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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WEDNESDAY
APRIL 29, 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 9:00 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
JENNIFER BOGENFREIF
MAUREEN DAILEY
JAMES GALLANT
GAIL MacINNES
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

(9:03 a.m.)

DR. WILSON: Good morning, everyone. My name is Marcia Wilson. I'm Senior Vice President of Quality Measurement here at NQF and I'd like to welcome you all, all of you in the room here in D.C., and a number of people who have joined us via the web.

Since this project began last fall we've consistently broken records in meeting attendance and nominations. The dedication to this work is really remarkable and the level of engagement we think indicates a pent-up demand for implementing more widespread measures of quality in home and community-based services.

We recognize that today and tomorrow there may be some impatience or even frustration about the fact that the current state of measurement is pretty fragmented. We hear that from a lot of our committees. And it's true that we need to do a lot more to measure and improve quality.

So, if that's your mind set, some parts of the discussion today and tomorrow may seem a little abstract, but I assure you that NQF has worked closely with our representatives from the Department of Health and Human Services, many of their agencies, and with our Co-Chairs to design this agenda, because we all agreed it was important to start with some building blocks. So think of this meeting as foundational, which will allow your future work. And we truly believe that when this project finishes in 2016 we will all be amazed at how far we have come.

National Quality Forum is recognized as a leader in quality measurement, and that's because we believe in the principles of transparency, balancing the interests of all stakeholders, and also the role of consensus.

Now, let me tell you what consensus is not. Consensus is not unanimity. I'm always amazed I can pronounce that word. Consensus is also not someone talking for so long that everyone else gets tired and they cave.

Consensus is about being collaborative.

You are all here because you're experts and you're advocates, and we encourage each of you to keep an open mind during today's discussion. And this is especially true with issues of terminology, because we know there are going to be differences among all of the stakeholders. But it's critically important that we communicate in a clear and inclusive way, and we'll all do our best to follow that.

So, now that I've asked you all to play nice together today and tomorrow, I want to welcome you all. Thank you for your participation in this work and we really look forward to the discussion.

CO-CHAIR CALDWELL: Well, good morning, everyone. I'm Joe Caldwell. I'm with the National Council on Aging and one of the Co-Chairs, along with Steve Kaye. And I'm really excited to be here. And I know a lot of you personally. There are some folks I don't know and hope to get to know over the next couple

days. But it's just a great group of folks. And I think with the support of the NQF staff we're going to have a great couple of days and get a lot of work done, because when you look at the materials and the agenda, it's pretty jam-packed and a lot to talk about, a lot to discuss. But I think we have a good process here.

And I think with that, Steve, did you want to just do short comments? And then we'll go around the room and have everyone sort of do a short introduction of yourself.

CO-CHAIR KAYE: I'm Steve Kaye, from the University of California-San Francisco, and just want to welcome everybody and just say that Joe and I are constantly saying to each other, wow, this is going great so far.

And the NQF staff have, I think, really done a good job of putting together all of the thoughtful input that the Committee members have given so far. And I don't know, I've been very optimistic that this meeting today and tomorrow will go well and produce some

interesting results. So I've been looking forward to it, which is kind of interesting for a process that's as fraught as this one might be.

CO-CHAIR CALDWELL: I think maybe just we'll go around. We did introductions on the phone, but it's so hard to connect with people over the phone, so maybe just go around and just shortly introduce yourself and where you're from and if you want to say anything about the meeting and your excitement about it. I guess we'll go around first with the Committee members. So, we'll start with Kimberly.

MEMBER AUSTIN-OSER: Hi, I'm Kimberly Austin-Oser. I'm the Long-Term Care Policy Director with SEIU Healthcare. I'm really excited to be here. I've been working in home and community-based services for 26-plus years and I'm really looking forward to a less-fragmented quality framework.

MEMBER YUSKAUSKAS: Hi, I'm Anita Yuskauskas, and I'm presently at Penn State University in Health Policy and Administration.

And I, too, have worked in home and community-based services my entire career. In fact, I just retired from CMS in August as the Technical Director for Quality in Home and Community-Based Services. So this is a wonderful exercise. I'm looking forward to a productive outcome.

MEMBER GALANTOWICZ: Good morning. Sara Galantowicz with Abt Associates up in Boston, Massachusetts. I've also been working in HCBS for a couple of decades, more on the measurement and research side, with some of the people in this room, including Anita. And happy to be part of this dialogue.

MEMBER MOHANTY: Good morning. My name is Sarita Mohanty, and I am with Kaiser Permanente Northern California. I am the Executive Director for MediCal Strategy and Operations. And I'm an internal medicine physician by training. I've been working on the Managed Long-Term Service and Support benefit with both Kaiser Permanente and previously I was with LA Care Health Plan in Los Angeles. And I'm

also extremely excited to be here. I've been very passionate about identifying strategies to how to best measure process and outcomes for the populations we serve, so thank you for having me here.

MEMBER CRISP: Hi, my name is Suzanne Crisp, and I work with the National Resource Center for Participant-Directed Services at Boston College. And self-direction has been a passion of mine since the old Cash and Counseling days in Arkansas. And I'm so happy that we're looking at quality and self-direction as we think about Section 2402(a), person-centered planning as a mandatory requirement for 1915(c) and (i). Self-direction, choice and control, and honoring the preferences and goals of individuals is critical to any quality project. So, thank you for inviting me.

MEMBER LAKIN: Hi, I'm Charlie Lakin. I'm retired and I think I'm the senior citizen representative for this Committee. Before that I was Director of the National Institute on

Disability and Rehabilitation Research for a while, and before that I spent 35 years as the Director of the Center on Community Living at the University of Minnesota. Done a lot of work in outcomes of community services, and I'm really glad that we're finally kind of bringing the focus on technical quality to this work that NQF is so committed to.

MEMBER KILLINGSWORTH: Good morning. I'm Patti Killingsworth. I'm the chief of Long-Term Services and Supports with the Bureau of TennCare, which is the Medicaid agency in Tennessee. I think that I, along with Camille Dobson, probably are here as the states' representatives, if you will, of states who operate these programs and provide these supports to people with disabilities across the country.

On a personal note, I've been a caregiver for most of my adult life, and so also bring that perspective to the table. I think that this is so important because states want very much to demonstrate, I think, the good

quality work that's being done, but we also want opportunities to identify and improve our programs and services on a continuous basis. So, having a standardized way to do that and to really measure system performance as well as program performance is critical.

MEMBER HOUSER: Hi, I'm Ari Houser, with the AARP Public Policy Institute. I'm actually in the middle of a two-month parental leave, so this is my first day working since my daughter was born a month ago. And I always get a little bit heavy in the second half of the day; I've been up since 2:00 a.m.

(Laughter)

MEMBER SMITH: Good morning. I'm Mary Smith. I am the Associate Director of Decision Support, Research and Evaluation for the Division of Mental Health in Illinois. So I've worked for the state for about 21 years, here and there, and have been mostly involved with performance measurement, development of our information system, and so have worked on quality measures

for a number of years.

I've been part of a number of work groups with SAMHSA and with the states and with NASMHPD and a variety of folks. Prior to that I worked at a community mental health center that was hospital-based. So I have the perspective of being a provider and being at the state level. Very interested in performance measurement for behavioral health and just want to be sure that we have some great indicators that focus on that population. Thanks.

MEMBER MARKWOOD: Good morning. I'm Sandy Markwood. I'm the CEO of the National Association of Area Agencies on Aging. It's really an honor and a privilege to be sitting at the table with all of you. And from my perspective, this issue of home and community-based services is one that is a personal passion as well as a professional passion of mine.

My members are area agencies on aging and Title VI programs that provide home and community-based services in every community in

the country, so measuring quality and moving to outcome measurements is certainly something that is really at the top of our priority list and looking forward over the course of this effort and moving the needle and getting there. Thank you.

MEMBER DOBSON: Good morning. Sorry I'm a little late. The commute from Baltimore was awful this morning, and I apologize.

Camille Dobson. I'm the Deputy Executive Director at NASUAD, which is the membership association for state aging and disability agencies. HCBS is our mission. That's what our states do. We're fully committed to a strong and robust HCBS system that works well for our members.

And I'm excited, along with Patti, to represent the states' perspective here. They've been out in the field doing this for 30 years, 35 years at this point since (c) waivers came into place. So I'm anxious to share what we've learned and hopefully help the Committee build on

what's already out there in our state universe.

I've also just recently arrived from CMS where I spent 10 years working on managed care policy, including quality. So I'm excited about applying my quality sort of perspective to the HCBS sphere. So, thank you.

MEMBER KENDALL: Good morning, everyone. My name is Jaime Kendall. I'm the government task lead for this effort, and I'm at the Administration for Community Living at the U.S. Department of Health and Human Services. So let me start by saying, first, thank you to all the Committee members for serving. You are national experts in this work. NQF, thank you for pulling such an expert panel together.

I'm really looking forward to the discussion today and hearing the perspectives that you bring to the table. As Marcia said at the beginning of the conversation, there is so much interest across the country in this work moving forward. And we are just very excited to have this Committee come together and think

through some tough things in terms of quality measurement for HCBS.

So, I'm looking forward to the discussion over the next couple days, and thank you again.

MEMBER PHILLIPS: Good morning. I'm honored to be here. My name is Lorraine Phillips. I'm an Associate Professor in the School of Nursing at the University of Missouri. I'm representing the American Nurses Association on this panel.

I have, long ago, experience as a home health nurse, delivered care in the home settings. And that was actually my favorite job of all in my entire career. Now I research functional outcomes, quality of care, actually, in more institutional settings, assisted living, nursing homes, and I'm a co-director of the quality improvement program for the state of Missouri. The University of Missouri School of Nursing has a contract with the state to oversee the education for nursing home staff throughout

the state.

So I come at this from a little bit different angle, but some of the same measurement issues across institutional long-term care settings as well. Thank you.

MEMBER OSTROVSKY: Hi there, I'm Dr. Andrey Ostrovsky. I'm the CEO of Care at Hand. We're a digital health technology that predominantly sells into the home and community based services space. I'm here hopefully to bring as much of the digital health innovation that's happening in the Silicon Valley and Boston space focused on wearables and trying to bring that level of innovation to a space that I think is entirely ignored by digital health innovation, which is home and community-based services and, I think, quality measurement.

Another thing to note is I'm a pediatrician even though most of my work is in the aging and elderly space. I just finished residency. I'm going to be an assistant professor at Children's National, and my work

with the complex care population with pediatrics is very relevant with regard to the services that our pediatric population has received. And so in that capacity I'll try to weigh in wherever appropriate.

And then one other brief comment is I serve as one of the community leads on the Electronic Long Term Supports and Services, the eLTSS Workgroup. And that focuses a lot on use cases and interoperability standards in home and community-based services. So however I can be helpful. Thank you. I'm very much honored to be at the table here.

MEMBER APPLEBAUM: Good morning. My name is Bob Applebaum. I'm a professor of gerontology and a researcher at the Scripps Gerontology Center at Miami University in Oxford, Ohio, to confuse you all over the place.

I wrote my doctoral dissertation on something called the Wisconsin Community Care Organization, in 1980. And when I went to interview people as part of that demonstration,

people said, well, I'm a little worried about what's happening in the home, because we don't really know that much about what's going on there. And so, since that time, including a stint on the national channeling evaluation in the '80s, I've been trying to figure out how to ensure quality. And so I'm very excited to be here as well. Thank you.

MEMBER LUZ: Good morning. I am Clare Luz and I am from Michigan State University. I'm on the faculty in the College of Human Medicine. I'm a gerontologist/health services researcher and almost all of my research for the last 15 years has been on home and community-based care, particularly the direct care work force.

And I would like to say that I started out as a personal care worker over 30 years ago, and then worked for 15 years in clinical settings, in long-term care settings, mainly nursing homes and home-based agencies as a social worker. And then went back to school and have been doing research and teaching ever since.

So I'm really happy to be here and I'm happy to meet this group of people and hopefully connect with many of you and we'll build on these relationships and do some good things.

MEMBER DELMAN: Good morning, everybody. My name is Jonathan Delman and I'm an assistant research professor at the University of Massachusetts Medical School where I focus on researching the needs of people with mental health and addiction conditions and focus primarily on psychosocial treatments.

I am also a senior researcher at the Technical Assistance Collaborative, which does a lot of work on home and community-based waivers, particularly with expertise on the housing piece. I do a lot of work on outcomes and quality measurement and I do feel that there are effective ways for pulling this off without spending a lot of money. I think that's something I'll have to talk about. But the other thing I've done is, as a mental health consumer myself, and have been involved in advocacy and

policy and research for quite a while, I have a long-term belief that people who have serious health conditions should be directly involved in deciding these measures. And they can, you know, there are ways to do it. And in fact directing at times a measurement development. So thank you and I look forward to participating.

MEMBER MORRISSEY: Good morning. I'm Gerry Morrissey. I'm presently with the MENTOR Network, which is a national human service organization serving children and adults across the country, and I've been doing that for about eight years as the chief quality officer focusing on quality improvement and customer engagement.

Previously, I served 35 years in state government in Massachusetts, the last 10 years as the director, and also served on the board and served as president of the National Association of State DD Directors.

My interest in this Committee and participating with everybody is I think we do an awful lot of things in community quite well, but

I would suggest two things: one, healthcare coordination and medical supports for individuals is an area that needs some focus. And I'd also like to think about, now being on the provider side, understanding more and making sure we include the voice of the people we support and also the caregivers and their expectations in terms of meeting quality.

MEMBER OXFORD: Good morning. My name is Mike Oxford. I'm the Executive Director of the Topeka Independent Living Resource Center in Topeka, Kansas, a cross-age, cross-disability advocacy organization that also provides services.

When I got involved in independent living in 1984, it was with a very small program that was mainly involved with assisting people with moving out of the big state hospitals, which were a real growing concern at the time, in our state anyway. And I thought that's what independent living was and what independent living centers did. And as I learned more, I

found out that that wasn't necessarily true, but I have spent just about the whole time since working to get independent living more involved with home and community-based services as a path to freedom for people with all kinds of disabilities.

I've been very involved with self-direction and control of services for many decades and kind of preaching that around the country and worked at the state level in the late '80s to pass state law that gives people in our state a right under state statute to direct and control their services.

I'm very glad to be here. I guess my passions are I also have a small organic farm. I live in the country, so they let me out to the city every once in a while.

MEMBER NE'EMAN: Hi, my name is Ari Ne'eman. I'm run the Autistic Self Advocacy Network, a national advocacy group run by and for autistic Americans seeking to increase the representation of autistic people and other

people with disabilities in disability policy.

I also serve as a member of the National Council on Disability where I chair the Council's Entitlements Policy Committee. And in both capacities I'm very interested in questions of HCBS quality, particularly in the context of our changing definitions of what is, and, equally importantly, what is not home and community-based. There are a lot of very exciting things happening in that direction right now and we've been monitoring them very closely. And I look forward to participating in that conversation here today and tomorrow.

I should also mention I'm a co-founder of the MySupport technology platform, designed to assist people with disabilities, direct support workers, and state governments in maintaining high-quality, self-directed service systems. Thank you.

MS. LASH: Good morning, everyone. I'll add my welcome on behalf of NQF to Marcia's, and thank you all again for being here. I'm

Sarah Lash, Senior Director at NQF. My résumé is shorter and much different than all of yours, but I've worked here five years and had the opportunity to contribute to a variety of projects on quality measurement on behalf of HHS, primarily our work since 2011 on measures for dual eligible beneficiaries and for adults and children enrolled in Medicaid.

MR. ANDERSON: I'll go next. My name is Drew Anderson. I am relatively new to NQF. I'm one of the project managers on the project and I'm excited to get started.

MS. FELDMAN: Good morning. My name is Juliet Feldman. I'm a project manager on this project. It's really been an honor to work on this work to-date.

I wanted to see if Barbara McCann -- she is a Committee member who's joining us remotely today. Barbara, are you on the line?

(No response)

MS. FELDMAN: Well, if she joins, we'll be sure to have her introduce herself.

MS. LASH: Great. I'd also like to introduce Nadine Allen -- our last team member, who doesn't have a microphone, but is running our slide deck today -- and a variety of HHS partners in the room and the public.

It's my task now to go over today's meeting objectives and really kick us off and get started.

So, over the course of the next two days this group is first going to continue the work you began on the web meeting, and discuss and agree upon a working definition of HCBS as the first component of our larger conceptual framework for quality measurement. We'll then be collecting input from all of you about how we want to conceptualize our conceptual framework in a visual way.

We'll move on to defining potential domains and sub-domains for measurement to operate with our framework. And finally, towards the end of tomorrow's discussion, identify where we think the most fertile ground for measurement

is, and so that the staff can direct our ongoing research efforts in terms of an environmental scan and synthesis of evidence in the most productive direction.

Next slide. As you know and have heard from us before, this project is all about providing multi-stakeholder guidance on the highest priorities for measurement. Multi-stakeholder really explains the diversity of people here today and the value that every person brings to the consensus process. And highest priority is very important. We know the potential for measurement is vast because there is so much we would like to know about quality. And I really think the trick is not to spend time arriving at the conclusion that we need more quality measurement. Because we're already there. But where to begin among so many very valuable opportunities that are somewhat competing with one another?

So this project will offer the opportunity to address the gaps in HCBS

measurement and provide direction for the future of performance measurement. We are supporting the aims of foundational things like the Affordable Care Act and the National Quality Strategy, HHS' Community Living Council, and throughout our work we want to maintain the broadest and most inclusive orientation to community living that we can.

We've heard a lot already about state-funded services, but we want to use other lenses as well to consider the variety of payer sources and all consumer populations and many other facets of HCBS as well.

Next slide. A cross-agency group of HHS leaders came together to fund this project. And as I said, many of them are here today, led by Jaime. And they have requested that this Committee first create a conceptual framework for measurement, including a definition. As I've sort of mentioned in the objectives, that's where we're going to be spending a lot of our time in the next two days. Later on in the project there

will be a synthesis of evidence, an environmental scan for measures, and measure concepts that are more seeds of measures that could be, identifying gaps in HCBS measures based on our framework and the scan results, and then finally making some prioritized recommendations for measure development and implementation.

So, your role in how we will accomplish this heavy lift is to contribute your content knowledge and expertise over the course of the project, and also to ensure that input is obtained from relevant stakeholders not at the table, but who are sort of part of your broader professional networks. And as experts who are engaged directly with HCBS, you can assist the NQF team with the identification of the most current research measures and resources to understand the performance measurement landscape.

We've already asked you to work together as a group to craft consensus in a really active way on these complex issues, and

ultimately we'll be making recommendations for the future state of HCBS quality measurement.

The role of NQF, as a converse to the Committee, is really just to facilitate. So you'll be hearing a lot of presentations from myself, Juliet, Drew, but we want the discussion really to be rooted from all of you. And so when it comes to Committee discussion time, we're going to try to keep our mouths shut as much as possible, let your expertise come to the forefront, and we will facilitate and referee as necessary.

Finally, just a few ground rules for today's meeting. We want to encourage open sharing, but respect for different viewpoints. We know that terminology is very important in this room, but it shouldn't be a barrier to building consensus. We want to work towards the four defined meeting objectives that I described. And though there are a lot of other very worthy discussion topics, things like data availability and survey methodology, we're going to need to

put those in the parking lot for discussion at a later a meeting so that we can accomplish what we need to in the space of these two days.

A note about how the microphones work. If it's lit up and red, you are broadcasting. They can hear you on the web. Our court reporter in the corner is transcribing all of today's dialogue. It's very important that your microphone is on when you're speaking so that the entire audience can hear you. But there are only three of them that can transmit at a time, so when you're not speaking it's equally important that you turn it off. If you try to speak and there are too many microphones on, it's going to flash green at you, and then you can sort of wave your hand at your fellow Committee members so that they can turn their microphones off.

When you are ready to make a comment or ask a question during our discussion, a way that you can signal that to our facilitators is to take your tent card and turn it on its side like this. And if you could even point your name

towards Steve and Joe until we all have a chance to get to know each other better, that would probably be helpful, too.

The bathrooms are through the double doors past the reception desk where you came in. And we will have some defined breaks, but you can also excuse yourself from the meeting at any time.

Members of the public are invited to help themselves to the drinks in the back so you don't dehydrate on us, but the food is reserved for the Committee members.

And finally, there is a dinner reservation tonight at 6:00 p.m. should any of you want to take the opportunity to socialize with your fellow Committee members. We'll pass out a sign-up around lunch so that we just have an idea how big the reservation needs to be.

And with that, let's get going.

MS. FELDMAN: Well, good morning, everyone. Again, this is Juliet. So I will be very briefly describing our process to-date in

coming about with a definition, and then asking the Co-Chairs to facilitate a discussion about where we go from here.

So, as the Committee is well aware, the first step in our consensus building is drafting an operational definition of home and community-based services. This is the first component of the conceptual measurement framework and we will be referring to this definition and drawing upon it throughout this project to help really scope and set boundaries for what will be applicable to this project.

The development of this definition has been iterative and it will continue to be. There will be multiple opportunities for the Committee and public input. As you all are aware, you submitted your own definition of HCBS to us a month or so ago. We also received definitions from our HHS liaisons and from members of the public. This session this morning we will be digesting those definitions and reflecting upon a definition that we have proposed based on what

you all have submitted.

After this meeting, we will be drafting our first of several draft reports that will be hosted on the NQF website July 15th. And there will be a public comment period on that draft report. So this really is intended to be iterative and with multiple opportunities for input.

So, these principles were presented at our February Committee web meeting. I just wanted to refresh everyone's memory and just go through these quickly.

So, we discussed that the definition will allow the Committee to reach a common understanding of what is meant by the term "HCBS." The definition should be brief but broadly inclusive, that emphasizes the goals of HCBS. We'd like it to be positive in tone with plain language, a definition that can be used across public and private payers and accountable entities. It will contribute to the understanding of high quality HCBS as part of the

conceptual framework. This definition is project-specific and it's not meant to replace existing guidance or regulations.

And finally, we hope that it will maximize applicability, avoid a laundry list of services, specific consumer populations, or types of settings.

So, our progress to date. We started about two months ago pulling together a list of over 200 information sources and scanning those sources for applicable definitions and frameworks related to HCBS. Following the Committee's first meeting in February, as I just said, we solicited definitions from the Committee, from HHS and from members of the public. A compilation of all these definitions was provided to the Committee as part of your meeting materials. Since that time, NQF has reviewed all these definitions to identify commonalities and developed a straw man definition, which we will be discussing in just a minute.

So, in the packet of materials on your

desk there was one document, the colorful rainbow document. That is the draft straw man. I'm looking for mine. So, I'm just very briefly going to describe what you see in front of you and then we really just want to facilitate conversation.

So, there are several aspects of this definition that are reflected on the slide: the what, the who, how HCBS is selected, the where. HCBS enables, assures, optimizes and HCBS system operations. So there was a lot that we tried to capture in this definition and we'll be eager to hear what you think. So, on this paper, each of these one, two, three, four, five corresponds to a specific colored piece of the definition on the right. So, I hope that makes sense to everyone. Here's the definition.

So, lastly, I just want to present some of the overarching themes that were reflected from all the definitions that we received.

In terms of the what, we heard that

HCBS should reflect a wide range of services and supports that are person- and family-centered, predominantly non-medical, selected by the individual, easy to access, flexible to change with a person's life experience, paid and unpaid, funded through public and private programs, needed for a sustained period of time, coordinated to maximize resources, provided by culturally and linguistically competent formal and informal providers and caregivers including family caregivers, and accountable through measurement and reporting of quality.

In terms of the who, HCBS should be provided to individuals, persons or participants, not recipients, of all ages, across all disabilities, with disabilities, limitations, impairments, and then a listing of those various types of disabilities, limitations and impairments. HCBS should be provided to people who need support services as a result of functional or age-related limitations, disabilities, multiple chronic conditions, or

other challenges participating in community life or accessing needed services.

In terms of the where, HCBS should be provided in the homes and communities of a person's choice using a person-centered planning approach, independent living in community-integrated, non-institutional settings, integrated in and in support of full access to the greater community. It should include opportunities to seek employment in competitive integrated settings and engage in the community if desired. It should be accessible and affordable to persons requiring them and does not segregate individuals by disability, specific disability, or other disability-related characteristics from the broader community.

And lastly, the why, which is really getting to the goals of HCBS. So, HCBS is provided in order to support the personal, social, health and employment needs of individuals and their family and paid caregivers. It's to assure the individual's basic human

rights to privacy, dignity, respect, and freedom from coercion and restraint. It should sustain community living and allow people to participate fully in society. It should optimize, but not regiment; maintain and improve; promote and protect individual choice control, autonomy, self-determination, initiative, personal living preferences, independence in making life choices, shared responsibility and informed decision making; inclusion, productivity, social engagement, involvement in meaningful activities; safety and reasonable access to needed services and supports; and health, physical and mental, and quality of life.

So, that was a mouthful. So, all of these things are what we tried to capture in this draft straw man definition.

I'll turn it over to the Co-Chairs to offer any opening remarks.

CO-CHAIR CALDWELL: Okay. Well, I think now is the fun part. We get to pick at the straw man definition. And so I think it would be

helpful -- it's on the screen -- or actually it's on this screen, but the actual definition that's in the different colors. And you also all have a handout.

So, I think one way to kind of facilitate this discussion is to walk through the different parts. There's eight different parts or eight different colors that are on the screen. And if you look on this sheet, there are some discussions questions that we worked together with NQF staff to put there. And those can help facilitate some of the discussion, but also just feel free to express your opinions on really anything related to that.

And one other thing. I would just echo what Sarah and Marcia had said about terminology. I mean, I think it's important to really focus on the concepts that are there. And the terminology is important, too, but we'll get to that. And I know a lot of you have been around long enough to see the terminology change. Like self-direction, you know, it used to be

consumer direction and it used to be Cash and Counseling or something before that. So I would just ask people to sort of keep that in mind, to kind of focus on the concept first and then we can try to come to consensus on the terminology that we want to use.

So, I think the other thing I would say is I think that this is a really good start. I was interested to see how this would all come together when I read everybody's definition. And there's a lot of common ground, but I think the way this was pulled together makes a lot of sense and it's a good starting point. It's a good straw man definition.

So, I think, you know, let's just walk through it. And if people first look at what's in yellow, that is the what. So, one of the discussion questions that we came up with that I think is really important to kind of talk about is you'll notice that it starts off with a definition of high quality home and community-based services versus a definition of home and

community-based services. So, that I think is a decision point for us to kind of talk about. Do we want this to be a definition of home and community-based services or do we want it to sort of focus in on what is high quality home and community based services? I know, Steve, you had some thoughts about this.

CO-CHAIR KAYE: Yes, well, first I just want to echo what Joe said. I think this is a good starting point for our discussion. I mean, I'm impressed with the input and how well it was put together. And that was my first reaction in looking at this, was we've kind of -- deliberately or not, I'm not sure, we seemed to have made a decision to go with a statement kind of, what is high quality HCBS?

And we might alternatively -- and we might still decide -- to come up with a definition of what HCBS is. And the reason that I'm focusing on this is I don't think -- this definition works well, I think, at emphasizing what we mean by "quality," but I think it works

less well as a way of defining what is and what isn't HCBS.

So, for example, I mean, my mother is 91 years old. I'll use her as an example, without her permission. She has modest functional limitations and doesn't do as many things as she used to, but I don't think she's at risk of institutionalization. She's always hired somebody to clean her house. I mean, I don't see anything in this -- I mean, it's very self-directive. She gets to hire and fire the person, and does. And I don't see anything in here that says that that is not HCBS, and yet I wouldn't think it is because she's always had it. It's not essential to her, I think. And if it is HCBS because she's 91, then when did it become HCBS?

So, it's awkward to say this, but I would want to put something about "at risk of institutionalization," or things that you really need in order to keep you participating in your community, or something like that. And I think that's out of there, that that's not stated.

You're facilitating. Ari has raised his hand.

CO-CHAIR CALDWELL: Yeah, I think we'll just open it up for discussion, particularly about this issue. So we'll go to Ari first.

MEMBER NE'EMAN: Yeah, I want to push back a little bit on the idea that we should put in a requirement that HCBS be something that prevents people from being at risk of institutionalization. I think the second potential qualifier you put in, "facilitates inclusion in the community," is something I'd feel a lot more comfortable with. But we're increasingly seeing, even in Medicaid HCBS funding streams, like the 1915(i) authority and others, that are very explicitly being utilized independent of the institutional level of care.

So I want us to be cautious about that for fear that we might lose access to some very important developments that are impacting people either with developmental disabilities or

psychiatric disabilities that are not going to, and are not imminent risk of, needing the institutional level of care.

MEMBER OXFORD: Yeah, ditto. I was just going to say that the 1915(i), the programs that aren't -- the old state plan option, the personal care, you know, that aren't tied to institutionalization. And really I always just kind of was thinking anything that would promote independent living. So, real broadly is kind of where I was going, too.

CO-CHAIR CALDWELL: Ari?

MEMBER HOUSER: It's not often you get Ari as the only doubled-up name.

(Laughter)

MEMBER HOUSER: I forgot to mention in going around, my background is actually as a statistician with a focus on measurement, so I may have some opinions about when we need to be precise and when we probably should not be precise.

I would tend to try to have as few

qualifications as possible, whether it's the criteria for risk of institutionalization, or even criteria for inclusion in the community, because we don't want to preclude something from being included in home and community-based services based on our definition. And I think there's always going to be services that are at the border line. And whatever criteria we include, we're just shifting where that gray area is.

Whether it's some homemaker services that at some point in someone's sort of smooth aging trajectory, well, maybe they should be considered home and community based services, whereas at one time they were clearly not. It just shifts that border to, well, is this person at risk of institutionalization or not? I'm not sure. Is this person at risk for being excluded from community life or not? I think we're not necessarily getting rid of gray areas by putting those criteria in. We're just moving them. So I would tend for the definition to want to be as

imprecise as possible so that we can be inclusive in what we consider.

