

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

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

2 (9:03 a.m.)

3 DR. WILSON: Good morning, everyone.

4 My name is Marcia Wilson. I'm Senior Vice
5 President of Quality Measurement here at NQF and
6 I'd like to welcome you all, all of you in the
7 room here in D.C., and a number of people who
8 have joined us via the web.

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

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

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

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

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

1 Consensus is about being collaborative.

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

14 (Laughter)

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

1 for a number of years.

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

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

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

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

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

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

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

1 what's already out there in our state universe.

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

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

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

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

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

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

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

1 the state.

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

7 I've been very involved with self-
8 direction and control of services for many
9 decades and kind of preaching that around the
10 country and worked at the state level in the late
11 '80s to pass state law that gives people in our
12 state a right under state statute to direct and
13 control their services.

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

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

1 people with disabilities in disability policy.

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

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

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

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

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

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

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

20 (No response)

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

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

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

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

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

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

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

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

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

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

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

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

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

19
20 We've already asked you to work
21 together as a group to craft consensus in a
22 really active way on these complex issues, and

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

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

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

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

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

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

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

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

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

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

19 And with that, let's get going.

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

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

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

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

1 you all have submitted.

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

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

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

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

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

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

22 So, in the packet of materials on your

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

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

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

22 In terms of the what, we heard that

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

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

1 other challenges participating in community life
2 or accessing needed services.

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

3 So, for example, I mean, my mother is
4 91 years old. I'll use her as an example,
5 without her permission. She has modest
6 functional limitations and doesn't do as many
7 things as she used to, but I don't think she's at
8 risk of institutionalization. She's always hired
9 somebody to clean her house. I mean, I don't see
10 anything in this -- I mean, it's very self-
11 directive. She gets to hire and fire the person,
12 and does. And I don't see anything in here that
13 says that that is not HCBS, and yet I wouldn't
14 think it is because she's always had it. It's
15 not essential to her, I think. And if it is HCBS
16 because she's 91, then when did it become HCBS?

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

1 You're facilitating. Ari has raised
2 his hand.

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

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

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

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

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

12 CO-CHAIR CALDWELL: Ari?

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

15 (Laughter)

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

22 I would tend to try to have as few

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

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

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

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

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

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

1 saying at risk for institutionalization?

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

13 MEMBER LUZ: Okay.

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

22 MEMBER LUZ: Right. Which plays to

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

11 CO-CHAIR CALDWELL: Good question.

12 Yes.

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

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

20 (Laughter)

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

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

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

1 bucket? I'll just throw that out there.

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

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

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

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

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

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

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

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

4 (No response)

5 CO-CHAIR KAYE: Yes, okay.

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

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

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

1 quality.

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

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

8 (Off mic comment)

9 MEMBER PHILLIPS: Right. Right.
10 Right. Yes.

11 (Off mic comment)

12 PARTICIPANT: Can you use your
13 microphone?

14 MEMBER PHILLIPS: Exactly. Yes.

15 MEMBER DOBSON: I think what Lorraine
16 is --

17 MEMBER PHILLIPS: Yes.

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

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

1 MEMBER DOBSON: Of those --

2 MEMBER PHILLIPS: -- important to the
3 definition.

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

7 MEMBER PHILLIPS: Right.

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

11 (Simultaneous speaking)

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

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

18 MEMBER PHILLIPS: Or choosing the
19 measures that --

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

22 MEMBER PHILLIPS: -- could then be

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

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

10 MEMBER HOUSER: I have a few.

11 CO-CHAIR CALDWELL: Go ahead.

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

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

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

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

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

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

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

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

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

5 MEMBER GALANTOWICZ: Sure. Thanks.

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

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

22 MEMBER MOHANTY: Yes, just a couple of

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

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

1 think that's something to consider.

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

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

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

1 HCBS should be.

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

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

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

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

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

15 CO-CHAIR CALDWELL: Kimberly?

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

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

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

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

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

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

3 One of my other comments. I share the
4 concern that in the first line -- well, I don't
5 know if "concern" is the right way to say it, but
6 that in the first sentence we are actually saying
7 it's an array of services, and then we're saying
8 what it's not mostly, and that's non-medical.

9 And I'd like to see that just not mentioned at
10 all, because while I do believe -- and I came up
11 strongly believing in the social model HCBS
12 system and totally understand why it's important
13 for us to have a system that isn't completely
14 medicalized and dominated by a medical model. I
15 think that if we're looking at this holistically,
16 it needs to include a rich array of services that
17 include medical; and saying it's predominantly
18 not that is just not helpful to me, and as a kind
19 of standard definition.

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

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

3 And did you have something?

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

6 (Simultaneous speaking)

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

9 (Laughter)

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

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

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

4 I think Sandy wanted to weigh in.

5 MEMBER MARKWOOD: Yes, thank you.

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

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

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

1 sentence out.

2 CO-CHAIR CALDWELL: Clare?

3 MEMBER LUZ: Just two brief comments.

4 On the last sentence -- I'll start with the last
5 sentence. I agree with Ari about the "through
6 measurement and reporting of quality and
7 outcomes," but I hesitate to throw the entire
8 sentence out because it also addresses
9 accessibility and affordability, and the services
10 aren't any good to us if we can't access them or
11 afford them. So it seems like we should keep
12 those concepts in somewhere.

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

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

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

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

1 services. That would be number one.

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

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

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

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

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

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

5 (No response)

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

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

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

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

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

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

1 (Laughter)

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

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

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

4 I'd actually like to raise one more
5 definitional issue, if I may, and it's in
6 relation to the point No. 4 in brown, the "and
7 safely delivered in a home or integrated
8 community setting of the consumer's choice."

9 This seems to be getting at something that I
10 think is very important to the definition of
11 HCBS, and that is an acknowledgement that system-
12 wide issues and system performance has a role in
13 determining whether or not something is or is not
14 HCBS, even regardless of the particular model or
15 quality of an individual provider.

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

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

10 CO-CHAIR CALDWELL: Okay.

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

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

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

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

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

1 system that's often unavailable and not helpful.

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

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

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

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

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

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

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

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

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

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

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

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

1 (Laughter)

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

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

22 MS. LASH: I think we would suggest

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

14 CO-CHAIR CALDWELL: All right.

15 Kimberly has a question or --

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

1 conversation about this or something.

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

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

21 CO-CHAIR KAYE: So should we use our
22 20 minutes that we have left to sort of try make

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

7 (No response)

8 CO-CHAIR KAYE: All right.

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

19 CO-CHAIR CALDWELL: Good point.

20 Patti?

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

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

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

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

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

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

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

22 MEMBER LAKIN: I was going to suggest

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

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

14 MEMBER LAKIN: Well, mine.

15 CO-CHAIR CALDWELL: Yours, of course.

16 (Laughter)

17 MEMBER LAKIN: No, I don't know.

18 There are a lot of them. And Ellen and many
19 others who aren't around this table submitted
20 good -- mine just said, "Home and community based
21 services are paid and unpaid," my printer was
22 running out of -- "services and supports provided

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

12 CO-CHAIR CALDWELL: Okay. Good.

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

3 And then I do think we have a series
4 of principles that are laid out here that we've
5 talked about: person-driven, paid and unpaid.

6 And I think we could come up with a list of those
7 principles that I think would get at the point of
8 being able to very clearly explain what we're
9 talking about. And they are principles. Because
10 you can have home and community based services
11 that is not consumer-directed. You can have it
12 be -- I mean, there are a lot of things you could
13 have. So I think we are establishing a set of
14 principles, and I really like pairing them with
15 that definition. And I think we're pretty close
16 to being able to do that.

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

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

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

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

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

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

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

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

5 So, Ari, did you have --

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

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

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

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

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

8 CO-CHAIR CALDWELL: Okay. And, Clare?

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

13 CO-CHAIR CALDWELL: Okay.

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

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

22 MEMBER LUZ: Principles and qualifiers

1 are going to go together?

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

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

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

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

1 that to more discrete topics for measurement.

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

5 (Laughter)

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

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

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

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

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

4 CO-CHAIR CALDWELL: Yes.

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

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

9 (Laughter)

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

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

17 (Laughter)

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

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

1 a break and potentially public --

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

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

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

14 (No response)

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

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

20 MS. LASH: Please go ahead.

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

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

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

17 OPERATOR: Yes, his line disconnected.

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

22 Are there others in the queue?

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

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

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

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

16 MR. GALLANT: Yes, I would. Okay.

17 MS. LASH: Go ahead. Thanks.

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

1 for people's rights, I learned that the DD Act of
2 2000 insures that people with developmental
3 disabilities, it's a little bit like three
4 violations of their legal and human rights. And
5 it appears that in your draft definition, that
6 piece about legal rights has been excluded.

