect for the workforce or

something like that. We can figure it out later, but I think it's good to -- yes.

CO-CHAIR CALDWELL: We'll make a note of it.

MEMBER APPLEBAUM: And we did recognize that this one does overlap with the workforce one but we just wanted to get it down there because it was so important to the system overall.

CO-CHAIR CALDWELL: And the other thing I would add, we added freedom abuse and neglect under this even though that was in another domain. So, that's an area where there seemed to be a like a lot of overlap.

MEMBER APPLEBAUM: And our third one. Okay, so this one was a little bit tough to articulate because in some ways, the words that kept coming up are meaningful and commitment to people being involved because we think that the system for a long time has paid lip service to consumer involvement or participation, but they weren't really serious about it.

And so, in some ways, the words probably aren't all that different and so I think the conversation this morning about trying to push ownership in and more forceful words we think were important.

And we did try to identify the concepts of both breadth and depth in terms of participation.

And but, this is one I think we'll need to do a lot more work on to try and get it to a domain and then measures because we recognize this is one that people have talked about but it probably hasn't ever made it very well into the measurement world.

So, obviously, we all think it's important but we've got some work to do on this one.

Anybody want to add anything to? No?

CO-CHAIR CALDWELL: Okay. All right, we'll got to -- oh, you wanted to say something, Anita?

MEMBER YUSKAUSKAS: I just have a

question. Can you explain is this your system, consumer owned system? Just a little bit about your discussion on that item?

CO-CHAIR CALDWELL: I think it was really about that consumers felt involved enough in the system to really participate and take ownership in the system itself.

And we talked, you know, we went off on various tangents including consumers sharing information with other consumers and really having much more of an ownership role in the system.

When we were doing Cash and Counseling and ran a focus group with self-directed participants, when we were done, they stayed around for like an hour sharing information and talking about resources and those kinds of things and trying to create a system where there's opportunities for sharing of information and for really being able to be a participant in a much different way than the current system. So, that was the idea for it.

CO-CHAIR CALDWELL: Okay, I guess we'll go to Group Number 2.

MR. NE'EMAN: So, I was asked to speak to this because I have the misfortune of being the only member of the group wearing a tie.

We'll start out with equity and fairness and we spent actually a fair amount of time trying to parse whether or not there was a difference between equity and fairness as concepts and reasonably sure they're synonyms.

The areas that we highlighted here are reduction and health and service disparities, transparency of resource allocation, and what we mean by that is essentially that the budget for services that you receive or the level of services that you receive is tied to a transparent equitably applied process.

The degree to which states have a waiting list or other barriers or few access for services, safe, accessible and affordable housing given the role that housing or lack of housing plays in barriers to access to services,

availability of services, timeliness not only of services but of assessment and evaluation for services and, this is a very tricky one, consistency across jurisdictions.

In county-based systems, do you suddenly have access to very different levels of service provision when you move across the county line? You know, with respect to systems, as most of our systems are, that are state-based, are there significant disparities from state to state and access to HCBS? And so on and such forth.

Any questions here or should we move on to the next one?

CO-CHAIR CALDWELL: Yes, Andrey?

MEMBER OSTROVSKY: A quick question about consistency. I think -- did you guys have a discussion about consistency, framing this as consistency versus a minimum standard?

Because each locality can be very heterogeneous or different from one another appropriately and the reflection of accommodating the populations within that location.

And I don't know if consistency would always be a great thing unless it was a minimum amount, sort of minimum standard.

Did you guys speak to that?

MR. NE'EMAN: I think from our standpoint, you know, we saw this less as a requirement that we homogenize the system and avoid experimentation or alignment with cultural competency and more of an issue of do you have drastically different levels of access to certain kinds of services depending on where you live?

And some of this gets into broader conversations on Medicaid portability and other things that are difficult to assess at an individual level but become very clear when looking at things comparatively across jurisdictions.

MEMBER OXFORD: I was wondering if maybe that didn't have to do with consistency of like high quality services across political subdivisions or whatever.

MR. NE'EMAN: And I think that's good

way of thinking of it. I mean if you look at a state just like Ohio, for example, were at least from the DD system, and I think the AD system as well, much of Medicaid is administered at the county level.

There's a question of equity if you had drastically different access to services if you need to move to take a job in Columbus, for example, from Cleveland. And ditto, you know, if you're moving from Columbus to Los Angeles or what have you.

That's really what we're trying to get at here.

CO-CHAIR CALDWELL: And Sandy, you wanted?

MEMBER MARKWOOD: Just a quick question. I know that you called out housing as part of that. And one of the issues that we see is transportation because if you don't have access, it has a quality and fairness barriers as far as being able to connect to services.

MR. NE'EMAN: I would have no

objection if the other members of my group feel the same way to adding transportation. I'm seeing nodding heads, so maybe we can make a note there.

MEMBER HOUSER: I might bundle transportation into that housing bullet point often housing is affordable because it's not well-served by transit, that you sort of substitute affordability for, you know, transportation accessibility.

And so, both are important and so we don't -- but I think to look at housing and transportation together because they're not separate.

MR. NE'EMAN: Any objection to housing and transportation in the same bullet point?

MEMBER SMITH: I think you can do that but because I understand the point you're making, but then I'd probably list transportation separately, because it's going to be much broader than, you know, that variable impacts more than just safe housing. But I get your point.

MR. NE'EMAN: Maybe we want to list access to transportation and include safe, accessible and affordable housing with access to community life.

CO-CHAIR CALDWELL: I think for now, we'll just make sure to make a note to add transportation, and then we'll figure out if it's a separate thing or not. Let's move on to the next section.

MR. NE'EMAN: Wait, Claire had one comment.

MEMBER LUZ: When we started this discussion yesterday about equity, my understanding was that it was consistency across populations. So, you can have different populations within a single jurisdiction and some are getting served well and some are not.

So, I thought we were -- sorry, my understanding was that we started this discussion so that we could get consistency across populations, and you have multiple populations within a single jurisdiction and some are getting

services, good services, and some are not.

And then to Ari's point, do we really want consistency or do we want consistency of access to all of these things? Because, you know, some populations don't need certain services. So, it's more do they have equal access?

MR. NE'EMAN: I have no objection to adding consistency of access across jurisdictions. That probably makes more sense and I would agree with you that there are certain populations that have more resource intensive needs, and we don't wish to encourage any sense of, you know, resentment because people with more significant levels of impairment are accessing more dollars. Does that address your concern, consistency of access to services across jurisdictions?

MEMBER LUZ: I think if you add access, and equal access, and across jurisdictions and populations, that would -- I would feel better about that.

CO-CHAIR CALDWELL: Isn't that in the first bullet?

MR. NE'EMAN: I feel like we're getting at populations in the first bullet and I am worried about using the term consistency in the context of populations. But let's say consistency of access to services across jurisdictions, does that work? Great.

MEMBER YUSKAUSKAS: I'm not sure I agree with just access. And one of the discussion points that we had is that our long term care system in the United States, for all intents and purposes, is not equitable. It varies from state to state, it varies in scope, it varies by population group. I mean there are so many ways that it's inequitable. And that was one of the things that we were trying to get at. So, I think it goes beyond access and I think we just need some additions there, consistent access and --

MR. NE'EMAN: Eligibility?

MEMBER YUSKAUSKAS: Eligibility and

scope and --

MR. NE'EMAN: Scope, I'm not sure -- yes, scope. Okay, across jurisdictions.

MEMBER YUSKAUSKAS: Well, depending on needs, you know.

MR. NE'EMAN: Yes, and I think as long as we're talking about across jurisdictions rather than across populations, then I think consistency in access eligibility and scope of services across jurisdictions.

CO-CHAIR KAYE: Well, we don't have time to get all these bullets exactly right.

MR. NE'EMAN: Let's move on to the next item.

CO-CHAIR KAYE: So, if you're not absolutely -- if you don't really strongly object, I urge you to pass.

MR. NE'EMAN: I will not read all of these. But we certainly benefitted from Andrew's ability to write very small, so we appreciated that. So, systems performance, from our standpoint, spoke to a wide variety of issues but

I think just speaking broadly, we had a set of issues relating to level of engagement from consumers and other stakeholders.

We had a set of issues relating to the availability of data and the integrity of data. We had a set of issues relating to equitable resource allocation, they're very similar to the first issue. And we had a set of issues with respect to the need to build in quality measures that specifically spoke to financing and service delivery structures.

CO-CHAIR CALDWELL: I think that's good. I think this one might be one people to think more about. I mean there's a lot of stuff in there, and, you know, when we get more feedback, there might be interesting to look like maybe some of this stuff overlaps with other domains. But that's a good job.

MR. NE'EMAN: And I think some of the overlap is inevitable, but I mean we should look at some of these other domains. When the same thing shows up in other domains, we might want to

look at it in the individual context and here, the system or the plan context.

CO-CHAIR CALDWELL: That's seems what's going on, yes.

MR. NE'EMAN: Next?

CO-CHAIR CALDWELL: Andrey wanted to say something.

MR. OSTROVSKY: Just a quick comment. We don't need to modify this here, but when the searching is happening as a takeaway from this meeting, I think interoperability is going to be really important just to specifically search for, because data integrity doesn't really address that, especially with how much emphasis O&C has placed on interoperability and the eLTSS work.

And then, also, directly calling out the intersection between traditionally either, you know, Medicare and Medicaid funded types of systems and deliver processes, I think that overlap in and of itself would be interesting and important to explore. But we're not updating this list.

MR. NE'EMAN: That's a really good point. We can just reflect in our notes, not only interoperability but coordination across payers, that's I think a point that we should have come up with, but I don't think we did.

Next section? Workforce, I'll run through this somewhat briefly. We started out the most basic issue, provider network adequacy. That providers exist in sufficient numbers and are appropriately disbursed, so there's access to providers in rural communities, low income communities and so on.

The providers themselves are dependable, they show up on time and so on and such forth. That providers have respect for the boundaries, privacy, values and other preferences of the consumers that they serve. That providers are skilled, and I actually am reasonably certain that what we wrote down was not training and education, but was demonstrated competencies because we had a pretty long discussion about that, where necessary, demonstrated competencies.

That providers be culturally and linguistically competent, sensitive and mindful. That providers have adequately compensated benefits, or are adequately compensated and have access to benefits.

We had a conversation about the safety of the worker. I think we also tweaked that language as well. Does anybody remember what we came up with? I know we had a long discussion about this. I feel like we might have been working off of an older version of our notes in this.

Where appropriate, demonstrated competencies. And we spoke about the importance at the agency level of having a strong culture of collaboration and values-based leadership on the part of agencies. I think the issue of values was something we really wanted to infuse throughout and that was a high priority for us.