As well, I did notice that our HCBS draft definition started with high-quality home- and community-based services. I don't think that's a bad idea, but I think it requires us to at least go through the whole list and identify what are statements that define HCBS, and which are statements that quality, so that if we cross out a line are we left with medium quality home and community based services or are we left with something that's not HCBS at all?

CO-CHAIR CALDWELL: Good point. We'll go right here.

MEMBER LUZ: I just want to make sure I'm understanding the two Aris. So are we saying the same thing -- because I appreciate your point, Steve, about at risk for institutionalization, but are you saying that facilitating integrated living in the community accomplishes that same goal? If we just phrase it that way it accomplishes the same goal as

saying at risk for institutionalization?

MEMBER NE'EMAN: Well, I think it accomplishes the goal without some of the drawbacks of saying at risk for institutionalization. There is a substantial population that would benefit from, and in some states is benefitting from, HCBS that is most likely not going to fall into institutional settings without it, but will have much higher quality of life and much greater integration in the community by virtue of being able to access these services.

MEMBER LUZ: Okay.

MEMBER OXFORD: And I would just add, for my part, is the institutional eligibility is so arbitrary and goes up and down in the same state, maybe even in the same year. And so, it seems like we could possibly have a definition that's going to go in and out based on this arbitrary stuff, which essentially is just a state sometimes just doing budget stuff.

MEMBER LUZ: Right. Which plays to

your point, I think. But I have a second comment. I agree with putting high-quality home- and community-based services in there, the term "high quality," because I think that's what we're shooting for. But when I was trying to put my definition together, I got snagged on that a little bit, because I'm wondering is our goal here to achieve the ideal definition? What would ideal home and community based services be, versus what is now or what is realistic?

CO-CHAIR CALDWELL: Good question. Yes.

CO-CHAIR KAYE: Yes, I think Anita was up first. And we'll go to Anita and then Andrey and then I think Charlie was next. And Camille's down there. Well, maybe Camille. We'll go to Camille. We'll go to Anita first.

MEMBER DOBSON: I've had my hand up for a while.

(Laughter)

MEMBER DOBSON: So a couple things. One, I can see us already sort of devolving into

payment issues, right, right referring to the publicly-funded system. And I think that's -- I don't know how we resolve it, but clearly there are other funding streams other than Medicaid. And not everyone's getting HCBS because they're at risk of institutionalization, right? Not necessarily. And maybe the private sector, or frankly the Older Americans Act to provide services to adults 60 and older. Not necessarily. So I don't want to devolve into the payment sources, right, as an issue.

The other thing is that if we need to use this for measurement purposes, if that's our end goal, it needs to be something that can be operationalized in a way that people identify what that is, so that we can figure out what it is we're measuring. And this is what -- it's a great definition. It just feels -- I come from the medical world. It feels fuzzy to me, and I'm struggling with how we would figure out how to -- what goes in, say, a denominator, right, if we get eventually to that point of what's in this

bucket? I'll just throw that out there.

CO-CHAIR CALDWELL: No, that's good. And actually that was one of the other discussion questions to kind of throw into the mix was right now it's totally silent on the payer, which my personal opinion, I like that, that we don't -- and it kind goes along with what Ari was saying, like not being overly prescriptive on some of this stuff. It's also silent on at risk for institutional care -- or institutional care. So just to sort of flag those, and feel free to comment on that. But I think we'll go to Anita and then over to Andrey.

MEMBER YUSKAUSKAS: Yes, I really agree with what Camille is saying, and in my mind I see home and community based services as an intervention to produce a particular outcome. And so the question for me has been what's the intervention, and what's the outcome that we're looking for? And when I read this, the thing that resonated with me was the whys, in order to. And so that to me is sort of -- they're the

outcomes we're looking for. And I agree, I think maybe we need to get them just a little more tight so that we can look at measurement.

The other point I wanted to make just slipped my mind. Oh, I know. When I was looking at this, I started to think about insulin, for example. My husband happens to have diabetes, so that came to my mind readily. And when I started thinking about insulin in relation to the categories for this definition, I started to think about the who, the where. And frankly, a lot of those questions started to become irrelevant to me. What really was important was what is insulin supposed to do? What is it that we want this to do? And again, I keep going back to the outcome. So that's where I ended up.

MEMBER OSTROVSKY: I'd like to echo what Ari and Ari pointed out in not overemphasizing institutionalization as a potential focus around how we define this. And the reason is that when folks have a change in functional status, especially if it's declining,

they may start out in a financial situation where they may not take advantage of publicly-funded home and community based services, and instead will go private, pay for certain services. And both these service providers and the technology solutions around that space I think should be held accountable to, and measured by similar quality measures, as we measure HCBS that is publicly-funded.

So again, back to the point around like let's be payer-agnostic, and as such keep scope as broad as we can. Because I can tell right now it is the wild, wild West, not just in Silicon Valley, but everywhere across the country around how technology vendors or service-for-profit private duty service providers -- there's really no way to commonly measure quality. And sales people will just claim, oh, we're the best at blah, blah, blah. It would be really great to have a common quality framework for HCBS all the way up through private pay, including publicly-reimbursed.

CO-CHAIR KAYE: I'm wondering if we have consensus that we shouldn't mention payer in this, in the definition. Anybody object to that?

(No response)

CO-CHAIR KAYE: Yes, okay.

MEMBER PHILLIPS: I just wanted to get back to the high-quality adjective, and it almost seems incongruent with the last statement in the definition, where measurement and reporting of quality outcomes will be -- are a tenet of the definition, and would not the quality be captured through that measurement, eventually?

CO-CHAIR KAYE: Can you say that again? I didn't quite understand.

MEMBER PHILLIPS: Using the adjective, "high-quality" to begin the definition seems a little bit incongruent with including quality then as a measure in the definition, in the blue -- the last statement because the purpose is to be able to measure the quality, report outcomes. And by using high-quality to define the concept, it's, in my mind, more difficult to measure high

quality.

CO-CHAIR KAYE: So where would you go with that? Would you take out that statement, or would you take out the high-quality adjective?

MEMBER PHILLIPS: I would take out the adjective high-quality. That's my opinion. From just kind of an internally consistent definition.

(Off mic comment)

MEMBER PHILLIPS: Right. Right. Right. Yes.

(Off mic comment)

PARTICIPANT: Can you use your microphone?

MEMBER PHILLIPS: Exactly. Yes.

MEMBER DOBSON: I think what Lorraine is --

MEMBER PHILLIPS: Yes.

MEMBER DOBSON: If it has all those things, all those aspects, it is in fact then high-quality by -- it's very minor.

MEMBER PHILLIPS: That you're measuring the outcomes that --

MEMBER DOBSON: Of those --

MEMBER PHILLIPS: -- important to the definition.

MEMBER OSTROVSKY: And we need to leave room for low quality, because there will be low quality.

MEMBER PHILLIPS: Right.

MEMBER OSTROVSKY: And we can't define low quality as -- yes, I think that's kind of what -- yes, it's a --

(Simultaneous speaking)

MEMBER PHILLIPS: And there's a continuum of quality. It's not either/or, in my mind.

CO-CHAIR KAYE: So would we solve this problem if we defined HCBS, and then said high-quality HCBS has these aspects?

MEMBER PHILLIPS: Or choosing the measures that --

CO-CHAIR KAYE: But is that a reasonable approach?

MEMBER PHILLIPS: -- could then be

analyzed to determine if a certain level of quality has been met.

CO-CHAIR CALDWELL: I mean, a lot of people seem to -- I felt like a lot of agreement with where you were going there, defining HCBS and then defining what is high-quality HCBS. Does that sound like a good plan? Anybody specifically on that like have any thoughts about that issue?

MEMBER HOUSER: I have a few.

CO-CHAIR CALDWELL: Go ahead.

MEMBER HOUSER: One, I just wanted to briefly go back to what Camille had mentioned, that the definition seemed fuzzy. And I think that's a feature. I think we need very rigorous operational definitions, but at the measure level, not at the guiding definition level.

In terms of Lorraine's comment, I wonder if it's the last sentence that should go, because to me that doesn't say anything about what high-quality HCBS is, or even what HCBS is. It's just saying that -- it's sort of a statement

about the role of quality measurement and reporting in the HCBS space. So I think that last sentence is kind of outside of the definition. It's sort of a statement of purpose. And the rest of it is the definition of HCBS or high-quality HCBS.

CO-CHAIR CALDWELL: That's a good point. I know Charlie's trying to get in on this issue.

MEMBER LAKIN: Well, I agree with the discussion. First, I want to reinforce what Ari said about at risk of institutionalization. I think that concept validates institutions, and we need to move away from that. Our goal is that no one is at risk of institutions. So let's not validate that in what we do. I do think we move too fast from a definition of what home and community based services are to what we think high quality is. I think there's a danger in that. And part of it is our straw man gets too big, but part of it is we aren't really being very incisive in this.

I look at the statement that these services are safely delivered in home and integrated community settings. It's not enough that the services are safely delivered. People need to be safe or safer because of these services and supports. And it's not enough that the individual pursues goals and desired outcomes in health. We need to help people be healthy, whether that's their goal or not. We're not going to help people be unhealthy.

So I think we really need to dig in to -- first we need to define what home and community based services are, and then we need to be really careful about what we think about the components of these being. And I think this is a little bit of a hodgepodge of different thoughts. I think we need to look at each of those thoughts very carefully.

CO-CHAIR CALDWELL: I think that's a good point. And I think if you keep in mind the whole purpose of this is it's the first part of the framework, which we're going to turn to next.

So I think that's going to dig down into more detail about what we're talking about in terms of the quality domains and that. But I know I had Sara, and then Sarita had that to get in.

MEMBER GALANTOWICZ: Sure. Thanks. As I'm listening to this conversation it seems that we're -- similar to what Anita was saying, we're talking about interventions, which sort of lead to process measures, and then outcomes. And I think a lot of our questions about the what will be easier to answer if we focus on what we want to see on the outcomes piece.

So some of these issues about whether it's at risk of institutionalization, or who's in, has sort of become less important if we think about what the services are supposed to accomplish. So we might be able to punt in some of that what. If we focus again on the number 5: this enables, assures and optimizes, I think it will help set the tone for what we're talking about.

MEMBER MOHANTY: Yes, just a couple of

things. I also was going to say the same thing about that last statement. I felt that there was an incongruence of that, the blue, in the definition. So I would recommend that -- like it was mentioned by Ari, that it is more of a statement of purpose and maybe could be considered to be taken out.

The other thing that I wanted to bring to the attention of the group was that in the first sentence about the predominantly non-medical services, we've struggled with that in our organization about calling it non-medical services. I know it says "predominantly," but I would make a suggestion that we try to -- and I'm still -- I would love to hear the thoughts of this group to think about what would be an alternative to saying "non-medical." I mean, we've tried to identify -- put in "social needs." Because personal care services can comprise medical-type interventions as well. So that was one other piece that I -- and I don't think I have the exact wording yet called out, but I

think that's something to consider.

And then the last thing, echoing what Sara mentioned, was that figuring out what our outcomes will be will help us kind of define this a little bit better. And I'm always thinking about the triple aim, and one of the things I didn't -- kind of wasn't called out, but I think is implicit in here is the idea of member experience, and also well-being. I also wanted to throw that in there as well. So those were just some kind of thoughts that I had that we should be thinking about.

CO-CHAIR CALDWELL: Okay. I think Bob was maybe next. Let's go Bob and then Kimberly.

MEMBER APPLEBAUM: So the difficulty I'm having with the definition is that it seems like we're combining sort of a basic definition, some aspirations of what we they should be, some objectives and some -- and even a little bit of operational measurement just to throw it all in. And I think that to me it seems like one approach would be to establish principles of what we think

HCBS should be.

Because you could take any one of these sentences, like safety, for example, and have some people say this person shouldn't get this because they're not safe and some people say it doesn't matter if that person's safe. If they want the service, they should be able to get it. And we're sort of getting into very difficult territory. I think if we can have an established set of principles that we can agree on, then we can then work to figure out how to operationalize those measures. But I think right now we're trying to do multiple things in one task, and I think that's why we're getting into so much trouble. But I think we could agree to some principles about what HCBS should do and maybe that would be good enough as a jumping off point to be able to develop the objective of measurement.

CO-CHAIR CALDWELL: Let me put Jaime on the spot and ask our official HHS representative if we came up with principles

rather than a definition if that would be just as good.

MEMBER KENDALL: I think that it's a foundational piece that guides the framework, and so I would leave it to the Stakeholder Committee to make that determination. But we need to have a foundational understanding of what HCBS is for this purpose. And whether it's principles or a definition is a little bit of semantics.

MEMBER YUSKAUSKAS: So, I heard two things. Bob said what HCBS does. And, Jaime, I heard you say what HCBS is. And so, I think if we're establishing principles, having that distinction would be important.

CO-CHAIR CALDWELL: Kimberly?

MEMBER AUSTIN-OSER: So, a couple of comments about -- well, touch a lot of things that have been discussed here.

I'm kind of more a keep-it-simple-and-basic person. And so, when I'm thinking about the use of the term "high-quality," I have a tendency to agree with Lorraine that the

definition should be the definition. It shouldn't give the impression that there's this level of HCBS, this level of HCBS and this level. This is what HCBS is.

And I like all the who, what, when, where, whys. I think that's important to have, and you can have that without having six pages. This definition is really not too long when you think about the years we've been talking about what is HCBS?

So I would be proponent of not using "high-quality," that this is what HCBS is. And I really think that high-quality -- then we can also say in high-quality HCBS what we would like to see, whether it's an optimal system. Something that is functioning at the level we want to see it functioning at looks like this, which is what our charge is here, coming up with a performance outcome measurement system. This is what we're looking for. And that it's really going to be up to the system then to drive and only pay for an incentivize regardless of payer

high-quality HCBS. And I feel like that's our charge here.

One of my other comments. I share the concern that in the first line -- well, I don't know if "concern" is the right way to say it, but that in the first sentence we are actually saying it's an array of services, and then we're saying what it's not mostly, and that's non-medical. And I'd like to see that just not mentioned at all, because while I do believe -- and I came up strongly believing in the social model HCBS system and totally understand why it's important for us to have a system that isn't completely medicalized and dominated by a medical model. I think that if we're looking at this holistically, it needs to include a rich array of services that include medical; and saying it's predominantly not that is just not helpful to me, and as a kind of standard definition.

CO-CHAIR CALDWELL: Yes, that's a good point. I think maybe we do need some more discussion about the term "non-medical" and if we

want to use that or something else. So we'll just throw that into the mix.

And did you have something?

CO-CHAIR KAYE: Medical and social services? I'm not --

(Simultaneous speaking)

CO-CHAIR CALDWELL: In my mind it would say social and medical.

(Laughter)

CO-CHAIR KAYE: Social and medical. Yes, I'm not -- this isn't helping any.

CO-CHAIR CALDWELL: I know in some of the individual definitions people did use the term like "social," "predominantly social services," or "social supports" or something. That's a little different. Like what Kimberly was saying instead of defining it what it's not, it's sort of defining it more positively, which was one of our principles. But there is a lot of concern in the community about I think that particular issue. They don't want this Committee to focus too much on the medical issues. So I

think that was maybe a little knee jerk too far to say we're not going to talk about medical. So that's something to discuss.

I think Sandy wanted to weigh in.

MEMBER MARKWOOD: Yes, thank you. Just several comments. Again, I agree with taking the "high-quality" out. And I agree with the concept of not including institutionalization. But, Ari, I think that in some way we have to address the issue that Steve raised. So is the goal here to keep people living independently? Because otherwise from a policy perspective I think we run into problems if it's everything. I think somewhere there has to be some level of distinction there.

The other thing on the predominantly non-medical, which jumped out at me as well, is maybe social and health-related, because health-related is broader but doesn't go specifically into the medical framework.

And the last point that I would make was agreeing with Ari about taking the last

sentence out.

CO-CHAIR CALDWELL: Clare?

MEMBER LUZ: Just two brief comments. On the last sentence -- I'll start with the last sentence. I agree with Ari about the "through measurement and reporting of quality and outcomes," but I hesitate to throw the entire sentence out because it also addresses accessibility and affordability, and the services aren't any good to us if we can't access them or afford them. So it seems like we should keep those concepts in somewhere.

And then my second thought is on the predominantly medical. I have concerns about saying "predominantly non-medical" because I actually bristle at any labeling, whether it's "old" or "institutional" versus "community care." I think we set up these sort of false dichotomies when in fact this isn't a linear path. People cycle through all of these different kinds of services throughout their life regardless of age. And so, to separate something out and label it as

not being part of the continuum of supports and services concerns me.

CO-CHAIR CALDWELL: Gerry's trying to get in.

MEMBER MORRISSEY: Just a few thoughts, one on the emphasis on high quality. There must have been something behind emphasizing high quality because people want to assure that community based services are high quality. And I would say that this group, we should be focusing on that home and community based services should be implicitly high quality. Honestly, I'd like to hear a little more about how we would accept low quality community based services. That to me is something that would I think be very challenging. So I would assume that home and community based services, along with the folks here, we shouldn't front-end it with high quality, that home and community based services are of a quality and we should be able to define that as a standard or principle or with specific things that undergird home and community based

services. That would be number one.

I think number two, anything we have in home and community based services; and I think that's part this collection here, should be individually driven. I think the system should be around individuals and individual choices. And I think sometimes when we don't think that way, we then use language that potentially delimits individual choice.

And thirdly, this non-medical to me is -- another thing to me. For individuals to be successful in their communities they need healthcare coordination or they will have less choices. So I'm not a big fan of the non-medical, but there must have been some thought around the success of the people that we want to be successful in the community. It does rely on their medical management and their healthcare coordination. And those issues are significant barriers for some folks to be successful living in their home and community, and I think we need to think about that.

CO-CHAIR CALDWELL: I think Suzanne Crisp hasn't weighed in. Give her a chance.

MEMBER CRISP: Yes, thank you. I just wanted to weigh in on the predominantly non-medical services and supports. If we're looking across funding source and including everything, then we have to look at our Medicaid friends. And I'm glad to see that this does not -- or Medicare friends. I'm glad to see that this is not drawing a distinction between acute care in the home and long-term care services and supports. So I mean, I don't know why we couldn't just say an array of services and supports and leave it open to anything that happens in the home that does promote independence and longevity and high quality of life.

CO-CHAIR KAYE: I sort of think I'm hearing that we're moving towards consensus that we should start maybe with a definition of HCBS proper. What is HCBS? And then perhaps make either a statement about what high quality is or

what we mean by quality, or have a list of principles of what quality is. I'm seeing a lot of nods. Is there somebody who thinks that this is not a good idea?

(No response)

CO-CHAIR KAYE: Okay. So that's some progress.

CO-CHAIR CALDWELL: I think we can come back to Mike and Ari over here.

MEMBER OXFORD: Yes, Steve, I was just going to say because otherwise if we use the definition like what we have here, it would exclude virtually all of the existing programs in the country since nobody's got all this together in one thing. And I don't think that's really what we want. So we need something really broad and basic and then the aspects, whatever, that we're going to get into measuring maybe, or differentiating levels of quality.

I'm concerned about the non-medical and want to push back a little bit. Because first of all, there's nothing intrinsic to mean

medical or not. It's just a definition with a lot of variation, a lot of politics, a lot of changes around it. And while it's true that more and more things are happening in home and/or community that heretofore would have only been in a hospital or institutional setting, and that's good. I'm not sure those things are HCBS. Okay? And so in other words having, for instance, a registered nurse come in and debride a wound that's infected or something -- I'm not sure that's HCBS. It's a necessary service. It's a good thing.

And so, I don't know. I just kind of want to push back a little bit there that maybe it doesn't need to be in the definition very broad and very basic and then we figure out how we come to quality. But I think there's something about medical services that really aren't home and community, because then we are going to not be able to get a way -- I mean, you don't self-direct a doctor. At least I never have. I've tried.

(Laughter)

MEMBER OXFORD: And so on, because of their licenses and all that kind of stuff. And so, I just want to be a little bit careful there and differentiate, not that whether it's good or not and not whether it's valuable or you need it or so on being in there, but rather whether it's really a home and community based services or a medical.

MEMBER NE'EMAN: And I'd like to second that, joining Mike. And speaking up in defense of predominantly non-medical and the definition, to me we have to be thinking about what we're more concerned by. And personally I'm much more concerned by the possibility that HCBS is going to become overly medicalized, and that's really something that we've had to consistently fight throughout the entire history of HCBS services than I am by the possibility that we are going to entirely remove the concept of care coordination across acute and long-term services and supports. I think we can take a holistic

approach while still acknowledging that we're coordinating different kinds of services that have some overlap, but nonetheless distinct.

I'd actually like to raise one more definitional issue, if I may, and it's in relation to the point No. 4 in brown, the "and safely delivered in a home or integrated community setting of the consumer's choice." This seems to be getting at something that I think is very important to the definition of HCBS, and that is an acknowledgement that system-wide issues and system performance has a role in determining whether or not something is or is not HCBS, even regardless of the particular model or quality of an individual provider.

And what I mean by that is you can be receiving HCBS in a residential group home, but you probably are not receiving HCBS if a residential group home is the only option of a setting in which you could have a choice to live under the HCBS funding authority. CMS articulated this to some degree when they put in

the new settings rule, a requirement that services be delivered in a setting selected by the individual from an array of options including a non-disability-specific setting. And I would suggest that we include similar language here and say something to the effect of "delivered in a home or integrated community setting selected by the consumer from an array of choices including non-disability-specific setting choices."

CO-CHAIR CALDWELL: Okay.

MEMBER NE'EMAN: I'll just add I think I consider that a definitional rather than a quality issue.

CO-CHAIR CALDWELL: Those are good points. I think also some of the other comments I think around that, the words "safely delivered," I think maybe some other thoughts about that and is that the right language, the right term? Do we want to use the word "safe" at all? So just throw that into the mix.

Maybe we could go to Jon, because I don't think Jon had a chance to weigh in yet.

MEMBER DELMAN: Yes, I just wanted to comment primarily on the green language, No. 2. I think it points to some -- what I've seen in a lot of these discussions is internal inconsistencies in values from my perspective. So we have something called a person-centered planning process. Nobody really knows what that means. I mean, they talk about that in mental health. Is it something you do to a person? Is it something that a person does to themselves or something? I really think if this is about self-determination, I like "person-driven," or "person-directed."

Because regardless, I think we can't tell the doctor what to do, but we can tell them and hope that they do it. And then if they don't do it, then we can negotiate with them. But any kind of decision making process has to be fully, I think, driven by the person and is a very practical piece to this, because part of the goal I think is for a person to develop some self-management skills so they're not reliant on a

system that's often unavailable and not helpful.

And part of that management development process is playing an extremely active role in decision making as much as possible and how we define that. But this has been a real problem in mental health. So I would like to see person -- if we're really going to talk about self-determination and independence, person-centered doesn't -- isn't going to make that happen. It really has to be person-driven or person-directed.

CO-CHAIR CALDWELL: I think the only thing I would push back a little bit, I think we've made a lot of progress. That's one of the terms that -- there's different terms that could mean similar things. But in terms of CMS, I think like there's been a lot more clarification of what at least the expectations are around person-centered planning. So I would just throw that in.

I think maybe go back to Andrey and then come to this side of this table again.

MEMBER OSTROVSKY: Thanks, Joe. Two quick comments. One is around the adjective, or adverb, I guess, "safely," the qualifiers. I think if we're going to be consistent with our approach of defining HCBS not as high or low quality, but just what is HCBS, then not only should we strip out "high-quality" as a qualifier, but also strip out any other qualifiers in the definition, like "safely." Now, that would be high quality if it was done safety, but is it not HCBS if it's not done safely? I think that might be something we want to be consistent about.

And the other point around non-medical, I think it is really important to distinguish HCBS as non-medical, or at least predominantly non-medical. And that comes down to licensure. For example, if a provider of HCBS is engaged in any way in skill -- terrible word -- skilled services, but services that could be, let's say, reimbursed by Medicare; not to get into the payer space, but just purely on what

qualifications does someone have to have to debride a wound, those are different qualifications that I think are outside of what we think of functioning as HCBS. And I think what that would allow us to do if we would crisply delineate non-medical is when we end up measuring quality and high -- when we end up having qualifiers for high quality.

I think a good qualifier could be do HCBS services integrate well with the medical services, because that's a direction that HCBS I think is starting to go in many instances from a new revenue stream perspective. So I think if we crisply define HCBS as non-medical, then we can have an easier way of measuring the quality with which HCBS interfaces with the medical realm of services.

CO-CHAIR CALDWELL: Yes, I mean, I think that's a really key point, because I think on our first call -- I mean, I think it's trying to make -- there's a lot of concerns about it being overly medical, but not totally closing the

door particularly to that integration. And then like all the work that happens when people transition from the hospital back to the home. And there's a lot of HCBS that is done there that area agencies are doing and other folks in care coordination.

So, yes, I think we're there on the concept. It's like how to articulate that in the definition.

MEMBER OXFORD: Well, I mean, Joe, at home -- the difference in Kansas between medical and non-medical; this gets messy, is if people self-direct, choose that option, then they are in control of things that would otherwise be medical. Okay? And then people who don't self-direct have to have a medical licensed professional in charge of those things. The services are exactly the same. It's the issue of whether or not you're exercising your right to self-direct in my state over those services.

So there you go. I'm sure that helps clarify things.

(Laughter)

MEMBER OXFORD: No. But, I mean, I just think that that's important in terms of being careful with using these kinds of qualifiers because we get into messy situations like that to where again it's nursing unless you self-direct it and then it's not nursing because we have an exemption under the Nurse Practice Act. And so, it's nothing intrinsic to the service. It's whefther or not you exercise this other right to self-direct and be more free.

CO-CHAIR KAYE: I know there are several other people who've raised their hands to speak, but I wanted to raise a sort of med issue, which is we have I think about 22 minutes left on the agenda for this discussion and I wonder how we're going to get from here to an actual definition and principles, or definition and -- dual definition, or whatever it is. What is the process? And I kind of wanted to ask the NQF staff what they think we should do now.

MS. LASH: I think we would suggest

that people make concrete suggestions for how we would rearrange what we have here such as identifying components you would put in the definitional bucket versus the aspects of quality bucket. And we can do some work overnight, because we do plan to bring back the definition tomorrow and a further finalization at that point. So we want to get farther than we are now, I think in understanding what we want to put in the definition HCBS itself, and what would be in the principles. And we can glean from what we've heard already in the conversation some ideas about how that might look.

CO-CHAIR CALDWELL: All right. Kimberly has a question or --

MEMBER AUSTIN-OSER: I just have kind of a process question to kind of add to that, because it feels like some of us -- I actually cannot believe that I'm arguing on the medical side because I've been so non-medical and social model, but I feel like we need to -- like maybe a subset of us or something need to have more of a

conversation about this or something.

So I don't know what the process is for a subgroup to come back and make a recommendation. I feel like me going away, or each of us individually going away and coming back and making recommendations feels less effective than if a small group of us caucused or did something. I don't know if that's appropriate or if it's within a process that you think is acceptable, but I'm just going to throw that out there.

MS. LASH: Sure. And there might be time to do that over lunch to some degree. I also think our later discussions about the conceptual framework will further clarify where the group is in some of these relationships about the boundaries of HCBS and its goals and the actions and influences of quality measurement. So I think we would knit that into the definition as well.

CO-CHAIR KAYE: So should we use our 20 minutes that we have left to sort of try make

concrete suggestions as to what goes in the definition so that the staff and the Co-Chairs when we huddle tonight at 5:00 we can try to come up with something that you're at least a little bit happier with tomorrow than you are today? Is that good?

(No response)

CO-CHAIR KAYE: All right.

MR. ANDERSON: I just have a quick suggestion. Maybe we can -- well, you guys can walk through each piece and have a small conversation about what you would toss out or what you would keep in, or maybe like Sarah said, categorize the HCBS definition or high quality so we could just have short conversation about each component.

CO-CHAIR CALDWELL: I think those are good ideas. I think on this issue of the non-medical, maybe that is one for a little group to maybe kind of talk more about, and people on both sides, and see if we can come to some sort of language or something that we could bring back

and maybe see if there's agreement about. And like Steve said, I think with your comments in the last 20 minutes, like try to be very specific about what we might want to change in this definition.

There's a few things we haven't got to. The very last question about providers and caregivers. And this may be a terminology thing. I think it's about a conceptual thing. One of the questions is we don't specifically mention family caregivers anywhere. And so that may be something to see if that should have a spot in this definition.

So I think Mary has been trying to get in for a while, so let's go to her because she hasn't had a shot.

MEMBER SMITH: Thanks, but I think you might be going in the direction that I was thinking about having a smaller group work on some of these things.

I don't particularly like the word "non-medical," but maybe what people are trying

to get at is; and I think someone over there said it, integration or either coordination with healthcare. So i would toss that out.

In terms of having "safely" as an adjective for delivered services, I think of safety as a quality indicator, so I would actually pull that out and when we get to the point where we're thinking about quality indicators stick that in.

Family, the issue that you just raised, I guess I thought caregivers covered that, so I'm not really sure that we need to be more specific there.

CO-CHAIR CALDWELL: I forget who was in the order, so let's just come up this way and get Ari.

MEMBER HOUSER: Thank you for bringing up that last question. It's actually what might tent was raised on for a while.

I do think family caregivers should be explicitly mentioned. We found that the term "caregiver" tends to be interpreted as a paid

caregiver and not as a family member or friend or other -- another disliked word is "informal," but caregiver is usually interpreted as sort of the formal paid home care worker. So I think it's important to call out family caregiver, not only here, but also explicitly as a client of HCBS, which is not done anywhere in this definition.

I think it's critical that we include in home and community based services, not only services for the person with the disability, but also services for caregivers of people with -- or family caregivers of people with disabilities. And I think there is movement towards that direction of including the caregiver with the care recipient in sort of as a unit for service planning and I think we need to include that in our definition of HCBS. So family caregiver both as client and as provider in that dual role.

CO-CHAIR CALDWELL: Good point. Patti?