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

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

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

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

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

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

22 And if you leave that in, or put that

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

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

18 MS. LASH: Thank you, James.

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

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

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

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

1 We'll distribute them in full to the Committee.

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

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

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

20 MS. LASH: Great, thank you.

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

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

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

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

1 standardization of electronic records in LTSS.

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

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

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

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

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

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

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

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

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

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

22 And then the other one is a framework

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

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

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

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

1 political, economic factors.

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

22 So, now we're going to quickly move

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

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

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

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

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

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

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

20 CO-CHAIR KAYE: And so?

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

1 first question.

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

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

7 CO-CHAIR KAYE: Okay.

8 MEMBER YUSKAUSKAS: Sorry.

9 CO-CHAIR KAYE: Mike, and then Charlie.

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

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

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

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

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

1 and community-based services.

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

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

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

21 CO-CHAIR KAYE: Sara, and then Sarita.

22 MEMBER GALANTOWICZ: You know, I agree

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

13 MEMBER SMITH: Well, that's ---

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

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

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

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

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

22 Who the --- the framework, itself,

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

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

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

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

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

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

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

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

18 MEMBER SMITH: Mary.

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

1 the significant damage that the standardized
2 assessment has caused, and other efforts to try
3 and sort of mush together the aging community,
4 the physical disability community, and the IDD
5 community has caused in the past. And, you know,
6 in terms of the framework, I think we can define
7 that broadly, but the more that we get down from
8 10,000 feet into the weeds, there I think we need
9 to be able to begin to look at things at least to
10 some degree on a population by population basis,
11 with some common principles, and probably even
12 some common measures between them.

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

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

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

9 (Off mic comment)

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

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

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

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

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

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

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

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

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

20 MEMBER DOBSON: Yes.

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

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

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

19 CO-CHAIR KAYE: Interesting. Mike?

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

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

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

1 develop a framework, I think, that makes sense.

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

1 conversation about that, too.

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

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

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

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

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

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

22 There was, certainly --- and it,

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

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

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

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

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

22 CO-CHAIR KAYE: Yes.

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

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

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

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

1 community do you need to be in place?

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

15 CO-CHAIR KAYE: This side first.

16 Kimberly, Anita, Charlie --- oh, earlier I said
17 Ari was going to go next, so Ari, and then
18 Kimberly.

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

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

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

14 And I think there's a couple of
15 different ways that we can parse quality into
16 domains. And those different ways of parsing it
17 would suggest different frameworks. So, that's
18 where I'm at. I want to know the boxes, so I can
19 ---

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

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

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

1 interface with this on those multiple levels.

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

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

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

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

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

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

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

17 MEMBER DOBSON: Measure consumer
18 satisfaction.

19 CO-CHAIR KAYE: Yes, and I also --- I
20 mean, consumers also have to be able to choose --
21 -

22 MEMBER DOBSON: Right. I don't want to

1 use that word.

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

4 MEMBER DOBSON: Right.

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

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

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

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

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

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

3 MEMBER YUSKAUSKAS: Yes. Back about
4 2000, maybe even before, Congress directed CMS to
5 do a survey because they were grappling with the
6 same issues that all of us are, and I think there
7 are probably some people in this room who might
8 remember the HCBS Quality Framework; Suzanne,
9 Bob, Sara, Gerry, and on and on.

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

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

22 CO-CHAIR KAYE: Okay, thank you. Those

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

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

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

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

1 my ---

2 CO-CHAIR KAYE: Yes. Okay. What else?

3 Anybody want to add?

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

19 CO-CHAIR KAYE: Andrey?

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

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

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

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

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

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

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

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

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

22 We can understand high quality support

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

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

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

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

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

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

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

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

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

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

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

1 (Off mic comment)

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

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

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

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

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

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

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

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

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

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

21 CO-CHAIR KAYE: So ---

22 MEMBER OXFORD: At the individual level

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

3 CO-CHAIR KAYE: And what is your
4 emphasis?

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

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

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

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

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

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

4 CO-CHAIR KAYE: No.

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

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

18 MEMBER DELMAN: The core values.

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

22 MEMBER DOBSON: Yes, I want to speak

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

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

1 mean to amend?

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

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

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

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

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

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

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

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

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

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

22 OPERATOR: Yes, ma'am. You have a

1 comment from James Gallant.

2 MS. LASH: Please go ahead.

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

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

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

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

9 OPERATOR: No, there are no other
10 comments.

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

18 COURT REPORTER: Could you turn your
19 mic on.

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

22 MS. LASH: Okay. I guess I welcome

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

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

10 MEMBER NE'EMAN: Just really quickly.

11 MS. LASH: Yes.

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

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

18 MEMBER NE'EMAN: Great, great.

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

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

1 1:20 p.m.)

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

12 PARTICIPANT: Where are we going?

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

16 PARTICIPANT: Okay.

17 (Off mic comment)

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

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

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

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

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

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

1 the essence of person-centeredness, I think.

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

16 CO-CHAIR KAYE: Okay. Gerry.

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

22 CO-CHAIR KAYE: Okay. Camille.

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

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

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

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

10 CO-CHAIR KAYE: Okay.

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

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

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

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

22 MEMBER DELMAN: I'm a little concerned

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

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

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

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

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

1 her; safety is important.

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

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

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

3 PARTICIPANT: Microphone, please.

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

11 (Off mic comment)

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

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

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

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

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

18 MEMBER HOUSER: Has them separate.

19 CO-CHAIR KAYE: What?

20 MEMBER HOUSER: Has them separate.

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

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

3 CO-CHAIR KAYE: I see. Okay.

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

7 CO-CHAIR KAYE: Interesting.

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

16 CO-CHAIR KAYE: Okay.

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

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

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

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

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

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

9 CO-CHAIR KAYE: Thank you, Charlie.

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

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

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

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

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

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

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

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

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

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

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

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

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

4 MEMBER LUZ: Right.

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

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

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

17 MEMBER LUZ: Yes.

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

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

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

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

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

22 MEMBER APPLEBAUM: You know, possibly.

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

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

8 (Off mic comment)

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

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

1 safe.

2 CO-CHAIR KAYE: Right.

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

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

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

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

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

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

22 CO-CHAIR KAYE: All right. We have a

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

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

8 CO-CHAIR KAYE: Go ahead.

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

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

12 In general, as I look at this list of
13 core values, and this is going to be a little
14 hard. I think what's missing, or a big area
15 that's missing is sort of real specifically ---

16 and I wouldn't know how to generalize it, but to
17 make sure that a core value is that having fun is
18 a real, real important thing. And it's not in
19 community engagement. I mean, so as I look at
20 kind of the way we're possibly thinking there is
21 integration. Well, that's a program, that's
22 something that we would do to make sure someone

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

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

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

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

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

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

18 ---

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

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

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

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

12 MEMBER OSTROVSKY: Thank you, guys. I
13 was just furiously going through my references
14 that I've written or alluded to in papers before,
15 because I think this notion of value and cost,
16 and outcomes relative to cost is cost part of
17 value, and all this getting down to being about
18 the consumer. So, you know, Michael Porter had --
19 --again, not to get academic, but I actually
20 think this is one of the better ways to balance
21 being consumer-centered, but also thinking about
22 the system, the health care system. And he

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

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

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

5 MEMBER OSTROVSKY: Okay.

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

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

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

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

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

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

19 CO-CHAIR KAYE: I would value
20 effectiveness before I value efficiency. Can I --
21 -

22 MEMBER SMITH: I was a little puzzled

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

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

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

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

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

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

1 CO-CHAIR KAYE: Yes.

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

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

6 MS. LASH: Separate?

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

10 (Off mic comment)

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

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

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

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

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

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

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

9 CO-CHAIR KAYE: You mean an equitable
10 system.

11 MEMBER MOHANTY: Yes.

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

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

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

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

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

17 MEMBER HOUSER: I don't know.

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

22 MEMBER HOUSER: I think appropriate

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

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

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

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

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

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

22 CO-CHAIR CALDWELL: Yes, I wanted to

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

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

22 DR. LAKIN: I can't answer that

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

6 CO-CHAIR KAYE: Kimberly.

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

1 -

2 CO-CHAIR KAYE: Exactly.

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

4 or ---

5 CO-CHAIR KAYE: Yes.

6 MEMBER AUSTIN-OSER: --- get it in

7 different buckets.