CO-CHAIR CALDWELL: Good, any comments or questions on this? Yes?

MEMBER AUSTIN-OSER: So, I probably

will want to have a conversation privately with folks. I'm not sure handle this, but I'm a little troubled by some of this. I get, Ari, that you don't want to say training and education, you want it to say where appropriate demonstrating competencies. I also understand that there were other people on the group and I would think that there needs to be much more broad conversation about the role of training, education and competencies and what that means.

MR. NE'EMAN: To be clear, I wasn't reflecting my views. I was reflecting the language that the group as a whole agreed to. If there are any members of the group that feel otherwise, please feel free to express that.

My edit was not to reflect my personal opinion, but, in fact, to ensure that the language that we put in our matrix over there was accurately reflected on the slides here. I'm sure we'll have many more discussions on this in the full group.

MEMBER AUSTIN-OSER: I would like to

hear from the other group members, because I also think this is consistent with what you have expressed in the past, and I think that it's something that, while this isn't necessarily the appropriate venue to hash out certain things, I think that the conversation about training and education and using those terms needs to somehow be remedied.

MR. NE'EMAN: If there's any concern that I'm not accurately communicating the preferences of the group, then I definitely welcome you to talk to the other group members either now or separately.

CO-CHAIR KAYE: All right, so it says demonstrated competencies, it doesn't say anything about training. And what was the other one that you were asking about?

MR. NE'EMAN: Safety of the worker. I think we tweaked that language. We reference safety but we put it within in a specific context. I may be wrong about that.

CO-CHAIR CALDWELL: John?

CO-CHAIR KAYE: I'm not seeing anything about safety up here.

MEMBER DELMAN: I have a red -- am I on? Can people hear me? Yes, I don't think that's the most recent version. I think what was critical for us was demonstrating those competencies. And under demonstrating competencies, and I don't remember what we settled on, I think we could -- how do people get to the point where they have those competencies?

I think one is who you hire and how you hire them. I mean I think, in some cases, there is -- I forget if we eliminated training and education entirely, but I don't think it's -- I think we're put in an unfair position because it wasn't -- the thing wasn't reflective of our discussion.

So, I don't recall. I mean I think we had -- what we settled on, or even -- I just don't recall. But, I don't see training and education as the primary goal, but trying to get people who can work well in the workplace, have

those competencies. And the question is, how do you get there? And I would think training and education is one of the ways you would get there. And at least in the mental health world, part of it's -- more important, I would say is your job description and who you hire.

CO-CHAIR CALDWELL: I think this is obviously one, you know, we need to keep talking about. And, you know, in some ways, you know, the full group hasn't weighed in yet. This was just a subgroup and there's, you know, people with expertise that didn't have a chance to sort of weigh in. So, this is definitely, we'll take note that, you know, we need to talk more about this one.

MEMBER SMITH: Could I just make a comment?

CO-CHAIR CALDWELL: Yes.

MEMBER SMITH: I was part of the workgroup, too. First, I would reorder the wording a little bit. I don't know if it would make any difference. I think it was demonstrated

competencies where appropriate, and we had a long conversation and the struggle was, you know, we're trying to come up with these terms that cut across lots of populations.

And there are some populations where you would look at, you know, training, education, skill, abilities, everything, and it might be different for other populations. So, it was, you know, it wasn't settled on lightly. We had a pretty long conversation.

CO-CHAIR CALDWELL: Patti?

MEMBER KILLINGSWORTH: Just a couple of other thoughts for consideration and future discussion. One would be around workforce satisfaction, which is pretty important, and the other would be around retention, both from the provider agencies perspective as well as the consistency of staffing from the person's perspective.

MR. NE'EMAN: I actually think we had a -- this goes back to the point I was raising earlier that this is not the most recent version

of our notes. We had something in there on recruitment and retention.

CO-CHAIR CALDWELL: Okay.

MEMBER AUSTIN-OSER: Yes, I would echo that that turnover and vacancy rates are -- they're not the end all and be all and, you know, you can't take the full temperature of a workforce system based on those things, but they are really good indicators of, you know, if something's working or not working.

CO-CHAIR CALDWELL: Okay. Let's move on. Was that -- Ari, was that all yours for your group?

MR. NE'EMAN: Unless anybody else from my group wants to add anything or feels that anything was left off or inaccurately reported, please.

CO-CHAIR CALDWELL: Andrey?

MEMBER OSTROVSKY: Thanks. Just a quick comment. I'll sort of just, perhaps as a side note, I haven't heard anyone speak about individual agencies capacities in particular.

For example, we work a lot with area agencies on aging and some have demonstrated really incredible capacity to do quality improvement.

Some have demonstrated incredible capacity to have certain levels of business acumen which translates into sustainability and then which translates into, perhaps, broader impact for their populations. I'm not sure exactly how do group that within the, you know, provider aspect. But, I think speaking to the ability to measure and compare different agencies and give them almost credit in that regard might be something worth looking into. But that could be, you know, at the table.

CO-CHAIR CALDWELL: Okay, well, let's move on to Group 3 then.

MEMBER KILLINGSWORTH: So, I don't have a tie, but I'm speaking for Group 3. Our first one was full community inclusion. And you'll notice at the very top, we included fun and added the word enjoyment to that.

I think what we tried to do was

basically to draw from the original list that we had and then also looked at the domain frequency chart, and then talked those through and be sure that we captured as many of the different aspects as we thought were appropriate. So, most of these, I think, are very intuitive.

I notice that choice and setting is now in two places, and we need to figure out where that rightfully belongs. We were trying to get at the notion of, you know, it's important where you live as well as where you work and where you play, and that there are opportunities for inclusion built into all of those things.

Accessible built environment pertains specifically to where you live and not necessarily to the accessibility of the community broadly, which we recognize is probably beyond the purview of the control of the HCBS system specifically.

CO-CHAIR CALDWELL: Okay, looks good. Any comments?

MEMBER KILLINGSWORTH: I think our

other two are --

MEMBER OXFORD: Well, I kind of want to go back on the accessible build environment and I know we touched on it in our group and I've heard it around is that, I think that maybe to get at quality, we're looking beyond just the service system per se, but also the linkages and referrals and things like that.

So, every state has a protection and advocacy system, room full of lawyers that can take on the larger built environment and so on an so on. So, to kind of get to quality, you know, are those referrals happening? I don't know. I hope that we look real broadly, because one of the things that I think is missing perhaps is some of how we put things together to make a whole package, as opposed to just looking at the program.

MEMBER KILLINGSWORTH: Makes sense.

CO-CHAIR CALDWELL: Okay, we'll go on to the next one.

MEMBER KILLINGSWORTH: I think we're

up, actually, back up after the first slide of Group 1 maybe, we were way up at the top. I'm not sure how that happened, but we passed it earlier. Keep going, there we go.

And I think the other one is above this one. We'll do this one first. So, caregiver support, this one was a little bit more of a struggle than I thought it would be. But we decided to keep training and skill building separate and then access to resources as broad really in terms of, you know, different kinds of services and supports that people might need, making sure that assessment and planning is a piece of that and also considering their compensation piece and access, essentially, to financial resources to defray some of the lost opportunities of caregiving.

MEMBER HOUSER: I just wanted to -- I'm not sure what's meant by carryover family assessment and planning. But caregiver assessments are quite common and, usually, caregivers are assessed on their ability to

assist in providing care so that they can substitute for care that the state has pay for. But, in order to support caregivers, caregivers also need to be assessed for what their own needs are --

MEMBER KILLINGSWORTH: That's the intent.

MEMBER HOUSER: -- and to be supported and so that, ideally, this caregiver assessment is part, and importantly, the caregiver actually has to be talked to in that caregiver assessment, which is not always the case.

But ideally, the caregiver assessment and the care recipient assessment would be a single process or together, and services for the care recipient and the caregiver would be determined to support both. So, you know, you might have services given for the care recipient, who's primary purpose is to support the caregiver because that's the best outcome.

CO-CHAIR CALDWELL: Yes, so it sounded like that was the intent.

MEMBER KILLINGSWORTH: It was.

CO-CHAIR CALDWELL: So, we'll make a note of that and, Sarita?

MEMBER MOHANTY: I just wanted to echo that. That was one of my comments, was on the caregiver assessment and making sure we incorporate what their needs are. The other thing with compensation, I would also lead to the scenarios of compensation and benefits, because one of the things that comes up with caregivers is their ability to access services, for example, health care. And, you know, we often see that with all the burdens that they have to, you know, often times managing their own family members, they encounter a lot of physical, mental, social issues.

MEMBER KILLINGSWORTH: We can probably address Ari's concerns with the caregiver family needs, right? Because it really is about their needs, and not just their abilities to contribute. I don't know, we can work that out later.

MEMBER HOUSER: Yes, I don't think we need to develop that language immediately, but I just wanted to make sure that that's where we were going.

MEMBER KILLINGSWORTH: Yes, it was.

MEMBER HOUSER: Okay.

MEMBER KILLINGSWORTH: Okay, and I think our other one is maybe above, yes, physical and emotional well-being. So, we wanted to be sure that we both got at functioning or status, as well as health and wellness generally. So, that's sort of the reason that those three categories are defined separately.

Here, we have another duplication, actually, two of them, one with safety and one with freedom from abuse, neglect and exploitation which were in different places, so we'll need to work our way through that.

CO-CHAIR CALDWELL: That's good. Any comments? Okay. We've got the last group, Group 4.

MEMBER CRISP: So, one of the hazards

of going last is that this is going to sound a little duplicative. I think we're realizing these aren't necessarily mutually exclusive domains in some ways.

So, our first domain that we worked on was the effectiveness and quality of services. So, we really looked at effectiveness as achieving outcomes and effective -- a measure of effectiveness is whether or not you accomplish what you set out to accomplish. So, you'll see that we've listed meeting goals, meeting preferences, health outcome achieved.

Under quality of services, this was a little bit tricky because this whole exercise is about measuring HCBS quality. So, we tried to think of quality of services somewhat narrowly as technical, quality technical competence of delivering a particular service or support.

So, that's why we have sort of technical skills, delivery of technical services, team performance. And then the final comment on rebalancing, and we're not necessarily wedded to

that word, but thinking at the system level, is the system effective if people are being served in the least restrictive setting? So, is your system balanced? And that's sort of a system level measure. So, let me see if there are questions or other members of the group want to comment.

MEMBER APPLEBAUM: Where is satisfaction of the services? Is that included in the technical services delivery?

MEMBER CRISP: So, satisfaction as being an outcome? So, I guess I would say, and others can weigh in, that that's part of preferences being met. You ask someone if their needs are being met, and that includes are they satisfied with what they received. So, it could fall there, it could be called out as its own separate sub-domain, also.