MEMBER KILLINGSWORTH: So just trying to be really practical and specific. In terms of

just a basic definition for HCBS, I think it's largely the first paragraph, if you will, but I also think that you have to include at least some statement of purpose, which I think at least entails the first bulleted item around allowing people to pursue and achieve those individual outcomes that they define. Some of the others might then move into a definition of high-quality HCBS where we begin to talk about and here's what we want it to look like when it's high quality.

I'm going to argue for the non-medical or some iteration of that needing to stay in. The reality is that while medical supports are really important, the vast majority of what we do and what people need is assistance with activities of daily living and instrumental activities of daily living. It's not primarily medical services. Those medical services are critical, but they are not the bulk of what is provided through home and community based services and supports. And I think that's an important distinction.

I think then we make a part of our high quality to include, as Mary suggested, something around integration and coordination to be sure that those health and other support needs are met. Health, behavioral health, all of those things have to be addressed in order for people to be well-supported in community.

In terms of family caregivers, maybe consider saying paid and unpaid, because it's not always family, right, but it still may be an unpaid caregiver, and that's more broad.

And in terms of "safely," I agree with dropping that out of the definition and think about putting it in under high quality in terms of assuring health, safety and welfare, but also balancing that out with individual choice and the right to assume risk. So we have to be careful about that piece.

CO-CHAIR CALDWELL: Great comments. And, Charlie? We'll just keep going here and then go around.

MEMBER LAKIN: I was going to suggest

rather than try to deconstruct this that maybe we would turn to some of the definitions of HCBS that people suggested and look at those that really focus on HCBS more generically, more broadly as a five or six-line definition of what it is and then move to kind of the features of it. I think that some of us in writing our definitions tried to be quite broad and general about what this is. And I think if we get into trying to deconstruct this, we will actually make it longer. So that would just be my suggestion.

CO-CHAIR CALDWELL: Is there one that was submitted that is a favorite of yours?

MEMBER LAKIN: Well, mine.

CO-CHAIR CALDWELL: Yours, of course.

(Laughter)

MEMBER LAKIN: No, I don't know. There are a lot of them. And Ellen and many others who aren't around this table submitted good -- mine just said, "Home and community based services are paid and unpaid," my printer was running out of -- "services and supports provided

to people with disabilities to assist them in living in homes and communities of their choice with maximum achievable independence, inclusion, productivity, self-determination, health and safety." I mean, just something very -- others would rework that, I know, but the idea is it's something broad that you can then take those aspects of it and begin to build these elements out of. And again, there are a number of those that are more kind of amenable to a broad definition.

CO-CHAIR CALDWELL: Okay. Good.

MEMBER GALANTOWICZ: So just picking up on the theme here with regards to high quality, I think it's important to remember that part of the point of quality measurement is to drive continuous quality improvement. And so, if we focus too much on high quality, then we don't allow ourselves to differentiate between providers offering different levels of quality.

And although I like Charlie's suggestion, if you wanted to work with this

definition, I think a practical approach would be to strip out anything that's aspirational in the definition as to what it should look like or what it shall be and then instead focus on processes and then the shoulds and the shalls become the definition of high quality. That's just a suggestion.

MEMBER YUSKAUSKAS: I just keep going around in circles in my mind, so I'm not even sure where to go. But at this point I agree with Charlie. I think it would be good to just sort of start over and take a look at something that's very succinct. Personally I really have a lot of problems putting the non-medical label in there. I think we'd be better off being silent. And I say that for a number of reasons: as a caretaker myself, and also because I can remember about 10 years ago Charlie was at a meeting where we identified some major health disparities that came forward over the years through a number of means. But at that time it was the Special Olympics that were doing health screenings on

children with disabilities that were participating, and the results that they found were astounding.

And so, if home and community based services are not a linkage to healthcare, to provide maximum health to individuals, then I'm not really sure what the main objective is. So anyway, I would like to be on a smaller group that discusses that in more detail.

MEMBER AUSTIN-OSER: Yes, I keep going in circles, too. When I was looking back at my definition and thinking, okay, what did we put together, I keep getting derailed by medical because I -- and I'm also a caregiver in addition to being in the field for many years and I'm just really troubled by the medical. And so, when I looked back, I'm like, oh, because I was focusing on health and I was focusing on health in odds many aspects: behavioral health, spiritual health.

So I guess I just really want us to think about that differently, because what we say

here -- I'm fine if we want to revisit it. I'm fine if we want to take the first paragraph, put a purpose with it and take some words out and work with it. I don't have a strong opinion on which way we do it. I think we just need to say what is it? What's the purpose of it? And then we work on the definitional stuff about -- I don't want to get into what's a definition of "medical," because there are medical services.

And I know we're not talking about payers here, but someone who's worked for many, many years in Medicaid home and community based services, we do have medical services as a part of our benefit packages. They are called home and community based services. They happen in the home. Yes, I completely agree the majority of the services offered on HCBS are not medical, but it falls within that realm.

So if we looked at it as a Venn diagram, I just really hate saying predominantly non-medical. I would rather say something that promotes this personal, social, health, whatever.

I'm looking more at economic security, housing security, health issues, all of the things that make it possible for us to live in our home and communities and have the lives of our choosing. And so that's what I would like to see this definition kind of get to the heart of.

CO-CHAIR KAYE: I'm looking at the definitions and I thought, well, let's look at the ones that are terse. And there was Charlie's that he read out. And Sara Galantowicz has submitted one that I think is equally on point. "Home and community based services comprise a wide range of services and supports that facilitate people of all ages with physical, cognitive, mental or behavioral health impairments to maximize their independence, personal living preferences and health status in their communities." I think that's a really succinct one.

Let me read Charlie's again. "Home and community based services are paid and unpaid services and supports provided to people with

disabilities to assist them in living in the homes and communities of their choice with maximum achievable independence, inclusion, productivity, self-determination, health and safety."

And the other really terse definition is Anita's, and it says, "HCBS is a needs-based system of community support services that enables individuals with multiple chronic and disabling conditions to access necessary healthcare, social integration and other essential resources necessary to optimize health, qualities of life and prevent or manage decline."

I would suggest that one of these, or a combination thereof, would be a good first part, a definition of what the HCBS is, or maybe combining those aspects.

MEMBER OXFORD: I agree, but I just kind of want to say also that we got to remember that we're starting from a place that we have an idea of what these things actually are and look like. And for someone who didn't have that

starting point, I just feel like maybe a "such as" and give a couple of examples along with that real basic statement would be very helpful. So a civilian out there who is trying to figure this out for the first time would have some kind of idea about what an example would be. I mean, we're saying services and supports I think, and we know what those are and have an idea. But what if you don't have any idea what those were? That's all I have to say. Other than that, I like the idea of using one of those.

CO-CHAIR CALDWELL: Okay. We'll go to Ari and Gerry and Jon.

MEMBER NE'EMAN: Just very briefly, I think in response to Kim's point, I certainly agree with you that we want to ensure that medical services are properly coordinated. And this has been an area of I would say considerable interest in the developmental disability community where at times we have forgotten the need to look at the health disparities facing people with intellectual and developmental

disabilities because our focus has been somewhat understandably on improving the significant issues and the significant dimensions of non-clinical measures.

But at the same time when I think about HCBS as a service that is delivered within a medical -- from medical payers by and large that is often administered out of state Medicaid agencies that are very rooted in the medical model, and I think about what we're at greater risk of, backsliding into medicalization or an inability to look at care coordination across different kinds of services, I really do think we need some kind of explicit acknowledgement of a non-medical nature of the majority; and that's where "predominantly" comes in, of these services.

I think we can couple that; and maybe this is where we get into the workgroup discussion, with the importance of having effective care coordination and effective integration with services that truly are medical

in nature. And certainly those points need to be balanced, but there needs to be a clear differentiation, otherwise services that are being financed through medical payers that are really thought of by the public in a medical context are just going to backslide into very explicitly clinical ways of thinking.

CO-CHAIR KAYE: Charlie pointed out to me that I didn't flip enough pages and there's another definition from Ellen Blackwell which I think is quite good. "Home and community based services are services and supports that a person chooses to use to be independent and participate meaningfully in his or her community in a manner that enables self-determination, health and well-being and that enhance the person's relationships and quality of life."

CO-CHAIR CALDWELL: I think we have maybe about five minutes or so. Oh, okay. Maybe a little longer. But so, let's get some final comments and then we'll figure out if we want to do a workgroup around the non-medical issue and

see who wants to be on that. Maybe that could meet around lunch time. So let's get some final comments here. Gerry?

MEMBER MORRISSEY: Just a few things. So I'm all for terse if we get it right, number one. And I think that whatever we put in place here is going to be our guidance for a number of years in some ways, so I want to make sure that we get it right. So brevity is good and I think why we probably a lot of things in here is we've probably seen a lot of good and challenging things in the past, so we want to try to get it right going forward. So I'm all for terse. I do like Charlie's for a number of reasons, but I think underneath that terse statement is going to have to come some specificity like Mike spoke about.

If we don't go terse, I'd like to just comment back to Jon's point about person-centeredness. We've come a long way and we have of a long way to go with respect to person-centered. And I like person-driven, but I think

there's a coupling there. It's also about person-centered in that the choice must reside with the individual. We can have a lot of person-centered processes that are directed by others, so I think the individual choice is important there.

And then with respect to the health issue, the non-medical to me is the healthcare coordination. And home and community based services does have a number of health-related things with it, but it doesn't operate in isolation. So I think this set of services and supports for individuals sits amongst other care-giving systems that have to be connected and integrated. So I guess the point that Mike raised is around who's making those determinations. So if the healthcare issues can be as individually-driven or agreed upon, I think that's good.

I think the other issue around healthcare, frankly, for individuals with disabilities and seniors has to do with our

history where there are some places where there's excellence, but there's a lot of places where the availability or the ability to choose medical caregivers or health caregivers is absent. So I think that's another particular challenge here. So those would be my points.

MEMBER DELMAN: Thanks. Yes, I was going to point to the Ellen Blackwell definition. And under that there's the Sean Terrell definition, which I think is very thoughtful. And the only question for me; and this is getting back to what Gerry said, is for a person-centered planning process that's kind of the process. Process delivered in a home and community based setting, integrated and in full access to the community. That's kind of like the delivery definition right there. And then after that it's sort of the outcomes we want or the specific processes.

But, I mean, if we have a definition -- I mean, I'm sure people have written about this for person-centered that people are supposed

to look at. My experience in mental health is that the definition is so vague that developing a training around it has been unsuccessful in helping workers understand what this process is. They see it as a group process. And I think it's inconsistent over different disability groups.

So we have to, I think, include a choice piece, that it's the informed choice of the person, because if the person doesn't have those choices, then (A) the quality is going to be worse; and (B) they're not going to learn, at least where I come from, to make choices.

And I think part of the goal here is independence. And if independence is a goal, they need to have a choice, a supportive choice. I mean, we have shared decision making in mental health and we have decision support, which I think could be part of this, but I really think choice should be part of the process, not just an outcome.

MEMBER APPLEBAUM: So I think I feel like we are coming to some consensus here, and I

also like Sara's and Ellen's and Charlie's, some form of that simple definition.

And then I do think we have a series of principles that are laid out here that we've talked about: person-driven, paid and unpaid. And I think we could come up with a list of those principles that I think would get at the point of being able to very clearly explain what we're talking about. And they are principles. Because you can have home and community based services that is not consumer-directed. You can have it be -- I mean, there are a lot of things you could have. So I think we are establishing a set of principles, and I really like pairing them with that definition. And I think we're pretty close to being able to do that.

And I do think even the principle of trying to talk about this as primarily non-medical services -- but the fact is that we do have a coordination responsibility. I think you could have that small group kind of figure out how to word that, because we don't -- a physician

going into the home, we don't want to call home and community based services, but coordination or services we do. But I think that small group could figure that out and that could be again one of the principles. And so I think we can get pretty close to coming up to a consensus on that, but we've got a little more work to do.

CO-CHAIR CALDWELL: That's good. I think those are great points. Maybe that's another workgroup around the principles, because it seems like that's the way folks are going, is some sort of short statement about what HCBS is, and then the principles particularly around quality or high quality or what would be the principles behind that which incorporate a lot of this stuff. So it seems like a good way to kind of separate it out.

So let's finish up with Patti and then Camille.

MEMBER DOBSON: I just wanted to make a note that we've been struggling with this medical/non-medical. And then the three

definitions that we like the most actually don't say anything at all. They just say a wide array of services and supports. And honestly, I think it's a death spiral, I mean, to have the struggle of figuring out what we say, "predominantly," "sort of," "maybe." HCBS services can include medical services delivered in the home. I mean, I know that's not most of it, but I think to not acknowledge that there's a mix out there and just talk about what it's supposed to achieve -- which I think those other definitions actually focus. Maximizing independence, control, dignity and ability to live safely on the document I think are the more important pieces than struggling over what goes in what bucket.

CO-CHAIR CALDWELL: I think that's a great point. I mean, I think there's a couple ways you could resolve that. Like one is being silent there, but highlight it in the principles, or try to come up with some other terminology. Like one was mentioned, like predominantly social and health-related. But that gets away from what

it's not. So I think that workgroup maybe should kind of figure out what the different options are and see if we can kind of come to consensus around that.

So, Ari, did you have --

MEMBER HOUSER: Yes, one of the things that I like is to include as -- and this would be in our sort of aspirational piece -- to have coordination with medical services. And that would -- you're not then excluding medical services from the definition, but you're clearly setting up medical services as an other thing that needs to be coordinated with.

CO-CHAIR CALDWELL: I think that's something I've heard several people talk about, so that seems like that coordination should be part of this potentially in the principles part.

Let's see, who else? Sandy, did you want to say --

MEMBER MARKWOOD: I was just going to echo that. I really think that somewhere in either the definition or the principles that we

really need to make it clear that this is non-medical, because I think otherwise the push will be to medicalize it. And, but I do believe and support the idea that -- on coordination and also the fact that HCBS is a bridge between the medical world and the world inside somebody's home.

CO-CHAIR CALDWELL: Okay. And, Clare?

MEMBER LUZ: So I want to make sure I understand this correctly because we're talking about two buckets now and I think we actually have three.

CO-CHAIR CALDWELL: Okay.

MEMBER LUZ: We have two workgroups shaping it, but maybe we need three. So we're talking about the definition of what it is, but then we have these qualifiers. What defines quality? And then we have principles. So are we looking at three different things here?

CO-CHAIR KAYE: I thought the second two of those would be one thing.

MEMBER LUZ: Principles and qualifiers

are going to go together?

CO-CHAIR KAYE: Well, I don't know. Do we need separate? Do we need to have separate -- I mean, I thought the principles is where we capture what we mean by high quality.

MEMBER LUZ: I guess I was thinking we were coming up with qualifiers based on certain principles. So there's the principle of independence or choice and then what are indications of that or qualifiers?

CO-CHAIR KAYE: Well, maybe "principle" isn't quite the word we want. Maybe it's here is what we mean by "high quality," and then a list of bullets.

MS. LASH: But that last comment of Clare's, the how will we be able to measure independence or -- that is what we're referring to as a measurement domain and that's very explicitly going to be a huge area of activity later today. So we will get there, but making more concrete these high-level principles of how we conceptualize high-quality HCBS, translate

that to more discrete topics for measurement.

CO-CHAIR CALDWELL: Okay. Well, for a while it didn't seem like we were making progress, but I think --

(Laughter)

CO-CHAIR CALDWELL: -- we did come to some agreement and some direction to go, just looking at my notes. And I think there were some really concrete things that we addressed in the definition.

So I guess the next step is to form two workgroups, the one about this issue of the non-medical and how to address that issue, I guess, and then the other around trying to hammer out the principles.

So, let's see. Should we like form them now with a show hands or -- and I think we would meet during lunch, so you could sit together and kind of do a working lunch.

MS. LASH: Yes, we don't need the show of hands now or anything, but we'll define -- I'll sort of huddle with the rest of the staff

about an area in the room where each group can meet with their food and do some brainstorming over the lunch break.

CO-CHAIR CALDWELL: Yes.

MS. LASH: So we'll give you a flip chart and some other resources to work with.

CO-CHAIR CALDWELL: Yes. And then the NQF staff will bring all this together tonight --

(Laughter)

CO-CHAIR CALDWELL: -- and we'll have more discussion in the morning so we can bring to the group like another iteration of this. And hopefully at that point we'll be pretty close to consensus, but --

MS. LASH: I think we're closer than maybe the screen is showing.

(Laughter)

MS. LASH: I think we've heard some of the same messages very consistently. I'm confident we can get there.

CO-CHAIR CALDWELL: Okay. Great. Well, great discussion. I think so now we're at

a break and potentially public --

MS. LASH: Well, we'd like to take public comment at the start of the break, and we will begin with folks in the room.

Juliet or Drew, could you take the microphone off the stand and help anyone in the room that would like to make a comment? And while we're doing that, I'll ask the operator to give instructions for how our remote participants might also add a comment.

OPERATOR: Okay. At this time if you'd like to make a comment, please press star then the number one.

(No response)

MS. LASH: Okay. It doesn't look like we have any public comments in the room. Are there any on line?

OPERATOR: Yes, ma'am. We have a comment from the line of James Gallant.

MS. LASH: Please go ahead.

MR. GALLANT: Hello there. My name is James Gallant with the Marquette County Suicide

Prevention Coalition here in Michigan. And I appreciate your efforts here and I would like to say that in working with my Michigan Developmental Disabilities Council and advocating for the rights of people with autism and other disabilities, what I've learned was that the Developmental Disabilities Act of 2000 protects the rights of people with developmental disabilities and that they could live their lives free of violation of their legal and human rights. And what I'm hearing from the definition, from your draft definition today is --

MS. LASH: We seem to have lost the audio feed from James. Operator, have we lost the line?

OPERATOR: Yes, his line disconnected.

MS. LASH: That's unfortunate. James, if you can hear us over the Web, please do dial back in and we can come back to your comment when we finish the break.

Are there others in the queue?

OPERATOR: No, ma'am, there are no more comments at this time.

MS. LASH: Okay. So we will sort of check again if there are additional comments or to hear the end of that comment when we come back from break.

Let's take 10 minutes. And that would be reconvening at 11:20 by my clock. Thank you, all. (Whereupon, the above-entitled matter went off the record at 11:10 a.m. and resumed at 11:25 a.m.)

MS. LASH: So, I understand that James Gallant, whose line we disconnected earlier is back on the phone. James, would you like to reiterate your comment?

MR. GALLANT: Yes, I would. Okay.

MS. LASH: Go ahead. Thanks.

MR. GALLANT: Oh, thank you. My name is James Gallant, like you said from Marquette, Michigan with Marquette County Suicide Prevention Coalition. And in my work with the Developmental Disabilities Council of Michigan and advocating

for people's rights, I learned that the DD Act of 2000 insures that people with developmental disabilities, it's a little bit like three violations of their legal and human rights. And it appears that in your draft definition, that piece about legal rights has been excluded.

And there is a class of non-paid and paid non-medical services, and it's the enforcement of court-ordered legal rights, and the specific court-ordered legal rights, such as custody and parenting time, personal protection orders, writs of restitution that may be specific to an individual, and I notice on your draft it talks about selected by the individual, individual assessment, strengths, needs, preferences, assured the rights of privacy, dignity, respect, and freedom, but it doesn't say they're court-ordered legal rights, which they come --- they have, you know, specific to them. And there's an entitlement opportunity, at least in Michigan, through every court that's the enforcement of the court orders.

And then --- and here in Michigan they don't refer people back to the court for enforcement of the court order, if somebody is telling them that they don't --- they're not getting those rights. You know, if a child with autism is being denied access to their family they don't live with, that's denying them of those interpersonal relationships, the family care givers that are issued --- that are ordered by the court are being excluded from that person's life.

And I found this in Marquette, the one guy said was "you cannot self-direct a doctor." And the Medical Director there said that he feels that he can specifically approve an individual plan of service that is in direct contradiction to the orders of the court of the state. And he's a doctor. As he said, "I'm a doctor. I get to do that."

Well, that's not true. And on this person-centered planning, you know the guys who -- no one knows what that means, because there

seems to be no minimum on person-centered planning when it should be less specific court-ordered legal rights. And we also have in Michigan, they recommend grandparenting rights, so these older individuals are being excluded from their family support structures, and it's not in their plan of service.

So, as a part of this, I ask you to include in your definition the legal rights, you know, your core --- your specific legal rights. And it says assures rights of privacy, dignity. I mean, maybe it should be right in there to say assure the specific legal rights, including privacy, dignity, and court-ordered. You know, because these people here in Michigan, they're telling me that well, it doesn't say that on this list, because it always says wants, and needs, and desires, you know, desired outcomes, whatever, but it doesn't say legal rights. So, they'll just look at it and say it doesn't say that here.

And if you leave that in, or put that

in --- and you're talking about predominantly the issue that you're working on there, that you can say both, you say predominantly social, and non-medical services; both of them, slash, and that would cover them both. Because we'll be getting into the idea that they will then direct it towards the medical end, because that's what a lot of the people are getting paid to do.

And this course --- they offer these services no charge to the consumer, no charge to the referring agency, or anybody because the court already has a person there that does the enforcement for you. And, you know, life-skills training, this is how you protect your own legal rights. You go in there, you help them, you show them how to do it. That's --- you know, this protects ---

MS. LASH: Thank you, James.

MR. GALLANT: Hello? Yes. And this kind of protects their personal --- you keep talking about you need to protect their interpersonal relationships, inclusion in your own family, and

access to the family care givers. And I just ask you to consider including that in your definition that it would be the court-ordered legal rights. And, you know, you're supposed to be flexible so that when somebody that didn't have court-ordered legal rights, you know, the children, and then all of a sudden their parents get divorced, and now they do next week, that should be now included in their plan. And I'll be participating along with you folks through this project, and will continue to submit a comment. I'll submit a written comment so you folks can go on.

MS. LASH: All right. Thank you for that suggestion. We'll definitely take it into consideration.

Drew is going to read maybe just one or two more brief comments, or Juliet will, that others have submitted through the web platform. Just so everyone on line is aware, we are reading all those, and taking them into consideration, as well, even if time doesn't allow for us to put all of them verbally on the record like this.

We'll distribute them in full to the Committee.

MS. FELDMAN: So one comment read, "Technology, policy, and culture are changing so quickly. It seems important to have a broad definition of what services are included. I'd vote for an array an array of medical and non-medical."

Another commenter says, "Concerning the care giver question, identifying informal supports, including family friends and neighbors is very important for consideration."

I'll read one more. "Regarding family care givers, include and broaden to include other outside the system care givers, family, other friends and loved ones, community supports; also include more in providers health, wellness, other services. And number 8 be provided to coordinated services, service providers, care givers, community supports, and loved ones."

MS. LASH: Great, thank you.

We're now going to begin the Committee's discussion of the process of

developing the HCBS Measurement Framework, so if we can move the slides. Drew will give you some background on this.

MR. ANDERSON: Okay. So, we're going to switch gears now into the next objective of the meeting. Like Sarah said, we'll be starting the discussion soon about developing the HCBS Measurement Framework.

Before that, I'm going to do a little stage setting. I'm going to move through this pretty quickly. There have been a lot of past and present efforts related to HCBS quality. Some of them are the environmental scans; for example, the AHRQ Environmental Scans of HCBS Measures for the Medicaid Program did a lot of identification of existing measures and measure concepts. And then there's also, you know, the more recent environmental scan of HCBS assessments and instruments, and this was a lot of foundational work for the TEFT Grant. And one of the projects under that is that the eLTSS initiative that Andrey mentioned earlier related to the

standardization of electronic records in LTSS.

The next one is --- there's been a lot of performance measurement across states. One of the larger initiatives that was developed by a number of disabilities agencies was the National Core Indicators, which measure quality on different ----in different domains that related to individual and care giver outcomes. And then another one is the AARP State Scorecard on LTSS. This measures quality through five different dimensions by 26 indicators across the U.S. This is a yearly collection that's done.

And the next, we have a lot of guiding principles and policies, so the National Quality Strategy, of course, has influenced a lot of the quality measurement work that's been done over the last couple of years through its three aims and the six priorities, as well as a recent Impact Act looking at post-acute care measurement.

So largely, as we were making points earlier, the --- we want to create a unified

picture of quality for HCBS. And the first step in this project to doing that is really hammering down a conceptual framework. So, I'm just going to quickly go over; a conceptual framework is a network of interrelated concepts that together provide some kind of comprehensive understanding of an event or a phenomenon. It's not merely a collection of concepts or components. They really --- each component really plays an integral role. And we --- it's meant to lay out key factors and variables, and really presumes the relationships amongst them, so we really have to put on our out-of-the-box thinking caps and a little bit more abstract here.

So, the potential uses for the HCBS measurement framework. This is really to establish a shared understanding of the mechanisms through which high-quality HCBS is achieved. It's a picture, an illustration of what does a high-quality HCBS look like, and it's meant to guide the environmental scan of HCBS measures and the synthesis of evidence, which is

the next step in this process. We'll be discussing that a little bit later, tomorrow morning, actually. And it's also to help guide you all as the Committee in prioritizing measurement opportunities. And we will also be providing input to HHS to guide HCBS programmatic initiatives.

And it's also meant to support standardization of HCBS measures by signaling to measurement developers across the country gaps in performance measurement. And we also hope for it to inform and stimulate future research.

So, just to kind of get you guys in the mind set of thinking about these frameworks, if you guys --- included in your meeting materials there were some example frameworks that we chose to highlight from the 200 sources that we reviewed, and we also have the source selection criteria. But these are just some examples that we've pulled to kind of get you in the mind set of thinking about how we would like to construct the HCBS framework.

The first one is the LTSS, the scorecard that I mentioned earlier. This is the framework that they developed for that. It looks at --- it starts out from a bottom up process, and it shows the 26 indicators at the bottom, and it's kind of blurry up there, but the five dimensions are tied to a high-performing LTSS system. And they're really looking at the crosscutting areas, and showing that these --- the data that's collected from these indicators are associated with these five dimensions.

The next framework was actually highlighted in your meeting packet. It's Steve Kay's framework of what does HCBS look like? There are six priority domains here, and it really highlights a better responsive LTSS system. It creates a feedback loop where adjustments to these different domains of LTSS resources, or program characteristics affect the quality that's seen. And I'm sure he'll go into more detail later.

And then the other one is a framework

for multiple chronic conditions. This one is a little complex, but it shows that the --- it's very person-centered. It's probably helpful to look at this, think about this three dimensionally because it's more of a dial or a wheel with the -- you can adjust the different rings based on the person or the population that you're looking at. So, it starts with the priority domains of measurement on the outer ring, then the types of care, the sites and providers, and then in the middle is the person and the family, the care givers and their preferences. And it's really meant to look at the changing over time. So, if you see the time, it changes based on their preferences over time, and it's all operating within the health policy context, and the social and environmental context.

This next framework was for the dementia and harmonizing --- maximizing quality of life and minimizing distress. It really --- it illustrates the trajectory of dementia starting

with populations that are at risk, leading into identification of symptoms, evaluation, care, management, all the way up until bereavement or end of life. It highlights some of those initial priority measurement domains in the beginning, and then shows the domains as you move along that spectrum that are most important for measurement. And then it all is being looked at through the lens of the National Quality Strategy and purposefully trying to align those domains and the framework with those guiding principles.

Now, this is another framework that's taken from Public Health. It's how to measure the performance of the Public Health System, which is very, very broad. This framework has six components. The central component is really the mission and the purpose of Public Health, and the core functions, which is tied to the measurement domains of structural capacity, processes and outcomes, all within --- while showing that the Public Health system is an open system that's influenced by the macro context, which is those

political, economic factors.

So, there are a wide variety of frameworks and ways to conceptualize or illustrate what we're trying to do. Some of the common themes amongst these frameworks were that the authors set out to --- they created criteria on how to select the framework components so they did it consistently. They thought about measurement burden, as far as the feasibility. They use the arrows to demonstrate conceptual relationships, is very common amongst all of them, I think. And they illustrated the highest level of measurement areas. They weren't too granular; they tried to do things from of a systems perspective. And they built on existing evidence and guiding principles, like the National Quality Strategy. And then they also looked at crosscutting areas that offered the greatest potential for reducing disease burden, or cost, or improving health and well-being. So, it is very high level.

So, now we're going to quickly move

over into the discussion portion, and how we want to approach the framework. We have some guiding questions here that we'd like the Committee to answer or to start a discussion. So, I'm going to turn it over to Steve.

CO-CHAIR KAYE: Okay. Thank you, Drew.

So, there are some questions on the screens about the target audience, an interesting concept from NQF of the title of the figure sort of explains what it contains, or what the purpose of doing the framework is, what level of detail should the framework include, and what should the emphasis of the framework be, such as system outcomes or consumer --- the system processes or consumer outcomes. What are the primary outcomes in the framework?

I just want to make a comment about the framework that Drew showed you that comes from our Center. And the purpose of that really -- I mean, I saw it as a map of the territory because so many people were working on so many different things somewhat involving HCBS quality,

and I wanted to understand where things fit in, and have a sort of mechanism for prioritizing, so sort of getting people together to reach consensus on what is important. So, that was what the purpose of that was. And I don't know whether that's what we want to do, but I just wanted to say that that's what I've done.

Shall we start with some answers to some of the questions, or whatever comments people want to make? Start with Anita.

MEMBER YUSKAUSKAS: Hi. I went to the definitions that you pulled out before and the "who" ended up from a compilation from all those definitions. The "who" was defined collectively as people with disabilities, mental health --- including mental health and substance disorders, older adults, people with multiple chronic and disabling conditions, and people who choose to be independent.

CO-CHAIR KAYE: And so?

MEMBER YUSKAUSKAS: So, I'm sorry, that would be the first --- I'm responding to that

first question.

CO-CHAIR KAYE: Is that the target audience for people to use the framework, or people to get services?

MEMBER YUSKAUSKAS: Oh, I'm sorry. I misread the question.

CO-CHAIR KAYE: Okay.