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

12 MEMBER MARKWOOD: Sorry, no.

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

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

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

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

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

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

14 CO-CHAIR KAYE: Right.

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

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

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

1 person-centeredness, self-directness.

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

4 MEMBER AUSTIN-OSER: Not really.

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

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

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

18 PARTICIPANT: Yes.

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

1 (Off mic comment)

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

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

15 (Off mic comment)

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

21 (Off mic comment)

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

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

9 (Off mic comment)

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

13 MS. LASH: I might suggest that ---

14 CO-CHAIR KAYE: Workforce.

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

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

22 (Off mic comment)

1 CO-CHAIR KAYE: Use your microphone,
2 please.

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

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

15 MEMBER DELMAN: Sorry. Characteristics.

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

18 MEMBER DELMAN: All right, never mind.

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

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

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

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

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

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

3 CO-CHAIR KAYE: Except that when we sat
4 down and came up --- and started drafting the
5 list, we started with this, and tried to capture
6 ---

7 MEMBER DOBSON: Okay.

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

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

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

17 MEMBER SMITH: Okay, I ---

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

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

22 CO-CHAIR KAYE: It was there, yes.

1 MEMBER SMITH: I think it's important.

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

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

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

10 (Off mic comment)

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

16 (Off mic comment)

17 COURT REPORTER: I'm sorry, your mic
18 isn't on.

19 CO-CHAIR KAYE: Integrated? Oh,
20 integrated system. How about that? Integrated.

21 MEMBER LUZ: Well, and I think data
22 integration, good systems of data management.

1 CO-CHAIR KAYE: Data integration over
2 here, too? Yes?

3 MEMBER LUZ: I would.

4 CO-CHAIR KAYE: Anybody object to that?
5 Okay. So, using shared --- well, efficient ---
6 it's a little hard to read with it moving up and
7 down. Efficient, well aligned, well allocated,
8 integrated --- how we say --- what's an adjective
9 to describe that the data is being --- that
10 there's good data and it's being shared?

11 (Off mic comment)

12 PARTICIPANT: Data integrity.

13 CO-CHAIR KAYE: Okay. So, now we can
14 delete coordinated system of service. We can
15 delete data integration, very good, and then
16 delete coordinated system of services. Is that
17 all right? Okay. And delete affordable, because
18 we've made it more aligned. Is that all right?
19 Because I think that was --- there was some ---
20 if we take that out, is it all right? Okay. All
21 right, good.

22 MEMBER OXFORD: Could we --- choice,

1 person-driven, consumer direct and control,
2 collapse that with --- maybe say person-driven,
3 focused on individual goals.

4 CO-CHAIR KAYE: Person-centered,
5 focused on individual goals?

6 MEMBER OXFORD: Not centered, driven,
7 person-driven, focused on individual goals and
8 rights, something like that, and put those
9 together.

10 CO-CHAIR KAYE: Okay. So, now instead
11 of that put after --- in the one above that,
12 choice, person-driven, focused on individual
13 goals. Is that good?

14 MEMBER OXFORD: Yes. Well, those would
15 be the two we'd collapse.

16 CO-CHAIR KAYE: Yes, exactly.

17 MEMBER OXFORD: Okay. Yes, there we go.

18 CO-CHAIR KAYE: All right, good. Any
19 more work we should do?

20 MEMBER OXFORD: I don't understand what
21 the first bullet actually means in this context
22 now of characteristics. It doesn't really appear

1 to apply.

2 CO-CHAIR KAYE: Sorry, I was talking to
3 Juliet. What were you saying doesn't apply?

4 MEMBER OXFORD: Well, the very first
5 bullet, individual value versus system value.

6 CO-CHAIR KAYE: Yes, I don't think it
7 does either.

8 MEMBER OXFORD: I don't think that
9 really is germane. I don't know, the triple aim
10 seems all right.

11 MEMBER OSTROVSKY: Can I make a quick
12 comment about triple aim. That triple aim that
13 I'm referring to, which is what originally was
14 published on is specifically improved outcomes,
15 decreased costs of care, and improved patient or
16 consumer experience.

17 PARTICIPANT: We cover it.

18 MEMBER OSTROVSKY: True, we cover it,
19 and that's fine. And I think we can think about
20 leaving the triple aim, or integrating across
21 other domains. But as it's written, it's how
22 other people have interpreted triple aim, but

1 that's now ---

2 CO-CHAIR KAYE: Okay. So, what you was
3 --- the first one was?

4 MEMBER OSTROVSKY: Improved outcomes.

5 CO-CHAIR KAYE: Improved outcomes,
6 which is --- we don't really ---

7 (Off mic comment)

8 COURT REPORTER: I'm sorry. Your
9 microphone isn't on.

10 CO-CHAIR KAYE: Say it again in the
11 mic, please.

12 MEMBER YUSKAUSKAS: I'm sorry, I
13 shouldn't have blurted out there, but I --- we
14 don't have evidence-based practices, so I'm
15 underscoring that I think that language is very
16 important.

17 CO-CHAIR KAYE: Okay. So, Juliet,
18 please take out the verbiage you have after
19 triple aim, and substitute improved outcomes.

20 MEMBER OSTROVSKY: And then if we
21 choose to keep this in here, decreased cost of
22 care.

1 PARTICIPANT: Affordable.

2 MEMBER OSTROVSKY: Not so much
3 affordable, it's actually just decreased cost of
4 care, however that ends up happening. And then
5 improved consumer experience, originally
6 published as improved patient experience, but
7 that was narrow sided to medical stuff.

8 CO-CHAIR KAYE: Okay. So, now ---

9 MEMBER OXFORD: Is decreasing of costs
10 really a characteristic of quality? I mean, is
11 the economic --- I mean, I just wonder how does
12 economics equate to quality? It just seems like a
13 whole other kind of goal.

14 CO-CHAIR KAYE: Andrey, before we go,
15 what do you want --- do you want to leave it like
16 that? Do you want to integrate it, do you want to
17 separate it out? What do you want to do?

18 MEMBER OSTROVSKY: I think it's an
19 excellent point in terms of decreasing --- you
20 know, whether we want to keep decreasing costs of
21 care in here, I think we do need to think about
22 systems issues, not just the consumer, which is

1 the most important, but thinking to systems, in
2 which case costs would be important. And cost is
3 part of the value equation, outcomes over cost.

4 CO-CHAIR CALDWELL: I think it might
5 help Mike --- this is what I was struggling with,
6 too, is like not just decrease the costs of HCBS,
7 but like if people had HCBS, how that could
8 decrease the costs like elsewhere in the health
9 care system. But I'm not saying one way or the
10 other whether I think --- I'm not sure if that
11 should be up front here, but that's exactly what
12 I was struggling with. I think if you put it in
13 the bigger health care context then it makes a
14 lot of sense, because HCBS --- if people had
15 HCBS, I think you could get savings and costs,
16 you know, elsewhere.

17 MEMBER OXFORD: Well, it depends. I
18 mean, the research I've read and knowing where it
19 comes from, it really it all depends, depends.
20 It's not like a linear sort of thing, just so you
21 know. I mean, sometimes HCBS just increase the
22 costs of long-term services because you have this

1 big latent demand, and so on. And if you don't
2 close beds behind you, then you pay for the beds,
3 and you pay for --- and on, and on, and on, so I
4 don't know. I just ---

5 MEMBER OSTROVSKY: I think we can
6 discuss the academic like, you know, studies and
7 compare where the actual peer reviewed literature
8 lies on this. I agree completely, Joe, that
9 framing this in the context of the system level
10 and triple aim as it applies to the system is
11 probably a better way to frame it, rather than
12 looking at HCBS exclusively decreasing costs of
13 HCBS services, because it's probably not the
14 right way of looking at it. I do think that the
15 dynamic of increased utilization of HCBS has been
16 shown in certain instances to decrease overall
17 costs of care, but we --- I don't think we should
18 ascribe the triple aim to any one individual
19 person or consumer's experience. It's a system
20 construct.

21 CO-CHAIR KAYE: Okay. If we can make
22 brief comments because I really would like to

1 start collapsing this list a bit. So, Gerry.