MEMBER YUSKAUSKAS: One of topics we talked about in our group was evidence based practices, and the lack thereof. And I'm just wondering how to get something about that on one

of these lists, so that it can be at least be acknowledged and hopefully addressed over time?

MEMBER GALANTOWICZ: So, I think we've talked about quality of services and ideally, that would mean that evidence based practices were being implemented, that best practices were being implemented and the absence of best practices or evidence basis for a lot of service delivery, it's sort of this notion of technically competent, or technically appropriate services being delivered. But, absolutely, there was a discussion around that.

CO-CHAIR CALDWELL: Yes, I think that's important to note, especially when you do the environmental scan, that evidence base will probably show up more than technical. Any other comments on this one?

MEMBER SMITH: Yes, I'd like to go back to not consumer satisfaction, but more like consumer evaluation of services. You know, those are -- you often seek that information using a survey, and the survey is actually more than just

saying are you satisfied with services. There's a whole array of things one would ask.

CO-CHAIR CALDWELL: So, we're taking note of that. Thanks.

MEMBER LUZ: So, we had a long discussion in terms of technical services, technical skills. What does that mean? Because you can deliver something technically, you know, deliver technical service, but did you do it well? Did you do it in a person centered manner?

So, it covered not it covered not only the technical skill, but the quality, or the art of the way in which it was delivered. And I don't know that we have that well enough defined there, but that was part of the discussion.

MEMBER GALANTOWICZ: I think that's an important point. We struggled with what is quality service to delivery look like? Not just did you do it, but did you do it well? And how do you assess that without evidence based practices? Maybe you only get the participant's perspective on whether it was done well or not.

But, that's a piece of quality that we struggle with how to reflect here.

MEMBER LUZ: And we could capture that through client evaluation. I said we could capture that through client evaluating their services.

CO-CHAIR CALDWELL: Let's go to Lorraine?

MEMBER PHILLIPS: I have a question and a comment. For team performance, was there any discussion of the professional diversity of the team? And where does that show up? And then, I'm not sure where care coordination fits in here and if it's in this, because I've lost track of the different -- it's in the next one, okay. So, I just go back to the --

MEMBER MARKWOOD: And I would just raise the point that a lot of the issues that you're bringing up are in the next one, and part of our discussion was whether these should remain separate, or whether these should be combined.

MEMBER LUZ: And I'll add that, like

the other group, I think some of our -- we had sub-bullets to our sub-bullets, and under team performance, we actually had it split into three things, and one was team composition to make sure there was diversity across disciplines and that consumers were involved in all of that.

And then team function, how well were they functioning as a team? And then team outcomes, was the team achieving what they were supposed to be achieving?

CO-CHAIR CALDWELL: Okay, anybody else? Then let's go on to the next one and you mentioned we need to -- there might be some merging here or overlap.

MEMBER GALANTOWICZ: Sure, this next one actually set us up nicely for sub-domains because it was written services are and it had five different -- or I think five or six different qualities. So, it considered each of those qualities, the domain and then the sub-domains under the sub-domains.

The first adjective was service -- it

was about service accessibility. So, we parsed that out into four different types of accessibility with their proximity, geographic accessibility, economic accessibility, which would include costs, physical accessibility think specifically around the ADA and the idea of being able to access and use services.

And then this somewhat more vague notion that public and private awareness, so just because a service is physically present in an area, if the person or individual or organization that is helping coordinate your care is not aware of that service, or doesn't have any connection to it, in effect, it is not accessible even though it's physically located in the area.

Appropriate services, this was a sort of we split this between, is it aligned with needs? Is the service appropriate because it's aligned with the individual needs? And is it appropriate because it's aligned with preferences? And as part of that, this notion of whether or not goals are being assessed, so that

it's appropriate because there's a goal that service is designed to contribute to.

Sufficiency, and again, this is where I think there's going be some overlap is, you know, sufficiency includes both the scope of what's available as well as the capacity of the service system or the provider network or what have you to meet both existing and future demand.

So, we didn't want to link sufficiency to just what's being provided. Now, but again, this notion is it going to be sufficient to meet all potential demand?

So, we can scroll down, because I think we have three slides on this one. So, the third adjective under services are was this notion of dependability which, I think, was on another slide. Again, we sort of tried to pull out the components of dependability, meaning that from a personal perspective, can you count on coverage? Does someone always come? Is it dependable in terms of being timely? Does the person or the worker show up on time? Is there

continuity?

And I think someone already mentioned turnover but from the individual perspective, is there consistency in what the individual you're dealing with? Competency in the sense that the -- there's two dimensions of competency that the person -- the services dependably knows the needs and preferences of the individual, and then there's also just sort of basic competency, the ability to provide what is required.

So, we felt like the ability to provide what is required is different than actually that more person-centered notion of knowing what the needs are and the preferences, so that you're competent to serve that individual, as opposed to just generally competent. We had this timely was one component, and because we had worker timeliness under dependability, we created the separate notion of timely initiation of services, which is more of a systems level measure.

You know, if you are eligible for a

program, do services start, you know, within the desired period of time, or do you have to wait, you know, months to get started? So, that's timely not on the day to day basis, but timely in sort of overall initiation. And then we do have this element of coordination which, again, is probably duplicative of other areas and we, again, tried to think of this as a process.

First, is the assessment that you received truly comprehensive, so it brings in all types of needs, not just HCBS, but it sets you up for coordination by identifying other needs like health care needs?

Then does that translate into development of a plan that's sufficiently comprehensive? Is information exchanged between all members of the care team including the individuals? So, you can't have coordination if people don't even know what they're expected to do. Is that actually implemented? Having a plan is not sufficient. And then it is evaluated?

And then we all laughed because really

that last bullet is classic CQI, you know, plan, do, check, action. You go back to the beginning and then do all those things and so forth. And I'm not sure if we have any more slides or not. No, that was it.

CO-CHAIR CALDWELL: Any comments on this? I think it's interesting like there's a lot here, and then there was a lot on Ari's like systems slide. So, I mean I think that's okay, like some are going to have more sub-domains than others. But I think it also tells you something about, you know, where we might be going with the conceptual framework that we're going to talk about next. So, any comments on this? Okay, so we finished all the sub-domains and now we're going to get into the conceptual --

MS. LASH: Let's do a quick public comment briefly before we go to the conceptual framework.

CO-CHAIR CALDWELL: Okay.

MS. LASH: Since that was a lot of content, maybe there's further reflections out in

the audience. And while we do so, Nadine and Drew or Juliet, I emailed you a slide that we need to show of the draft conceptual framework, if you could work on bringing that to the screen. No one in the room is moving. Operator, is there anyone on the phone that would like to make a public comment at this time?

OPERATOR: At this time, if you would like to make a comment, please press star then the number one. There are no public comments at this time.

MS. LASH: Thank you. Okay, from the web then?

MS. FELDMAN: One commenter submitted a comment through our webinar platform saying, culturally competent is not an accurate term as it denotes a level of mastery. However, this is not attainable. Cultural and linguistic humility, as well as an understanding of historical trauma is the preferred language as it encompasses multiple issues across race and ethnicity.

This individual also said, training and education often do not equate equity process, and restructuring systems is more effective than training alone. The approach should be tailored to the needs and/or goals, in parentheses, system change versus service providers versus users.

MS. LASH: Thank you, Juliet. And thanks to those members of the public. We're getting a little bit behind, so I'm not going to give you another break, but do feel free to excuse yourself for a couple of minutes if you need to go out into the hall.

This is the very first iteration of a conceptual framework so that we would have something to show and share with you all, and get your thoughts about whether you think this represents the thinking of the group. So, we heard yesterday that we would like sort of a nationally relevant framework that is broad and high level enough that it really encompasses quite a bit.

Also, that it would be fairly simple

and not overly complex, to kind of interpret different mechanisms and shapes and things like that. We wanted to reflect the primary role of consumer outcomes in the conceptual framework, and to sort of demonstrate the role of quality in all of this.

So, in a nutshell, we've taken the domains that we fleshed out today and organized them into those that relate primarily, not exclusively perhaps, to system level concepts, service level concepts, and then outcomes, knowing that one influences the other influences the other, and that there very well might be topics in the domains that span all three.

And we might be able to visualize that a little differently, but, essentially, there is a kind of a causal, linear relationship from left to right in the diagram. And that what it is intending to really represent is quality home- and community-based services, and then the action of measurement increases accountability, transparency and improvement efforts.

So, this is the product of some tired brains. Last night we had pyramids, we had circles for a while. We ended up with this arrow. So, we'd like any concrete suggestions you have for how this might be able to be enhanced. If it's missing the boat entirely, we can probably spend until, it is now going to be 2:30 on this topic, and then this is also something that you'll be able to give us written email feedback on after the meeting, since we're just kind of throwing this out at you without too much other preparation. Joe and Steve, did I capture that correctly?

CO-CHAIR CALDWELL: Yes, I think, you know, we heard from the discussion to keep it simple, so we tried to do that. You know, personally, I'm not a very visual thinker, so I'm not good at this sort of stuff. There may be people within this group that are better at visually representing things.

And I think we tried to put things in buckets knowing that there is overlap on all this

stuff, but tried to come up with some way to kind of, instead of having 13 boxes like the scorecard, which I personally like, but instead of having the 13 different domains, if there's a better way to try to pull it all together and make it a little more simpler. So, that's what I'll share as our thinking. And then we got tired.

CO-CHAIR KAYE: And also, we were going to point out that NQF has a graphic designer on staff who will make this -- I mean actually, I'm really impressed with how pretty you made it, Sarah. But, you know, it won't -- the final thing won't necessarily look like this. They might have better ideas about how to visually to represent it. But does it seem like does it make sense to you for one thing?

MEMBER YUSKAUSKAS: I think it makes sense and I like it for its simplicity. I guess I'm wondering where we're going to go with this? So, is this a foundation for a quality framework, or is it a beginning for us to be able to

understand HCBS as a construct?

MS. LASH: I don't know that it helps us understand HCBS as a construct. That's really what the definition I think is designed to do. And this goes next to that as a visualization of the concepts of quality this group has articulated related to HCBS. But if it needs to do more, you know, the group can guide us down that path.

MEMBER OXFORD: I just have a question and I'm with Joe, I don't think visually or colorfully. Well, colorfully maybe, but not in colors. But I guess my question is, so I thought that I kind of heard a pretty common comment around that the main thing was serving people and that's what the programs and services and the quality measurement was all about. But I don't see the people anywhere in this diagram. So, that's the only thing that occurred to me.