MEMBER YUSKAUSKAS: Sorry.

CO-CHAIR KAYE: Mike, and then Charlie.

MEMBER OXFORD: Well, I mean, I think for the framework, at first I was thinking well, anybody. But, actually, I think it's really a higher level, so I think, you know, planners and professionals would want to use it. But, also, I think providers and possibly people that use services or want to use services would use it. So, I guess what I'm saying is, I'm not so sure that just the general public would want to get that deep into it.

CO-CHAIR KAYE: Right. Charlie, and then Sara.

DR. LAKIN: Well, I don't want to jump

the gun to the problems we're going to face down the road but, you know, the "who" question really raises questions about where do the results of our recommended measures go. And, you know, some measures can be used to improve supports for individuals, some can be used by agencies to improve the quality of the programs they provide to people. Many of these measures we've seen really operate the state level for evaluating programs. And each of those has a totally different set of methodologies that need to be employed, extremely important resource costs associated with them, and a whole range of methodological issues related to who does the interviewing, who's interviewed, on, and on, and on.

So, you know, I think that question is really important, and I don't know if we need to address it right now, but it really directs where you go when you look at this stuff, and when you think about what's going to work in answering the kinds of questions we have about quality in home

and community-based services.

CO-CHAIR KAYE: Does the answer to the question of who's going to use the measure determine the answer to the question of who's going to use the framework?

DR. LAKIN: Well, some are generic. I think your's is sort of generic; although, it operates at I would say the program level, not the individual level. It's not really focused at improving things for an individual. Your feedback loop goes to the program.

They all assume something in the person's head about what --- well, what's the frame for the framework? And I think we'll need to do that, too, and we maybe even need to think about different kinds of quality assessments for different kinds of --- for different entities that impact quality, including the individual, perhaps, depending again on what we decide this is all about.

CO-CHAIR KAYE: Sara, and then Sarita.

MEMBER GALANTOWICZ: You know, I agree

with what Charlie is saying, and I just wanted to add to Mike's list. Who the target audience is I think includes the people who will be developing the measures, so not only the people that are designing the programs and organizing the programs, but I would think part of the goal of having a framework is that we can have some consistency on the goals of measures and the way that measures are structured. So, I would add measure developers regardless of what level of the system they reside as part of the target audience for the framework.

MEMBER MOHANTY: Yes, and I would also agree with Charlie. And I think, you know, it is important to look at who --- you know, what the target audience is as we're starting to develop this. I mean, you know, I think we can continue to expound on what the audience is going to be because, I mean, I think of different levels. You know, there's the individual, the care givers, I mean --- and, also, I think about the care team, so the members of the patient's care team and how

they could actually apply this conceptual framework and help them understand what are the drivers of how they do their work, you know, work with the member.

And then, you know, of course there's the state regulators, you know, and as well as the federal --- you know, as they're looking at quality, you know, health plans and delivery systems. So, I don't know. I see a whole gamut of entities that would be influenced by these conceptual frameworks, so I think that's important to think about as we go through this exercise.

CO-CHAIR KAYE: All right. Anita, and then Kimberly.

MEMBER YUSKAUSKAS: I would see this as a national framework so that in a system that's already primarily a state centric system funded by Medicaid, you'd have an opportunity to present this from a much broader perspective for anyone and everyone. You know, as Sarita was saying, I think it --- there are so many stakeholders that

this would apply to, so I think it needs to be very, very broad, almost like a national perspective.

MEMBER AUSTIN-OSER: Yes, I kind of really love this conversation because we're --- obviously, I think that the target, you know, some of the target audience needs to be state, federal regulators, administrators, funders, you know, but also providers, people delivering the actual services. What an incredible opportunity we have to build something where a quality framework would touch all people in the service delivery system.

You know, having worked in this field for a really long time, it's kind of like certain of us know about the quality indicators and are measuring the health of the system sort of, and then nobody else knows about that, you know, outside of maybe administrators, or funders, or regulators. And it would be really incredible if we were able to get all the way down to the front line worker engaged in providing, you know,

quality service delivery, and understanding how it links in, too. So, I definitely think the target is, you know, anywhere from regulator, funder, administrator, and then deliverer of service, but that means we're going to have to create something that is accessible in a different way than we have before.

CO-CHAIR KAYE: Very interesting. So, Andrey and then Mary.

MEMBER OSTROVSKY: I broadly think about quality measure in terms of who can influence the quality measure, or who can use the quality measure data to change their behavior. And those are two buckets that I think behave differently, and I think we can group a lot of what everyone has said into those two buckets. And I'm wondering if we could start at a high level with that kind of dichotomy, or maybe another way to distinguish who the target audience is because, ultimately, we probably should stay relatively broad since the user experience of the measures will be quite varied.

And we probably can't even anticipate all of those uses of the measures, or how folks will try to change the measures, but maybe if we could keep it relatively broad from a functional perspective that may help move us forward and accomplish ---

MEMBER SMITH: Well, I think we should put another little tick mark next to keeping it broad. You know, I could envision seeing a wide array of folks using these measures from --- or the framework from the bottom up all the way to the top. But the caveat, and I would go back to something Charlie said, is having some specific measures for different populations. You know, because, obviously, if we go broad, every broad concept or every broad measure is not going to apply to the specific populations. So, again, I would argue for keeping it broad. You know, I would hope that the framework that we come up and the measures, you know, an individual receiving services might be able to look at the information that's generated and help them choose who they

want to go to to be served, or family member might use some data in the same way, or a state might use some data to decide, you know, who they're going to fund based on the best outcomes achieved.

CO-CHAIR KAYE: And, you know, we can take advantage of the fact that it's not our task to actually come up with measures. You know, we can make it difficult for the next committee, and then we can decide not to be on that committee that actually has to select endorsed measures I suppose. Right?

MEMBER SMITH: Well, that's ---

CO-CHAIR KAYE: Because I kind of on your broad, you know, I would obviously vote for broad.

MEMBER SMITH: Well, I think that's true, but I'm kind of hoping that our recommendations, you know, if we talk about experience of patient care, you know, I hope that the next group that goes forward looks at that and says, you know, what are --- what would the

appropriate survey be for different populations, because it's not a one-size-fits-all. But, you know, that's sometimes a lot of what I see in the field.

CO-CHAIR KAYE: Right. Okay. Bob and then Ari Ne'eman.

MEMBER APPLEBAUM: So, I think this question about the who the target audience for the framework is, I don't think that's the right question, because the people out trying to figure out what quality is, and we've heard people mention this in various ways. You know, Quality Management says --- one of the first questions is who are the consumers of our quality framework, or a quality measurement? And what we've heard is that there's a lot of consumers, there's consumers, there's regulators, there's funders, there's --- so, when we develop our quality framework we have to think about all those different groups and develop measures that meet all of their different needs.

Who the --- the framework, itself,

that's sort of an academic concept that is important that underlies our work, but the --- sort of the proof is in sort of what we come up with as what these categories are. So, I don't think it makes a lot of sense to spend a lot of time worrying about who's going to be the consumer of the framework. The framework is the vehicle for getting the product that we lay out to people, and what they're going to look at is the product, not the framework. So, I think yes, we have to have a strong framework, but I don't think we should spend a lot of time worrying about who the --- you know, it's really what comes after the framework that's important to what we're doing here.

CO-CHAIR KAYE: But what does come after the framework? I mean, we're not going to come up with a list of measures.

MEMBER APPLEBAUM: Well, for example, getting consensus on the array of who are the customers of home and community-based services, because one of the big challenges, of course,

we've got obviously the consumers, but consumers are --- we've already talked about families, individuals receiving services. We have people who are paying for those services, we have people who are regulating those services, we have a whole array of folks who are all customers from a quality management perspective. And sometimes those customers don't want the same thing, and sometimes what they want may even be in conflict. So, setting out the parameters for that I think are really important first steps to be able to then develop measures, because if we don't have a good sense of what those things are, then it's very difficult to go down the road and develop measures. So, maybe that is what underlies the framework, and so I'm not arguing against the framework, it's just that I think it's sort of the next step after that, which is what's going to be important for the people who are moving on down the road.

CO-CHAIR KAYE: I mean, regardless of whether this is the right question to ask or not,

it seems like --- I'm sort of starting to hear there's consensus of what --- I guess, maybe Kimberly possibly put it best, that it needs to span all --- needs to span a spectrum. And I think that's a nice goal to have a framework that a person who actually provides services can see, and understand, and realize what their part is in the picture. I mean, this is a tough target to achieve but, you know, I'm as ambitious as anybody in impossible tasks.

It sounds like --- I mean, we are --- can we see a nod of heads or frowns about, are we agreed that it should apply broadly? I think we are. Go ahead. Put your microphone on.

MEMBER NE'EMAN: So, I mean, I would agree with the comment made by, I'm sorry, I didn't catch your name.

MEMBER SMITH: Mary.

MEMBER NE'EMAN: With Mary that we really do need to be able to bifurcate specific measures to specific populations to some degree or another. I just --- I look at what seems to me

the significant damage that the standardized assessment has caused, and other efforts to try and sort of mush together the aging community, the physical disability community, and the IDD community has caused in the past. And, you know, in terms of the framework, I think we can define that broadly, but the more that we get down from 10,000 feet into the weeds, there I think we need to be able to begin to look at things at least to some degree on a population by population basis, with some common principles, and probably even some common measures between them.

The other thing that I would just really quickly submit here, is I think we're really talking about three different kind of measures; measures that states can use to evaluate payers or MCOs, measures that states, or MCOs, or payers in general can use to evaluate providers, and measures that can measure the effectiveness of particular providers, or particular provider methodologies on individual consumers and consumer outcomes. So, again, I

would just suggest --- again, all of that can go into a common framework, but the more specific we get in operationalizing that framework the more I think we're going to be down different paths.

CO-CHAIR KAYE: And I think there's a slide that we'll see tomorrow, is it, that --- later today that has basically what you've said on it so, yes.

(Off mic comment)

CO-CHAIR KAYE: So, let's see. Why don't we --- how about Camille, and then Clare, and then Mike. Am I missing anybody? No.

MEMBER DOBSON: So, maybe I'm the only one struggling with this, so I just throw it out there. You know, I think of a framework as like a skeleton, right, that you hang things off of, you build around, so what I'm struggling with is how the framework is different than the areas we care about? And maybe that's the struggle that I'm having so, you know, I'm thinking about things like integration and care coordination, and choice and control, and person-centeredness are

all areas we care about that ideally we want measures in. Right? So, how does that --- maybe you can --- maybe I didn't find the framework conversation very helpful for me in thinking about how to take that, where I think we could right to domains now and start talking about the areas we want to measure. Figure out how do you go up one, and think about it a higher level. I'm struggling with that, because to me the domains we care about maybe need to be connected to the people, the payers, I mean, like the people who are interested in it. Is that the connection? I don't know. Help me.

CO-CHAIR KAYE: I'm supposed to have the answer to that question? Yes, I mean, I guess that's what I was --- what I was thinking about when I made that diagram was what you're saying. These are the things that people that I, you know, talked to and I care about. And I grouped them in categories that I thought were conceptual. And I didn't --- and that's --- you know, so I didn't start with some theoretical

principle. I said what is everybody working on, and what do I care about, and how do I see these as related to each other?

And if we were to do something like that, I'd be happy with it. I don't know whether --- I don't --- this is not an academic --- this is not a super academic crowd, so I don't see that we need --- I mean, I don't think that we need to get fancy about causal relationships or anything like that. So, I would think so, but maybe some other people will comment. Do you have more to say?

MEMBER DOBSON: Well, I was going to say the --- I know it's not a good example, but the thing that spoke the most to me of the examples we got were the --- was the one from the chronic care, I think. Because it had --- not the inner rings because that's all medical stuff, but the concept on the outer part, and maybe that's what I'm missing. So, the domains of measurement I get, so those all make sense to me. Right? You could fit those in. You could fill those --- that

outer circle with the things that I just talked about. Right? Choice and control, you know, integration, and person-centeredness. What I don't get is what --- why this is a frame --- what do we put in the center? Maybe that's what I'm struggling with. If we use --- even just thinking about it this way, because this --- you said this is a framework. Right? So, we could put --- do we put the --- inside is the people who are getting services, and then around them the people who help provide the services, and then around those the people who pay for the service.

CO-CHAIR KAYE: I don't see any reason to get as complicated as this diagram. But, I mean, I do think it's very interesting that you think that the domains that are listed on the outer ring are a set of domains that we could use. I mean, that's a really good start, you know, if we agree on that.

MEMBER DOBSON: Yes.

CO-CHAIR KAYE: I forgot who I --- did I say Clare next, and then Mike and Andrey.

MEMBER LUZ: So, I'm all for keeping it simple and having a broad definition, or a broad framework. But even within a broad framework we have different audiences, so it seems like a policy maker would use this framework differently than somebody who's coming after us to produce measures.

So, I'm intrigued by this chronic conditions one. It's too complicated for me, but the thing that I thought I heard Drew say was that those circles could spin, which is what intrigued me, so that you could line it up so that the policy maker or the measure maker would have sort of a different flow chart than somebody else. You might have different outcomes for a policy maker than for a program planner. I kind of like that idea of being able to adjust it according to who the more specific audience is.

CO-CHAIR KAYE: Interesting. Mike?

MEMBER OXFORD: Yes, I just kind of want to stay with the broad. It seems like there's two or three different levels. I mean, at

the individual level, it's kind of different, you know, it's going to be different than like let's say the funder level. Your goals are different, and what you're looking at, I think. But, also, is just, you know, things are confused. Like as I look at these, I sort of feel like a lot of times family care giver is a proxy for informal or unpaid, except for we know that in a lot of programs in a lot of states the majority of the care givers are family. I mean, I know several big ways we're serving thousands of people. Most of the folks that are hired are family members, so it's not really actually a proxy for informal or unpaid any more.

And we also get into some of the programs that I hope would fall under this where, you know, the individual is the employer, or even is running like a micro-business, or something like that, so to a certain extent becomes their own provider. And then you have issues if you're doing that, than if you're a more passive recipient. But at the same time we're trying to

develop a framework, I think, that makes sense.

So, I sort of like the idea if we could have a framework that was adjustable. So, we --- it might be more complicated but that you could mix and match the parts depending on really what made the most sense in terms of where you were coming from.

CO-CHAIR KAYE: Okay. Andrey, and I saw Sandy, and then I saw Gerry. At some point, I think it would be good to move on to the next question about what --- I mean, Camille touched on it, but what is it actually --- what is it in the framework? Is it these are the things we care about, which maybe it is. So go ahead, Andrey.

MEMBER OSTROVSKY: Thank you very much. I think simplicity is going to really win out here. I'm ordering these framework on my table here in order of if I were someone charged with creating quality measures, what would give me the least headache and the most flexibility? And I'm coming up with well, this is kind of simple, you know. There's some domains, and there's the least

number of boxes kind of the better is what I'm thinking. And then I'm thinking okay, this little wheel game is fun. It's a fun game, not to take away from the design work. I think it's actually very creative the way it's done, but then it almost makes me think too hard about well, how do I align this with that, and then oh, God, then what quality --- so, the fact that I'm even thinking that level already tells me it's a little too complex.

So, I think distilling everything to like the bare minimum, I think it is important to think about who are going to be the end users of the measures, and whether it be populations, or payers, or provide --- whatever it might be. And then focusing on the themes or the principles that we were all kind of circulating around, and that's it. And then letting the people who make the quality measures kind of figure it out from there, but erring on the side of over-simplifying rather than being too much detail. I don't know if that helps at all, but I just ---

CO-CHAIR KAYE: Well, I think it does. That's the third question, what level of detail should the framework include? And I think I saw a fair number of nodding heads about that, so we're starting to address that, too. Sandy?

MEMBER MARKWOOD: Thank you. I think that I, too, would err on the side of simplicity, but I also --- I see this as an opportunity to define this from a national framework. I really think when we're talking about quality of home and community-based services one of the things we run up against is what are home and community-based services? So, I think if we start trying to be all things to all people, then I think we run the risk of being --- looking at some of those charges Andrey said, and it just becomes more complicated than what anybody is going to discern.

I think the other part of it is --- and I just wanted to reinforce it, because I think somewhere around the table I heard it. Just like we were talking about in the definition is

being payer agnostic, I want to make sure that as we walk through this, that the same principle applies because, otherwise, I think, again, you've gone down a different route than what I think the intention of this group was, which was to be as broad and all-inclusive as possible.

And then I think the last point that I would make is make --- to Camille's point is, you know, what I want to get out of this is, and what I think our members want to get out of this is the specific elements of home and community-based services that we want to then measure. And what are we going to be held accountable for, and what are we going to measure?

CO-CHAIR KAYE: So, when you say --- I think you said national framework. What is that? Does that mean policy framework?

MEMBER MARKWOOD: Well, I think it goes --- and I think we've had a discussion around the table. You know, policy makers I would think would be one of the audiences for this. I mean, because part of what we're looking at in this

framework is how are all of these systems coordinating or not, and how we can use this framework to bring those in and try to coordinate those, and then measure the outcomes? So, I'm looking at it --- and maybe national --- I'm not talking just policy makers by any means, I'm talking about what --- and I think that we defined it. You know, what are the systems maybe not getting down to the granular consumer level, which I really think is a little different, but who is involved in the development and delivery of home and community-based services that needs to see this, and for whom they will be measured as part of this. Does that make sense?

CO-CHAIR KAYE: Yes, I think so. Yes. Thank you. Gerry, and then Jon, and then Ari Houser.

MEMBER MORRISSEY: Just a few things to add. One, I'd go with a keep it broad. I don't go with this national framework or systems approach. But, also, there's got to be alignment. I don't think there's one audience. I think there's got

to be alignment with, if you will, from a national point of view with the multiple consumers of this, be it at a state level, provider level, individual level. And if there could be some alignment, maybe that wheel works on the alignment activity, if you will.

Secondly is, does the --- does it help us or inform us of what's the current framework, and what are the successes of that, what are the problems with the current framework, as we're thinking about this. The current framework of how home and community-based, you know, HCBS services are done today.

CO-CHAIR KAYE: You don't mean a quality framework, because I don't think we have such a thing. Do you?

MEMBER MORRISSEY: Well, I think people do practice in a quality framework. So, I --- if there's not one stated, I certainly believe people practice within a framework today; providers do it, states do it. The waiver expects it to have a framework, but we can have a

conversation about that, too.

I think the issue is, are we saying that there's no framework today around home and community-based services?

CO-CHAIR KAYE: I don't think there's any explicitly --- you know, did you find any when you were looking?

MS. LASH: Someone turn off their mic. We found many, but specific to maybe waiver services, but not with a relationship to other types of private payer services, or some of them were disability-specific, or aging-specific. So, we hope that the conceptual framework arising out of this work I think can depict and make connections between some of these disparate pieces.

So, I was hearing who is involved in the development and delivery of HCBS? I think those are some boxes that might end up being in this conceptual framework. And how is accountability operating through quality measure? So, what connects to what? Maybe some ideas in

that vein, so we are running a little bit short on time, though. We might want to move to the next slide, which is just a question of what things should we be depicting, and how they go together, and what's on the top, or the center, or the bottom. The middle we'll do more small group work around after lunch, but the more we can get some good group agreement about what's going to be important to represent will mean that the small groups will be --- have more in common as a starting place.

CO-CHAIR KAYE: Let's just go back to the previous slide for a second. So, let's see. We didn't resolve the issue of who the target audience would be, but there was either --- there was some discussion of sort of a lot of different target audiences. But there was a sort of sense of it's got to be a national framework, so it's got to be --- there's got to be some policy, strong policy focus in it. I think that's what I'm hearing, anyway.

There was, certainly --- and it,

certainly, sort of broad high level, so the third question seems to be, you know, simple, straightforward. There was a --- with respect to the fourth question, I heard a little bit about systems. I don't know, we're not --- we didn't address that really.

With respect to the second question, I think the only thing I heard about really was Camille's statement of, you know, your title might be the skeleton of what we care about, which I like, actually. Not so much --- I wouldn't use that as an actual title of the drawing ---

MS. LASH: No, I wouldn't either.

CO-CHAIR KAYE: But is that what we want? Here's what we care about in quality when quality is measured? Is that sort of ---

MEMBER KILLINGSWORTH: I would tweak that just a little bit to less what we care about than about what the people who are supported care about.

CO-CHAIR KAYE: Yes.

MEMBER KILLINGSWORTH: I'd really like for us to think about this in looking at the fourth question from the perspective of the people who receive the services and supports. And for that to be the primary focus of both the framework and really our work generally.

CO-CHAIR KAYE: Yes, thank you. Jon?

MEMBER DELMAN: Yes. My comment is related to this, and I think for me, who's someone who develops conceptual models for programs, I always end up back in the Donabedian model that's depicted here in the last one, conceptual framework with regard to a Public Health System. This looks much more complicated than it really is.

You know, you have a chance to put your mission, but you really need to establish what is --- what do you need staffing wise, and describing what resources you need. And then you go into the processes, person-centered, you know, another piece of capacity is that is it done in the community? So, you know, what aspects of the

community do you need to be in place?

This is a very, for me, user-friendly way for describing how a model is supposed to work. And I view --- I find it --- if people start with values in philosophy you should be able to connect that all the way to the outcomes. And it's just my --- just thinking about this, how we would deal with structural capacity. But, you know, I think we need to think about what needs to be in place, or who are the people, who are the people who are going to be providing or offering these services? And then you go into how that's happening. But I find this to be very useful.

CO-CHAIR KAYE: This side first. Kimberly, Anita, Charlie --- oh, earlier I said Ari was going to go next, so Ari, and then Kimberly.

MEMBER HOUSER: I think the title something along the lines of these are the things that we care about, or to give ourselves some credit and say these are the things that are

important, which is why we care about them is a good title, something along that theme.

Steve, I think you described the process for the framework that you developed, and I developed the one for the LTSS scorecard, and I think it is generally the same process, is that we decided what the boxes were and then we drew lines that connect them to show what the relationships were. And I think that makes sense, but we don't have any boxes yet, so it's hard for me to, if we're going to use that as a model, to get to the next step without knowing what the boxes are.

And I think there's a couple of different ways that we can parse quality into domains. And those different ways of parsing it would suggest different frameworks. So, that's where I'm at. I want to know the boxes, so I can ---

CO-CHAIR KAYE: So you want to move on to the next slide. So, can we briefly --- the three of you who are still up, can we briefly

comment on that and then we'll move to the next slide?

MEMBER AUSTIN-OSER: Yes, I can briefly comment. Something that keeps coming up for me when I'm reading this, and I don't want to take us backward or anything like that is why? So, we're using the framework, who's going to be using the framework, for what? What are we trying to illustrate to do what with? What level of detail should it include? Well, to me is like why, so it keeps bringing me back to why. And the fourth one is also why, why are we doing this? Why are we measuring quality? Quality for what purpose? So, we can do the continuous quality improvement, so we can make sure whatever our definition is, is actually happening? I mean, why are we doing it? So, it keeps like begging the question to me, and maybe I just missed something really fundamental, but it keeps like why am I keep going back to why are we doing this? Because then I think that there are a variety of reasons why we're doing it, and we have to be able to

interface with this on those multiple levels.

On the fourth question I would argue for both, that we can't --- I don't want to see a system that just focuses on system outcomes, but I don't want to see a system that just focuses on consumer outcomes because sometimes when we just focus on consumer outcomes we fail to identify the very important structures that actually go in --- and I think keeping about workforce. We've had consumer outcome-based measurement systems in the past and it --- oftentimes when those fail, or those don't meet up to our standards, we try to address a host of issues, the root causes, and we sometimes miss the boat because we're not focusing on the right entity, for instance, you know, workforce-related, infrastructure, or supports. So, I would argue for a system that does both.

And maybe it's serving different aspects. You know, maybe it goes right back to the when I'm interfacing with it, I'm interfacing it from a system perspective. When a consumer is

interfacing with it, they're interfacing it from a different angle, and it actually serves both ends. So, sorry that wasn't as brief as I was hoping.

CO-CHAIR KAYE: Do you have an answer to the question of why?

MEMBER AUSTIN-OSER: Well, to me, I think it's a way --- it's a measuring stick for us to know the health of the system, the health of the system based on what? Well, based on our definition, our principles, and our values, and what we would like to see the home and community-based system accomplish. What are we trying to achieve here? Which I think takes us back to the beginning of our conversation, and what is HCBS? What's the purpose of it? And what we're measuring then needs to kind of give us an idea of how well we're doing at meeting those objectives. And maybe, you know, our principles -- to me, I see those oftentimes as value statements, too. This is what's important to us, this is what we want to see the system

accomplishing for people. Is it doing that? And if not, then we need to go back up and regroup, but we need to be able to measure the right things in such a way that we can get to the root cause so we can fix it.

CO-CHAIR KAYE: All right. So, we have health of the system as one of the whys. I mean, I would say comparison. I mean, I would like to be able to compare across settings, across populations, across service provision models, across providers and programs. What other whys are there, why are we doing this measuring? Continuous quality improvement is one reason. Just jump in anybody who wants to add an additional why, because I also think this is a critical question.

MEMBER DOBSON: Measure consumer satisfaction.

CO-CHAIR KAYE: Yes, and I also --- I mean, consumers also have to be able to choose ---

MEMBER DOBSON: Right. I don't want to

use that word.

CO-CHAIR KAYE: --- which setting, provider.

MEMBER DOBSON: Right.

CO-CHAIR KAYE: You know, so that's another comparison.

MEMBER SMITH: I would like to know if people are getting better from receiving the services. You know, I think that's really the bottom line. And you can talk about doing comparisons, you know, at a higher level when you roll the data up, but that's the ultimate question. If people aren't getting better because of the services, what's the point?

CO-CHAIR KAYE: Well, that depends on what you mean by getting better here. Okay, but let's not --- please don't open the can of worms right now.

MEMBER SMITH: Well, I will give you my definition for my population.

CO-CHAIR KAYE: Okay. Let's put that on our parking lot list. All right. So, anybody else

want to weigh in before we go to the next slide and pick which domains? Anita.

MEMBER YUSKAUSKAS: Yes. Back about 2000, maybe even before, Congress directed CMS to do a survey because they were grappling with the same issues that all of us are, and I think there are probably some people in this room who might remember the HCBS Quality Framework; Suzanne, Bob, Sara, Gerry, and on and on.

Anyway, it really is a framework that gets at a lot of what we've been talking about. It lays out six, seven domains, participant access, person-centered service planning and delivery, provider capacity and capabilities, participant safeguards, rights and responsibilities, outcomes and satisfaction, and system performance.

Anyway, Sarah, I sent you the link. It might be helpful to pull it up at some point just to see, because I think it has a lot of applicable components.

CO-CHAIR KAYE: Okay, thank you. Those

of you who have your cards up; Sara, do you want to ---

MEMBER GALANTOWICZ: I know you may be ready to move on, but I just wanted to comment on the question of why, why are we engaging in quality measure. You mentioned continuous quality improvement, someone else measured satisfaction, which is part of facilitating consumer choice. I would just add the two other --- and, again, not to open a can of worms, potential uses for quality measurement would be public reporting, and also eventually thinking about value-based purchasing and how measures might be used to drive purchasing, as well.

CO-CHAIR KAYE: Right. Okay. All right, Charlie, you put your card down, so let's move to the next slide finally. So, what are specific components? Camille said those things on the outermost circle of the --- I've lost it.

MEMBER DOBSON: Things like integration, care coordination, choice and control, person-centeredness, just off the top of

my ---

CO-CHAIR KAYE: Yes. Okay. What else? Anybody want to add?

MEMBER OXFORD: Depends on what person-centeredness means. I mean, for one, because, I mean, if that's just the process where you get to choose the location of your meeting, that you get to be in charge of who's at --- or not in charge, but that you get choice about who else participates in the meeting. I mean, you know, then there definitely needs to be some more stuff in there. If it means that you get to actually express your own real goals and dreams, and so on, and then you actually get the support you need to go after those things, then maybe it's okay. But that's the problem with person-centered, no one seems to know --- everyone's got one, but no one's quite sure what it is.

CO-CHAIR KAYE: Andrey?

MEMBER OSTROVSKY: So, the Commonwealth Fund has embarked on a really interesting body of work with some folks out of Texas, and their

information is to be published. They'll be releasing interesting work, but I think the themes that are emerging in several conversations that I've heard in the work of the Commonwealth Fund --- I sit on their Advisory Board for the Breakthrough Opportunities Program, and it's publicly available information. In particular, I'm referencing they have a document from 2012 around local health system performance measurement.

So, some of the things that I think are interesting to measure; one would be care coordination we referenced. Another would be around the extent to which information and data are being shared. And I think there's specific alignment there with the work of the eLTSS workgroup, and ONC is referenced in their 10-year vision, and interoperability roadmap, the sharing of data. I think that has to be a really important component of this and how we frame it depends, but data sharing, information sharing becomes pretty important.

And I think however we frame it, or chop it up, or put it together, the triple aim is a really good guiding principle, and out of each of the components of the triple aim, I think we can dissect, you know, more granularity or less, but I think using the triple aim as a guidepost specific to how HCBS contributes to achievement of the triple aim. I think those are --- it's not an exhaustive list, but those are things that are probably going to be important to include.

CO-CHAIR KAYE: All right, thank you. Ari Houser and then Charlie.

MEMBER HOUSER: So, one thing I'm thinking of is if we're going to get to something on the order of 10 domains, it might make sense to have a smaller break to start with. Whether that's the policy, process, outcome buckets as sort of a primary cut, and to take something with --- that could --- or thematic buckets like, for example, person-centeredness as a domain, and you can have process and policy, and outcome measures that are all about person-centeredness.

I'm not sure which direction we want to go. I think it would be easier to do the policy, process, outcome, but I think we might be more productive going straight into the subject matter. But I think that's a decision to make at the beginning before really delving in.

CO-CHAIR KAYE: Okay. Charlie, and then Mary.