2 MEMBER MORRISSEY: Well, on the
3 decrease of costs of care, might it change to
4 fairness of resource allocation? Fairness, to me,
5 seems like a better characteristic ---

6 CO-CHAIR KAYE: Is that --- so, we have
7 equity down on the bottom. Should that be under -
8 -- should we add health disparities, equitable
9 system, fairness of resource distribution?

10 MEMBER MORRISSEY: Yes.

11 CO-CHAIR KAYE: Okay. Please do that.
12 Thanks, Juliet. All right. Clare, or Bob. Bob
13 first, then Clare, sorry.

14 MEMBER APPLEBAUM: I was just going to
15 say I just thought that the --- all of the items
16 in triple aim are already on the list. We've got
17 well allocated, which I think, to me, kind of
18 goes with the whole fairness of resources issue.
19 We've got an effectiveness category that does get
20 at the improved consumer experience. So, I think
21 we can collapse some of these things that are in
22 the triple aim because they're already reflected

1 in these other items.

2 CO-CHAIR KAYE: What do you think,
3 Andrey?

4 MEMBER OSTROVSKY: I think you would be
5 --- given that the intent here is just to guide
6 where quality measures go, I think whether we
7 call it triple aim explicitly, or allude to it in
8 other ways totally fine, as long as we're keeping
9 in mind the systems level implications of things.
10 So, I'm not married to the triple aim. I do think
11 it is a nice, well condensed construct, but I
12 agree there are other things here. So, in the
13 interest of consolidation, I think we should try
14 to consolidate.

15 CO-CHAIR KAYE: All right. So, let's
16 remove the triple aim as a separate item, and
17 anything you want to add from that to the other
18 two existing items, we'll do that.

19 MEMBER OSTROVSKY: I think outcomes are
20 important, so improved outcomes.

21 CO-CHAIR KAYE: Improved outcomes as a
22 separate item. Okay.

1 MEMBER OSTROVSKY: I think so, if we
2 get rid of the triple aim all together.

3 CO-CHAIR KAYE: Okay. Speak and use
4 your microphone please, Kimberly.

5 MEMBER AUSTIN-OSER: It seems to me
6 that if we want to condense some of this stuff,
7 choice, person-driven, focused on individual
8 goals, to me that's outcome, that's, you know,
9 outcome-oriented. When we just talk about
10 improved outcomes, I'm not sure what we mean. But
11 if we're talking about improved outcomes based on
12 individual goals, individual choice, a person-
13 driven program, I think that makes more sense.
14 So, I guess I just want to get more clarity about
15 what you mean around improved outcomes.

16 MEMBER OSTROVSKY: I think outcomes, we
17 could describe them in probably multiple domains,
18 but we could look at as medicalized as, you know,
19 the hemoglobin A1C will improve if HCBS
20 contributes to a more supported consumer that can
21 adhere better, et cetera, et cetera. I think
22 outcomes can also be less medicalized than that,

1 and could be very much in the vein of achieving
2 an end result that's very much aligned with an
3 individual's goals. So, I think in some cases we
4 could consolidate exactly how you just said it. I
5 think in other cases there may be specific
6 outcomes that may not necessarily be, you know,
7 is a goal achieved, or is a consumer's experience
8 improved?

9 CO-CHAIR KAYE: Okay. I'm going to ---
10 right. So, you're going to take off the triple
11 aim, and leave improved outcomes as it is. And
12 I'm going to take Co-Chair's prerogative and say
13 please don't cheat. You have three votes. We're
14 going to read each one and raise your hand if you
15 want to spend one of your three votes on that
16 one, and we can get --- okay, Clare, you can say
17 one ---

18 MEMBER LUZ: Can I recommend two more
19 collapses?

20 CO-CHAIR KAYE: Okay.

21 MEMBER LUZ: And I can anticipate that
22 there will be people here who don't agree with

1 this.

2 CO-CHAIR KAYE: Put the microphone
3 closer to your mouth, like move it forward.

4 MEMBER LUZ: Sorry, it's on, but I'm
5 not --- I don't talk very loud. So, what about
6 the possibility of combining workforce and care
7 givers and family, because they're all providing
8 supports and services, some are paid, some are
9 unpaid, but we go back to this idea of paid and
10 unpaid care giving.

11 CO-CHAIR KAYE: A few people shaking
12 their heads, so let's not do that.

13 MEMBER LUZ: Okay. How about --- and
14 then one more. How about in terms of employment,
15 I've always seen that listed under community
16 integration to the extent that one is able to
17 also seek employment.

18 CO-CHAIR KAYE: Yes, I do, too. I mean,
19 I actually consider economic and social
20 participation to be kind of a single bucket, but
21 I don't know whether Charlie would be happy with
22 that.

1 (Off mic comment)

2 CO-CHAIR KAYE: So, can we do that? Can
3 we collapse --- is it all right if we collapse
4 employment and productivity under the community
5 integration one? That would be great. And, Sara.

6 MEMBER GALANTOWICZ: Can we
7 additionally collapse safety and freedom of abuse
8 to just freedom from harm? So, that would ---

9 CO-CHAIR KAYE: Where is Ari Ne'eman
10 when we need him?

11 (Off mic comment)

12 MEMBER OXFORD: No, I don't want to
13 speak for Ari, but I kind of think from what I
14 recall of the conversation, that those are really
15 kind of different.

16 CO-CHAIR KAYE: I'm a little worried
17 about that, because I think we're coming at it
18 from different ---

19 MEMBER OXFORD: Yes.

20 CO-CHAIR KAYE: I mean, I see why it
21 would be collapsible, but I see why it wouldn't
22 be. Ari gets the last word before we vote.

1 MEMBER HOUSER: One thing that in terms
2 of ----we don't have to collapse everything
3 before we vote. If there are things that kind of
4 borderline and thematically related, after we
5 vote then maybe we can ---

6 CO-CHAIR KAYE: Yes. Okay. Three votes.
7 Please don't cheat. Improved outcomes, please
8 vote on that. Who's counting? Sarah is going to
9 count. So, improved outcomes as a general thing.

10 MS. LASH: I see seven.

11 CO-CHAIR KAYE: Yes, did you get Mike?

12 MS. LASH: Yes, I did.

13 CO-CHAIR KAYE: Okay.

14 (Off mic comment)

15 MS. LASH: Oh, sorry, keep them up.
16 That's eight.

17 CO-CHAIR KAYE: Okay. Choice, person-
18 driven, focused on individual goals, consumer-
19 directed and control.

20 MS. LASH: Seventeen.

21 CO-CHAIR KAYE: Okay. Enhanced well-
22 being that includes privacy, dignity, respect,

1 freedom, independence, physical and emotional
2 health.

3 MS. LASH: Seven.

4 (Off mic comment)

5 MEMBER OXFORD: I used up all my votes
6 on the first three.

7 CO-CHAIR KAYE: Okay, you have three --
8 - Ari, you have three votes. Don't cheat. Legal
9 rights.

10 MS. LASH: I'm sorry, seven for the
11 enhanced well-being category.

12 CO-CHAIR KAYE: Seven for enhanced
13 well-being. Legal rights, how many people want to
14 vote for legal rights?

15 (Off mic comment)

16 MS. LASH: Two.

17 CO-CHAIR KAYE: Okay. Inclusion to the
18 same degree as people not receiving HCBS.

19 MS. LASH: Also, two.

20 CO-CHAIR KAYE: Community engagement,
21 integration, participation, employment, and
22 productivity.

1 MS. LASH: Twelve.

2 CO-CHAIR KAYE: Having fun, social
3 connectedness.

4 MS. LASH: Two.

5 CO-CHAIR KAYE: You didn't vote for
6 your own thing.

7 (Off mic comment)

8 CO-CHAIR KAYE: Services that are
9 accessible, sufficient, and dependable.

10 MS. LASH: That's one.

11 CO-CHAIR KAYE: Effectiveness, quality
12 of care. Nobody? All right, one.

13 CO-CHAIR KAYE: Efficient, well
14 aligned, well allocated, integrated, and data
15 integrity.

16 MS. LASH: I see five, oh, six, late-
17 breaking vote, six.

18 CO-CHAIR KAYE: Six, okay. Safety,
19 safety by itself. Only one?

20 MS. LASH: One for safety.

21 (Off mic comment)

22 CO-CHAIR KAYE: Okay. Freedom of abuse

1 or exploitation, and neglect. What? Okay.