CO-CHAIR CALDWELL: I think that's good. Like in other iterations we had like this pyramid and the people were at the top and then,

you know, so that's a good observation. We can go to Bob and the Andrey.

MEMBER APPLEBAUM: So, one of the challenges in thinking about this is what's an outcome? And so, when I look at, for example, the services box, things like satisfaction with services, to me, is an outcome, and a lot of these things in terms of consumers' experience, in terms of if they feel like they're being treated with choice and control, that's an outcome. It also is a sort of throughput, and so I think it does get tricky to figure out which things are outcomes and which things are outputs, or whatever.

But I think, to me, certainly satisfaction with services, satisfaction with the experience, how people are treated, those are outcomes of a home and community based service. And I'm not sure which things got put in the services box, and which things got put in the outcomes box.

CO-CHAIR KAYE: What if it were

relabeled as consumers? System services consumers, does that help any? And it puts the people in it.

MEMBER APPLEBAUM: Well, I mean I guess I was trying to sort of put a logic model on to this, and in terms of -- so, from an evaluation, we try to figure what the intervention is that people are getting? What happens to them? And then what are the outcomes?

And somehow, this doesn't quite -- because things like satisfaction with services, to me, is a really important outcome of the system, and we spent a lot of time and resources trying to develop measures for that. And so, how is that not an outcome compared to, I mean the same as whether your functional ability is the --

CO-CHAIR CALDWELL: We can keep thinking about it. Go to Ari.

MEMBER HOUSER: I was going to suggest something similar but not as creative. But, I agree, I think if we replace outcomes with consumers, then we have three boxes that are not

co-branded with the three boxes of structure, process, and outcome.

And I think we might say that the system box tends to lend itself to sort of structural measures and the services box tends to lend itself to process measures and the consumer box tends to lend itself to outcome measures without actually labeling it as so and tying ourselves into that framework. So, I think that would work.

CO-CHAIR CALDWELL: That's good. Patti?

MEMBER KILLINGSWORTH: I don't think in pictures either, but I must admit when I looked at the picture, I thought where's the arrow going?

So, there was a part of me that wanted to move outcomes to the point of the arrow. Right? Because everything that we're doing at the system level and the services level is really to support outcomes in people's lives.

Now, that doesn't work if you change

it to consumer or something else. But I think if it stays outcomes maybe that's the whole point of what we're doing.

CO-CHAIR CALDWELL: And that's a good point. And maybe the arrow isn't the best representation. We had --

MS. LASH: You know, we have PowerPoint limitations. I was, you know, it would be better if each of these rectangles had like the angular arrow side and they all fit into one another with, you know, the consumer and family at the end so that they really are present in the framework and it's clear that this is all leading up to -- there are outcomes if we change the purple box to be labeled consumers to be in both places.

CO-CHAIR CALDWELL: Sara?

MEMBER GALANTOWICZ: So, two comments. I think having worked on the group that discussed the effectiveness domain, I think the way we thought about operationalizing the domain really was all about outcomes, that an effective system

is one that realizes the outcomes for individuals.

So, you know, some of this is going to come down to semantics where we put different domains and, again, it, you know, there's the level of measurement as well. So, we could think about individual outcomes.

And then I just wanted to make a comment on satisfaction. Having worked on a couple of different surveys, I think just to make a note that maybe to talk more about experience rather than satisfaction because from a quality measurement point of view, experience is actionable, satisfaction is a lot harder to tease out what the correlation to satisfaction are.

But if we ask people about their experience and the things that matters to them then we essentially assess their satisfaction of the system.

CO-CHAIR CALDWELL: I wonder if Mary's term of consumer evaluation is a little more specific than consumer experience?

Anita?

MEMBER YUSKAUSKAS: I just have one suggestion and I like what Patti mentioned. If you do move the outcomes it starts to look like a logic model with inputs and outputs. And I think a logic model might be a really good approach to something like this. Just a suggestion.

CO-CHAIR CALDWELL: Mary?

MEMBER SMITH: Yes, I like moving the outcomes to outside of the arrow there so that things are pointing towards it, but I would call it consumer outcomes. I mean just to call it consumer seems a little weird to me. I don't know what that would mean.

MEMBER OXFORD: Yes, and if you actually read what's in the outcome, physical and emotional well-being, people being served, right, et cetera, et cetera.

MEMBER SMITH: I would also agree with --

MEMBER OXFORD: Human legal rights for people being served.

MEMBER SMITH: -- moving that effectiveness piece over to outcomes. I'm kind of puzzled why it's in there with services.

MEMBER OXFORD: I think maybe what the folks who put this together were thinking is that it may be about outcomes but it's really talking about services.

Whereas, physical and emotional well-being, human and legal rights, full community inclusion, those aren't about services. Services can get you there or they can be preventive from keeping you from getting there.

But there's really nothing intrinsically service based about those.

Whereas, everything on the services box are carryover supports, maybe less so. But the other four are all about the actual provision of services. And I can see how that logic flows.

And there's certainly there are services outcomes and there's outcomes that can be affected services but they're not service outcomes.

CO-CHAIR CALDWELL: That's a good point. Is there anybody else that we didn't get?

Okay, I think that's good. Yes, I think this is really helpful.

And we did -- I mean when we were putting it together, it was I think we were trying to somehow graphically represent that the consumer was, you know, the main outcome. So, I think we can work on that.

MS. LASH: Okay. So, let's see, do people need a break or are you ready to - yes, let's keep going. I know we're all anxious to finish the meeting.

The next topic of discussion, since we're through that is Juliet to share with you sort of like a preview of what's coming next in the project in research process so you have a sense of how the products of today will be carried forward.

MS. FELDMAN: So, we obviously have quite a few next steps and follow-up to do after this meeting.

One of the major buckets of work that NQF staff will be undergoing over the next several months is a deeper dive into the evidence and the existing measures that are in use or have been used or out there.

So, just some overarching considerations, our research approach will emphasize the factors shared across the facets of HCBS and acknowledge the distinctions.

We'll be devoting specific attention to understanding previous efforts to measure and improve HCBS quality. We know that there has been a number of efforts that have measures in use and that have done existing scans. So, we don't want to reinvent the wheel and we want to build off of what work has been done.

And at the very end of this project, which concludes September of 2016, a final list of measures that staff has identified all throughout the process will be accompanied by the formal report narrative.

So, this just is a visual

representation of our research efforts. So, we can kind of put a checkmark next to our Phase I which was really preparing for this meeting in terms of scanning the existing definitions and frameworks for HCBS.

In the spring/summer or 2015, our first draft report is due which will be focused on the operational definition and framework.

Our environmental scan and synthesis of evidence will continue through the fall of 2015 with our second draft report due on the environmental scan in November.

The committee will then reconvene next March of 2016 to do -- what NQF staff will share with you where we are to date and really focus on the prioritization piece and discussing where the -- of all we found, where should the priorities be? What are the recommendations? And what are the surrounding issues in terms of feasibility and data that needs to be considered.

So, a lot more to come.

So, just -- this slide just shares

that our approach is going to be iterative. We will be providing continual updates to the committee and to the public.

We will -- after each report is released, there will be a 30-day public commenting period and we will also be working with various outreach to stakeholders and relying on you to help us put us in touch with the right people we need to speak to.

So, the synthesis of evidence, it directly informed the development of the operational definition and conceptual framework and will now support the scan for measures by identifying the concept and ideas that should be measured based on the literature.

I'm going to keep going.

So, for Phase I, NQF consulted a predefined list of sources that were identified by HHS, the committee and members of the public. This was the list of 200-some sources that we've been referring to.

For our next phase, we will be

conducting an organized literature review guided by the HCBS definition and framework and domains and sub-domains that we've been discussing over the last two days.

Phase 2 may also include key informant interviews if information is sought isn't likely to be published and we'll be seeking the committee's input on that piece as well.

For the environmental scan, our objectives are to identify existing measures applicable to HCBS with an emphasis on those that map to the conceptual frameworks, domains and sub-domains.

We will identify promising examples of HCBS quality measures to guide the committee's discussion of implementation barriers and mitigation strategies as well as identify measure concepts and ideas that should be further developed into future performance measurement.

So, similar to the synthesis of evidence, NQF has collected and compiled various predefined measure sources with input from the

committee. We are going to continue to scan based on the framework domains and sub-domains and the measures will be organized for the committee's later review.

So, in terms of next or more broadly in terms of our next steps, NQF is going to begin Phase 2 of the research efforts based on the domains and sub-domains we've been discussing.

The committee is set to reconvene via webinar in August on August 28th. At that time, we will provide the committee an update on where we are with the research and we'll, at that time, we'll also have a draft definition and framework that will be just finished going through public comment. So, we'll be able to provide the committee updates on those pieces as well.

And then, as I mentioned, our second draft report is due in November of 2015 and then there will be a 30-day public comment period on each of those reports.

So, that was really just intended to share with the committee kind of where NQF staff

is going with this work and there'll be, I mean, continuous touchpoints with the committee. I think that's important to emphasize.

(Off mic comments)

MS. LASH: Thanks, Juliet.

So let's just launch right into our closing round-robin. We'd like to hear from each of you one at a time on some closing discussion thoughts and any other parting thoughts you think are really critical to voice, although we don't need you to recap, you know, every point that you've made over the course of the meeting or anything like that. That's why we have the court reporter.

So if we could go to those questions, they really are intended to inform where we go from here. And because there were so many domains and sub-domains that surfaced out of the discussion, you can imagine that the volume of paper we might, or Google results we will find using all of those as search terms, to be completely massive. So we are actually looking

to you as experts in all of this to help point us to resources you know are valuable and relevant and relate to the topics we've discussed, especially not related to quality measurement. You know, that's the real heart of what we're trying to get after.

So any observations you want to share now about quality measurement activities you know that are promising and should be taken into further account, where you think measurement is going to be feasible to operationalize in the next couple years, where we have the most evidence or where is it growing most rapidly that sort of demonstrates the importance of a new set of emerging quality HCBS, and then as I said, anything else you wish to share.

Let's see. Yes, we'll go around. Maybe Ari, are you comfortable starting at this end or do you need a minute?

MEMBER HOUSER: Sure. Why not?

MS. LASH: Thank you.

MEMBER HOUSER: So I think the major

thing that comes to mind in terms of next steps is thinking about what kinds of measures might make sense to operationalize these domains and sub-domains.

In the past I've been very positive about the National Core Indicators Project, and I still think that survey measures of that type bring a lot of value and should be incorporated into state quality management systems. But it seems clear to me that with some of the domains and sub-domains that we've articulated we also need measures that can be directly tied to claims data and we'll be less dependent on the vagaries of how questions are asked and things of that nature.