DR. LAKIN: Well, I just find this list to be a hodgepodge of things. Some are process variables, some are outcomes. I think we need to focus on outcomes, and I think we need to kind of go back to some abbreviation of the Reinhard model. Those buckets aren't the right buckets, but we need to find some buckets. We need to add some intermediary variables. I think you've done that well in your framework. What are the things that yield outcomes? But these things don't add up to high quality support for people. They may for some people, but not for others. Their presence does not create high quality support.

We can understand high quality support

from the outcomes that people have. And these are a combination of things that may or may not contribute to that, except in some cases where we talk about quality of life, health outcomes, and so forth. So, I'd really start with the outcomes; what is it we expect high quality services --- what are the lives that we expect high quality services to help people live? And then what are the things that may or may not contribute to that? But this is such a mixture, that I don't quite see how they fit together in a meaningful way. And why institutional care is there, I'm not at all sure.

CO-CHAIR KAYE: All right. So, this is a list of terms that NQF Staff put together just to give people --- get people started thinking. But what you're saying sounds like we should start with the principles and maybe use those as the boxes.

DR. LAKIN: I think we've got to base this on something, and I sort of thought we were moving in the direction of saying what really

mattered was the outcomes people experience in their lives. And some of that's here, but a lot of it are the things that contribute, or we hope contribute to those outcomes. And I think they're important to capture in any quality measurement, as your model makes evident. But they're not all equal, and we need to decide what is the most equal of all of them. And it seems to me that's the outcomes that people experience.

CO-CHAIR KAYE: I bet you there would be a lot of people in this room who would agree with you on that. Anybody disagree, please speak up. Okay. That's progress.

DR. LAKIN: I'm not accused of that often.

CO-CHAIR KAYE: Okay, some remaining comments, who else? Mary, and Clare is putting her's up, and then we'll stop.

MEMBER SMITH: So, yes, I agree with the comment on outcomes. Again, I think that's the most critical thing, but I think it's sometimes hard to explain outcomes without

focusing on some other things. So, I would go back to, you know, maybe it's the Reinhard model, but I've changed some of the boxes. So, I would look at access to care, because I think that's critical. You're not going to have an outcome unless you --- services are accessible. Again, I have my outcome box. I have a separate box for quality and appropriateness of treatment. I have a separate box for structure, which probably relates to policy, and some other critical processes. And then a choice bucket. So, that's what I would recommend.

CO-CHAIR KAYE: Okay, thank you. Clare.

MEMBER LUZ: So, I agree with Charlie that it should be outcomes; we should be looking at outcomes. But outcomes are driven by our values and our principles, and these broader themes that we've identified, and that hodgepodge there includes both. So, I keep going back to the Handler model here, which is the Public Health model where they have the themes and the principles.

(Off mic comment)

CO-CHAIR KAYE: So, could you put the slide up for the --- could you put the Public Health slide up.

MS. ALLEN: It's up right there. Oh, it's on mine.

CO-CHAIR KAYE: Yes, we have different --- there are two different sets of things.

MEMBER LUZ: It seems to me this incorporates what everybody is saying, and under where it says "PHS Mission and Purpose," is where we would be listing our values, or our principles, or our themes. And then under --- and then go to what Charlie is talking about, go to the end where we have the outcomes, and list the outcomes that --- you know, the things that are important to us as outcomes, list those there. But it shows it being driven by our values, and our core themes. And the fact that in order for us to reach those outcomes, there has to be structure and process in place to be able to obtain those outcomes. You can't do one without

the other. It seems to me you have to have both, so you have the principles guiding the structure and the processes to get to the outcomes you want. But, you know, you're looking for boxes, Ari.

CO-CHAIR KAYE: It doesn't have to be boxes. We're not stuck with boxes. We can do anything we want.

MEMBER LUZ: Can we have circles or triangles? So, under processes, you know, you could have 10 boxes there, but you have one box that says the 10 essential services, so what are the 10 essential outcomes? What are the 10 essential processes that gets us to these outcomes? What are the 10 essential core themes that drive all of this? That's what seems to make sense to me.

CO-CHAIR KAYE: Okay, that's --- we're getting somewhere. Mike, and Jon, and then we'll break for lunch, please.

MEMBER OXFORD: Yes. I sort of see it's like we need a framework maybe to get to some of

the smaller frameworks we're talking about. But it just seems to me, though, that maybe at a smaller level --- at a system level the stuff --- the measures, the outcomes are just going to be so very different than at the individual level, I mean, so once you start getting in a little deeper, you know, you're just very, very different. I mean, at the individual level don't really care if you're cost-effective. You know, you don't really care about even access, you know, to sufficient providers, you just care about if you get access to the one you need, and so on and so on like that. So, you know, I started looking, you know, it's really control over your life, you know, you live where you want at the individual level, do you have financial resources, including work? Are you able to get around where you want to go? Do you have fun, do you have relationships? Are you satisfied with how you feel? People might call that health ---

CO-CHAIR KAYE: So ---

MEMBER OXFORD: At the individual level

those are real different than, again, at the system level.

CO-CHAIR KAYE: And what is your emphasis?

MEMBER OXFORD: Personally, I mean, my emphasis is on people, it's on the individual, so that's what I would be ---

CO-CHAIR KAYE: Right. So, you're echoing what Charlie had to say.

MEMBER OXFORD: Yes. I mean, I guess if we ----- I don't know. I mean, that's the big question. I mean, I guess what are we trying to solve? Are we trying to solve sort of systemic, or are we looking at the end quality for people?

CO-CHAIR KAYE: Okay. Jon and then Camille.

MEMBER DELMAN: Well, my comments are really on some of the issues that I think may be holding us back. And the first one is really the limitations. Are we limited by what CMS has already done? When I mentioned person-driven, you mentioned there's already been some work done

around person-centeredness. Are you --- how are ---why should --- how well --- are we held back by that?

CO-CHAIR KAYE: No.

MEMBER DELMAN: So, A and B, it's not clear to me that we all agree on the values here for this. I think --- so, granted that we have this large pallet that we can choose to work from, it's not clear to me that we have like five primary values that we agree to, or three primary values. I may say self-determination, other people might put that down at six or seven. And without that, we're not going to, I think, make progress.

CO-CHAIR KAYE: So, you're saying that we should probably as a group hammer out those core values.

MEMBER DELMAN: The core values.

CO-CHAIR KAYE: Right. And I'm starting to hear that. I kind of agree with you. Camille, and then Suzanne.

MEMBER DOBSON: Yes, I want to speak

directly to Mike. I think we need both process and outcome measures. I mean, I think the problem is we want to assess one of the things that we thought --- we felt very critical --- is a critical area from a state perspective is to assess member outcomes -- consumer, individual, participant, whatever the word is -- outcomes, but we also have to be able to assess health plans, the overall state system, providers by disability types, all the things that you talked about, Steve. I think I liked Ari's original concept where he said policy, structure, right -- - or policy, process, and outcomes broadly. I think actually we ought to find those blocks and address different kinds of measures that address each of those. I mean, I think we have to have both.

CO-CHAIR KAYE: Well, the usual trio is system structure --- system process --- structure, process, and outcome. And Ari substituted policy for structure, which is sort of --- did you mean to substitute, or did you

mean to amend?

MEMBER HOUSER: I meant to use the standard. I've just seen it as policy more than structure.

CO-CHAIR KAYE: Yes, okay. So ---

MEMBER HOUSER: But I'm not a quality expert full time.

CO-CHAIR KAYE: No, me neither. Okay. Suzanne, and then can we break for lunch? Would that be all right?

MEMBER CRISP: I'll be real quick. In order for me to get my head around quality, I've always taught it as a system endeavor, and then an individual endeavor, but they operate under very similar values. So, my vote would be let's talk about values and go upward.

CO-CHAIR KAYE: Okay. Yes, I'm liking this. Okay. Sarah has some things to say. Right?

MS. LASH: We are running quite behind, and I apologize for that, but this discussion has been really productive and important, and we will need to continue it.

We will take public comment before we allow everyone to get lunch, and I think that the Staff and the Co-Chairs will huddle about how we want to productively use the next hour or so. It might be small group illustration; it might be more productive to talk values as a large group, something like that. So, do bear with us if we sort of change the agenda up on you're a little bit, and I'll sort of stop there and ask the operator to give the instructions for public comment over the phone while we see if there's anyone in the room that would like to come to the microphone.

OPERATOR: Okay. If you'd like to make a comment please press star one.

MS. LASH: Drew, are there written comments being submitted on the Webinar? Okay, we will read those when we come back from the lunch break so that we have a chance to parse them out a little bit. Is there anyone on the phone that would like to make a comment?

OPERATOR: Yes, ma'am. You have a

comment from James Gallant.

MS. LASH: Please go ahead.

MR. GALLANT: Oh, yes. Yes, just to speak out on this a little bit, and considering you're talking about the quality and the core values, and the outcomes and whatnot. I would hope that everybody --- and to get back to the part about, you know, people come in to services and then they get --- in getting services they end up with court-ordered specific legal rights. And I would think that it would be the values of everybody here today that if a person has specific legal rights that they would then be provided that. And if they're not, get them over --- you know, refer them back to the court that wrote the court order and that's where you would get the competent people. They know what it's about. There was clear and convincing evidence in open court to say that these family care givers are fit and proper to be family care givers, to have them in control of the person, and I'm talking mostly about children. That you would

think that it could be --- a measurement would be how many consumers have these type of court orders, how many of them are not receiving what they have been court-ordered to have, and how many of them --- now what's the research of the court, they do a follow-up, and you say okay, now how many of them got those issues resolved, so they could then move on with their life as the way that the court has ordered. Because it comes down to a court-ordered standard of care, which should be fundamental that nobody can override that, nobody can exclude that because it was issued by the state. And it says this is what's in the best interest of this person, and it should be automatically --- it should be on everybody's bio, psychosocial assessment to say this is a social issue, this is a cultural issue. You know, the National Association for Social Workers has actually determined that marital status is a cultural issue. So, if the marital status in this child's family is that they're divorced and separated, and they have that

configuration of a life, that's a cultural issue. And then you say okay, now what does it mean to these people, and to this person? Well, it means that they need to be afforded time with the family they don't live with.

CO-CHAIR KAYE: Thank you for that comment. Are there other people on the phone who would like to comment?

OPERATOR: No, there are no other comments.

MS. LASH: Could I see a quick show of hands about if people are still interested in having a small group about the medical, primarily non-medical services, or whether that should be in the definition, who might be interested in that dialogue over lunch? Or we could skip it, I mean, I'm not forcing anyone.

COURT REPORTER: Could you turn your mic on.

MEMBER OXFORD: I'm sorry. Or would that issue be resolved if we talked about values?

MS. LASH: Okay. I guess I welcome

those folks who had raised their hands, raise them higher. You can look at each other and have a little bit of offline conversation while we eat, if you'd like. And bring that to the larger group when we bring the values conversation back. I think that would work well, and I thank you for your flexibility.

We will reconvene at quarter after, after I take a comment or a question from Ari.

MEMBER NE'EMAN: Just really quickly.

MS. LASH: Yes.

MEMBER NE'EMAN: Are we still planning on convening a small group to discuss principles, or that is going to be in the full ---

MS. LASH: I think that's what we mean by continuing the conversation about the values of what constitutes high quality HCBS.

MEMBER NE'EMAN: Great, great.

MS. LASH: Put a lot in that bucket. Okay, thanks, everyone.

(Whereupon, the above-entitled matter went off the record at 12:48 p.m. and resumed at

1:20 p.m.)

MS. LASH: Okay, I hope everyone enjoyed their lunch. Sorry to rush you through it. We have still a lot still to do. Before we really get back into the swing, I want to ask for a quick show of hands about which committee members might be interested in dinner this evening at 6:00, just so we know what the reservation would be. And then you can sort of put your name down on the list with Nadine at a break later.

PARTICIPANT: Where are we going?

MS. LASH: The front runner is called Mio. It's kind of a Pan-Latin restaurant right around the corner.

PARTICIPANT: Okay.

(Off mic comment)

MS. LASH: Great. Thanks, everybody. And now we wanted to take a moment to read back some of the public comments that we received prior to taking our lunch break now that we've had a chance to read them a little bit. Drew?

MR. ANDERSON: Sure. There seemed to be a lot of agreement around outcomes, so here's one comment said, "Agreed, quality is better measured by outcomes, things like freedom of choice, supporting independence, I think beginning with mission, vision, and principles is a great idea. What individual outcomes are often much first dependent on a good system outcomes." Another one, this person thinks that the vision framework is a good way to start the values and principles discussion. Let's see. And following that comment it says, "It is for a subset of what HCBS supports, but I think it's a very rich and holistic view of what home and community need to offer for individuals across a variety of population subsets. Within each piece of the pie and surrounding information/communication ring, there needs to be --- there is a need for structure, process, and outcome measures.

CO-CHAIR KAYE: Okay. So, don't shoot us, but over lunch we looked at the strawman definition and some of the things that people had

said that were in Juliet's notes, and we came up with some sort of vague ideas about what kinds of things might be in a value. You know, what kind of things we might pick as values, and this basically just to start the discussion off.

And in some cases --- and there's an awful lot of overlap, so we grouped things according to what we thought were more distinct and less distinct. So, some of these things are --- we may or may not think of them as values. And we separated --- so, we started with choice and we thought that person-driven was more about choice than --- more related to choice than the concept of person-centeredness, so we grouped choice, person-driven, and consumer-directed into one kind of thing. And we don't know how to express this, but maybe we can come up with something.

And then the second one is person-centered, focused on individuals goals. Because the goal --- the fact that there are goals and the fact that an individual sets them is really

the essence of person-centeredness, I think.

We grouped a whole bunch of stuff into enhancing well-being, such as privacy, dignity, respect, freedom or independence, physical and emotional health, which is listed twice, by the way. Then stuff about participating in the community, so community engagement, integration, and participation, accessibility, affordability. Safety, do we want to talk about --- do we want safety as a value? And as Charlie was putting it, it's not just safely delivered, it's keeping people safe. Is that something --- yes.

And then question of care givers, family members, do we want --- you know, does that get included? I think Ari Houser was the first person to bring up the importance of stuff involving that. Something about the workforce, well supported, well prepared, coordinated workforce, sufficient workforce. And then care coordination, and data integration.

So, just some very, very drafty strawman, you know, skeletal strawman stuff here.

So, where do we want to go with this? It would be nice if we had some buckets of real value. I mean, I think maybe core values is more of where we're going than principles. And I think if we do this in a reasonable way these might end up being our high-level domains for a conceptual framework, but I don't think we have to guarantee that right now. What do you think? Go ahead, Andrey.

MEMBER OSTROVSKY: We may not end here, but should we maybe start with the triple aim as buckets, as one option?

CO-CHAIR KAYE: Okay. All right. You're putting that in.

MEMBER OSTROVSKY: What is that? So, improving outcomes, decreasing cost of care, and improving consumer experience. I'm paraphrasing Berwick Health Affairs 2011.

CO-CHAIR KAYE: Can everybody see the --- so, what's displayed on these four screens here is the stuff that Juliet it typing. Right? And what's displayed on those screens is not. Can

everybody on the Committee see one of these four screens? All right. So, please look at that rather than looking at those screens that are up on the wall over there, because they won't be kept up.

All right. Who's next? Ari Ne'eman.

MEMBER NE'EMAN: I would suggest that we include something very explicitly around facilitating community inclusion to the same degree as individuals --- I didn't intend that instead of the triple aim, but to the same degree as individuals not receiving HCBS.

CO-CHAIR KAYE: Is that a different value than the community engagement, integration, and participation?

MEMBER NE'EMAN: I would argue yes. I think we often mean very different things from inclusion when we talk about engagement, or integration. You know, I think the relevant metric here is are we delivering services in a setting that is the same as this which would be utilized by individuals without disabilities, or

who are not receiving HCBS to live, work, or play. And just as notably, do individuals have the same rights, opportunities, and access to relationships as those not receiving Medicaid HCBS? Engagement, integration, and participation are conditional values; inclusion is, as I see it, an absolute.

CO-CHAIR KAYE: Okay. So, inclusion as a separate item from community engagement, integration, and participation. Gerry is next. Sorry, you were in the middle of ---

MEMBER NE'EMAN: Sorry, just one quickie. Can we specifically caveat inclusion to the same degree as individuals not receiving HCBS?

CO-CHAIR KAYE: Okay. Gerry.

MEMBER MORRISSEY: Just wanted to add under the choice person-driven, consumer-directed line the concept of control. That would be one, and then the second one is --- I'll come back to it. I forgot it now.

CO-CHAIR KAYE: Okay. Camille.

MEMBER DOBSON: I would just modify Ari's statement that said to the extent that the person wants that setting, because there are some individuals who prefer --- there are a number of folks, elderly folks who want to live with other elderly folks, so it's a person's choice, and the opportunities ought to be provided.

MEMBER NE'EMAN: Let me push back on that, if I may. I would argue that elders who want to live with other elders are still covered by the sentence to the same degree as individuals not receiving HCBS. We see this in the context of the conversations around the settings reg. There are many seniors that live in assisted living contexts, or in congregate contexts outside of the context of receiving HCBS. You can't really say that about non-elderly people with disabilities. I don't think there's a concern vis a vis elder congregate care within the context of to the same degree as. I think there is in the context of non-elderly people with disabilities, but I would argue that congregate care is not a

meaningfully community-based model in the context of the non-elderly population.

MEMBER DOBSON: I think community norms are important. I just want to make sure when we spell this out that we make that clear, because I'm not sure I would see inclusion to the same degree as people not receiving HCBS necessarily in the same way. I just want to make sure we're clear when we get to the details.

CO-CHAIR KAYE: Okay.

MEMBER NE'EMAN: We can definitely flesh that out as long as we can bifurcate the elderly/non-elderly definition.

CO-CHAIR KAYE: All right. Gerry has a comment to make, and then Jon, and then Clare.

MEMBER MORRISSEY: My thought was where would legal rights as a core value be here? Maybe it's implicit, but maybe legal rights at least are open for discussion in terms of a core value.

CO-CHAIR KAYE: You added legal rights? Yes.

MEMBER DELMAN: I'm a little concerned

that some of these core values can push into each other, start with affordable. I mean, defining affordability is a challenge because I think some of what we want is not affordable in the current state of affairs, and yet we want it to be affordable. So, affordable might mean that we do less than we would like to in order to serve a number of people. So, I'm a little concerned that that kind of clashes with some of these values that might take some funding. Training, in particular, for staff to really support.

Safety, that's a little paternalistic to me. You know, and choice is the dignity of choice, and that is the self-determination. That's the right to do stupid things in a sense, which everybody has a right to do. And if a person decides --- if an elder or person with disabilities decides they want to --- and they're competent, they want to, I don't know, go to the track, that's their right. And if they need a guardianship, they should have a guardianship, but I don't think safety --- I think choice is

driving that in personal --- in intra personal assessment. But I don't see why safety is core to this. I'm not sure it's a core for any service per se.

CO-CHAIR KAYE: Safety always makes me squeamish in these things. What --- who --- is there somebody who wants to speak up in favor of safety as a core value? Anita, and then Sara.

MEMBER YUSKAUSKAS: Yes. I'm a caretaker for my mother who has Parkinson's, and she's living at home right now because she has personal care services. And I told her where I was going and what I was doing, and I said, "So, what do you see as the priorities for measurement?" And the first thing she said was "safety." She's an extremely high fall risk, and she knows that if she falls at home she's probably going to go into some kind of a nursing home or a rehab facility for a few months, and she doesn't want to do that. So, personal care, by keeping her safe, she's able to stay in her home. And that's why it's extremely meaningful to

her; safety is important.

MEMBER GALANTOWICZ: I think I would just piggyback on that. I mean, safety I think is probably relevant across all domains of care when we think about any kind of care errors or things that put people at risk because there's a provider competency issue, which I think is a little bit different than letting people make safe choices. It's just making sure that providers in any setting are --- can keep the person safe and can deliver care in an appropriate manner.

CO-CHAIR KAYE: Ari and Charlie, but before that, how can --- so when you say the provider keeps the person safe, that seems to be very consistent with Jon's objection that it's paternalistic. So, I mean, I understand --- you know, I agree with what Anita said that, you know, failure of safety is what is --- prevents people from being independent in a certain sense, but how could you express that in a way that Jonathan would object less? Sara.

MEMBER GALANTOWICZ: I think I misspoke when I said keep person safe more ---

PARTICIPANT: Microphone, please.

MEMBER GALANTOWICZ: Sorry. I think the choice of keep as a word was probably an inappropriate word. It's more the concept than Anita is talking about, that the goals of care are ones that meet a person's needs and enhance the likelihood of safe outcomes for that individual.

(Off mic comment)

CO-CHAIR KAYE: Sorry, I wasn't using the mic. Ari, and then Charlie.

MEMBER HOUSER: Thanks. I would --- this is not my main point, but just to speak up in favor of safety. I think the idea of why do we think safety has to be something that the provider enforces? It seems to me a measure that could be easily measured by outcomes to look at rates of falls or other preventable acute events of that type. You know, if we're scoring a provider on quality, a provider whose measured

fall rate is three times the average, there's something going on there that would indicate lower quality of care. And I don't --- maybe, but at an individual level, I don't know, but there's --- I think that's clearly in the domain of quality.

My thoughts further on the list would be this list may be too broad for the concept of quality. Not everything that is good is quality. For example, affordability may be --- we would love to have HCBS be affordable, but does that mean that affordability is part of quality, or is it --- or is quality, like affordability, a good thing to have for home and community-based services?

CO-CHAIR KAYE: Well, your own framework has affordability ---

MEMBER HOUSER: Has them separate.

CO-CHAIR KAYE: What?

MEMBER HOUSER: Has them separate.

CO-CHAIR KAYE: No, but affordability is part of the scorecard.

MEMBER HOUSER: Yes, but the scorecard doesn't purport to measure quality ---

CO-CHAIR KAYE: I see. Okay.

MEMBER HOUSER: It purports to measure system performance, which is sort of a higher level trait.

CO-CHAIR KAYE: Interesting.

MEMBER HOUSER: And there are --- it's not that, you know, we identified five domains. It's not that they're completely separate, so that there's no relationship between them. But I could make a much stronger case for arguing why choice could belong under the umbrella of quality, but I have hard doing that with affordability.

CO-CHAIR KAYE: Okay.

MEMBER HOUSER: And it seems to me of this list there are some things that are clearly quality, and some things that may or may not --- that are good principles for system performance that may or may not fall in under quality.

CO-CHAIR KAYE: Okay. Right. And we are

talking about our core values, so this is really what we think is important then. I mean, Charlie, do you --- you took your thing down. Do you still want ----

DR. LAKIN: People are speaking in support of safety, and I was going to --- I just think it's really key that you attend to people's safety. And there are people who don't need that attention as much as others; some very much need it. And I don't see that as an issue of control. Indeed, much of what we do, probably the thing we do most under waiver services for safety is to provide people with alerting systems to allow them to live in their home, and to alert someone if they should need help. I just think if people need that, they need it, and to not attend to it just is sort of an abrogation of responsibility to me.

With regard to accessible, I would also like to add sufficient. I think a lot of people get services but they don't get what they need, as much as they need, so forth. Somewhere

in there, too, I would add dependable. I think the number one complaint I hear from people receiving HCBS is, "I didn't get out of bed Thursday because they didn't show up," or "I can't go to work because the bus didn't" --- I mean, it's just --- that dependability is so, so important. And I think we need to attend to that in our assessments.

CO-CHAIR KAYE: Thank you, Charlie.

DR. LAKIN: By the way, coordinated workforce, to me, I've spent my whole life working in this area. I think that is an intermediary variable. That's a variable that gets us to the outcomes we want, but it is not an outcome in and of itself. It's not an outcome for an individual to have somebody who ---

CO-CHAIR KAYE: Right, but we didn't say that our core values were all individual outcomes, did we?

DR. LAKIN: Well, then I think we get in --- we're going to go down the slippery slope toward how big the place people can live in,

because we know that has a big impact on their outcomes. Whether they own and control the house in their own name has a big impact on the outcomes they receive. I mean, where do we end if we're going to start to include what we consider predictors of quality, and that's what I'd say workforce, it's ---

CO-CHAIR KAYE: Okay. All right. So, you're saying --- what you're basically saying is it's not a core value.

DR. LAKIN: I think it's a slippery slope if we start to include sort of second-order variables, variables that we believe, sometimes with good evidence, are --- lead to outcomes, but are not themselves outcomes.

CO-CHAIR KAYE: Okay. Let's go to this side of the room. Clare, and then Bob.

MEMBER LUZ: So, I think you've chosen to mix up some concepts here that core values are the same as what we find most important, or what we find most important you're calling our core values; when I think they're slightly different.

And what I find most important is that we have some core values, and then we set up structures in order to make sure that we can actualize those core values. So, it's really important to me to have the proper structure in place. And just to give an example, I think safety is important, and I'm not disputing that personal choice; people have the right to make what some people might call unsafe choices -- but to defend you over there -- I think what we're trying to say is that the supports and services need to be provided in a safe way. And one way to do that is to have a trained workforce. And, to me, I see that as a structural issue. And it's really important to me to have a trained workforce that will help us achieve our core value of choice and safety.

CO-CHAIR KAYE: Yes. Okay, we're getting somewhere here.

MEMBER LUZ: So, I think some things just don't belong on this list.

CO-CHAIR KAYE: All right. So, this is supposed to be the core values. Right? Which is

not necessarily going to be the domains and quality, but at least should help us guide --- should help get us to the domains.

MEMBER LUZ: Right.

CO-CHAIR KAYE: All right. So, let's --- right. So, if it's not a core value, then it doesn't need to be on the list. But we can make a separate list for --- we can, you know, we have a --- right, so we have domains that Sarah has been writing up. Okay, so right. So, to drop something off this list does not mean that we're going to forget about it forever.

MEMBER LUZ: Or that it's not really important to us.

CO-CHAIR KAYE: Or that it's not really important. Okay.

MEMBER LUZ: Yes.

CO-CHAIR KAYE: All right. I think that's good. So, Bob.

MEMBER APPLEBAUM: So, on the safety issue, to me the value is that individuals basically have the opportunity to feel safe in

their living environment and their receipt of the services. So, it's not about safety for them, it's that the individual is able to feel safe. That to me is the value, and that I think gets around some of the issues that sound more paternalistic, because it's the individual's value on being able to feel safe.

I also would suggest that efficiency is a core value. We need to have an efficient system. And on the workforce, I'm okay with the coordinated thing, but I do believe that well supported and trained is an important value for the workforce. Whether it's coordinated or not, that gets into the slope, but I think in terms of we do have a value that we want to have a workforce that's trained and prepared to do the work that they do.

CO-CHAIR KAYE: So, would you put safety under --- so you're basically talking the sense of safety. Would you put that under the well-being bucket?

MEMBER APPLEBAUM: You know, possibly.

I mean, I'm just trying to think of the core values that I have for a system of home and community-based services, and one of them is for individuals to feel that they are safe. Whether it goes --- I don't know exactly where ---

CO-CHAIR KAYE: Yes. I mean, it's not the same as what Charlie was talking about.

(Off mic comment)

CO-CHAIR KAYE: Yes, so it's interesting.

MEMBER APPLEBAUM: No, but the problem I think that when you get to safety, it very quickly gets into whose safety are we talking about, because we know that we have a system where care managers think that this person isn't safe, but the person that's not --- so, I think that's where --- to me, we can agree on the fact that individuals calling their own safety safety is fine, but when your start getting into the professional saying no, that's not safe. I mean, we have many instances for people telling old people that they can't do that because it's not

safe.

CO-CHAIR KAYE: Right.

MEMBER APPLEBAUM: And that's where we have to be careful.

CO-CHAIR KAYE: Who hasn't weighed in yet on the other side? Patti hasn't, so ---

MEMBER KILLINGSWORTH: I just want to try to reframe it maybe in a way that makes us a little bit more comfortable instead of characterizing it as safety, if we can talk about management or mitigation of risk, or prevention from harm. And I know that still makes folks a little nervous, but there is the dignity of risk. It is about an individual's choice; and yet in that choice we want to do everything that we can to prevent harm, and to mitigate risk.

CO-CHAIR KAYE: What do you think, Jon?

MEMBER DELMAN: It's a slippery slope. And I agree that safety is important but, you know, the value --- when I think of values, I think of like one word things, like self-determination, independence. Now, I would say

those are values. I'm not sure everyone in the room would agree with that, and that --- but when I say self-determination and independence, I get concerned about safety because my focus --- and it might not be a consensus thing here -- is really the person should have an opportunity to do what they want to do subject to, you know, guardianships or other efforts to contain them. And I think my experience as I guess a care giver is that, you know, there are different ways of containing people. And I think sometimes when people say safety, they just want to get a court order or a guardianship. But I get concerned about respectful communication not being part of this, and that's what I --- I think --- I do think safety is a concern. I'm just not sure if I see it as a core value. I think I see it as sort of a process or an outcome. I don't know, but I get concerned about --- I think --- I don't know. I don't think I have an answer to this, I have to admit. I just am pointing it out as an issue.

CO-CHAIR KAYE: All right. We have a

lot of people who want to weigh in. Should we continue commenting, or should we try to say what things we think from this list are really core values?

MEMBER OXFORD: I've kind of got maybe a little different perspective that might help generally.

CO-CHAIR KAYE: Go ahead.

MEMBER OXFORD: So, safety and some of these other things, I mean, most of the conversation I've heard has really been around safety, sort of the responsibilities for a third party, you know, to insure an individual is safe, the program is safe, safety is covered somehow, and so on, as opposed to looking at it like well, safety is generally a good thing for anybody in any situation, and who's most interested in our own individual personal safety? We are, and so you invest your energy, and resources, and thinking and so on, I think the first level, so the core value would be that individuals need to be supported so that --- you could say so that

they're safe, or individuals, or support needs to be provided so individuals are safe, or safety is covered, however you want to wordsmith that. But I guess what I'm trying to do is really make sure that going back to our earlier conversation, the energy, and the emphasis, the quality measure is in supporting, I think, the individual to get to safety, and it could be very different things, right, for different people and all that, whether it's dealing with medication, to skydiving, or what have you.