2 (Off mic comment)

3 MEMBER APPLEBAUM: The flaw in this
4 system, because a lot of these are important, and
5 limiting people to three, I don't think this is
6 the right way to do this, because ---

7 CO-CHAIR KAYE: All right. How would
8 you do it?

9 MEMBER APPLEBAUM: Well, start --- I
10 would --- there are several ways to do this, but
11 you could --- assuming that there's only --- I
12 mean, if you have three, then you're trying to
13 get down to three core ---

14 CO-CHAIR KAYE: All right. Well, we can
15 only throw --- we can throw away the ones that
16 are really low, and then we can do this again.

17 MEMBER APPLEBAUM: Right. And then,
18 obviously, a lot of people used their votes in
19 the beginning, and then they ran out. I mean, I
20 guess I would say that one way to do this is to
21 have people to really go from the top, let people
22 vote, is this really important? Is this a you

1 have to have this on, and let people vote. And,
2 hopefully, people won't vote for everything on
3 the list as a way of trying to ---

4 CO-CHAIR KAYE: That's certainly
5 another way of doing it. And I'm not an expert on
6 consensus methods, so I went with what Sarah told
7 me. Would you think that we could do it the other
8 way?

9 MEMBER OXFORD: Come on, can't we run
10 a multiple regression analysis, covariant? Don't
11 tempt me, Mike, I'll start doing that.

12 MS. LASH: It's my experience on
13 committees that once you have a list people are
14 very reticent to continue to take things off of
15 it, so the whole is it important, yes/no, might
16 not work, but Andrey, do you have a suggestion?

17 MEMBER OSTROVSKY: I'm sorry. It
18 probably wouldn't take long to create a quick
19 doodle or a Google survey, email it to the group,
20 and bang out what do you rank 1-17, and that's
21 it.

22 MS. LASH: Yes. Would people commit to

1 answering this overnight ---

2 MEMBER OSTROVSKY: We can do that like
3 now before we leave.

4 MS. LASH: Okay.

5 MEMBER OSTROVSKY: It would be quick.

6 CO-CHAIR KAYE: Turn off your
7 microphone please, Andrey. Do we need this before
8 the end of the day?

9 MS. LASH: Not necessarily.

10 MEMBER NE'EMAN: Quick point of order.
11 Can I just ask, can we assign multiple votes to
12 the same category?

13 CO-CHAIR KAYE: Sure, you have two
14 hands.

15 (Off mic comment)

16 CO-CHAIR KAYE: Well, no, no. So, we
17 could do this thing where we rank them. Right? We
18 could do a poll, we could rank them. And then
19 what? And then we'd score one point for, you know
20 --- 17 points if you're on the top, and then, you
21 know, 16.

22 MEMBER OXFORD: Well, I mean, are we

1 trying to get down to just three things, or are
2 we trying to get down to like the best things
3 without regard to how many, or what will fit on
4 half a page? What's the deal?

5 MEMBER OSTROVSKY: Yes, you aggregate
6 all the scores, and the lowest score is the top,
7 the highest score is the worst. And then we look
8 at the bottom three, and we can decide does it
9 make sense to eliminate these highest worst
10 three, and then we can decide if that makes sense
11 or not, but at least we'll have a little bit more
12 granular and quantitative way of doing it. And it
13 could be just as quick.

14 CO-CHAIR KAYE: Okay. Should we
15 continue with this anyway, and ---

16 (Off mic comment)

17 CO-CHAIR KAYE: All right. So, let's
18 continue with this, anyway, and see what we
19 think. Care givers, family. Anybody want to vote
20 for that one?

21 (Off mic comment)

22 MS. LASH: Mark it as one.

1 CO-CHAIR KAYE: One. Workforce? Two.

2 MS. LASH: Two.

3 PARTICIPANT: That's not right.

4 CO-CHAIR KAYE: That's not right. There
5 are two free votes. I agree with you. All right.
6 And what about the last one?

7 PARTICIPANT: Health disparities.

8 CO-CHAIR KAYE: Health disparities,
9 equitable system --- okay. So, the problem is
10 that we all spent our votes on the top ones, and
11 we wish --- so, it's not ---

12 (Off mic comment)

13 CO-CHAIR KAYE: Do we want to do
14 another round or do you just want to wait to do
15 the rank thing?

16 MEMBER NE'EMAN: I would like to
17 reassign my vote from legal rights to inclusion,
18 and use my remaining vote on inclusion, as well.
19 All three of mine on inclusion. Thank you very
20 much.

21 MEMBER OXFORD: I think that motion is
22 out of order, Ari. No, I mean, I am curious. I

1 mean, are we just generally trying to get, I
2 mean, how many? Is there any kind of goal, or
3 just whatever ones rise to the top?

4 CO-CHAIR KAYE: What I would do is see
5 where there's a break in the list.

6 MEMBER OXFORD: Okay.

7 CO-CHAIR KAYE: I mean, if we were to
8 keep the numbers now, then I would certainly take
9 out the --- I would take all the zeroes, ones,
10 and twos and then we'd look at it again. Right?
11 But we realize this vote is biased, and so not
12 very meaningful. I mean, we could achieve the
13 same goal by giving people five votes and then
14 start taking off ---

15 MEMBER OXFORD: Well, I was going to
16 say, I mean, if you just want to get down to like
17 say four or five, no matter what happened you'd
18 probably end up, I mean, with the same ones.
19 Right? You've got, obviously, consumer choice,
20 direction is the ones real high. Obviously,
21 enhanced well-being and freedom and independence,
22 and emotional, you know, that's a pretty long ---

1 the other thing is those two, second and third
2 bullets, have a lot of stuff. Right? You know,
3 they're long and so they include --- you know,
4 and so on. But if you look at the top few, I
5 don't know if doing anything different would end
6 up with something different. Maybe it would
7 because I agree, I think workforce would probably
8 migrate up higher than two. But I don't know what
9 other people think. It might end up the same way;
10 depends on how many ---

11 CO-CHAIR KAYE: Go ahead, Anita.

12 MEMBER YUSKAUSKAS: I was looking at
13 the Institute of Medicine, the priorities around
14 quality and, you know, that's another guiding
15 document that a lot of folks have been using. And
16 I think we've covered just about all those items
17 except timely, which isn't even there. But I
18 wonder if it might not be helpful to refer back
19 to some of those to give us perspective.

20 CO-CHAIR KAYE: Okay. I think we're
21 going to go to public comment, and then --- I'm a
22 little concerned that it's not a good idea to

1 wait until tomorrow to have the answers to this.

2 MEMBER OXFORD: I wouldn't mind seeing
3 the list of everything but the ones and the
4 zeroes, and seeing what people think of that.

5 CO-CHAIR KAYE: I'm a little concerned
6 about the bias of --- the top-weighted bias of
7 that.

8 MEMBER OXFORD: Right.

9 CO-CHAIR KAYE: So, I would want to
10 revote with five votes, and then --- if we were
11 to do this. If we're okay with not having this
12 list until tomorrow, then I think the
13 prioritization is good.

14 MEMBER OXFORD: Okay.

15 CO-CHAIR KAYE: Is it all right if we
16 go to public comment? Yes.

17 OPERATOR: Okay. If you would like to
18 make a comment please press star one. Okay. You
19 do have a comment from James Gallant.

20 CO-CHAIR KAYE: Please hold and we'll
21 take comments in the room first.

22 MS. DAILEY: Hi, I'm Maureen Dailey

1 from the American Nurses Association, and I'd
2 like to give support to the IOM six aims of care.
3 I think they're very applicable here and a good
4 grounding. I also would like to support patient
5 safety. Patients that are disabled or have
6 functional issues, their number one priority is
7 not to be institutionalized, or hospitalized, or
8 lose function when they can avoid it. I come to
9 this with a background of 30 years in home and
10 community-based services experience. Thank you.

11 MS. MacINNESS: Good afternoon. My name
12 is Gail MacInness from PHI, the Paraprofessional
13 Healthcare Institute, and I'll submit more
14 detailed comments in writing. But I just wanted
15 to take the opportunity to support and encourage
16 you to include workforce variables as you look at
17 the issue of quality measurement for HCBS. We
18 believe, as I think many of you do, that because
19 direct care workers are the primary paid delivery
20 mechanism for LTSS, that it's essential to
21 include those variables to fully understand the
22 relationship that influence HCBS quality.

1 We know from recent surveys money
2 follows the person program directors and state
3 unit on aging directors, that lack of available
4 direct care workers can impede access. And we
5 know that astronomical turnover rates among
6 direct care workers interfere with long-term
7 services and supports quality.