In the past, you know, there's been good use of claims data to differentiate between institutional and HCBS LTSS. And now we're beginning to see better articulation of core service definitions of different kinds of HCBS as well. So my hope is as the staff compiles information about existing quality measures that

there's also some consideration given to what kinds of quality measures could be constructed utilizing the more specific service definitions that are emerging around residential employment and day services in the context of HCBS.

MS. LASH: Thank you. I guess we're going counterclockwise. Joe, do you want to?

CO-CHAIR CALDWELL: I'll weigh in.

You know, in the short term I really think the most feasible are some of the systems and the process measures, particularly what is happening in the MLTSS world. And there's been, you know, there was an environmental scan that is a couple years old that I think that was looking at, you know, what was out there in terms of HCBS quality. But since then there's probably more states, and Tennessee keeps coming up with good measures and things. So I think really trying to get some of those from the states would be really helpful.

And then on the, you know, the consumer outcome, the quality alliance, I think

there's obviously like Ari said, NCI I think is, I know other folks have mentioned that, but I think that's fruitful ground. And the HCBS experience survey, that is getting close to being, you know, at a point where it could come for endorsement in the near future.

CO-CHAIR KAYE: I'm only the third person to speak, and yet almost everything I have to say has been said.

I'm impressed with how much progress there's been lately in survey -- development of surveys for consumers. The more recent trial version of the National Core Indicators, the one for people with physical disabilities and elderly people is -- Well, no, I'll compliment you guys on it. I mean it's a big improvement to me over the original DD version of it. And the HCBS Experience Survey is a big improvement over the Personal Experience Survey that came before it.

And there are a couple of other tools that I like. The Money Follows the Person Survey, you know, follow-up surveys is quite

good. And there are different sets of domains and such that I think are really, are interesting. I don't think anybody is there. Certainly, you know, we came up with an exhaustive list of things we want to measure and those surveys are not, do not span the whole space even just on the ones that are very consumer relevant.

I agree with Ari Ne'eman that we need other sources of data other than consumer surveys. And, you know, so I've got people in my center who spend time emailing and calling people up in state government and asking them, you know, program administrators, and asking them how many people they serve. And I think that's kind of ridiculous, you know, and what the policies are at the state level. And that's, you know, and they write and publish papers on that and I use that data. I mean I just did an analysis of trends in HCBS participants and, you know, LTSS participants over time.

So I really want a comprehensive data

system that, you know, lets us do much more of the stuff they want. And I don't think it's really -- it's more than claims data. It's a lot. It's bigger than claims data I think.

MEMBER McCANN: Probably will involve the perspective of health, if I might. One of the most imperfect things that is happening on the health measurement side now is the concept of harmonizing. We cannot speak to each other across settings.

The concept of harmonizing has been very helpful in health because we can't speak to each other across settings. So just the idea of if you're going to look at well-being, function, whatever, to make it broad enough so that you can ask those questions or assess it regardless of the types of services people are receiving, just start out that way instead of unique as often as possible to make it similar.

IMPACT is an act that people are involved in, probably more than they ever wanted to be. But that's part of that: how do we

assess disability, function? So I think there's so much wonderful work going out there that if you can take advantage of that, how great to do that.

It would be interesting to look at an analysis of claims or see if it's even possible because the Medicaid systems vary so much from state to state. I'm not sure that they even have the standardization of HIPAA codes or such other policies. It gets a little bit crazy. However, the long-term care measure on using payroll to look at staffing, accessibility, a lot of that capacity and who does what, payroll systems are already talking to CMS about doing that. And so that may be a way to get that for the variety of folks out there.

In all the DUALss contracts, we work in most of the DUALss states, they have specific outcome measures in there.

HETUS and NQQA for managed care to see if there's anything that can be pulled considering the populations, look at the variety

of health plans. And PCORI, I mean they just do incredible research on person-centered.

So I guess what I'm saying is there's so much out there and there is, as we talked, such similarity regardless of different services. So not to throw the health side out because of the word health. They may have processes that they painfully had to go through under the Affordable Care Act for five years that might actually be of help in this process. They have many scars to share, so. My comments.

MEMBER AUSTIN-OSER: Yes, this has all been good stuff. I mean I don't have a lot to add as far as like the broader bodies of knowledge. I think those have, you know, already been pretty adequately identified.

But one of the things I do want to say is something about some pockets of innovations that are going on around the country that may not be, you know, I think we can try to bring some of that to the surface to be looked at, but that may not be a part of, for instance, CMMI grant. Some

of them are, some of them aren't.

But a lot of things that are happening, especially around work force and looking at this concept of job quality and work force quality, which aren't the same thing, job quality and work force quality, and the impact on, for instance, the triple aim, so the impact on health, you know, improved health outcomes, just improved outcomes let's say for people-effective training or, excuse me, effective service delivery, greater levels of satisfaction and experience of care and then lower cost.

I think there are some really interesting things going on out there in how we could look at, especially when we get to the work force side of it. You know, what do we need to look at and what makes sense, and actually looking at the job quality, not just the quality of the work force, looking at those two things.

So I think there are -- I just want to throw that out that there are some things that may not be widely known but that we probably want

to bring up and say, hey, these have been successful. Are there measures here that we need to elevate?

MS. LASH: And if you have particular communities in mind you want to email us about we can make more specific note of that.

MEMBER AUSTIN-OSER: Thanks.

MS. LASH: And that sort of goes universally to everyone.

Anita?

MEMBER YUSKAUSKAS: Yes. Some promising measurements activities that are taking place now have to do with some things I was working on, so I'm going to bring them up.

Under the TEFT grant there are two measurement initiatives, and I think Joe mentioned one, which is the Experience Survey for HCBS which is going to eventually have endorsement and a CAHPS trademark, hopefully.

The other one is the CARE Functional Assessment. And we were looking at the CARE as -- testing it across not just post-acute care

populations but also folks in LTSS, so that as people move in and out of different environments we can begin to make some comparisons. So that's gone through some changes; I'm not quite sure where it is.

But as we develop a truly person-centered system I think we're going to have to be able to look at ways that we can compare measures across settings.

The most feasible I would say, I would really concur with Ari, administrative data capabilities are a really important area. D.E.B. Potter who is over there did probably the first real study that highlighted administrative data in long-term service and support. And CMS has a lot of information. I don't think it's even been closely -- I don't think we've begun to tap it. And I think there's a lot of information we can learn.

There's also state-collected information on quality. And I'm thinking primarily of the 1915 waivers. While we're not

going to be able to do a pure comparison because those measures differ, from an indicator perspective we'll at least be able to look across states. And that is all -- well, no it's not. Never mind. In the design phase it's electronic but it's not in the back-end, so that will have some challenges.

I think some of the areas that are going to be most interesting will be to take a look at larger managed care organizations that truly have the capacity to do integrated person-centered care. Once a person has all of their services coordinated then they are truly person-centered, then I think we really start to look at long-term services and supports with a different set of glasses.

Sarita and I were talking about that in relation to Kaiser, who is really just starting to touch the tip of the iceberg with that. I think that's going to be something very interesting to watch.

And finally, I think the area that has

been keeping me up at night for a very long time is the fact that we really don't have true evidence-based practices in long-term services and supports. And that's because we have no standard interventions. We have no standard service definitions in order to even begin to look at causality. And I think that's something we have to do because that's one thing we have not even talked about here. Other than labeling it as services and supports we haven't drilled down on that issue at all.

We've talked about who and we've talked about for what purpose, but we have not talked about that elephant in the room. And I think that that's really important.

So that's it.

MEMBER GALANTOWICZ: I just wanted to offer a couple of comments and caveats based on personal experience with some of the initiatives that have been described so far.

First the compendium of HCBS measures that Potter and I worked on now many years ago

because it's been more than just a few.

Thinking from a methodological point of view, when you do your scan we found the vast majority of what's included in that compendium not by doing the literature review but more looking at the gray literature, doing web searches, but really what we did was reach out to all of our contacts in the states and ask them what they were doing. And so I think if you look just narrowly at what's been published you'll miss all the richness of what's going on.

When I think of the 200-plus measures in that compendium, most of them came from the states. So I think that's the first suggestion.

With regard to experience surveys, I worked on the original PES, I worked on the HCBS experience survey before I switched jobs. I feel very strongly about the importance of getting participant feedback. I think so many things we've been talking about can only be measured by talking to people who receive services. But it is really feasible. I think they're the source;

I think we have to be honest about that. It's very expensive to collect that data.

It was harder than you think to come up with a consensus list of things that should be asked. And for some of that work we started with asking with individuals in programs what they thought we should measure. And I think we're coming at it from one lens of what we think needs to be measured but a good consumer survey starts with what people say is important as far as the research. So I would just add that.

On the whole care, LTSS, I was on that project for a little while too.

MEMBER AUSTIN-OSER: You were on all of them. And I apologize for not bringing that up. I really do.

MEMBER GALANTOWICZ: No, no, no. And I also, and I'm working on IMPACT Act measures now. So I think standardization is really important but we can't lose sight of how different HCBS is from some of the other post-acute care settings. So we can only standardize

so much. On that care project it was, at least at the beginning, just getting people to understand how HCBS is different and what you assess was a real challenge. So that's the caveat for that.

And finally, on the claims issue I agree that there is an incredible amount of administrative data out there. I'm working with one state right now where we are trying to use their claims data to look at HCBS participants. Months of discussion of even which HIPAA codes we use on the claims to even flag someone as an HCBS user.

So I would just echo what Anita said, there is no standard definition of what's in HCBS, and that's just one state that's trying to come to consensus for what services we put in the HCBS bucket for the purpose of profiling HCBS users. And I think it only gets exponentially more complicated when you're talking about all the different programs.

So not to be a downer, but those are

all the caveats.

MEMBER MOHANTY: I appreciate what Sara just said because just in our own system to code HCBS as a new benefit for Kaiser Permanente was a bear. And so I can -- and this was just in certain little pieces of the benefit. I mean we haven't even expanded it in California yet, so more to come; it is quite complicated.

You know, I think some of, a lot of, I think pretty much all the things, the themes have been mentioned. But some of the things I'd like to highlight that I also believe that the claims, data there's more than just the claims data. But you can glean some important information from the claims data.

In our system, for example, what we're finding is that in our care planning we have integrated the care plan within our HealthConnect or Epic system, and there are certain elements of that care plan that can be pulled out and offer some information about the long-term services supports, for example, and some of the home- and

community-based service needs or the care experience. So there's some opportunities there.