In general, as I look at this list of core values, and this is going to be a little hard. I think what's missing, or a big area that's missing is sort of real specifically --- and I wouldn't know how to generalize it, but to make sure that a core value is that having fun is a real, real important thing. And it's not in community engagement. I mean, so as I look at kind of the way we're possibly thinking there is integration. Well, that's a program, that's something that we would do to make sure someone

else --- again, objectifying and then a third party does it. You know, freedom, independence, access to --- oh, gosh, I'm sorry, I'm looking around. But, anyway, I mean, having fun is real important, I guess as a core value, and doing what we can to make sure that people are in charge of that. I'm sorry, I'm trying to read real fast. But, anyway, that's just something that I think is real, real important, and that we always miss specifically, and that's different than engagement, integration, and so on. Those are just oftentimes little pieces, as opposed to feeling like you really have a life that's fun.

CO-CHAIR KAYE: Kimberly is eager to say something, and you've got to move the microphone close to your mouth, please.

MEMBER AUSTIN-OSER: So, I'll preface with I'm sorry if I'm the only one, we don't have to do this, but I'm really struggling with core values for what? And is it --- are we talking an HCBS system that values bullet, bullet, bullet, bullet, are we talking about --- I'm having a

hard time with the framing because I feel like we're all coming from different perspectives. And I'm looking at this differently, so I see a lot of things that aren't what I would call values here.

Like when I think about it, I think let's talk about our core values. We value an HCBS system that does what, or an HCBS system that values the following. And maybe it's for consumers and families, it values this. And for workers it values this, or maybe it's just a list of its person-centered we value choice, we value, you know, balancing risk and choice. You know, a system that values what? So, I'm just struggling with it, if we could try to frame it a little better.

CO-CHAIR KAYE: Right. I mean, I think ---

MEMBER AUSTIN-OSER: Unless I'm the only one, and then I'll ---

CO-CHAIR KAYE: No, I think that's a good question. And where this came from was the -

-- you know, we said we would divide the HCBS definition into what is HCBS, and then some kind of statement about what quality is. So, this came from there. So, Bob said principles, and then we've relabeled that as core values because that might, you know, fit into our framework better. But I think yes, I think it is, you know, we value an HCBS system that, you know, supports consumer choice, you know. Right. I think so.

We'll go with Andrey, and then Sarita, and Ari Houser.

MEMBER OSTROVSKY: Thank you, guys. I was just furiously going through my references that I've written or alluded to in papers before, because I think this notion of value and cost, and outcomes relative to cost is cost part of value, and all this getting down to being about the consumer. So, you know, Michael Porter had --

--again, not to get academic, but I actually think this is one of the better ways to balance being consumer-centered, but also thinking about the system, the health care system. And he

basically defines value in the following way. He basically says, you know, it's not --- it's neither an abstract ideal, nor a code word for cost reduction; rather, he points out that it should be defined --- value should be defined around the customer, consumer, and in a well functioning health care system the creation of value for patients or consumers should determine the rewards for all other actors in the system. I think it almost sets up two domains here; value or the values we're describing really should center around the consumer. And then if we're thinking about escalating to like a really well functioning health system, then we should take into account the system's factors, as well. So, I think that may be helpful in us balancing everything we do here and everything we're talking about should be focused on the consumer, the values. But when we talk about things like cost, you know, consumers themselves may not care about the cost of a service to the payer if it's not coming out of their pocket, or even if it is.

But it is still something important to keep in mind when we're developing this framework.

CO-CHAIR KAYE: I'm not sure I buy your conflating of values and value.

MEMBER OSTROVSKY: Okay.

CO-CHAIR KAYE: But I may be the only person who feels that way. Let me go to the other side of the room finally. So, Mary has had her thing up for a very long time, sorry.

MEMBER SMITH: So, let's see. I wanted to just comment on a couple of things. I agree with you about the community integration and the having fun piece. I think that the way that we've looked at it is kind --- and I don't know if this is going to capture it -- but it's the social connectedness piece that says that you're connected to other people, and you do fun things in the community like everyone else.

In terms of safety, you know, when we've spoken to individuals, you know, consumers or folks with lived experience, they'll tell you that they are concerned with their safety, so I'm

more aligned with what Bob was saying, you know, just in terms of people want to be safe. You know, they want to get better, they want treatment, but they do want to be safe.

In terms of the workforce, it seems to me that, you know, I think a key piece of our definition for HCBS was that the workforce was culturally, I don't want to say competent because I'm not ever really sure if folks can be culturally competent, maybe mindful. But culturally and linguistically aware, so I would say that, you know, that's an important value that we should have for any service delivery.

And then someone mentioned efficient. You know, I guess, do we not think effective, or is that already --- do we think that's covered in terms of enhancing well-being, privacy, et cetera?

CO-CHAIR KAYE: I would value effectiveness before I value efficiency. Can I --

-

MEMBER SMITH: I was a little puzzled

why it --- you know, I didn't know if folks thought effectiveness was covered somewhere else in this list.

CO-CHAIR KAYE: Yes, I guess it's not.

MEMBER SMITH: Or that we just --- you know, we weren't saying it because we figured a quality system was effective, or what?

CO-CHAIR KAYE: I know you want to speak, Bob, but Sandy has been waiting forever, so sorry about that.

MEMBER MARKWOOD: Thanks. Just a couple of comments, again. I echo the belief that safety is a core issue because from a consumer perspective that's --- and a care giver perspective, that is one of the first things that any consumer or care giver raises.

The question I have on the workforce development issue is coordinated there. I see coordinated as part --- missing from the core values. I think we have efficiency, but I think what we hear with the system is that it's not coordinated and seamless.

CO-CHAIR KAYE: Yes.

MEMBER MARKWOOD: And that should be part of the core values of the system.

CO-CHAIR KAYE: Yes. So, a separate item for ---- yes.

MS. LASH: Separate?

CO-CHAIR KAYE: Separate item, you know, a coordinated system of services, however you want to put it.

(Off mic comment)

CO-CHAIR KAYE: Is it? Do we have that already? Care coordinated, yes, that's true.

MEMBER MARKWOOD: Yes. I think the way that I read that last bullet on care coordination and data integration was care coordination as a thing, as what we call care coordination rather than care coordinated ---

CO-CHAIR KAYE: Yes, yes. I see what you're saying. Right. So, let's put that as a bullet, and take out care coordination, but leave in data integration as to the bottom one so we have that as a bucket.

Let me --- Sarita hasn't had a chance to speak, and then Ari Houser, and then Ari Ne'eman.

MEMBER MOHANTY: No. I mean, that's exactly the coordination piece, was an area that I think needs to be emphasized kind of more broadly, and then you can put components of that, how coordination happens within. Because, you know, we're talking about how we make care seamless for the consumer, and so, you know, often --- we hear it all the time, the fragmentation, the silos. So, to the extent possible, that what we want from HCBS is the ability to be able to break down those silos and reduce the fragmentation. So, that was one area.

The other thing, and it gets back to I think what Andrey was saying about, you know, there's the individual level needs, and then there's also the --- I also think of the system or the population health needs. And, you know, one of the things that I always see with --- you know, especially working with Medicaid, is the --

- you know, how do we reduce health disparities? And, you know, what are the socioeconomic, cultural, linguistic issues, so to me that's a core value, you know, is how HCBS can help to reduce disparities in health and healthcare delivery. So, I wanted to bring that up as a core value, so help disparities. And I think HCBS can --- equitable healthcare for ---

CO-CHAIR KAYE: You mean an equitable system.

MEMBER MOHANTY: Yes.

CO-CHAIR KAYE: Yes, I think that's great. Andrey, you've got your mic on, if you don't mind turning it off. And now I've forgotten who I said next. Ari Houser, I think.

MEMBER HOUSER: I'm struggling how to sort of operationalize this, but one thing that I think is missing is what I would consider precisely quality of care, or the quality of the actual services received. We have on this list that you've got enough services, that they actually come, that their provider, respect is

off the screen, but respects the dignity. But what we don't have is do they actually do the tasks that are needed? If you need a bath, do you get a bath? If you need to be dressed, do you get dressed? And then how well they're done. Do you look good when you're dressed?

That --- and I think there's a wide variety of services, and the way that we can define how well that these tasks are done, and whether they get done might be difficult, but I think that's a core value of quality, is that you actually get what you're supposed to, and it's done well.

CO-CHAIR KAYE: And how do you express this so that it doesn't seem like it's the whole theme?

MEMBER HOUSER: I don't know.

CO-CHAIR KAYE: I mean, is it part of the --- is it part of, you know, we have accessible, sufficient, dependable; if we added appropriate, would that be ---

MEMBER HOUSER: I think appropriate

covers some of it, but I also think like services performed well. I don't know if there's a --- probably a better way to phrase that, but I think that's an important part of quality.

CO-CHAIR KAYE: So, as Sarah asked, is this the same as effectiveness? This Sarah. Okay. And, Ari Ne'eman, I apologize for leaving you waiting a long time.

MEMBER NE'EMAN: No, not a problem at all. Maybe we should just do Ari H and Ari N, harkening back to middle school here. Two points very briefly.

I wonder if the concerns around safety as a core value, and I share those concerns, might be different if we could replace the word "safety" with freedom from abuse or exploitation. It seems that that may well be one of the concerns that the proponents of safety as a core value are trying to get at. And, certainly, I would have less concerns with a framework that's focused on preventing abuse or exploitation, or even neglect, if we want to add that, than with a

model that views the role of service providers to insure the "safety" of those they support.

The other point I'd like to make here, just a suggestion of core value that may in some ways be a better fit than affordability, or may make sense in its own right; aligning resource allocation with need. And what I mean by that is we have a lot of systems that really have this odd combination of placing large numbers of people with relatively low support needs in very restrictive, high-cost settings -- nursing homes, residential group homes, intermediate care facilities, and others --- while at the same time providing no services, or virtually no services to individuals on a waiting list, or individuals who do not meet eligibility criteria. So, just a conversation at a systems-wide level about how we do or do not align resources, align how we allocate resources with well established measures of need, like the Supports Intensity Scale and other things, seems to me to be a core value.

CO-CHAIR CALDWELL: Yes, I wanted to

pick up on what Ari just said. The thing I'm struggling with with affordability, because I think it's an important concept at the systems level. But what I'm struggling with is we're trying to limit this just to HCBS, which doesn't seem fair, because when you think about the bigger system, you know, a lot of the affordability stuff has to do with, you know, switching from institutional care to HCBS, or integration with the other health care system where you could, you know, bring down costs overall. So, I'm kind of --- that's the thing I'm struggling with the most, is that if this is just about HCBS, like the affordability stuff, I'm having a hard time translating that; what would the measure actually look like around affordability and HCBS?

CO-CHAIR KAYE: I'm wondering how we're going to get from this very long list to a manageable list of core values that we really can support. Charlie.

DR. LAKIN: I can't answer that

question, but I do think that in light of evolving expectations for HCBS programs, that somehow employment or productivity needs to be included in this list that we haven't --- I thought it might come around, but it didn't.

CO-CHAIR KAYE: Kimberly.

MEMBER AUSTIN-OSER: I'm still struggling a little bit with the difference between like characteristics and attributes versus values. You know, I think of values as honesty, you know, dependable, those sorts of things, and then attributes are it's affordable, and it's, you know, we're looking for the following attributes in an HCBS system versus --- and that could be at the system level and the individual level -- versus what are our core values. And I think one of the core values of an HCBS system is that it values self-determination and independence. So, I'm still struggling a little bit with this list of -- and maybe we don't take this list and get it ---- you know, whittle it into something. Maybe we're able to --

-

CO-CHAIR KAYE: Exactly.

MEMBER AUSTIN-OSER: --- bifurcate it, or ---

CO-CHAIR KAYE: Yes.

MEMBER AUSTIN-OSER: --- get it in different buckets.

CO-CHAIR KAYE: Right. Okay. So, can we do a sort of consensus process? Sandy, is your thing still up from before, or do you still want to talk?

MEMBER MARKWOOD: Sorry, no.

CO-CHAIR KAYE: Okay. Oh, Lorraine, you have your's up. Do you want to talk first, and then we'll deal with this. Microphone, please.

COURT REPORTER: Ma'am, your microphone isn't on.

MEMBER PHILLIPS: Sorry. I'm equally as confused as Kimberly, because I feel like we have structures, and processes, and outcomes, and values together in this list, if we want to look at that framework that we discussed earlier. So,

it seems to be conceptually --- it's conceptually confusing for me.

CO-CHAIR KAYE: Okay. So, if we --- instead of calling it core values, if we use the alternative phrasing that's at the top there, "We value an HCBS system that." All right? Or we --- how else would be put this that maybe doesn't even have the word "value" in it? Can you use your microphone, please?

MEMBER LUZ: Can we go back to what Bob suggested and call --- because we value certain outcomes, we value certain processes, we value certain underlying principles ---

CO-CHAIR KAYE: Right.

MEMBER LUZ: --- that drive it all, so can we go back ---

CO-CHAIR KAYE: How about core principles? Does that help? Does it help or is it worse to make it core ---

MEMBER LUZ: Because we value all these things. We just need to separate them out. Let's see, what are the underlying principles? Is it

person-centeredness, self-directness.

CO-CHAIR KAYE: Okay. Does that help at all or not?

MEMBER AUSTIN-OSER: Not really.

CO-CHAIR KAYE: All right. Well ---

MEMBER AUSTIN-OSER: I feel like the sentence is maybe if we want to have a list of values, and really they don't have --- there doesn't have to be a really long list. We want an HCBS system that values the following, as opposed to we value an HCBS system. That seems like we're saying a little bit different. I don't know if that makes any sense, or is helpful at all, but if we ---

CO-CHAIR KAYE: Or a high quality HCBS system is one that --- we could start off the way we started originally. Right? Does that help?

PARTICIPANT: Yes.

CO-CHAIR KAYE: Okay. So, a high quality HCBS system has the following characteristics. Right? And we'll fix this later to be more, you know --- okay.

(Off mic comment)

CO-CHAIR KAYE: Right. So, take out the core values from that, and that helps a little bit. Okay. So, can we weigh in on which of these things are really important, you know, have the highest priority to us for system characteristics? I propose that --- see, we have too long a list to even see this on one page. How do we get this so we can see it all? We can use a smaller font, I suppose, but then I'm not sure everybody can read it.

Wait a minute. Let's take out the --- let's get rid of the safety thing, or at least condense safety. I don't know how to do that.

(Off mic comment)

CO-CHAIR KAYE: Yes, let's put the whole thing as safety. And I do think that --- actually, I think Ari's thing of freedom of abuse, exploitation, and neglect is actually a separate thing. Can we do that?

(Off mic comment)

CO-CHAIR KAYE: All right. So, let's

make two things, and we can talk about --- so, then take out that, and take out the discussion after safety, and then at least it will fit. Take out that, management --- yes, because I don't think we're going to reach consensus on that. Take out that whole thing, just safety. Okay? And then does that fit on one page? Yes, it does, I think. Anything else below ---

(Off mic comment)

CO-CHAIR KAYE: Yes, aligning resources with need. We're almost --- see one more thing we can get out?

MS. LASH: I might suggest that ---

CO-CHAIR KAYE: Workforce.

MS. LASH: --- having fun and social connectedness is part of well-being.

CO-CHAIR KAYE: I don't think so. I think that seems like a separate thing. You know, if we just --- how about just put workforce instead of well supported, well prepared? Just put workforce and then it will all fit, I think.

(Off mic comment)

CO-CHAIR KAYE: Use your microphone, please.

MEMBER DELMAN: There's always, particularly when you have this many, a question of consistency with regard to values. And I'm not going to --- I mentioned something before, but some of these are important, but I don't know if they're the core values. You can have core values which might be five things; and, nevertheless, you're also paying attention to some other related things in the measurement piece.

CO-CHAIR KAYE: Okay. Well, we're not talking about core values any more. We're calling it ---

MEMBER DELMAN: Sorry. Characteristics.

CO-CHAIR KAYE: A high quality HCBS system has the following characteristics.

MEMBER DELMAN: All right, never mind.

CO-CHAIR KAYE: All right? And we don't want a list that has this many items on it, which is like 15 or something like that. So, I propose that everybody has three votes, and we'll go

through the list, after Camille what she wants to say, and then we'll ---

MEMBER DOBSON: Just really quickly, I think the Staff did a really good job. If I can go back to our original --- the definition we had this morning. We stopped it, right, after the definition because there was all these other things that we thought an HCBS system should have in it, and I think they do a good job --- they did a good job of capturing it. If we started with it enables the individual to pursue goals and desired outcomes, assures right of privacy, dignity, and respect, optimizes individual initiative and control. We've got some of that already, and I hate to lose those bullets.

CO-CHAIR KAYE: But we started with that. That was what we started with.

MEMBER DOBSON: Right, but we stopped at what an HCBS definition was at the top part, and we said all the rest of that stuff are actually characteristics of the system. So, that's what I'm wondering, if we can't --- it

does start to condense some of the things that are on this long list already.

CO-CHAIR KAYE: Except that when we sat down and came up --- and started drafting the list, we started with this, and tried to capture ---

MEMBER DOBSON: Okay.

CO-CHAIR KAYE: --- everything that was on this --- in this already, so I'm not sure that --- I don't know. Is that helpful?

MEMBER SMITH: Before we vote, I just want to make sure that my comment about the cultural and linguistically prepared workforce isn't missed.

CO-CHAIR KAYE: We had that on workforce, and then we just ---

MEMBER SMITH: Okay, I ---

CO-CHAIR KAYE: --- made it into workforce so it would fit.

MEMBER SMITH: I didn't see it. I want to be sure ---

CO-CHAIR KAYE: It was there, yes.

MEMBER SMITH: I think it's important.

CO-CHAIR KAYE: So, we'll remember that that's part of the ---

MEMBER LUZ: Collapse some of these under efficiency. To me, coordination of care and data integration are all markers of efficient --- of an efficient system.

CO-CHAIR KAYE: Yes? So, should we collapse --- let's see, where did the ---

(Off mic comment)

CO-CHAIR KAYE: Affordable. All right. So, if we made an efficient system well aligned -- efficient, well aligned, you know, well allocated, something like that, and coordinated -- coordinated system or the care is coordinated?

(Off mic comment)

COURT REPORTER: I'm sorry, your mic isn't on.

CO-CHAIR KAYE: Integrated? Oh, integrated system. How about that? Integrated.

MEMBER LUZ: Well, and I think data integration, good systems of data management.

CO-CHAIR KAYE: Data integration over here, too? Yes?

MEMBER LUZ: I would.

CO-CHAIR KAYE: Anybody object to that? Okay. So, using shared --- well, efficient --- it's a little hard to read with it moving up and down. Efficient, well aligned, well allocated, integrated --- how we say --- what's an adjective to describe that the data is being --- that there's good data and it's being shared?

(Off mic comment)

PARTICIPANT: Data integrity.

CO-CHAIR KAYE: Okay. So, now we can delete coordinated system of service. We can delete data integration, very good, and then delete coordinated system of services. Is that all right? Okay. And delete affordable, because we've made it more aligned. Is that all right? Because I think that was --- there was some --- if we take that out, is it all right? Okay. All right, good.

MEMBER OXFORD: Could we --- choice,

person-driven, consumer direct and control, collapse that with --- maybe say person-driven, focused on individual goals.

CO-CHAIR KAYE: Person-centered, focused on individual goals?

MEMBER OXFORD: Not centered, driven, person-driven, focused on individual goals and rights, something like that, and put those together.

CO-CHAIR KAYE: Okay. So, now instead of that put after --- in the one above that, choice, person-driven, focused on individual goals. Is that good?

MEMBER OXFORD: Yes. Well, those would be the two we'd collapse.

CO-CHAIR KAYE: Yes, exactly.

MEMBER OXFORD: Okay. Yes, there we go.

CO-CHAIR KAYE: All right, good. Any more work we should do?

MEMBER OXFORD: I don't understand what the first bullet actually means in this context now of characteristics. It doesn't really appear

to apply.

CO-CHAIR KAYE: Sorry, I was talking to Juliet. What were you saying doesn't apply?

MEMBER OXFORD: Well, the very first bullet, individual value versus system value.

CO-CHAIR KAYE: Yes, I don't think it does either.

MEMBER OXFORD: I don't think that really is germane. I don't know, the triple aim seems all right.

MEMBER OSTROVSKY: Can I make a quick comment about triple aim. That triple aim that I'm referring to, which is what originally was published on is specifically improved outcomes, decreased costs of care, and improved patient or consumer experience.

PARTICIPANT: We cover it.

MEMBER OSTROVSKY: True, we cover it, and that's fine. And I think we can think about leaving the triple aim, or integrating across other domains. But as it's written, it's how other people have interpreted triple aim, but

that's now ---

CO-CHAIR KAYE: Okay. So, what you was --- the first one was?

MEMBER OSTROVSKY: Improved outcomes.

CO-CHAIR KAYE: Improved outcomes, which is --- we don't really ---

(Off mic comment)

COURT REPORTER: I'm sorry. Your microphone isn't on.

CO-CHAIR KAYE: Say it again in the mic, please.

MEMBER YUSKAUSKAS: I'm sorry, I shouldn't have blurted out there, but I --- we don't have evidence-based practices, so I'm underscoring that I think that language is very important.

CO-CHAIR KAYE: Okay. So, Juliet, please take out the verbiage you have after triple aim, and substitute improved outcomes.

MEMBER OSTROVSKY: And then if we choose to keep this in here, decreased cost of care.

PARTICIPANT: Affordable.

MEMBER OSTROVSKY: Not so much affordable, it's actually just decreased cost of care, however that ends up happening. And then improved consumer experience, originally published as improved patient experience, but that was narrow sided to medical stuff.

CO-CHAIR KAYE: Okay. So, now ---

MEMBER OXFORD: Is decreasing of costs really a characteristic of quality? I mean, is the economic --- I mean, I just wonder how does economics equate to quality? It just seems like a whole other kind of goal.

CO-CHAIR KAYE: Andrey, before we go, what do you want --- do you want to leave it like that? Do you want to integrate it, do you want to separate it out? What do you want to do?

MEMBER OSTROVSKY: I think it's an excellent point in terms of decreasing --- you know, whether we want to keep decreasing costs of care in here, I think we do need to think about systems issues, not just the consumer, which is

the most important, but thinking to systems, in which case costs would be important. And cost is part of the value equation, outcomes over cost.

CO-CHAIR CALDWELL: I think it might help Mike --- this is what I was struggling with, too, is like not just decrease the costs of HCBS, but like if people had HCBS, how that could decrease the costs like elsewhere in the health care system. But I'm not saying one way or the other whether I think --- I'm not sure if that should be up front here, but that's exactly what I was struggling with. I think if you put it in the bigger health care context then it makes a lot of sense, because HCBS --- if people had HCBS, I think you could get savings and costs, you know, elsewhere.

MEMBER OXFORD: Well, it depends. I mean, the research I've read and knowing where it comes from, it really it all depends, depends. It's not like a linear sort of thing, just so you know. I mean, sometimes HCBS just increase the costs of long-term services because you have this

big latent demand, and so on. And if you don't close beds behind you, then you pay for the beds, and you pay for --- and on, and on, and on, so I don't know. I just ---

MEMBER OSTROVSKY: I think we can discuss the academic like, you know, studies and compare where the actual peer reviewed literature lies on this. I agree completely, Joe, that framing this in the context of the system level and triple aim as it applies to the system is probably a better way to frame it, rather than looking at HCBS exclusively decreasing costs of HCBS services, because it's probably not the right way of looking at it. I do think that the dynamic of increased utilization of HCBS has been shown in certain instances to decrease overall costs of care, but we --- I don't think we should ascribe the triple aim to any one individual person or consumer's experience. It's a system construct.

CO-CHAIR KAYE: Okay. If we can make brief comments because I really would like to

start collapsing this list a bit. So, Gerry.

MEMBER MORRISSEY: Well, on the decrease of costs of care, might it change to fairness of resource allocation? Fairness, to me, seems like a better characteristic ---

CO-CHAIR KAYE: Is that --- so, we have equity down on the bottom. Should that be under --- should we add health disparities, equitable system, fairness of resource distribution?

MEMBER MORRISSEY: Yes.

CO-CHAIR KAYE: Okay. Please do that. Thanks, Juliet. All right. Clare, or Bob. Bob first, then Clare, sorry.

MEMBER APPLEBAUM: I was just going to say I just thought that the --- all of the items in triple aim are already on the list. We've got well allocated, which I think, to me, kind of goes with the whole fairness of resources issue. We've got an effectiveness category that does get at the improved consumer experience. So, I think we can collapse some of these things that are in the triple aim because they're already reflected

in these other items.

CO-CHAIR KAYE: What do you think, Andrey?

MEMBER OSTROVSKY: I think you would be --- given that the intent here is just to guide where quality measures go, I think whether we call it triple aim explicitly, or allude to it in other ways totally fine, as long as we're keeping in mind the systems level implications of things. So, I'm not married to the triple aim. I do think it is a nice, well condensed construct, but I agree there are other things here. So, in the interest of consolidation, I think we should try to consolidate.

CO-CHAIR KAYE: All right. So, let's remove the triple aim as a separate item, and anything you want to add from that to the other two existing items, we'll do that.

MEMBER OSTROVSKY: I think outcomes are important, so improved outcomes.

CO-CHAIR KAYE: Improved outcomes as a separate item. Okay.

MEMBER OSTROVSKY: I think so, if we get rid of the triple aim all together.

CO-CHAIR KAYE: Okay. Speak and use your microphone please, Kimberly.

MEMBER AUSTIN-OSER: It seems to me that if we want to condense some of this stuff, choice, person-driven, focused on individual goals, to me that's outcome, that's, you know, outcome-oriented. When we just talk about improved outcomes, I'm not sure what we mean. But if we're talking about improved outcomes based on individual goals, individual choice, a person-driven program, I think that makes more sense. So, I guess I just want to get more clarity about what you mean around improved outcomes.

MEMBER OSTROVSKY: I think outcomes, we could describe them in probably multiple domains, but we could look at as medicalized as, you know, the hemoglobin A1C will improve if HCBS contributes to a more supported consumer that can adhere better, et cetera, et cetera. I think outcomes can also be less medicalized than that,

and could be very much in the vein of achieving an end result that's very much aligned with an individual's goals. So, I think in some cases we could consolidate exactly how you just said it. I think in other cases there may be specific outcomes that may not necessarily be, you know, is a goal achieved, or is a consumer's experience improved?

CO-CHAIR KAYE: Okay. I'm going to --- right. So, you're going to take off the triple aim, and leave improved outcomes as it is. And I'm going to take Co-Chair's prerogative and say please don't cheat. You have three votes. We're going to read each one and raise your hand if you want to spend one of your three votes on that one, and we can get --- okay, Clare, you can say one ---

MEMBER LUZ: Can I recommend two more collapses?

CO-CHAIR KAYE: Okay.

MEMBER LUZ: And I can anticipate that there will be people here who don't agree with

this.

CO-CHAIR KAYE: Put the microphone closer to your mouth, like move it forward.

MEMBER LUZ: Sorry, it's on, but I'm not --- I don't talk very loud. So, what about the possibility of combining workforce and care givers and family, because they're all providing supports and services, some are paid, some are unpaid, but we go back to this idea of paid and unpaid care giving.

CO-CHAIR KAYE: A few people shaking their heads, so let's not do that.

MEMBER LUZ: Okay. How about --- and then one more. How about in terms of employment, I've always seen that listed under community integration to the extent that one is able to also seek employment.

CO-CHAIR KAYE: Yes, I do, too. I mean, I actually consider economic and social participation to be kind of a single bucket, but I don't know whether Charlie would be happy with that.

(Off mic comment)

CO-CHAIR KAYE: So, can we do that? Can we collapse --- is it all right if we collapse employment and productivity under the community integration one? That would be great. And, Sara.

MEMBER GALANTOWICZ: Can we additionally collapse safety and freedom of abuse to just freedom from harm? So, that would ---

CO-CHAIR KAYE: Where is Ari Ne'eman when we need him?

(Off mic comment)

MEMBER OXFORD: No, I don't want to speak for Ari, but I kind of think from what I recall of the conversation, that those are really kind of different.

CO-CHAIR KAYE: I'm a little worried about that, because I think we're coming at it from different ---

MEMBER OXFORD: Yes.

CO-CHAIR KAYE: I mean, I see why it would be collapsible, but I see why it wouldn't be. Ari gets the last word before we vote.

MEMBER HOUSER: One thing that in terms of ----we don't have to collapse everything before we vote. If there are things that kind of borderline and thematically related, after we vote then maybe we can ---

CO-CHAIR KAYE: Yes. Okay. Three votes. Please don't cheat. Improved outcomes, please vote on that. Who's counting? Sarah is going to count. So, improved outcomes as a general thing.

MS. LASH: I see seven.

CO-CHAIR KAYE: Yes, did you get Mike?

MS. LASH: Yes, I did.

CO-CHAIR KAYE: Okay.

(Off mic comment)

MS. LASH: Oh, sorry, keep them up. That's eight.

CO-CHAIR KAYE: Okay. Choice, person-driven, focused on individual goals, consumer-directed and control.

MS. LASH: Seventeen.

CO-CHAIR KAYE: Okay. Enhanced well-being that includes privacy, dignity, respect,

freedom, independence, physical and emotional health.

MS. LASH: Seven.

(Off mic comment)

MEMBER OXFORD: I used up all my votes on the first three.

CO-CHAIR KAYE: Okay, you have three -- - Ari, you have three votes. Don't cheat. Legal rights.

MS. LASH: I'm sorry, seven for the enhanced well-being category.

CO-CHAIR KAYE: Seven for enhanced well-being. Legal rights, how many people want to vote for legal rights?

(Off mic comment)

MS. LASH: Two.

CO-CHAIR KAYE: Okay. Inclusion to the same degree as people not receiving HCBS.

MS. LASH: Also, two.