8 So, like I said, I'll submit more
9 detail in writing, but I just wanted to put in a
10 plug for workforce variables among the items that
11 you include.

12 MS. POTTER: Hi, everybody. I'm D.E.B.
13 Potter. I'm currently with the Office of the
14 Secretary of ASPE. I've been involved in the HCBS
15 measurement since --- not nearly as long as
16 anyone in this room, but for a while. But I
17 thought it might be helpful to provide a context
18 on quality. I listened in amazement of the
19 discussion around quality.

20 So, I want to read you some testimony
21 that was presented to Congress in 2009 to try and
22 convince Congress so they could understand what

1 quality was. "Simply put, health care quality is
2 getting the right care to the right person at the
3 right time, every time." And that this is a
4 broader concept to like getting at all of those
5 things, the right person at the right time, every
6 time, is sort of a way to think about quality in
7 a bigger context, but also in a context of HCBS.

8 MS. LASH: And we can take a brief
9 comment from the phone.

10 OPERATOR: Okay, your comment comes
11 from James Gallant.

12 MR. GALLANT: Yes. I had a couple of
13 comments here. About the part you were talking
14 about coordinated or coordination, or integrated,
15 what I found in my travels is trying to track
16 down policies that actually don't exist. A lot of
17 people say it's policy, but to be integrated you
18 actually have to have an agreement, your
19 coordination between agencies. They have an
20 agreement between each other, it's not just over
21 the phone, somebody says I'm working with that
22 person, working over there. That these actually

1 be real, you know, agreements, integration
2 instead of, you know, somebody --- and then they
3 leave that job, and then all of a sudden it falls
4 apart.

5 And, also, I guess just because it
6 went this way in this debate that you're doing
7 here, and you're going to vote, what exactly are
8 the rules in this deliberative assembly that is
9 here in the National Quality Forum? You know,
10 according to the general parliamentary rules in
11 America, you know, like the Robert's Rules of
12 Order, the rules of the governing body that
13 appointed this group apply here, so how would
14 they make the decision? That's how --- you're
15 supposed to be following their rules. They
16 appointed you. Unless you make your own rules,
17 and say, you know, this should have been already
18 done because now is not the time to talk about
19 what are we --- how are we going to vote.

20 The rules that already, I guess the
21 Board of Directors of the National Quality Forum
22 apply here. And if that's Robert's Rules of

1 Order, there should have been a motion pending
2 right from the beginning. You know, when the
3 agenda item comes up, you say motion to approve,
4 we second that, now we have discussion, and then
5 we vote. And that would have kind of resolved
6 everything, the confusion you're having right
7 now, because you would have already had motions
8 pending. And I'd ask you to please make a motion
9 to refer this to the nominating committee, and
10 ask them. Okay, you nominated us to be here, what
11 happened? What are the rules? What are we
12 supposed to then go by, or is the co-chair, or
13 the leaders, or I'm not really sure.

14 I didn't find it on your website of
15 the bylaws and the rules of procedure. But that's
16 important for people with disabilities. They come
17 to the table, and then you get people at the
18 table, they're making it up as they go. And it's
19 going to be in their favor, and they're going to
20 win the debate, and then all of a sudden it's not
21 really informed consent on the part of people in
22 a consensus-building mode. It's like well, you

1 have to object. You have to be the guy that's
2 saying man, you're always objecting to stuff.

3 MS. LASH: So, while we appreciate the
4 comments. This committee isn't run on
5 parliamentary procedure. We're in a collaborative
6 transparent consensus-based process. It's free
7 form right now. The results of the process will
8 be made available for more formal public comment
9 and a written product. And thank you; I'm afraid
10 we have to move on. Is there any other comment
11 from the phone, or from the webcast that we need
12 to read out at this time?

13 OPERATOR: There are no comments from
14 the phone line.

15 MR. ANDERSON: Just from the web chat,
16 a lot of people have been reiterating the
17 importance of including safety, looking at the
18 triple aim, and the impact. Like one of these is
19 impact on the triple aim of the population is
20 important. Having healthy --- including healthy
21 community/population, improved health care
22 outcomes and experience, and improved per capita

1 cost of care, so that are the aims, generally
2 reflecting the same sentiments of the group.

3 MS. LASH: I think we'd like to call
4 about a 5-minute break so that the Staff can
5 confer with the Co-Chairs about what the next
6 steps are. If we want to do a different voting
7 exercise, or move on, translate this forward into
8 a domain discussion. So, just take five,
9 everyone. Thank you.

10 (Whereupon, the above-entitled matter
11 went off the record at 2:46 p.m. and resumed at
12 3:12 p.m.)

13 CO-CHAIR KAYE: Okay. We had an
14 eloquent plea from Charlie Lakin, so it's his
15 fault, not mine, that we're going to do another
16 round of consolidation on the list. And then the
17 NQF Staff are printing out the items from the
18 list, and they're going to put them up on the
19 final sheet up there. And we're going to do a
20 consensus process. You have --- most of --- do
21 you have these little sticky things that notice I
22 don't have them. And so you can put up to what,

1 is it 10 stickies distributed however you want.

2 (Off mic comment)

3 CO-CHAIR KAYE: Right. So, Ari Ne'eman,
4 you can put them all on the same one, if you
5 want. Okay. So, let's --- so, what would you
6 like to consolidate? Charlie had some ideas.

7 DR. LAKIN: Okay. Well, with consent of
8 Ari and Mike, we would like to first on the third
9 bullet, just remove enhanced well-being. That's
10 too generic to mean anything, and move legal
11 rights up into that list. We can't not vote
12 attending to people's legal rights.

13 Yes, and move legal rights up into
14 that space, or at the end of the string. We don't
15 think physical and emotional health belongs in
16 that category. It may belong somewhere, but not
17 there.

18 CO-CHAIR KAYE: Okay, hold on, hold on.
19 Would you like to make a separate category for
20 physical and emotional health?

21 DR. LAKIN: Well, I'd do that now
22 because it's not my decision whether that stays

1 or not.

2 CO-CHAIR KAYE: Yes. So, we came up
3 with a whole giant well-being bucket. So, I'm
4 okay with --- I mean, I guess I was the one who
5 came up with that bucket. I'd be fine with moving
6 physical and emotional health to a separate line.

7 DR. LAKIN: Okay.

8 CO-CHAIR KAYE: Is that what you want?

9 DR. LAKIN: Yes.

10 CO-CHAIR KAYE: Okay. So, Drew, can you
11 do that?

12 DR. LAKIN: The other one was moving
13 inclusion down into community engagement.

14 CO-CHAIR KAYE: Okay. So, Ari Ne'eman,
15 how do you feel about that?

16 MEMBER NE'EMAN: I support it, and if
17 possible I'd like to find a way to include to the
18 same degree as within the new category.

19 DR. LAKIN: Yes, so, I don't know what
20 that meant, but ---

21 CO-CHAIR KAYE: And second from Mike.

22 And --- DR. LAKIN: Actually, I think

1 that we would like to do is move --- just remove
2 integration and put inclusion in that string, if
3 we could.

4 CO-CHAIR KAYE: How about take the
5 entire phrase --- yes, take out integration and
6 take the entire --- the inclusion with the
7 parenthetical, and put it where integration was.
8 That make sense, Drew? Okay.

9 DR. LAKIN: And also to move having
10 fun, social connectedness onto that line above
11 it.

12 CO-CHAIR KAYE: Anybody object to that?
13 Mike, you were the one who ---

14 MEMBER OXFORD: No, no.

15 CO-CHAIR KAYE: That's good? You say
16 no, so you put more stuff in so make sure it has
17 more votes. Okay. Any other consolidation ---

18 MEMBER OXFORD: I have an idea that we
19 put workforce together with care givers and
20 family.

21 CO-CHAIR KAYE: Right, that was already
22 proposed. Is there anybody who still objects to

1 that? Some people object, okay.

2 MEMBER OXFORD: Whoa, a lot of people.

3 CO-CHAIR KAYE: Okay. So, then Mary had
4 a comment. Can you use your microphone, please.

5 MEMBER SMITH: Move the effectiveness,
6 quality of care up to improved outcomes. You
7 don't think it's the same?

8 CO-CHAIR KAYE: Well, let's see.
9 Improved outcomes came from ---

10 MEMBER SMITH: Eight people ---

11 CO-CHAIR KAYE: --- Andrey. What do you
12 think?

13 MEMBER OSTROVSKY: I think that would
14 be fine to group together. In the interest of
15 consolidation, it's aligned enough.