And, you know, one of the things I, you know, I think everybody kind of mentioned is that there are so many assessments, so many care plans, so many definitions of how things are measured. What we're trying to do in our own organization is try to take all that information from the external entities and trying to incorporate into one master care plan or trying to come up with some master assessments.

And so it gets back to that comment of harmonizing. How do we do that? So that I think going to what I think also Sara said is talking to some of the delivery systems that are working on this and exploring with them some of the approaches they've taken. And I think that will be very useful in how we, you know, start to think through measurement a little bit more carefully.

The other thing I just wanted to highlight is also the use of vendors. There has

been a lot of use of vendors in a lot of systems to help with the LTSS or home- and community-based service delivery or assessment base. And I've noticed that some systems have not actually fully leveraged that information from their vendors. Their vendors will do these assessments and then maybe come up with some key themes: oh, here are some, you know, here is a care plan we developed for you.

But sometimes there's that back-end data that the vendors have that the system hasn't necessarily, you know, utilized to the best of the ability. So I think just another piece of, another source of information I think is what I'm getting at.

And, you know, I think the other, the last thing I would probably say, I mean the one thing, HETUS and NCQA I think is important but it's lack -- you know, right now we know it's limited. So it will give us some of our physical health measures and some access issues but not fully -- it will be comprehensive.

And then, you know, I had a conversation I guess a few days ago. And I think pretty much everybody knows that, or most people know that SCAN Foundation is also working on some home- and community-based measurements. And so to the extent that we're partnering or working closely with the entities that are also embarking on this process I think will be important.

Thank you.

MEMBER CRISP: Well, this is a tough act to follow.

Of course I agree with everything that everyone has said. And in an effort to come up with something new, one of the most promising quality measure activities, measurement activities I see is that we're disembarking on person-centered planning and what that means and what is the thinking behind that and what kind of changes are being made, how participants are going to be educated on person-centeredness. And then what are the measurable items that we can look at and analyze to see is that really

happening, how is it happening, and is it a good thing?

I know a lot of people are working on this. Michael Small, SCAN, I know our division, our center is working on this. We're in the process of interviewing service coordinators now as to what it used to be and what it is now and where do you hope it's going to go. So that's a promising measurement for us.

The most feasible in the short term is data collection, as everyone has said, in particular service utilization. What services are being purchased? Who are purchasing those services? And what happens when they purchase those services?

I think there's a lot of not only data collection that can happen but also a lot of analysis, synthesis, and a lot of assumptions can be drawn from that levy of data.

Strongest, of course, in the realm of personal outcomes; that's a thing that we've been talking about for years and never quite achieved

it. Certainly with the core indicator project for disabled and elderly, that's going to be a huge step in the right direction.

I also think that there is strong evidence growing in looking at coordinating not just care but integrating systems and getting Medicare to talk to Medicaid, and the Elder Americans Act to talk to everybody else, and whatnot. So I look forward to that being strong in the future.

Thank you.

MEMBER LAKIN: Well, thanks for inviting me. I've had an interesting and good time.

You know, when we, when we presented our system effectiveness list one of the things that got buried in there and not mentioned was that, you know, whether we're talking systems level or intermediary levels we really need to base our analysis on individual outcomes whenever, whenever possible. And to not do that sort of gets us caught up in process measures

which I think have at times some connection to outcomes but not the kinds of connections that we would like.

I guess rather than give answers to the questions I'd really like to kind of ask other questions because I'm, I'm really, I'm aware that we're going to have so many measures that map up really well with the domains and sub-domains we've created. And some of them are very lightly used. But few come anywhere near meeting the quality that the NQF applies in its standing committees to other, to the other measures that are submitted for review.

And it is for me a real challenge to think about how we're going to get to that standard of quality from where we are today. And I think we can but it's going to take a very major investment. And I don't know where that investment's going to come from but it will need to be made if any of this will be realized at the standards that the NQF has applied to other measures.

I'm excited about the widespread use of measures. I'm excited about the communities of practice that have developed around the NCI and other instrumentation. I think when data is something raised, entities, states, providers get together to talk about what they're doing, why they're getting the results they are, what they can do to improve, it gives you a reason to collect all this stuff. And I think that's happening in really important ways.

But as Sara mentioned, all of this stuff is so expensive. And there's a methodological complexity to it that I think we often fail to appreciate. We have respondent problems. We have proxies answering the same question as we have people with disabilities answering for themselves. We have response biases that we know exist, particularly among people with cognitive limitations. We have different kinds of interviewers doing these surveys in different places. They have different levels of training, if any. And rarely have they

been tested to meet some sort of criterion for the effective implementation of those interviews.

So there's just a lot to do. And I hope that rather than just kind of move items from all these instruments into boxes, we really get into the technical quality of what we're doing. I'm really I'm concerned about people using claims data without understanding what's underneath them.

I just had an experience in a state using claims data where I said, Great, this variable says it measures this and we can use it for this court-ordered assessment. And they said, Well, it doesn't really, doesn't really mean that.

And so, you know, just to grab claims data and think that the HIPAA code is going to tell you what's happening is really not used. And so we need to be careful.

But anyway, I think we're off to a good start. I hope we will be serious about the complexity of what we're taking on.

MEMBER KILLINGSWORTH: Wow, so there's no one who has spoken thus far that I've not wanted to say, Yes, I agree with that. And so lots of great ideas already. So I'll probably just be reemphasizing a few things.

One, I agree with Sara that there is a lot of information to be gleaned from states and work that states have done. I think it would be interesting to look at the domains most frequently measured by the states. So I do think that would be really an interesting exercise as well.

I do, and I think echoing some of the things that Ari said and Steve said, I think I never want us to move far away from the experience of the consumer. And I think that's one of the richest areas for development and exploration. I think we're getting there with some of the things that are happening. There are a lot of good tools. That standardization -- and this harkens back to what Sara said as well -- is just it's so important for us to be able to

compare performance across health plans, across states, across programs, so I encourage us to do that.

I think, and this is probably jumping ahead of Andrey just a little bit, there is so much opportunity with technology. We are -- I don't even think we can conceive the potential that is there for us to leverage technology. We will begin later this fall to collect real-time quality data from members at the conclusion of every in-home service that they receive. That's just such a rich source of data that we'll have at our fingertips.

So I think, you know, we need to, even though we think it's all expensive, and it's not always expensive, right? There are, especially if we design systems with the measurements in mind -- and we've done that -- it can be relatively inexpensive to build quality into something that we're doing anyway, and to be sure that we can actually measure performance on the back-end of that.

In addition, I think, as Suzanne said, there are great opportunities with respect to beginning to measure community inclusion in new ways and with new expectations. And so even though it's something that we've often looked at, I'm not sure that we're looking at it in the same way every day, as we always have. And I think the same is true for care giver supports, whatever we want to call them. I think we've looked at them for a long time but we're beginning to look at them differently. So those are all rich areas for us to explore as we move forward.

MEMBER HOUSER: I can probably echo what a lot of, a lot of people have said. A few things that were, that I want to sort of add some emphasis to. I think the most expensive part of this is data collection. So, as much as we can, it's useful to use sources of data that are already, that already exist. I know there is incredibly rich state data.

I can't count the number of

presentations I've been to where someone presented some very, very rich state data. And it seems like the bottom line was, you know, we now have 45,000, you know, people receiving services in our state and, you know, one or two other top-line items. It seems that's all the capacity that this under-staffed state agency had to analyze this data source. But there's a lot more that could possibly be done.

A number of people I've talked to are very optimistic about the capacity of T-MSIS to provide, you know, high quality claims experience data that could be used. I know second-hand of at least one effort to link claims data to functional assessment data so that you can have a measure of, imperfect perhaps, of services and some information about the recipient of that service, which is not in the claims data, typically.

And then the last thing that I would mention is to keep in mind what the goals of quality measurements are. And so fertile -ground

for measurement can be: where do we think we can find the data set to measure? And also, the other question would be is: where is it important to have measures for positive impacts on the system?

And an analogy would be do we want to look where the light is, or do we want to look where we dropped our keys? And where the light is is where the data is. And where we dropped our keys is where we can actually effect positive change. And those are probably different places, and yes, just another way of thinking about it.

MEMBER SMITH: So I guess ditto for a lot of things that folks have said. But I have a couple of things that I'd like to mention. And I think I've mentioned this a couple of times and keep struggling with the fact that, you know, this area is so broad and there are so many populations that are subsumed under it. And there's a lot of work going on in some of those other areas that I think we might not pick up here.

You might pick it up. You know, I thought I heard folks say that you were going to cast a broader net. You know, instead of looking at HCBS, perhaps you would look at some of the domains that we came up with. And so that may bring in some more initiatives.

You know, but it's not lost on me that in mental health, you know, we've been working probably for the last 20 years -- maybe more, God only knows, might be 30 -- but we've been, you know, putting together our own performance measurement framework. And, you know, the really interesting thing is many of the measures that we talked about here today and the domains, they're the same ones that we've been looking at in mental health. And I don't want to speak for substance abuse because I've been more focused on mental health.

But, you know, not that you would use the exact same measure across all populations, but I think that we've come up with definitions for safety, you know, for well-being, for looking

at employment. So I would direct us to look at some of the things like, you know, at one point we, there we brought together a large group of stakeholders.

They were providers, policy makers, consumers, family members, folks from managed care companies. And we actually put together something called the Mental Health Quality Report, which has been around for quite a while. It had, we actually started doing this kind of stuff back in '98, when we were looking at like something called the MHSP Report Card. And then that kind of rolled into the Mental Health Quality Report, which was an updated version.

So I think we should look at things like that. Also many of the, well, all of the states and U.S. territories have been working with census, mental health, let's see, mental health services, Center for Mental Health Services and others to come up with performance measures. And pretty much every state mental health authority is reporting what are called

National Outcome Measures. You know, they're not perfect, but they do include a lot of the domains that we talked about here.

And the substance abuse folks are doing the same kind of reporting. You know, and it's not like somebody plucked the measures out of the air. You know, I can tell you that, you know, if you think these last two days had a lot of detail, you know, sometimes we spent like a year talking about how to get to one measure. So I guess I'm just saying I hope that we can look at some of those other things.

The evidence, I think Mike talked about, you know, the evidence that one looks at before adopting NQF measure, I think that's going to be a challenge. But what we're talking about are measures that the states already collect, and that people have spent a lot of time developing.

In terms of consumer evaluation of care, you know, again I think that is of critical importance. And, you know, the struggle here for

me, even back in Illinois, is that folks have adopted the CAHPS Survey. And, you know, that's not particularly a good survey for our population. You know, we developed a survey in mental health. You know, again that probably tracks back to ten years. There's an inpatient version that was endorsed by NQF already.