CO-CHAIR KAYE: Community engagement, integration, participation, employment, and productivity.

MS. LASH: Twelve.

CO-CHAIR KAYE: Having fun, social connectedness.

MS. LASH: Two.

CO-CHAIR KAYE: You didn't vote for your own thing.

(Off mic comment)

CO-CHAIR KAYE: Services that are accessible, sufficient, and dependable.

MS. LASH: That's one.

CO-CHAIR KAYE: Effectiveness, quality of care. Nobody? All right, one.

CO-CHAIR KAYE: Efficient, well aligned, well allocated, integrated, and data integrity.

MS. LASH: I see five, oh, six, late-breaking vote, six.

CO-CHAIR KAYE: Six, okay. Safety, safety by itself. Only one?

MS. LASH: One for safety.

(Off mic comment)

CO-CHAIR KAYE: Okay. Freedom of abuse

or exploitation, and neglect. What? Okay.

(Off mic comment)

MEMBER APPLEBAUM: The flaw in this system, because a lot of these are important, and limiting people to three, I don't think this is the right way to do this, because ---

CO-CHAIR KAYE: All right. How would you do it?

MEMBER APPLEBAUM: Well, start --- I would --- there are several ways to do this, but you could --- assuming that there's only --- I mean, if you have three, then you're trying to get down to three core ---

CO-CHAIR KAYE: All right. Well, we can only throw --- we can throw away the ones that are really low, and then we can do this again.

MEMBER APPLEBAUM: Right. And then, obviously, a lot of people used their votes in the beginning, and then they ran out. I mean, I guess I would say that one way to do this is to have people to really go from the top, let people vote, is this really important? Is this a you

have to have this on, and let people vote. And, hopefully, people won't vote for everything on the list as a way of trying to ---

CO-CHAIR KAYE: That's certainly another way of doing it. And I'm not an expert on consensus methods, so I went with what Sarah told me. Would you think that we could do it the other way?

MEMBER OXFORD: Come one, can't we run a multiple regression analysis, covariant? Don't tempt me, Mike, I'll start doing that.

MS. LASH: It's my experience on committees that once you have a list people are very reticent to continue to take things off of it, so the whole is it important, yes/no, might not work, but Andrey, do you have a suggestion?

MEMBER OSTROVSKY: I'm sorry. It probably wouldn't take long to create a quick doodle or a Google survey, email it to the group, and bang out what do you rank 1-17, and that's it.

MS. LASH: Yes. Would people commit to

answering this overnight ---

MEMBER OSTROVSKY: We can do that like now before we leave.

MS. LASH: Okay.

MEMBER OSTROVSKY: It would be quick.

CO-CHAIR KAYE: Turn off your microphone please, Andrey. Do we need this before the end of the day?

MS. LASH: Not necessarily.

MEMBER NE'EMAN: Quick point of order. Can I just ask, can we assign multiple votes to the same category?

CO-CHAIR KAYE: Sure, you have two hands.

(Off mic comment)

CO-CHAIR KAYE: Well, no, no. So, we could do this thing where we rank them. Right? We could do a poll, we could rank them. And then what? And then we'd score one point for, you know --- 17 points if you're on the top, and then, you know, 16.

MEMBER OXFORD: Well, I mean, are we

trying to get down to just three things, or are we trying to get down to like the best things without regard to how many, or what will fit on half a page? What's the deal?

MEMBER OSTROVSKY: Yes, you aggregate all the scores, and the lowest score is the top, the highest score is the worst. And then we look at the bottom three, and we can decide does it make sense to eliminate these highest worst three, and then we can decide if that makes sense or not, but at least we'll have a little bit more granular and quantitative way of doing it. And it could be just as quick.

CO-CHAIR KAYE: Okay. Should we continue with this anyway, and ---

(Off mic comment)

CO-CHAIR KAYE: All right. So, let's continue with this, anyway, and see what we think. Care givers, family. Anybody want to vote for that one?

(Off mic comment)

MS. LASH: Mark it as one.

CO-CHAIR KAYE: One. Workforce? Two.

MS. LASH: Two.

PARTICIPANT: That's not right.

CO-CHAIR KAYE: That's not right. There are two free votes. I agree with you. All right. And what about the last one?

PARTICIPANT: Health disparities.

CO-CHAIR KAYE: Health disparities, equitable system --- okay. So, the problem is that we all spent our votes on the top ones, and we wish --- so, it's not ---

(Off mic comment)

CO-CHAIR KAYE: Do we want to do another round or do you just want to wait to do the rank thing?

MEMBER NE'EMAN: I would like to reassign my vote from legal rights to inclusion, and use my remaining vote on inclusion, as well. All three of mine on inclusion. Thank you very much.

MEMBER OXFORD: I think that motion is out of order, Ari. No, I mean, I am curious. I

mean, are we just generally trying to get, I mean, how many? Is there any kind of goal, or just whatever ones rise to the top?

CO-CHAIR KAYE: What I would do is see where there's a break in the list.

MEMBER OXFORD: Okay.

CO-CHAIR KAYE: I mean, if we were to keep the numbers now, then I would certainly take out the --- I would take all the zeroes, ones, and twos and then we'd look at it again. Right? But we realize this vote is biased, and so not very meaningful. I mean, we could achieve the same goal by giving people five votes and then start taking off ---

MEMBER OXFORD: Well, I was going to say, I mean, if you just want to get down to like say four or five, no matter what happened you'd probably end up, I mean, with the same ones. Right? You've got, obviously, consumer choice, direction is the ones real high. Obviously, enhanced well-being and freedom and independence, and emotional, you know, that's a pretty long ---

the other thing is those two, second and third bullets, have a lot of stuff. Right? You know, they're long and so they include --- you know, and so on. But if you look at the top few, I don't know if doing anything different would end up with something different. Maybe it would because I agree, I think workforce would probably migrate up higher than two. But I don't know what other people think. It might end up the same way; depends on how many ---

CO-CHAIR KAYE: Go ahead, Anita.

MEMBER YUSKAUSKAS: I was looking at the Institute of Medicine, the priorities around quality and, you know, that's another guiding document that a lot of folks have been using. And I think we've covered just about all those items except timely, which isn't even there. But I wonder if it might not be helpful to refer back to some of those to give us perspective.

CO-CHAIR KAYE: Okay. I think we're going to go to public comment, and then --- I'm a little concerned that it's not a good idea to

wait until tomorrow to have the answers to this.

MEMBER OXFORD: I wouldn't mind seeing the list of everything but the ones and the zeroes, and seeing what people think of that.

CO-CHAIR KAYE: I'm a little concerned about the bias of --- the top-weighted bias of that.

MEMBER OXFORD: Right.

CO-CHAIR KAYE: So, I would want to revote with five votes, and then --- if we were to do this. If we're okay with not having this list until tomorrow, then I think the prioritization is good.

MEMBER OXFORD: Okay.

CO-CHAIR KAYE: Is it all right if we go to public comment? Yes.

OPERATOR: Okay. If you would like to make a comment please press star one. Okay. You do have a comment from James Gallant.

CO-CHAIR KAYE: Please hold and we'll take comments in the room first.

MS. DAILEY: Hi, I'm Maureen Dailey

from the American Nurses Association, and I'd like to give support to the IOM six aims of care. I think they're very applicable here and a good grounding. I also would like to support patient safety. Patients that are disabled or have functional issues, their number one priority is not to be institutionalized, or hospitalized, or lose function when they can avoid it. I come to this with a background of 30 years in home and community-based services experience. Thank you.

MS. MacINNESS: Good afternoon. My name is Gail MacInness from PHI, the Paraprofessional Healthcare Institute, and I'll submit more detailed comments in writing. But I just wanted to take the opportunity to support and encourage you to include workforce variables as you look at the issue of quality measurement for HCBS. We believe, as I think many of you do, that because direct care workers are the primary paid delivery mechanism for LTSS, that it's essential to include those variables to fully understand the relationship that influence HCBS quality.

We know from recent surveys money follows the person program directors and state unit on aging directors, that lack of available direct care workers can impede access. And we know that astronomical turnover rates among direct care workers interfere with long-term services and supports quality.

So, like I said, I'll submit more detail in writing, but I just wanted to put in a plug for workforce variables among the items that you include.

MS. POTTER: Hi, everybody. I'm D.E.B. Potter. I'm currently with the Office of the Secretary of ASPE. I've been involved in the HCBS measurement since --- not nearly as long as anyone in this room, but for a while. But I thought it might be helpful to provide a context on quality. I listened in amazement of the discussion around quality.

So, I want to read you some testimony that was presented to Congress in 2009 to try and convince Congress so they could understand what

quality was. "Simply put, health care quality is getting the right care to the right person at the right time, every time." And that this is a broader concept to like getting at all of those things, the right person at the right time, every time, is sort of a way to think about quality in a bigger context, but also in a context of HCBS.

MS. LASH: And we can take a brief comment from the phone.

OPERATOR: Okay, your comment comes from James Gallant.

MR. GALLANT: Yes. I had a couple of comments here. About the part you were talking about coordinated or coordination, or integrated, what I found in my travels is trying to track down policies that actually don't exist. A lot of people say it's policy, but to be integrated you actually have to have an agreement, your coordination between agencies. They have an agreement between each other, it's not just over the phone, somebody says I'm working with that person, working over there. That these actually

be real, you know, agreements, integration instead of, you know, somebody --- and then they leave that job, and then all of a sudden it falls apart.

And, also, I guess just because it went this way in this debate that you're doing here, and you're going to vote, what exactly are the rules in this deliberative assembly that is here in the National Quality Forum? You know, according to the general parliamentary rules in America, you know, like the Robert's Rules of Order, the rules of the governing body that appointed this group apply here, so how would they make the decision? That's how --- you're supposed to be following their rules. They appointed you. Unless you make your own rules, and say, you know, this should have been already done because now is not the time to talk about what are we --- how are we going to vote.

The rules that already, I guess the Board of Directors of the National Quality Forum apply here. And if that's Robert's Rules of

Order, there should have been a motion pending right from the beginning. You know, when the agenda item comes up, you say motion to approve, we second that, now we have discussion, and then we vote. And that would have kind of resolved everything, the confusion you're having right now, because you would have already had motions pending. And I'd ask you to please make a motion to refer this to the nominating committee, and ask them. Okay, you nominated us to be here, what happened? What are the rules? What are we supposed to then go by, or is the co-chair, or the leaders, or I'm not really sure.

I didn't find it on your website of the bylaws and the rules of procedure. But that's important for people with disabilities. They come to the table, and then you get people at the table, they're making it up as they go. And it's going to be in their favor, and they're going to win the debate, and then all of a sudden it's not really informed consent on the part of people in a consensus-building mode. It's like well, you

have to object. You have to be the guy that's saying man, you're always objecting to stuff.

MS. LASH: So, while we appreciate the comments. This committee isn't run on parliamentary procedure. We're in a collaborative transparent consensus-based process. It's free form right now. The results of the process will be made available for more formal public comment and a written product. And thank you; I'm afraid we have to move on. Is there any other comment from the phone, or from the webcast that we need to read out at this time?

OPERATOR: There are no comments from the phone line.

MR. ANDERSON: Just from the web chat, a lot of people have been reiterating the importance of including safety, looking at the triple aim, and the impact. Like one of these is impact on the triple aim of the population is important. Having healthy --- including healthy community/population, improved health care outcomes and experience, and improved per capita

cost of care, so that are the aims, generally reflecting the same sentiments of the group.

MS. LASH: I think we'd like to call about a 5-minute break so that the Staff can confer with the Co-Chairs about what the next steps are. If we want to do a different voting exercise, or move on, translate this forward into a domain discussion. So, just take five, everyone. Thank you.

(Whereupon, the above-entitled matter went off the record at 2:46 p.m. and resumed at 3:12 p.m.)

CO-CHAIR KAYE: Okay. We had an eloquent plea from Charlie Lakin, so it's his fault, not mine, that we're going to do another round of consolidation on the list. And then the NQF Staff are printing out the items from the list, and they're going to put them up on the final sheet up there. And we're going to do a consensus process. You have --- most of --- do you have these little sticky things that notice I don't have them. And so you can put up to what,

is it 10 stickies distributed however you want.

(Off mic comment)

CO-CHAIR KAYE: Right. So, Ari Ne'eman, you can put them all on the same one, if you want. Okay. So, let's --- so, what would you like to consolidate? Charlie had some ideas.

DR. LAKIN: Okay. Well, with consent of Ari and Mike, we would like to first on the third bullet, just remove enhanced well-being. That's too generic to mean anything, and move legal rights up into that list. We can't not vote attending to people's legal rights.

Yes, and move legal rights up into that space, or at the end of the string. We don't think physical and emotional health belongs in that category. It may belong somewhere, but not there.

CO-CHAIR KAYE: Okay, hold on, hold on. Would you like to make a separate category for physical and emotional health?

DR. LAKIN: Well, I'd do that now because it's not my decision whether that stays

or not.

CO-CHAIR KAYE: Yes. So, we came up with a whole giant well-being bucket. So, I'm okay with --- I mean, I guess I was the one who came up with that bucket. I'd be fine with moving physical and emotional health to a separate line.

DR. LAKIN: Okay.

CO-CHAIR KAYE: Is that what you want?

DR. LAKIN: Yes.

CO-CHAIR KAYE: Okay. So, Drew, can you do that?

DR. LAKIN: The other one was moving inclusion down into community engagement.

CO-CHAIR KAYE: Okay. So, Ari Ne'eman, how do you feel about that?

MEMBER NE'EMAN: I support it, and if possible I'd like to find a way to include to the same degree as within the new category.

DR. LAKIN: Yes, so, I don't know what that meant, but ---

CO-CHAIR KAYE: And second from Mike. And ---

DR. LAKIN: Actually, I think

that we would like to do is move --- just remove integration and put inclusion in that string, if we could.

CO-CHAIR KAYE: How about take the entire phrase --- yes, take out integration and take the entire --- the inclusion with the parenthetical, and put it where integration was. That make sense, Drew? Okay.

DR. LAKIN: And also to move having fun, social connectedness onto that line above it.

CO-CHAIR KAYE: Anybody object to that? Mike, you were the one who ---

MEMBER OXFORD: No, no.

CO-CHAIR KAYE: That's good? You say no, so you put more stuff in so make sure it has more votes. Okay. Any other consolidation ---

MEMBER OXFORD: I have an idea that we put workforce together with care givers and family.

CO-CHAIR KAYE: Right, that was already proposed. Is there anybody who still objects to

that? Some people object, okay.

MEMBER OXFORD: Whoa, a lot of people.

CO-CHAIR KAYE: Okay. So, then Mary had a comment. Can you use your microphone, please.

MEMBER SMITH: Move the effectiveness, quality of care up to improved outcomes. You don't think it's the same?

CO-CHAIR KAYE: Well, let's see. Improved outcomes came from ---

MEMBER SMITH: Eight people ---

CO-CHAIR KAYE: --- Andrey. What do you think?

MEMBER OSTROVSKY: I think that would be fine to group together. In the interest of consolidation, it's aligned enough.

CO-CHAIR KAYE: Okay. Anybody object seriously to that? All right. So, Drew, would you move effectiveness and quality of care to after improved outcomes, just the first one.

MEMBER SMITH: So while Drew is doing that, is --- I want to go back to a question someone else raised. Are we trying to get to a

certain number, because right now, if we --- no, if we think these are all important things, I guess I'm not really sure why we're trying to shrink them down. Are we trying to put them on an index card or what? No, I'm serious.

CO-CHAIR KAYE: Well, because we had --- we started out with 20 of them, which is not a tenable list. I mean, now that we're combining them --- well, I mean, the question is are there things that are not well supported? I mean, I think we have --- we're going to have to deal with safety, for example.

MEMBER OXFORD: While we're thinking on that, would someone help me out with the discussion on the difference between workforce and care givers?

CO-CHAIR KAYE: The person who said care givers I assume meant ---

MEMBER OXFORD: Is it paid/unpaid?

CO-CHAIR KAYE: Do you mean --- who was it who --- it was Ari, and do you mean unpaid, or do you mean family care givers, or ---

MEMBER HOUSER: I think it's critically important to include family care givers as a client user of home and community-based services. And I think they --- family care givers are also, obviously, providers, but I think they're different from formal paid providers, in that they also have a role as a consumer of service -- --

CO-CHAIR KAYE: All right. So, Drew, would you change the third from the last to be family care givers with the acknowledgment that it's not only family. Okay? I mean, we know that. That's our code word for family and friends. Patti.

MEMBER KILLINGSWORTH: Are we talking about with respect to family care givers and informal care givers supports for them? I just want to understand when we say it has the following characteristics. Right? That a part of what that system does is support those family care givers?

CO-CHAIR KAYE: Yes. So, you would want

--- Ari would want --- Ari Houser would want something that says family care givers are supported.

MEMBER KILLINGSWORTH: Yes.

CO-CHAIR KAYE: So, can we change it to family care givers are supported? Okay. Sarita, did you want to make a comment? Microphone, please.

MEMBER MOHANTY: No, I think I'm --- so far I was --- you know, I think some of the categories are fine, are good, and I think we're narrowing them down. I'm going to come back and maybe we'll talk about this later, and I'm not trying to add to the complexity of this. But in terms of the triple aim, I just want to just mention that I know we took it off, and I'm just going to advocate that we still somewhat think about the total cost of care in our model as part of just something to --- I mean, bring it to this group, if there's a feeling of not including it. Obviously, it is consensus-driven, but I do --- you know, I'm an advocate of trying to be able

to think about that as part of this HCBS system that we're trying to explore.

CO-CHAIR KAYE: Okay.

MEMBER MOHANTY: So, I'm going to --- and put that there. And then just with the improved outcomes, I know we put effectiveness and quality of care. I would also --- maybe it is implied somewhere in there, but just also about as part of that member --- or consumer experience, just their overall experience of how they --- how help is --- maybe it's in there. You think it's all in the ---

(Off mic comment)

MEMBER MOHANTY: Okay. I just want to make sure that it's not --- you know, that we always want to make sure that we, as part of --- we want to make sure we understand how they're seeing their care.

CO-CHAIR KAYE: Right. So, these are the characteristics of a high quality system. Right?

MEMBER MOHANTY: Yes.

CO-CHAIR KAYE: And I --- and our hope is that these will guide us in the selection of domains, but there may be also additional domains. I would imagine there will be additional domains besides these that were not sort of part of our system.

MEMBER MOHANTY: Okay.

CO-CHAIR KAYE: I mean, that's the way we're seeing it so far.

MEMBER MOHANTY: Okay. Great, thank you.

CO-CHAIR KAYE: All right. One last comment from Gerry before we go ---

MEMBER MORRISSEY: Just on that point about consumer's voice. I guess that would be under --- for me, under number 2, choice and person-driven. You would anticipate the voice of the individual would be part of that process.

CO-CHAIR KAYE: Okay. Bob.

MEMBER APPLEBAUM: The only one I don't get now is the very last one, if you put in the term high quality system has following

characteristics. I don't know what health disparities means. We're trying to have a health disparity system?

CO-CHAIR KAYE: Right. So, we want --- reduces health disparity, is equitable and reduces health disparities. Right? Go ahead, Sandy.

MEMBER APPLEBAUM: Well, wait.

CO-CHAIR KAYE: Sorry.

MEMBER APPLEBAUM: I'm still --- how the HCBS system is going to reduce health disparity?

CO-CHAIR KAYE: Is equitable enough?

MEMBER MARKWOOD: I guess to your point, because I had the same question, Bob, is are we talking there about cultural competency? Are we talking about cultural sensitivity and the delivery of home and community-based services, not just in the workforce, but in the way the whole system is delivered, in which point that makes it into an aspiration of what we're trying to do, rather than tackling a disparity.

CO-CHAIR KAYE: So, do we need to add to this issue? I mean, so --- all right. So, when Mary proposes it was in the context of the workforce, and proposed the cultural awareness, sensitivity, competence. So, would you like this to be --- that to be a separate item distinct from workforce, that HCBS must be delivered in a culturally appropriate way?

MEMBER MARKWOOD: Well, I guess what my question was, the friendly amendment is whether the way that that last bullet is framed now is a bit of a jumble to me, because you've got a whole lot of things in there. But I think the point of the bullet is to insure that there is equity and sensitivity in the delivery of home and community-based services across cultures and ethnicities. And maybe somebody could frame it differently, but I think that's the point behind it. I'm not sure that the verbiage there --- I think the verbiage there restricts it.

CO-CHAIR KAYE: I'm sorry, go ahead.

MEMBER OXFORD: Well, I was going to

say also, I mean, fairness of resources. I was also thinking about across populations of people being served.

MEMBER MARKWOOD: Right.

MEMBER OXFORD: And ages, age and --- across age, across disability, equity, too. Is that part of it?

MEMBER MARKWOOD: I'm fine with that.

MEMBER MOHANTY: Yes, and I think that was the intent. I mean, when I also brought this up, too, I think that was my idea that we're looking across the population that home and community-based services can definitely help in reducing health disparity, or eliminating health disparities with --- not even -- cultural/linguistic, absolutely, but also socio-economic status, housing status when you think about what home and community-based services can provide. Those are some examples.

CO-CHAIR KAYE: Gerry.

MEMBER MORRISSEY: Mary's thing of cultural --- I thought --- I think it's better to

say cultural competence than cultural sensitivity. I think --- it can either can go in the workforce or potentially could go up with choice and person-driven, are the choices of the individual, potentially.

CO-CHAIR KAYE: Or the bottom one. I mean, should we put --- should cultural competence, or whatever that concept is, go in the bottom?

MEMBER SMITH: I think that's a different thing than what you just described. I mean, we should try to make sure things are looked at fairly and equitably across populations, but having a workforce that's trained to interact with lots of different populations I think is a totally different thing.

CO-CHAIR KAYE: Okay. Suzanne has her card up.

MEMBER CRISP: Yes. I wondered what happened to paid and non-paid family care givers?

CO-CHAIR KAYE: Family care givers are supported. Does that ---

MEMBER CRISP: Yes.

CO-CHAIR KAYE: Do you want it to say paid and unpaid, also?

MEMBER CRISP: Well, I think that's an important differentiation. They both have to be supported, but they're supported in different ways.

CO-CHAIR KAYE: Is that okay with you, Ari?

(Off mic comment)

CO-CHAIR KAYE: Yes. Well, that's the question, is does it count as workforce or not?

MEMBER HOUSER: I think the amount of family care that is compensated is such a small portion of the entire amount of family care provider that I think it's --- I'm taking that's to include it.

CO-CHAIR KAYE: Also, family care givers being supported could be paying them, I think.

MEMBER HOUSER: That is one way in which they may be supported, yes.

CO-CHAIR KAYE: Right.

MEMBER CRISP: Okay. Improved outcomes, I'm still not sure what that means. I know dealing with the elderly at the end of life crisis issues, I mean, what is an improved outcome there? And, also, if a person meets their outcomes, isn't that a quality designation?

CO-CHAIR KAYE: Yes, I don't quite --- I mean, it seems like we have lots of domains that are about outcomes, consumer outcomes, so I'm not quite sure what this adds.

MEMBER CRISP: And I'm not done. I also wanted to say under safety, in self-direction we don't use the word safety, we use the word dignity of risk, assessing the individual situation for safe and unsafe, and other situations, anything that might be or could be perceived as harmful to him or herself, or others. So, we use a risk identification and management system that is based on person-driven interventions. But I understood everybody was --- or most people except Patti, was a little

hesitant to go that route. So, I wonder if we could at least add safety based on informed and expressed choices.

CO-CHAIR KAYE: Any objection to that? You object?

MEMBER LUZ: I don't object, but I think safety is bigger than that, because I'm thinking in terms of the supports and services being provided in a safe way, so it's not just about individual choice. It's about the quality of the services they're receiving.

MEMBER CRISP: Yes, and I see that, too. I just --- I'm just compelled to bring up the fact that individuals do have a right to make choices about their safety issues. And safety is a judgmental thing. What is safe to a fireman is not safe to maybe me cooking in my own kitchen. It's a judgmental thing, but I can live with that.

The other thing I wanted to bring up is that nowhere do I see that one of the characteristics of a high quality system would be

that there is participant engagement in the design, implementation, and evaluation of that program. I don't see that anywhere.

CO-CHAIR KAYE: Could we add that as a separate domain at the end, Drew?

MEMBER OXFORD: I thought that would be included in being person-driven, myself.

CO-CHAIR KAYE: Well, that seems like the services are person-driven, as opposed to the service system.

MEMBER OXFORD: Which is what this is about.

MEMBER CRISP: It's a difference between consumer-controlled and the independent living movement, and developing your own plan of care and implementing it, and managing the services. I see those as two different things.

(Simultaneous speaking)

MEMBER OXFORD: You guys parsed that finer than I do, is all.

CO-CHAIR KAYE: Wait. No, so say again what this one is. Participant engagement in the

planning.

MEMBER CRISP: Participant engagement in the design, the implementation ---

CO-CHAIR KAYE: Design.

MEMBER CRISP: --- and evaluation of the program.

CO-CHAIR KAYE: Of the program.

MEMBER CRISP: Not the plan.

CO-CHAIR KAYE: So, that's different --

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MEMBER CRISP: The program.

CO-CHAIR KAYE: Evaluation of the program.

MEMBER CRISP: The program for which they are receiving services under.

CO-CHAIR KAYE: So, the waiver program, or

the--

(Off mic comment)

CO-CHAIR KAYE: No, not the ---

COURT REPORTER: I'm sorry, your microphone isn't on.

CO-CHAIR KAYE: Yes, you need to use the microphone, Anita.

MEMBER YUSKAUSKAS: Sometimes they're just services through the state plan. I know, I grapple with that all the time.

CO-CHAIR KAYE: But that's a program.

MEMBER YUSKAUSKAS: A service.

CO-CHAIR KAYE: No, it's a program. I mean, a personal care services program is a program.

MEMBER CRISP: To me it's one of the important trends we've been seeing from CMS, to have community inclusion. For example, a state cannot submit an 1115 demonstration without full community participation in the design, implementation, and evaluation of that program. And I think for us to be progressing ---

(Off mic comment)

MEMBER CRISP: I'm not saying it happens. I'm saying --- I mean, maybe none of this happens. I'm saying it should be a characteristic, though.

CO-CHAIR KAYE: All right. So, on safety you talked about dignity of risk. Now, are we --- you know, so now there's --- so, we do have --- we've been pushing under the rug the issue of safety in the sense of services delivered safely, and the person being safe, and yet that is still distinct from the sense of safety. What do we want to do with this? Do we want to put safely delivered in some sort of --- in with where, the quality of care bucket, I guess. Jon.

MEMBER DELMAN: Maybe something like opportunity for safety, or right to safety. I'm just trying to put it in the perspective of the consumer. You know, again, and I've written about this. One safety is another person's safety, and for those of us who have mental illness people tend to underestimate what we can handle and what we can do. So, you know, when you're told you shouldn't work, you don't listen because --- but that's what you're told quite a bit. So, the workforce tends to want to play it more safe than

people who are trying to self-determine and grow. So, that's just the reality, and that's the concern I share about that term. And I'm not against the concept of people having a right to be safe, but we also have a right to the dignity of risk, and to do things as any other human being would do to advance ourselves or otherwise have fun.

CO-CHAIR KAYE: All right. So, if we were to change this to right to safety and dignity of risk, would that satisfy anyone?

(Off mic comment)

COURT REPORTER: Sorry, could you turn on your microphone?

CO-CHAIR KAYE: Freedom from injury, abuse, exploitation, neglect. Ari, is that okay?

DR. LAKIN: Yes, I think that's what we're sort of talking around. I think many of us are concerned about people falling down stairs, tripping, getting hurt. And safety in other areas is sort of safety from feeling bad and being ignored by your peers. So, I think, you know,

freedom from physical harm, or freedom from injury, and then abuse, exploitation, and neglect might go together in a way that doesn't "protect" people from having --- being abused by coworkers, not abused, being neglected, ignored, made to feel bad by coworkers and so forth. I don't know but, you know, I think --- when I say safety, I'm thinking about physical safety. And I think a lot of the discussion has been about psychological safety, and ---

CO-CHAIR KAYE: Well, I mean, I think there's another issue, which is if you want to keep somebody from physical harm, you tend to want to keep them at home, and not take --- not going to a dangerous event where ---

PARTICIPANT: Many of them want to go to a place that could be considered dangerous, just like anybody else around.

COURT REPORTER: I'm sorry, I can't hear you.

MEMBER DELMAN: I'm saying, you know, a person with disabilities such as a mental

illness, may choose to go skydiving, or other things that people do that are considered dangerous, but because they're mentally ill it ---- you know, people are going to deny them, or elderly. Elderly people have the right to skydive. George Bush did it. You know, the problem with this is that families suffer around people who make bad choices. I don't think --- I think that's life. Life is full of suffering and we can't ameliorate that. People who are able to make independent decisions make bad ones. Now, you can get a guardianship, or this or that. I had to deal with this with my father, and it hasn't been easy, but he has the right. He has the right to do what he wants. If he wants to go homeless, I'll try to talk him out of it, but I can't stop him.

MEMBER NE'EMAN: So, with respect to the issue of either safety or freedom from abuse, exploitation, and neglect, I would really, again, argue for replacing safety with freedom from abuse, exploitation, and neglect, because to me

the issue is what is the duty of care from the provider? And we really want to very explicitly affirm, as Jon is really referencing here, that people have a dignity of risk. People have the right to make bad choices, and the duty of care of the provider is not to intercede when somebody who is fully informed and has full capacity makes a choice that they might disagree with.

There's a very significant difference from saying you have a duty to keep people safe versus you have a duty not to abuse, exploit, or neglect people. And the latter seems much more aligned with the values of the community-based system.

CO-CHAIR KAYE: And what about people who do ----who value safety as a personal goal, like Anita's mother, or friends of mine with OI who don't want to be dropped.