16 CO-CHAIR KAYE: Okay. Anybody object
17 seriously to that? All right. So, Drew, would you
18 move effectiveness and quality of care to after
19 improved outcomes, just the first one.

20 MEMBER SMITH: So while Drew is doing
21 that, is --- I want to go back to a question
22 someone else raised. Are we trying to get to a

1 certain number, because right now, if we --- no,
2 if we think these are all important things, I
3 guess I'm not really sure why we're trying to
4 shrink them down. Are we trying to put them on an
5 index card or what? No, I'm serious.

6 CO-CHAIR KAYE: Well, because we had --
7 - we started out with 20 of them, which is not a
8 tenable list. I mean, now that we're combining
9 them --- well, I mean, the question is are there
10 things that are not well supported? I mean, I
11 think we have --- we're going to have to deal
12 with safety, for example.

13 MEMBER OXFORD: While we're thinking on
14 that, would someone help me out with the
15 discussion on the difference between workforce
16 and care givers?

17 CO-CHAIR KAYE: The person who said
18 care givers I assume meant ---

19 MEMBER OXFORD: Is it paid/unpaid?

20 CO-CHAIR KAYE: Do you mean --- who was
21 it who --- it was Ari, and do you mean unpaid, or
22 do you mean family care givers, or ---

1 MEMBER HOUSER: I think it's critically
2 important to include family care givers as a
3 client user of home and community-based services.
4 And I think they --- family care givers are also,
5 obviously, providers, but I think they're
6 different from formal paid providers, in that
7 they also have a role as a consumer of service --
8 --

9 CO-CHAIR KAYE: All right. So, Drew,
10 would you change the third from the last to be
11 family care givers with the acknowledgment that
12 it's not only family. Okay? I mean, we know that.
13 That's our code word for family and friends.
14 Patti.

15 MEMBER KILLINGSWORTH: Are we talking
16 about with respect to family care givers and
17 informal care givers supports for them? I just
18 want to understand when we say it has the
19 following characteristics. Right? That a part of
20 what that system does is support those family
21 care givers?

22 CO-CHAIR KAYE: Yes. So, you would want

1 --- Ari would want --- Ari Houser would want
2 something that says family care givers are
3 supported.

4 MEMBER KILLINGSWORTH: Yes.

5 CO-CHAIR KAYE: So, can we change it to
6 family care givers are supported? Okay. Sarita,
7 did you want to make a comment? Microphone,
8 please.

9 MEMBER MOHANTY: No, I think I'm --- so
10 far I was --- you know, I think some of the
11 categories are fine, are good, and I think we're
12 narrowing them down. I'm going to come back and
13 maybe we'll talk about this later, and I'm not
14 trying to add to the complexity of this. But in
15 terms of the triple aim, I just want to just
16 mention that I know we took it off, and I'm just
17 going to advocate that we still somewhat think
18 about the total cost of care in our model as part
19 of just something to --- I mean, bring it to this
20 group, if there's a feeling of not including it.
21 Obviously, it is consensus-driven, but I do ---
22 you know, I'm an advocate of trying to be able

1 to think about that as part of this HCBS system
2 that we're trying to explore.

3 CO-CHAIR KAYE: Okay.

4 MEMBER MOHANTY: So, I'm going to ---
5 and put that there. And then just with the
6 improved outcomes, I know we put effectiveness
7 and quality of care. I would also --- maybe it is
8 implied somewhere in there, but just also about
9 as part of that member --- or consumer
10 experience, just their overall experience of how
11 they --- how help is --- maybe it's in there. You
12 think it's all in the ---

13 (Off mic comment)

14 MEMBER MOHANTY: Okay. I just want to
15 make sure that it's not --- you know, that we
16 always want to make sure that we, as part of ---
17 we want to make sure we understand how they're
18 seeing their care.

19 CO-CHAIR KAYE: Right. So, these are
20 the characteristics of a high quality system.
21 Right?

22 MEMBER MOHANTY: Yes.

1 CO-CHAIR KAYE: And I --- and our hope
2 is that these will guide us in the selection of
3 domains, but there may be also additional
4 domains. I would imagine there will be additional
5 domains besides these that were not sort of part
6 of our system.

7 MEMBER MOHANTY: Okay.

8 CO-CHAIR KAYE: I mean, that's the way
9 we're seeing it so far.

10 MEMBER MOHANTY: Okay. Great, thank
11 you.

12 CO-CHAIR KAYE: All right. One last
13 comment from Gerry before we go ---

14 MEMBER MORRISSEY: Just on that point
15 about consumer's voice. I guess that would be
16 under --- for me, under number 2, choice and
17 person-driven. You would anticipate the voice of
18 the individual would be part of that process.

19 CO-CHAIR KAYE: Okay. Bob.

20 MEMBER APPLEBAUM: The only one I don't
21 get now is the very last one, if you put in the
22 term high quality system has following

1 characteristics. I don't know what health
2 disparities means. We're trying to have a health
3 disparity system?

4 CO-CHAIR KAYE: Right. So, we want ---
5 reduces health disparity, is equitable and
6 reduces health disparities. Right? Go ahead,
7 Sandy.

8 MEMBER APPLEBAUM: Well, wait.

9 CO-CHAIR KAYE: Sorry.

10 MEMBER APPLEBAUM: I'm still --- how
11 the HCBS system is going to reduce health
12 disparity?

13 CO-CHAIR KAYE: Is equitable enough?

14 MEMBER MARKWOOD: I guess to your
15 point, because I had the same question, Bob, is
16 are we talking there about cultural competency?
17 Are we talking about cultural sensitivity and the
18 delivery of home and community-based services,
19 not just in the workforce, but in the way the
20 whole system is delivered, in which point that
21 makes it into an aspiration of what we're trying
22 to do, rather than tackling a disparity.

1 CO-CHAIR KAYE: So, do we need to add
2 to this issue? I mean, so --- all right. So, when
3 Mary proposes it was in the context of the
4 workforce, and proposed the cultural awareness,
5 sensitivity, competence. So, would you like this
6 to be --- that to be a separate item distinct
7 from workforce, that HCBS must be delivered in a
8 culturally appropriate way?

9 MEMBER MARKWOOD: Well, I guess what my
10 question was, the friendly amendment is whether
11 the way that that last bullet is framed now is a
12 bit of a jumble to me, because you've got a whole
13 lot of things in there. But I think the point of
14 the bullet is to insure that there is equity and
15 sensitivity in the delivery of home and
16 community-based services across cultures and
17 ethnicities. And maybe somebody could frame it
18 differently, but I think that's the point behind
19 it. I'm not sure that the verbiage there --- I
20 think the verbiage there restricts it.

21 CO-CHAIR KAYE: I'm sorry, go ahead.

22 MEMBER OXFORD: Well, I was going to

1 say also, I mean, fairness of resources. I was
2 also thinking about across populations of people
3 being served.

4 MEMBER MARKWOOD: Right.

5 MEMBER OXFORD: And ages, age and ---
6 across age, across disability, equity, too. Is
7 that part of it?

8 MEMBER MARKWOOD: I'm fine with that.

9 MEMBER MOHANTY: Yes, and I think that
10 was the intent. I mean, when I also brought this
11 up, too, I think that was my idea that we're
12 looking across the population that home and
13 community-based services can definitely help in
14 reducing health disparity, or eliminating health
15 disparities with --- not even --
16 cultural/linguistic, absolutely, but also socio-
17 economic status, housing status when you think
18 about what home and community-based services can
19 provide. Those are some examples.

20 CO-CHAIR KAYE: Gerry.

21 MEMBER MORRISSEY: Mary's thing of
22 cultural --- I thought --- I think it's better to

1 say cultural competence than cultural
2 sensitivity. I think --- it can either can go in
3 the workforce or potentially could go up with
4 choice and person-driven, are the choices of the
5 individual, potentially.

6 CO-CHAIR KAYE: Or the bottom one. I
7 mean, should we put --- should cultural
8 competence, or whatever that concept is, go in
9 the bottom?

10 MEMBER SMITH: I think that's a
11 different thing than what you just described. I
12 mean, we should try to make sure things are
13 looked at fairly and equitably across
14 populations, but having a workforce that's
15 trained to interact with lots of different
16 populations I think is a totally different thing.