So, you know, I'm wondering why if we are -- you know, if we care to look at some specific populations, why don't we look at some of these surveys that the states have adopted and are in use? You know, because some of them those are some of the same populations. Let's see, there might be one other point. No, I think those are the major things. Thanks. Thanks for inviting me. I enjoyed this.

MEMBER MARKWOOD: Well, I'd like to thank the group as well, and say that through the robust discussion that we've had over the past two days, you know, I've learned a lot from different perspectives that I really value. But I think from my perspective in representing

community-based organizations in this area is just to reiterate their excitement about measuring quality, and their commitment to doing this to the best degree that they can. And I say that because, echoing Sara and Charlie's comment about the fact that in an already overstretched system this is important work, but it also needs to be invested in.

And that being said, recognizing that the states are doing a lot in this arena, I also wanted to raise the point though, too, that especially with the evolution of managed care that there are also some information lessons that can be learned both in the managed care front and also in the care transitions front that are not necessarily at the state level but more regional or locally specific. And those, some of the champions that are leading those efforts, I'd be happy to forward to you.

Additionally, I think that, as Patti said, that I think that there are things at the local level that we're trying to do and would

welcome more guidance in doing with the resources that we have. But again, when you're looking at IT through the ACL business collaborative that we're doing with the aging and disability community, that the investment in IT has been raised as one of the greatest barriers in moving forward in this regard.

So I just think that that needs to be a recognition as we're looking at collecting more comprehensive data and being able to analyze and use it. But that being said, I think that, again, the commitment on the part of the community-based organizations is that this is where they know they need to go, this is where they want to go, they just need some help in getting there.

MEMBER DOBSON: I echo what Sandy said. I learned a lot from different perspectives. It's extremely useful. As -- representing states who are, you know, in the middle of this, I think there are a couple of things that I would share that are of importance.

One, I can't stress enough the use of consumer surveys, obviously. Steve and Ari already mentioned NCI, NCIAD which is going into -- is going live June 1st with 13 states on our first year. That's not public but I will make the survey available to the staff so that you have it.

And so we're excited to see how that goes. And it really does reflect the nuances of individuals with physical disabilities and the elderly that are slightly different, in many cases very different than individuals with IDD.

I would tell you if you're not aware -- I'm sure you all are aware that, you know, 20 states now are using capitated health plans to deliver most, if not all, of their HCBS services to individuals. And so that raises opportunities and complexities, I think, I would say on both sides.

It is very clear that, I echo Sara about the level of intensity and the cost for person-reported outcomes and how hard those are,

and so the need to find administrative -- I'd go beyond claims -- but administrative data, ways to use administrative data to extract information from care plans, for example, to assess timeliness of services. That is a critical part, or the system will collapse under the weight of the measurements, I think is really the concern that we've got.

So I would -- I know you're already pulling out what all the states are doing, so I don't need to say that already. But I think a place where maybe you, maybe if you haven't started is to talk to the health plans themselves. A number of them even if the states don't have rigorous quality members around HCBS performance, that's part of their standard QM activities, and so I think there are a number of the duals plans, obviously, several national health plans, and very significantly, a number of small, locally-based plans who have been in HCBS for a long time I think could provide some lessons.

So I can provide those contacts for some of those national folks that would be useful to provide you some data. And yes, I think that's it. I don't have anything else to say. Other people have stuff to add I'm sure.

MEMBER PHILLIPS: Well, I think I'm -- I've really been outdone. I'm not sure I have a lot more to add about specific measures. But I would like to see -- and we haven't talked about the populations of persons with dementia living in the community and promoting their tenure in the community.

Building dementia-friendly communities is not quite here yet. There are countries in Europe who are doing better jobs of that. And I'm not sure how it's being measured, obviously. Eliminate or preventing nursing home admission or other institutionalization. So I would like to suggest that at some point we explore that avenue. Along with people ageing with physical and, you know, mental cognitive disabilities and keeping them in the community rather than moving

to higher levels of care.

MEMBER OSTROVSKY: Thank you very much for having me here. I have a couple of points to make. One is that my line of work focuses almost exclusively on home- and community-based service providers getting reimbursed for the outcomes that they produce. And this is predominantly through new lines of service outside of traditional home- and community-based services, care transitions being one of them, use of chronic disease self-management outside of just, you know, having a CPT code or with having a CPT code and other ways.

Transportation can be, can be a very valuable service for a managed care entity when a return on investment can be proven. And I think it's incredibly challenging to watch particularly area agencies on ageing now where we're working with more and more Meals On Wheels programs where they're really doing -- they're working really hard to try to show their return on investment. But the only data they have available is the data

that, say, my technology provides which, fortunately, is getting them closed deals, but I don't think my technology is going to be great for every single ACBS provider in the country.

So it would be really powerful in having a way for health systems' preparers to be able to have a common way to evaluate ACBS providers in an ROI that is relevant to the payer and the provider. I know we want to be consumer-centric here but I think for sustainability purposes our quality measurement really needs to take into account how will we demonstrate value for payers and providers.

The other notion I think is really important is I, as a for-profit technology vendor, I just hired three salespeople. And I hired three salespeople because I have to get the word out. And when I hire people, I hire them based on their ability to educate rather than to sell. And I think we need to move away from salesmanship in the vendor, technology vendor community and more into how does the technology

contribute to improving a validated quality measure?

I think that would take away from the, you know, the big rah-rah, like, how much money do you have to spend in marketing, and rather focus on how does the technology really improve the quality of home- and community-based services. So I think that would equalize what we in the vendor community do.

And then the final thing is ONC, I really commend them because in their language, and I mentioned this earlier, in their language in a few of their recent publications they have specifically called out home- and community-based services. They have specifically called out harmonization of quality measurement.

I think we need to really heavily harmonize with those efforts, because if we can enable data integration to facilitate quality measurement, not just what an EMR can do but rather what any other technology, especially with more innovation, technology innovation

hopefully coming to our space, I think that will facilitate that alignment of where the keys are and where the light is shining, to borrow Ari's metaphor.

And then I'd like to propose just one thing that a colleague of mine Mike Doyle says: return on information. How can we, through quality measurement, not just show a return on cash investment, but a return on how many megabytes do we have to spend of data to actually get meaningful quality measurement. So, happy to elaborate on that.

MEMBER APPLEBAUM: So, in 1982 when I was evaluating the Channeling demonstration I did some interviews as part of the evaluation. And several people, many people said, we think this home- and community-based service stuff is a good idea but we're kind of worried about quality of what's going on inside the home.

And if you think about the many billions of dollars we now spend on something that we were worried about in 1982, I think

obviously the importance of this activity is quite obvious.

I was thinking back as people went around the room to the book that some of us read, some of us who were born before 1982, A Tale of Two Cities that we used to have to read in high school and that starts out with It was the best of times, it was the worst of times, and your English teacher teaches you about what a paradox is. So as I sat here listening to what people said I was listening to the many paradoxes.

So we talked about the innovations in measurement and the excitement about that. And then I sort of thought about, okay, well what's one of the oldest measures we have? Sid Katz came up with the ADL score in 1963. And I can tell you that that measure actually is not very good for doing and measuring functioning. I can't tell you how many times I sat in the homes of individuals who are getting service and they ask Can you dress independently? And the one that lives with her daughter says no, and the

person who lives alone says yes. They have exactly the same functional impairment.

So we think we know how to do that. That's in the books, and it's not. So at one level we have all these exiting new measures and at another level this is still hard, which I think reflects some of the things that Charlie said.

Claims data: we were talking about the importance of administrative data and claims data which I use them a lot. It's great. But I will tell you, and we've mentioned the integrated care demonstrations, right now at least the data that we're getting from integrated care demonstrations, everybody who's in the Medicaid integrated claims data, they all look the same. They have the capitated rate, there's no encounter data, there's nothing.

And so the claims data has just gotten way worse in any of the states doing integrated care. Now maybe the plans will develop their own data systems and there will be some way of

sharing those data systems with everybody else. But right now that isn't happening.

And then finally, we were talking about nationally unifying measures. But long-term care and long-term services is a state system. And at one level it is great to go after what states are doing. I've been working on a 22-year longitudinal study for the state of Ohio. We have lots of great data but it's very difficult to get those centralized all together. So I think we have some challenges.

And that leads me to my two, maybe, final pieces of this. One is that -- and I really like what Patti said about being creative about how we collect data, because the fact of the matter is that we can think differently about how we collect data, particularly if we recognize that this is a state-driven system.

And so one example, we had one of the area agencies that we were working with who wanted to be able to collect satisfaction data on all of their 5,000 participants. And if they did

a random sample survey of independent data collection, they couldn't get much sample. And they wanted to be able to compare across providers.

So what we did was we went in and trained care managers who were going into the home anyway and trained them to collect data. And then we actually validated that with independent research interviews. And we said, hey, looks pretty much the same. And that agency now collects data every time the care manager walks in the door. And they have tremendous amounts of quality data that they can use to be able to compare across providers.

So I think in general we have to be way more creative about how we think about collecting data. We designed something some years ago, it was kind of like a Nielsen family rating. Everybody knows the Nielsens for television. We had consumers keep a log of something as simple as home delivery meals. Did they show up on time? Were the meals good?

It was very inexpensive to do. And people liked doing it. I mean when they didn't send out -- didn't get their logs they were like calling up and saying, Hey, where's my log? Nielsen pays people a dollar to fill out their little Nielsen form out for two weeks of recording their T.V. watching every, you know, half hour.

And then finally I just wanted to say that this is an evolutionary process, and whatever measures we come up with today, in five years we'll be going like, Wow, can you believe we used to measure it that way? And so I think we have to always remember that this is an ever-evolving process. Thank you.

MEMBER LUZ: I would like to say thank you, too. I think it's a privilege to be among this group and to be able to be in active dialog with you. And I appreciate the staff and the consensus process. It's really fun and interesting. Learning a lot.

I'm not going to try to add.

Everybody has said things very eloquently about HCBS in general. I'm going to focus just on one aspect of it which is near and dear to my heart, which is the work force issues, particularly the PCAs.

In terms of process, I just want to make sure that, you know, there is a way between now and our next meeting that we are able to sort of revisit some of these areas where we weren't -- maybe didn't have consensus. If there's a way for us to be in communication and carry on the dialog before we meet again, that would be really helpful.

And with respect to the, really full respect for the full range of thoughts and feelings about training and education of PCAs, there are some of us in the room who are really excited about the fact that it's even being discussed in this meeting. And if we talk about, you know, identifying fertile ground for measurement, this is really it. Because right now there are absolutely zero federal training

requirements for PCAs. And so this is a huge step forward and I am excited about it.