MEMBER NE'EMAN: So, what I would argue is that that speaks to neglect. I mean, if you're dropping some --- if somebody is dropping you, then you're being neglected or abused. If you

don't feel safe with your service provider, not because your service provider is going to stop you from making decisions you want to make, but because your service provider is not providing you with a quality of care that you feel like your physical safety, you know, requires, then to my mind that fits under abuse, exploitation, and neglect.

CO-CHAIR KAYE: Anita, and then Clare.

MEMBER YUSKAUSKAS: With all due respect, I think my sense is that you're looking at this very narrowly, because my mother, given her Parkinson's, has difficulty walking. Her brain and her body don't work together, and so she needs assistance in order to be safe. It's not neglect or abuse. She wants that assistance in order to have her freedom. Without that assistance, she would not have freedom.

(Off mic comment)

MEMBER YUSKAUSKAS: But that's safety.

(Off mic comment)

MEMBER DELMAN: I mean, for some people

you can't have --- I don't think we have independence in here, our choice. You can't have that without safety. I'm not minimizing that. I think a person --- part of these services --- I mean, I'm not sure how to describe it. We want to help people to feel safe. We can't convince people to feel safe. I mean, you know, we can do what we can, we can reassure them and things like that. But I'm not -- but safety is too broad a term. I mean, you're saying narrow. I think we're thinking too broad.

MEMBER YUSKAUSKAS: Honestly, there are so many different diagnostic categories that are attributed to the people who utilize home and community-based services, and what I hear you talking about is paternalism associated with services. Safety for some groups is an end goal in itself, and there are many, many, many, many people that use home and community-based services in addition to the group that I believe you're talking about.

MEMBER DELMAN: Fortunately, they get

grouped in with the rest of us. We have to find a word ----

MEMBER YUSKAUSKAS: Well, everyone is grouped together. It's a needs-based system.

MEMBER DELMAN: But we can't use a word that some groups don't like.

MEMBER OXFORD: Yes. Safety, where we see it, I guess in my provider hat, as a real big barrier is in housing, and in community integration. So, Ari can't move out of a group home because the only housing is in a bad neighborhood. So, aside from the code words and so on there, it's this idea that he wants to move out. And he knows he's only got SSI income, he knows where the housing is that he can afford, he knows that --- you know, and so on and so on, and so it becomes a real big barrier there, and also in sorts of community integration activities that adults do besides where --- what you think about them, going to the strip bar, getting drunk, you know, having sex. I mean, all these community integration things for safety is the biggest

barrier that we run into, and I don't know if it's the old health and safety in Medicaid thing that comes in, but without regard to funding source. Recently, there's been these articles about Florida and Delaware, I've seen them about these gated communities that are being built, a whole community that now we're going to have the same disability, same diagnosis kind of non-integrated housing because relatively well to do parents have figured out how to get money and the tax subsidies and so on to build these gated communities privately and so on. And, again, it's in safety, so I guess with respect to --- everyone wants to be safe as a certain level, and with some disabilities I think it becomes more of a service issue than others, is what you're trying to say. But, boy, it is such --- it's a word that is so loaded with barriers and problems that we've seen, that if we could just figure out a way to maybe satisfy the needs here without getting into safety, because I think it's going to continue to be this problem.

MEMBER YUSKAUSKAS: I agree it's a semantic issue, because I think what you're talking about is paternalism. But I also have some difficulty putting it with abuse, neglect, and exploitation, because I think safety in many regards is an end in and of itself for some people.

MEMBER NE'EMAN: So, let's instead of saying abuse, and neglect, and exploitation, let's add to that inadequate support. I mean, to my mind you've made a compelling argument that there are subgroups within the HCBS eligible population that look at safety as an important value. But at the same time, it's also been made very clear that there are other subgroups, and we can argue about who's the majority or what have you. I don't know that that's particularly productive for whom safety as a crosscutting quality characteristic would be actively harmful. To me, the point ---

CO-CHAIR KAYE: Ari, you're not going to satisfy Anita with that change. I don't think

that's going to --- I cut you off because Clare and Mary have had their cards up for a very long time. So, Clare first.

MEMBER LUZ: So, we have several concepts of safety going on, and one of them is the right to a sense of safety, to feel safe. To me, that falls under emotional health, psychological and emotional health. That's a key part of feeling emotionally healthy is to feel safe. So, maybe if we clarify it under there, that that's included there.

In terms of supports and services being provided in a safe way, I see that falling under workforce, because part of workforce is making sure we have a qualified, trained workforce. And when we train our workforce, we're training them how to deliver supports and services in a safe way. It's a key part of workforce.

In terms of choice, whether you want to take risks or not, it seems like that falls under choice, person-driven choice includes the

right to make bad choices, or risky choices.

CO-CHAIR KAYE: Yes. I was thinking of trying to propose something to the effect of changing safety --- right, taking out the sense of safety and the services safely delivered, and then safety in the bullet by itself could be changed something like control over your level of risk or, you know, control over how safe you are.

(Off mic comment)

CO-CHAIR KAYE: That satisfies Jon, but I have a feeling it might not satisfy anybody else in the room. Anita is looking unhappy.

(Off mic comment)

CO-CHAIR KAYE: Microphone, please.

MEMBER DELMAN: I guess I'm trying to look up something and it does say in this of many things, safety is defined as the control of recognized hazards to achieve an acceptable level of risk. But I do think the person has the right --- is the control --- I mean, to control hazards. I don't know. I agree. I want people to have a right to safety as they have the right to

the dignity of risk. I'm not sure, though.

CO-CHAIR KAYE: What about balancing safety against dignity of risk? Would that be a way of changing that bullet?

MEMBER DELMAN: No. Dignity of risk stands on its own.

CO-CHAIR KAYE: But we don't have dignity of risk.

MEMBER DELMAN: You're right.

MEMBER MORRISSEY: We have dignity on three, and I guess one of the things if we're talking about characteristics of a system, number two, the second bullet there, we have that bullet, and then all of a sudden we talk about all those things in that bullet elsewhere. When we talk about choice, it's the individual's choice to make good decisions, or poor decisions. Right? When we talk about person-driven, we're talking about culturally people making choices about who their care givers are. When we talk about consumer-directed and control, we're talking about what are the choices they want to

have over their resources. So, I think that is a pretty inclusive bullet that can deal with the issues of safety, and also can deal with the issues of workforce. Right?

CO-CHAIR KAYE: So what do we do about safety then? Leave it as it is?

MEMBER SMITH: My proposal, and probably nobody will like this either, but I would say safety from the perspective of the consumer, or the individual. Because I really think that's what we're talking about.

CO-CHAIR KAYE: Safety as defined by the consumer.

MEMBER SMITH: And that's, you know, that's different than this perspective of delivering services safely, et cetera. So, that's my proposal for that.

CO-CHAIR KAYE: Let's see. Safety from the perspective of the consumer. Does that help anybody? Does that sound good? Jon is happy. Anybody seriously object?

(Off mic comment)

CO-CHAIR KAYE: As a separate thing, or semicolon, dignity of risk? What do you say, safety from the perspective of the consumer.

MEMBER AUSTIN-OSER: What's the problem with dignity of risk? What's the problem with that?

CO-CHAIR KAYE: I don't think anybody objects to it.

MEMBER AUSTIN-OSER: Oh, okay.

CO-CHAIR KAYE: The question is should it be a separate bullet.

MEMBER AUSTIN-OSER: Oh, should it be a separate bullet.

CO-CHAIR KAYE: Does anybody object to dignity of risk? Should that be ---

(Off mic comment)

MEMBER SMITH: I don't think it's the same. It's not the same.

(Off mic comment)

CO-CHAIR KAYE: What if we had a bullet that was dignity of risk, safety from the perspective of the consumer?

MEMBER OXFORD: Could we add like informed ----no, never mind.

CO-CHAIR KAYE: No, let's just leave it. All right. It's not going to be perfect. We don't have to wordsmith now. Okay. So, I would like ---

MEMBER SMITH: Wait, I wasn't finished. Can I ---

CO-CHAIR KAYE: Can you hold for a second, because I want to ask Drew to add --- okay. You have physical/emotional health, including sense of safety. That's one thing. And the other thing is we took off all the stuff about workforce because there wasn't room, and now that there is room, I want to --- so, we had with workforce, we had trained, cultural competence, and safely delivered services, something like that. I mean, it's not quite what we want, but at least it captures those concepts. So, could you put those after workforce?

MEMBER DELMAN: I don't think --- dignity of risk and safety should not be in the

same line. Dignity of risk should be under choice. You can't --- I mean, they contradict each other. Dignity of risk is the right to damage yourself.

CO-CHAIR KAYE: All right. So, can we put dignity of risk under choice, and then take it out of safety?

MEMBER DELMAN: I mean, I don't ---

CO-CHAIR KAYE: Or do we not need to put --- do we need not to mention dignity of risk at all?

(Off mic comment)

CO-CHAIR KAYE: All right. So, under --- sorry to keep --- dignity of risk under choice, and safety from the perspective of the consumer is a separate item. Is that right? I think that's the best we're going to do.

MEMBER DELMAN: That's great.

CO-CHAIR KAYE: All right. This is supposed to be --- so trained, culturally competent --- workforce trained, culturally competent, adequate and ---

(Off mic comment)

CO-CHAIR KAYE: Sufficient numbers of people. All right. And we'll remember that we might want to put items about safely delivered services in there. All right. Can we go on, please? Okay.

(Off mic comment)

CO-CHAIR KAYE: Oh, I'm sorry. I'm sorry, Mary.

MEMBER SMITH: That's all right. I was patient. So, I was a little bit, or am a little concerned that, you know, eight people voted for those improved outcomes, but when we've talked about it, people say they don't know what it means. So, I'm actually wondering if improved outcomes is really that dot with community engagement all of that other stuff. And that the delivery of effective treatment is really a separate thing.

CO-CHAIR KAYE: I think so. I wonder if Andrey would be willing to take out improved outcomes and just put effectiveness and quality

of care.

MEMBER OSTROVSKY: I think that's totally fine. I think it will be important to keep in mind, and we actually may cover it with integrated --- the part about integrated system.

CO-CHAIR KAYE: Right.

MEMBER OSTROVSKY: I just want to make sure that we can have a clear bridge between what home and community-based services can do and its impact on morbidity, mortality, and other valued outcomes that the medical provider/payer systems look at as valuable. Because I don't want to disconnect us from that, because I do think that would be a really important key to sustainability. So, I think the way you framed it is great. And a lot of these things are outcomes, I mean in many cases outcomes focused, so that's, I think very appropriate.

MEMBER SMITH: Us behavioral health people have that mortality and morbidity concern to them.

(Off mic comment)

CO-CHAIR KAYE: Oh, I'm sorry. Mary, since I cut you off before, are you done? I apologize for forgetting.

MEMBER SMITH: Well, let me think. Yes.

CO-CHAIR KAYE: Okay, thank you. And sorry for not getting back to you. Okay. Mike, do you have to say something now, or can you wait until --- okay, wait until -- Patti and Sandy have their cards up.

MEMBER KILLINGSWORTH: Now that we've agreed to delete something from the list, I just --- I'm a little concerned about us taking out the whole notion that a high quality system should not result in people achieving the outcomes that are important to them. Right? And I'm not sure that's implicit in all of these other things.

CO-CHAIR KAYE: Focused on individual goals ---

MEMBER KILLINGSWORTH: We talk about being focused on individual goals, but being focused on them and achieving them are two very

different things. So, I am a little worried about that. Just want us to think that through before we drop it off the list.

MEMBER OSTROVSKY: What if you just call it achieving individual goals, because that's measurable, or we could create measures around that. It's not just how well are we focusing on it, but how well are we actually helping people achieving ---

MEMBER KILLINGSWORTH: I agree. I like that better.

(Off mic comment)

MEMBER KILLINGSWORTH: I just don't want to lose the notion that what we really want to get to is not just that we focus on them, but we actually achieve them.

MEMBER OXFORD: I was actually thinking improved outcomes was more of a system thing. So, you go to the emergency room less, you get sick, your weight gain, or your weight loss gets better, those kinds of things, that's what --- I mean, heck, I thought I knew what it meant, but

apparently --- so, I was not thinking of like that on the individual level at all. I was thinking of that whole line as a system.

MEMBER OSTROVSKY: I think that's covered under --- alluded to in quality of care and effectiveness, and also under achieving individual goals, because we're getting at systems and individual levels. And, I mean, outcomes I think really it's just a distinction. Like are we talking about structural measures, process measures, outcome measures, and then a lot of these do fall under the outcome domain. And I think to put it into context, this is the high level framework. Whatever quality measures get developed can get at the issues you're addressing, which I think is important. Like ED utilization may be, or some reference to it could be very important to measure as part of HCBS quality measurement, but it will be --- it has to be appropriately contextualized. And I think we speak to that --- those types of --- we leave room for those types of measures the way this is

set up.

MEMBER OXFORD: So, you're talking about like the chart that we're going to draw, and I was actually thinking about the services.

CO-CHAIR KAYE: Right. So, we're taking out improved outcomes. Right? All right. So, got it. Who else has their --- Sandy, do you still? Yes. Patti, are you still waiting?

MEMBER KILLINGSWORTH: No, sorry.

MEMBER MARKWOOD: On the physical/emotional health, I would include and well-being, because that was --- I think that that needs to be in there. Also, back on the next to the last bullet on health disparities, I still believe it should read equitable system, fairness of resources, and eliminate disparities, and disparities period, not just health disparities.

CO-CHAIR KAYE: Okay. Equitable system, fairness of resources, eliminate disparities. Yes.

MEMBER MARKWOOD: Yes, fairness of distribution of resources, eliminate disparities.

CO-CHAIR KAYE: Okay. Is wellness okay for the --- I mean, we took out well-being before, and now we're putting it back in, but in a different place. Is this okay? Anybody object to that? Thumbs up from Gerry. Nobody is saying no. Ari, do you still want to comment?

MEMBER NE'EMAN: Oh, no. I'm fine.

CO-CHAIR KAYE: Lorraine wanted to --- has her card up.

MEMBER PHILLIPS: Yes. And I'm not sure exactly where this should go, but I appreciate the long conversation on safety. I agree with what's on the screen. I'm not sure it encompasses safety in the sense that --- from the perspective of the consumer. The consumer may not recognize when there is an omission, or error in care. And the event occurs, and then the realization comes that they were not safe. I'm not sure how to include that, but I think safety is a bigger issue than is portrayed.

CO-CHAIR KAYE: So, we have --- we explicitly have safety twice, and we implicitly

have it a third time. The third being workforce --

MEMBER PHILLIPS: Right.

CO-CHAIR KAYE: You know, to safe services, but that's still different --- I mean, you're talking about safety as kind of a subset of quality of care, so that the care is ---

MEMBER PHILLIPS: I am, so maybe that's where it needs to come later.

CO-CHAIR KAYE: Is that --- is it okay to leave it like that and make a mental note that it's ---

MEMBER PHILLIPS: Yes.

CO-CHAIR KAYE: That we want, you know, safety in the sense of care --- and that's also neglect kind of thing, too.

MEMBER PHILLIPS: Well, it's also workforce training, and accountability, and responsibility.

CO-CHAIR KAYE: Okay. Kimberly, do you ---

MEMBER AUSTIN-OSER: So, I have a

question. I'm looking over this, "A high quality HCBS system has the following characteristics." And we don't actually have any kind of verbs or whatever, but it's kind of like a system that honors or is centered around choice, person-driven, focused, that sort of thing. One of the things I don't see, and maybe it's just kind of implicit, and that is that --- has the following characteristics of delivering the right service at the right time, and the right place. And all this stuff is really talking about service delivery, how it gets delivered, but we don't say anything about the service delivery. And maybe that doesn't matter, but to me, if I'm kind of a lay person, I'm not familiar, I'm looking at a high quality HCBS has the following characteristics, has all these characteristics, but it doesn't say anything about the actual service delivery, which to me is --- when you were talking, Anita, about safety, that's what your mother needs. She needs services that keep her safe, that keep her from falling, that keep

her -- and that's a part of her plan. It should be a part of a person-centered plan that's built around her needs. But when I was looking on here, I'm like I don't see it anywhere, and maybe it's just a given, but --- and then the other thing is around workers. I'm not necessarily saying that it's on here, but we're very consumer-focused, and I think that's important. But we have kind of another group of folks in this picture, and I'm hoping that we'll be able to deal with it in the workforce relation, or the workforce component, about them being well supported, or whatever.

We're also talking about in many ways whether it's a family care giver or a workforce, kind of a marginalized group of people, and it's not always safe for them either. So, we're talking about safety for mom, but the training is so important so workers have some safety, some safeguards in place for them, as well. And that's just something that's been stuck in craw, I want to get out there.

CO-CHAIR KAYE: Patti, could you turn

your microphone off, please. So, do we want to add safe after the colon in workforce, or injury, you know, injury prevention, or something?

MEMBER AUSTIN-OSER: I mean, we could, but then I feel like we're starting to get really specific.

CO-CHAIR KAYE: Yes, I know. I do, too.

MEMBER AUSTIN-OSER: I'm fine saying like a well supported, adequate workforce, because then I feel like when we start having the conversation, what does that mean?

CO-CHAIR KAYE: Okay.

MEMBER AUSTIN-OSER: And we can --- we get into things like wages, and safety, and training, and you know, that sort of thing for them, so I don't feel like we have to get that detailed. But I love culturally competent workforce, that goes to training, in my opinion, also goes to reflecting the cultural diversity of our workforce, as well as the cultural and other diversity, you know, other aspects of diversity of the folks that we're supporting, and all that

sort of thing.

CO-CHAIR KAYE: All right. Ari Houser, and then Ari Ne'eman, and then Anita.

MEMBER HOUSER: To answer the issue that was recently brought up, there actually are two bullet points that are about services which don't have services written in. In the middle where it says accessible, sufficient, and dependable we might want to say services are accessible, sufficient, appropriate, and dependable.

CO-CHAIR KAYE: I support that. Any objections to that? So, services are appropriate, accessible, sufficient, and dependable, or you had --- no, no, not a separate bullet. Under where it says accessible down below. Services are at the beginning, no, at the beginning. Services are accessible, appropriate. Okay. And what else were you going to say?

MEMBER HOUSER: I think in the top bullet when it says effectiveness, that's actually effectiveness of services.

CO-CHAIR KAYE: Why don't we change that, effectiveness of services, quality of care. Okay. And Ari Ne'eman. You're done, right?

MEMBER HOUSER: Yes.

CO-CHAIR KAYE: Okay. Ari Ne'eman.

MEMBER NE'EMAN: Let me just pause briefly to communicate in response to Kimberly's point. I certainly agree that the quality and adequacy of the workforce is an important sort of instrumental issues towards insuring other quality outcomes that we care about. At the same time, I want to express sort of preemptively, because I'm sure we're going to have this discussion down the line, that I would be very concerned, and I think a number of other people would be very concerned about looking at workforce outcomes, or worker outcomes as measures of HCBS quality, particularly if it involves minimum training requirements, or a set of requirements around worker safety that would seem to subject people's homes or residences to a set of rules that, you know, are perhaps

appropriate for a workplace, but don't acknowledge that at the end of the day people live there. So, I mean, I think there is always a natural tension between disability and labor advocates on this issue, and I'm sure we'll have the opportunity to engage and find appropriate middle ground. I just want to express the likelihood of us needing to reconcile that down the road.

CO-CHAIR KAYE: Yes. Could we please not get into that debate now. And Anita, and I wonder, Clare, are you still waiting, or is that from before? Okay. No, first, Anita.

COURT REPORTER: I'm sorry, ma'am, your microphone isn't working.

MEMBER YUSKAUSKAS: I'd like to propose a change based on what Kimberly said before, which is a high quality HCBS system provides the right services to the right person at the right time, every time, and has the following characteristics. Is that where you were going with that, because that's sort of how I heard it.

And it seems like that might be a really sort ---

CO-CHAIR KAYE: No.

MEMBER YUSKAUSKAS: No? You don't like that.

CO-CHAIR KAYE: No. I mean, we could put --- we could have it in there, but I don't want to just, you know ---

MEMBER YUSKAUSKAS: Okay.

CO-CHAIR KAYE: I'm not sure that's the top thing. I mean, that gives it a huge heft.

MEMBER YUSKAUSKAS: Well, yes. And I think the reason that I did suggest that is because we're still keeping high quality in there, so that's a high bar to meet.

MEMBER AUSTIN-OSER: While I appreciate that, I wasn't suggesting that it change the kind of the top header. And I'm not even necessarily thinking that we have to have it in as a bullet. And I feel like services are accessible, appropriate, sufficient, dependable, effective, and high quality. I'm not sure what quality of

care means. I like right services, right time, right place, but that means different things to different people. And I'm thinking about it very broadly, but I think that we probably have the essence of what I was talking about covered. But I also --- I see where you're coming from.

CO-CHAIR KAYE: Okay. Clare.

MEMBER LUZ: So, right services would be appropriate, appropriate covers that. Right? Right time, could we just add the word time, services are accessible, appropriate, timely?

CO-CHAIR KAYE: Yes.

(Off mic comment)

MEMBER LUZ: Okay. And then back to your point about workforce, and I really respect Ari and Mike's viewpoint over here, but I would like to see, or have the group entertain a thought of having workforce training, culturally supported, adequate and supported, because we don't want them getting hurt, or working for $6 an hour.

CO-CHAIR KAYE: Is that okay,

culturally --- trained, culturally competent, adequate and supported?

MEMBER LUZ: I think you said well supported, adequate numbers and supported, you know.

(Off mic comment)

CO-CHAIR KAYE: Same as it was --- same as it is already, workforce: trained, culturally competent, adequate, and supported.

MEMBER LUZ: I mean, I think if we're going to look for social justice, or equitable system, social justice for consumers we want social justice for everybody.

CO-CHAIR KAYE: Right. But you know there's an ongoing war about this.

MEMBER LUZ: Yes, I know that.

CO-CHAIR KAYE: Right.

MEMBER LUZ: And it's --- I'm sorry. I don't want to ---

CO-CHAIR KAYE: I'm fine with everything in there except for trained. And if we define that a little bit more, I'd feel more

comfortable with it.

MEMBER LUZ: Well, that's ---

CO-CHAIR KAYE: All right. Well, you --- okay. I understand, but let's not address this now.

MEMBER LUZ: So, just one last thought. I think it's implied in all of this, but all of our discussions have been around people who are capable of making decisions on their own, and I don't know if we need to more blatantly address people with dementia, or people who are not able to make decisions on their own?

CO-CHAIR KAYE: And how would you do that?

MEMBER LUZ: I'm not sure. Maybe, you know ----in the earlier rendition of this we said these services would be for everybody regardless of age, or mental cognition. We had some qualifiers in there, and if we just added something like that.

CO-CHAIR KAYE: Right, and we probably will have that in the --- I mean, this is --- so,

one of the purposes of this is to have this below the general definition of what HCBS is. And I think we probably will have the different types of disabilities that are served. Right? But that may not fully address what your concern is.

MEMBER LUZ: Well, I think if --- I think somewhere we said individuals of their proxy was in there somewhere.

CO-CHAIR KAYE: Right. Okay.

MEMBER LUZ: Which sort of covered it, didn't it?

CO-CHAIR KAYE: Can we put that in the ---

MEMBER LUZ: I don't know if it covered it sufficiently enough for everybody, but that's one way of at least addressing it.

CO-CHAIR KAYE: Okay. So, now there's the question, we have, I believe, 13 bullets here. And 13 bullets is not necessarily too much. I would prefer half that many, something like that but, I mean, that's just me. Do we --- I mean, as Sarah Lash said, I mean, we seem pretty

wedded to most of these. Do we need to --- should we vote? If we voted we would be effectively prioritizing them, and that might be useful for our later --- for later use. I mean, we could list them in order of priority, if we wanted to. If we don't vote then that's the statement that we're pretty happy with these 13. Ari.

MEMBER HOUSER: I think that it would be a useful exercise to vote, whether or not we decide to include all 13, just to get a sense from ourselves, you know, if --- you know, right now we have 13, and clearly some are higher priority than others in general.

CO-CHAIR KAYE: Right.

MEMBER HOUSER: But we don't necessarily know --- we may have a vague sense, but not a statistical sense, and it may be that there's, you know, a clear dividing line on some subset, or there may not be.

CO-CHAIR KAYE: Okay, I kind of agree with you. What do you think, Sandy?

MEMBER MARKWOOD: I'm just wondering --

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CO-CHAIR KAYE: Can you use the microphone? Turn off your microphone, please, Mary.

MEMBER MARKWOOD: If we want to vote on these or if there is a way just to do something so we're prioritizing them.

CO-CHAIR KAYE: That's what we're going to --- we're going to put stickers on the ---

MEMBER MARKWOOD: Okay.

CO-CHAIR KAYE: --- board up there, and you can put as many stickers as you want as indication of your priority. And we may decide to cut or consolidate the ones that are less, that are lower priority, or maybe decide to list --- you know, maybe we'll --- I mean, this could be --- in addition to having these as characteristics of the system, we might --- the idea would be to start to use this to help us form what the domains of quality are, and we may decide that some of these don't belong there, or some of these get wrapped up into other things,

or something like that. So, we may not want 13 high-level quality domains. Mary.

MEMBER SMITH: So, I'm going to present the other side. It seems to me that we've spent like three hours wordsmithing each and every one of these. I don't think there's not one that we've talked about in excruciating detail sometimes. So, I guess I'm really not sure again why we ---you know, we can't just go with these as critical things that this group sees as important to HCBS services.

CO-CHAIR KAYE: Well ---

MEMBER SMITH: I mean, what's the burning need to prioritize them?

MEMBER OXFORD: Well, in a little bit different angle, I'm sensing there's also a certain level of frustration and feeling like we just need to move, to move with some of this in terms of finalizing things. And maybe it would be best just to say, you know what, that's a good list, we've worked it real hard. Maybe it should just simmer a little while and this, I think,

captures --- I agree with Mary, including the fact that continuing to work this thing after all this time, and including with the frustration I'm beginning to sense around maybe wouldn't be helpful.

CO-CHAIR KAYE: Okay. I mean, we're only talking about taking five minutes and everybody get up to the board and vote, so it's not a big deal.

(Off mic comment)

CO-CHAIR KAYE: Let's just do it? Okay. So, take --- so, you have 10 --- so use 10 stickers, use them any way you want. The colors don't mean anything. Stick them on to the items that are up there.

MS. LASH: Ten dots, no more, no less.

CO-CHAIR KAYE: Okay. Please use 10 stickers. You don't want to use all 10 of your stickers, that's fine, but try not to use 15 of them, Ari Ne'eman.

(Whereupon, the above-entitled matter went off the record at 4:12 p.m. and resumed at

4:22 p.m.)

CO-CHAIR KAYE: Okay. Well, we've got quite a range. There are two items that have --- two bullets that have 23 votes, one that has 22, and that at the other extreme there's one that only has five, so there's quite a range of stuff. And I think we'll talk about that tomorrow morning, and you're going to go to public comment. Right?

MS. LASH: Right. So, thank you, everyone, for a very productive and long day. We're going to redo some of the agenda so that we begin tomorrow with a thorough recap of some of the things we've decided on today, including sort of the results of this prioritization exercise, and what we think it tells us about potential measurement domains.

A reminder that there is a dinner reservation made on behalf of the Committee tonight at 6:00. You can speak to Nadine for more details. And we will take one last round of public comment before we adjourn for the day.

Anyone in the room?

MS. BOGENREIF: Hi, my name is Jennifer Bogenreif, and I work for the American Occupational Therapy Association in their Regulatory Affairs Department. And I just --- it's been very interesting discussion, and the whole issue about safety, it seems to be a hot topic. I just --- the huge problem with falls risk that we see as occupational therapists is so huge, and it leads to re-admissions and re-hospitalizations, and it would prevent people from being able to be in their home, which is what they truly want. So, I just urge everyone to really think about safety in that way, because it's extremely important in this setting, in this whole area. Thanks.

MS. LASH: Any public comments from the phone?

OPERATOR: Okay. Once again, to make a public comment please press star one. You have a comment from the line of James Gallant.

MS. LASH: James, if you could be

brief, please go ahead.

MR. GALLANT: Yes, James Gallant, again. Actually, under the part about --- you were talking about the abuse, neglect, and exploitation part, I would recommend you use actually the quote out of the Developmental Disabilities Act of 2000. And it says that, "A person should live free of abuse, neglect, exploitation, and violations of their legal and human rights," which kind of covers the whole gamut of all of it. And because, you know, the example that I gave about the family and custody and parenting rights that, you know, it's a human right, a child has a human right to their family and people, to their family, they have a human right to that. That's under the UN Conventions, and their legal rights, and it kind of wraps it all up there.

And, also, I would ask you to please come together as a group and contact the author of a book called, "Roberts Rule of Order for Dummies," and he's a qualified parliamentarian.

He's the Louisiana Senate's parliamentarian. And in the book, the back of the book he's got his telephone number. And I've already contacted him, and he said yes, he'd give you a free quote on writing a report, and figure out where you're at now on the parliamentary part of it, you know. I mean, somebody appointed this group. There are some rules, and you could just lay it out. And like you said about the nominating committee, to have the stakeholder missing from this meeting, and like the Action Alliance for Suicide Prevention is also missing, as a parliamentarian, somebody keep track. So, it's not --- you know, and you get sidetracked here and there, and different opinions, to get an actual opinion of a qualified parliamentarian would be important. And I'm assuming that it would probably, you know, change the face of what's happening here before you get too far into it. And thank you very much.

MS. LASH: Any other comments from the phone?

OPERATOR: There are no comments at

this time.

MS. LASH: All right. And we thank everyone that submitted written comments on the web. We'll be making a summary of those for the Committee's review. We appreciate everyone's attention and efforts today, and we'll see you in the morning.

(Whereupon, the above-entitled matter went off the record at 4:27 p.m.)

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C E R T I F I C A T E

This is to certify that the foregoing transcript

In the matter of: Addressing Performance Measure Gaps in HCBS To Support Community Living

Before: NQF

Date: 04-29-2015

Place: Washington, D.C.

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