And I hope that we have an opportunity to just really reach some consensus around it that satisfies everybody and how to measure it. And it's going to help us establish, you know, a lot of what everybody else has been talking about: this association between work force development and training, and the goals of the triple aim, and the goals of this group.

And it's not just about, it's not just a work force issue, I think it's a social justice issue and an economic development issue. So, you know, we're touching on a lot of ground that hasn't been measured to date at all. So I'm excited about this. And I had one question. I don't know if anybody is interested in this, or maybe it's already available, but sharing each other's contact information.

MEMBER DELMAN: Well, I'm honored to be here too. I'm really happy to be at a frontier. I prefer being at the frontier than at the

stayed-at-home, typical place. It's where I'm most comfortable. And I think we have a lot of great thinkers here, and everybody is on the right path.

And I have very little to add. So instead, I did some research and the IOM came up on a Report on Long-Term Quality care in 2001. I don't know if people are familiar with that. Apparently made a lot of great recommendations that moved the field forward. But of about the 18 or so people, brilliant people, a third of the people dissented on one point. And I just want to read from their dissent: If quality of life is seen as a legitimate goal of long-term care, -- this will be brief, not the whole dissent.

(Laughter)

MEMBER DELMAN: -- the consumer's view of quality may sometimes involve conditions and circumstances that professionals view as a threat to health or safety. This tradeoff and the possibility that consumers might knowingly assume risks in order to maximize other benefits were

not expressed in the final version of the report, yet it is an important reality.

Moving on: Consumer-centered care calls for the consumer, or his or her agent, to be involved to the extent desired and practical in all goal-setting and planning for care, and to have direct input into the evaluation of his or her care.

One more part from this dissent. The report marginalizes 'consumer-centered care,' stating that it is not for all people. This, we believe, is a misunderstanding of the concept. The principle of consulting consumer preferences directly or through their agents has widespread applicability to people of all ages in all settings, including nursing homes. It has been applied to people with cognitive impairment, including Alzheimer's disease, and developmental disability. The emergence of new models of care, including client-directed home and community assisted living is a direct result of consumer choice about how they want to live while needing

care.

And this was written by smart people, and I think their view has prevailed. My only, and just referring to what Bob said, people -- technology really is cheap. And I work with a lot of young adults. Think text messaging. I mean that's -- people are knocking data all over the place. And we have things available. And the young people, you know, half the people, or more, of age groups use the internet now. And I see a lot of people here text messaging so, you know, think about it.

MEMBER MORRISSEY: Jon, that's because we're young too. I'll, like everybody, just maybe add a few points. So I appreciate being part of the group and learning and listening. And to the NQF staff, thank you very much for facilitating 25 individuals who have a lot of different views and converging that into arrows and pie charts and pretty cool things.

I guess in terms of adding a couple of things, I'd just say one is the best practices

really occur at the state level in the state systems. And I really think that we, we believe we know where those best practices are, but I think we need to figure out really using the state, the national state organizations, I think, could help facilitate some of that discovery in terms of best practices, number one.

Number two would be the NCI. I think you know I'm a pretty big fan of that. Been around for 18 years. And this gets to there's an awful lot of quality frameworks and measures that are already under way. So I hope we're not starting with, you know, whole cloth. I think we, to do something for 18 years it's evolved. And there's, you know, many, many states involved now. And with the seniors now joining I think the beauty of that is that we're all about relationships and partnerships, and everybody working together. And I think that gets to alignment.

Third is while we can come up with maybe 152 domains and sub-domains, I think one of

the things it really is about the people we serve. It's about relationships. It's about -- I'll use my word -- safety. It's about health and safety and relationships and living in the community in a very thoughtful way and in a prosperous way.

So we are not very good at investing in those kinds of things as much as we need to. And I'm very concerned about our zeal for technology without financing some of that technology.

And then I think we're building, we're trying to build an architecture for 10 to 15 years from now, not today. So I think we need to be bold and we need to kind of really think about what is the system for individuals and families and providers and the work force 10 to 15 years from today, not think about it in terms of today's view.

And then I think I didn't hear much, I know we didn't talk much about certain populations, but the ABI population in the

veterans are an emerging population. And I think we need to be thinking from the representation point of view, if not seeking out some information about the emergence of the ABI waiver and how the veterans in the company are going to be supported in the community long term. So those would be my additional thoughts. Thank you.

MEMBER OXFORD: Yes, well I don't know what I would add after all that. But I do want to thank everybody for working with me and I appreciate being here. I particularly want to thank the staff who have worked hard behind the scenes and so on. And I know, speaking personally, they, you know, did some extra stuff to accommodate me and help me out. And I appreciate that very much.

Just some random thoughts. I mean I'm not a researcher, I'm an advocate. So just some perhaps random thoughts -- but I also am a provider; I run a program in my agency -- is I hope we think about whatever we do and as this

work goes forward, which is incredibly important, to think about utility for hands-on, kind of, on-the-ground application so that people that are perhaps running a program, providing services and, you know, providers, and I mean agencies, are so varied these days, little bitty company serving just their family, to just a few people, to just a certain area, and so on.

And I know across all these different kinds of providers there is a lot of interest I think, genuine interest in doing the best job possible. And quality is important. And so tools, ideas, information that can be useful at that level, I think, would be very much a good idea and needed.

I appreciate, you know, in terms of being an advocate how, you know, it wasn't that long ago that there would have been quite an uproar over consumer control and, you know, some of these things. But now it's like ho-hum, yes, yes, you know, everybody's in agreement. And that's, that's definitely rewarding to see over

time.

One of the things that I'm worried about that I noticed is, you know, access to data and need for data. And I am concerned with moving around into different kinds of environments that we're getting into with 1115 waivers and so on, about transparency of data, about privatization of data and so on and that that needs to be addressed so advocates, researchers and so on have access to the same level of information that, you know, that they need, whether the state is ultimately providing this service, or that's been to privatized.

And thinking ahead about perhaps some of the political outcomes that are being tossed around here in this town, that may be even more important but that we don't, you know, we don't want to block grant and privatize data.

Let's see. Just another thought that I heard kind of addressed that I think is real, real important in terms of, you know, ultimate goals around quality is that other environmental

issues really, really are going to need to be addressed. They need to be considered, or we're never going to get to where we want to go. And those came up in several places I just kind of want to kind of reiterate in particular: housing and transportation.

I mean unless those are addressed on a real systematic basis, you know, we can have the most self-directed, best training, best services in the world and people are just going to be stuck, you know, in their house and not being able to get where they want to go. And it seems to me like a lot of the goals that we're all trying to achieve are not going to be met unless these real critical linkages are also addressed along the way.

Finally, I just want to say and just remind everyone, this is not a scold, just a reminder, that I appreciate the sensitivity that people have shown around the fact that at the end of the day these programs, you know, these are real people with real lives and people with

disabilities, and there's all sorts of curve balls and stressors and things that you go through in dealing with a disability and that, you know, people, you know, aren't experiments and don't need to be objects of anything. And, you know, again that's kind of another thing that I think, you know, folks are sensitive to and I appreciate hearing that. That's it.

MS. LASH: Thank you, Mike, and thank you, everyone. I want to ask Jamie, since she has been listening so intently over the course of this meeting but not said much, as one of our project sponsors, if she'd like to add anything.

MEMBER KENDALL: Thank you, Sarah. So I have a few things to say. First and foremost is thank you, everyone for coming here and showing up and actually being present and focused and committed and engaged throughout these two days. And I know that you all have very busy lives and multiple competing priorities in our work life.

And to have all of you here as part of

the stakeholder committee and really bringing your subject matter expertise is just extremely valuable to the Department of Health and Human Services. So we were very thoughtful with the approach and structure of this stakeholder group, because all of you bring a very unique, valuable contribution. And with that said, the whole is greater than the sum of our parts. And I think that throughout this couple days it's been a little messy. Collaboration, when you do it and do it in a genuine way, usually is. And very thoughtful.

And so to the stakeholder, thank you very much. I'd also like to thank NQF. You have kept us organized and on track and worked to really create a great structure for the stakeholder group to thrive. So I really appreciate all those efforts.

And then I also want to say thank you to my federal colleagues. So we have a great group. There has been multiple federal staff in listening mode. We are listening to you

throughout this couple days. So D.E.B. Potter and Ellen Blackwell, Mike Smith, Shawn Terrell, thank you for being here throughout the meeting and being here to listen and engage. And we will take all of this back and continue to think through how to support this task order most appropriately.

I know the NQF is going to be sending you out some documents that reflect this conversation. I just want to encourage you all to comment on them. I don't think that will be a problem, given this group.

(Laughter)

But we really do want to hear from you. So with that I will turn it back over to the co-chairs and to Sarah.

CO-CHAIR KAYE: Just to add my thanks to everyone for their very thoughtful presentation and contributions. We got off to a kind of slow and rocky start I thought, but in the end we've pretty much done what we were -- what was on the agenda, which is pretty amazing.

I think we forgot to say that we decided not to show you the definition again today, but the staff are going to try to combine some of those really terse basic HCBS definitions and then use our characteristics, our now 11 characteristics and write them up as, you know, with actual verbs in them, and circulate that along with a list of domains and sub-domains, whatever else, and the picture. And so there will be lots of stuff to comment on.

And as Jamie said, I don't think we really need to encourage you to do that. But I really appreciate everybody's very thoughtful participation.

CO-CHAIR CALDWELL: I'd just echo that. I've just really enjoyed the last two days and just being with all of you and hearing all these ideas. And, amazingly, I think we did meet our objectives. If you look, you know, at the objectives of the meeting at the outset, somehow we got there and we've got a lot more work to do, so. So thank you.

MEMBER OXFORD: Joe or maybe staff, is there -- I forget who said it, I think it's a good idea, is there any way, I mean what do we need to do to get a list of contact information?

MS. LASH: We have that, definitely your emails, and I don't know if you want to exchange phone numbers as well. I think we collected most of those through the nomination process. So we'll quickly pull that together and put it up on your SharePoint site --

MEMBER OXFORD: Super.

MS. LASH: -- where you downloaded today's meeting materials.

MEMBER OXFORD: Thank you.

MS. LASH: You can look for that next week some time.

MEMBER OXFORD: All righty.

MS. LASH: Thank you all.

(Whereupon, the above-entitled matter went off the record at 3:34 p.m.)

J

C E R T I F I C A T E

This is to certify that the foregoing transcript

In the matter of: Home and Community-Based Services Quality Committee in-Person Meeting

Before: NQF

Date: 04-30-15

Place: Washington, DC

was duly recorded and accurately transcribed under my direction; further, that said transcript is a true and accurate record of the proceedings.

Neal R. Gross

Court Reporter