17 CO-CHAIR KAYE: Okay. Suzanne has her
18 card up.

19 MEMBER CRISP: Yes. I wondered what
20 happened to paid and non-paid family care givers?

21 CO-CHAIR KAYE: Family care givers are
22 supported. Does that ---

1 MEMBER CRISP: Yes.

2 CO-CHAIR KAYE: Do you want it to say
3 paid and unpaid, also?

4 MEMBER CRISP: Well, I think that's an
5 important differentiation. They both have to be
6 supported, but they're supported in different
7 ways.

8 CO-CHAIR KAYE: Is that okay with you,
9 Ari?

10 (Off mic comment)

11 CO-CHAIR KAYE: Yes. Well, that's the
12 question, is does it count as workforce or not?

13 MEMBER HOUSER: I think the amount of
14 family care that is compensated is such a small
15 portion of the entire amount of family care
16 provider that I think it's --- I'm taking that's
17 to include it.

18 CO-CHAIR KAYE: Also, family care
19 givers being supported could be paying them, I
20 think.

21 MEMBER HOUSER: That is one way in
22 which they may be supported, yes.

1 CO-CHAIR KAYE: Right.

2 MEMBER CRISP: Okay. Improved outcomes,
3 I'm still not sure what that means. I know
4 dealing with the elderly at the end of life
5 crisis issues, I mean, what is an improved
6 outcome there? And, also, if a person meets their
7 outcomes, isn't that a quality designation?

8 CO-CHAIR KAYE: Yes, I don't quite ---
9 I mean, it seems like we have lots of domains
10 that are about outcomes, consumer outcomes, so
11 I'm not quite sure what this adds.

12 MEMBER CRISP: And I'm not done. I also
13 wanted to say under safety, in self-direction we
14 don't use the word safety, we use the word
15 dignity of risk, assessing the individual
16 situation for safe and unsafe, and other
17 situations, anything that might be or could be
18 perceived as harmful to him or herself, or
19 others. So, we use a risk identification and
20 management system that is based on person-driven
21 interventions. But I understood everybody was ---
22 or most people except Patti, was a little

1 hesitant to go that route. So, I wonder if we
2 could at least add safety based on informed and
3 expressed choices.

4 CO-CHAIR KAYE: Any objection to that?
5 You object?

6 MEMBER LUZ: I don't object, but I
7 think safety is bigger than that, because I'm
8 thinking in terms of the supports and services
9 being provided in a safe way, so it's not just
10 about individual choice. It's about the quality
11 of the services they're receiving.

12 MEMBER CRISP: Yes, and I see that,
13 too. I just --- I'm just compelled to bring up
14 the fact that individuals do have a right to make
15 choices about their safety issues. And safety is
16 a judgmental thing. What is safe to a fireman is
17 not safe to maybe me cooking in my own kitchen.
18 It's a judgmental thing, but I can live with
19 that.

20 The other thing I wanted to bring up
21 is that nowhere do I see that one of the
22 characteristics of a high quality system would be

1 that there is participant engagement in the
2 design, implementation, and evaluation of that
3 program. I don't see that anywhere.

4 CO-CHAIR KAYE: Could we add that as a
5 separate domain at the end, Drew?

6 MEMBER OXFORD: I thought that would be
7 included in being person-driven, myself.

8 CO-CHAIR KAYE: Well, that seems like
9 the services are person-driven, as opposed to the
10 service system.

11 MEMBER OXFORD: Which is what this is
12 about.

13 MEMBER CRISP: It's a difference
14 between consumer-controlled and the independent
15 living movement, and developing your own plan of
16 care and implementing it, and managing the
17 services. I see those as two different things.

18 (Simultaneous speaking)

19 MEMBER OXFORD: You guys parsed that
20 finer than I do, is all.

21 CO-CHAIR KAYE: Wait. No, so say again
22 what this one is. Participant engagement in the

1 planning.

2 MEMBER CRISP: Participant engagement
3 in the design, the implementation ---

4 CO-CHAIR KAYE: Design.

5 MEMBER CRISP: --- and evaluation of
6 the program.

7 CO-CHAIR KAYE: Of the program.

8 MEMBER CRISP: Not the plan.

9 CO-CHAIR KAYE: So, that's different --

10 -

11 MEMBER CRISP: The program.

12 CO-CHAIR KAYE: Evaluation of the
13 program.

14 MEMBER CRISP: The program for which
15 they are receiving services under.

16 CO-CHAIR KAYE: So, the waiver program,
17 or
18 the--

19 (Off mic comment)

20 CO-CHAIR KAYE: No, not the ---

21 COURT REPORTER: I'm sorry, your
22 microphone isn't on.

1 CO-CHAIR KAYE: Yes, you need to use
2 the microphone, Anita.

3 MEMBER YUSKAUSKAS: Sometimes they're
4 just services through the state plan. I know, I
5 grapple with that all the time.

6 CO-CHAIR KAYE: But that's a program.

7 MEMBER YUSKAUSKAS: A service.

8 CO-CHAIR KAYE: No, it's a program. I
9 mean, a personal care services program is a
10 program.

11 MEMBER CRISP: To me it's one of the
12 important trends we've been seeing from CMS, to
13 have community inclusion. For example, a state
14 cannot submit an 1115 demonstration without full
15 community participation in the design,
16 implementation, and evaluation of that program.
17 And I think for us to be progressing ---

18 (Off mic comment)

19 MEMBER CRISP: I'm not saying it
20 happens. I'm saying --- I mean, maybe none of
21 this happens. I'm saying it should be a
22 characteristic, though.

1 CO-CHAIR KAYE: All right. So, on
2 safety you talked about dignity of risk. Now, are
3 we --- you know, so now there's --- so, we do
4 have --- we've been pushing under the rug the
5 issue of safety in the sense of services
6 delivered safely, and the person being safe, and
7 yet that is still distinct from the sense of
8 safety. What do we want to do with this? Do we
9 want to put safely delivered in some sort of ---
10 in with where, the quality of care bucket, I
11 guess. Jon.

12 MEMBER DELMAN: Maybe something like
13 opportunity for safety, or right to safety. I'm
14 just trying to put it in the perspective of the
15 consumer. You know, again, and I've written about
16 this. One safety is another person's safety, and
17 for those of us who have mental illness people
18 tend to underestimate what we can handle and what
19 we can do. So, you know, when you're told you
20 shouldn't work, you don't listen because --- but
21 that's what you're told quite a bit. So, the
22 workforce tends to want to play it more safe than

1 people who are trying to self-determine and grow.
2 So, that's just the reality, and that's the
3 concern I share about that term. And I'm not
4 against the concept of people having a right to
5 be safe, but we also have a right to the dignity
6 of risk, and to do things as any other human
7 being would do to advance ourselves or otherwise
8 have fun.

9 CO-CHAIR KAYE: All right. So, if we
10 were to change this to right to safety and
11 dignity of risk, would that satisfy anyone?

12 (Off mic comment)

13 COURT REPORTER: Sorry, could you turn
14 on your microphone?

15 CO-CHAIR KAYE: Freedom from injury,
16 abuse, exploitation, neglect. Ari, is that okay?

17 DR. LAKIN: Yes, I think that's what
18 we're sort of talking around. I think many of us
19 are concerned about people falling down stairs,
20 tripping, getting hurt. And safety in other areas
21 is sort of safety from feeling bad and being
22 ignored by your peers. So, I think, you know,

1 freedom from physical harm, or freedom from
2 injury, and then abuse, exploitation, and neglect
3 might go together in a way that doesn't "protect"
4 people from having --- being abused by coworkers,
5 not abused, being neglected, ignored, made to
6 feel bad by coworkers and so forth. I don't know
7 but, you know, I think --- when I say safety, I'm
8 thinking about physical safety. And I think a lot
9 of the discussion has been about psychological
10 safety, and ---

11 CO-CHAIR KAYE: Well, I mean, I think
12 there's another issue, which is if you want to
13 keep somebody from physical harm, you tend to
14 want to keep them at home, and not take --- not
15 going to a dangerous event where ---

16 PARTICIPANT: Many of them want to go
17 to a place that could be considered dangerous,
18 just like anybody else around.

19 COURT REPORTER: I'm sorry, I can't
20 hear you.

21 MEMBER DELMAN: I'm saying, you know,
22 a person with disabilities such as a mental

1 illness, may choose to go skydiving, or other
2 things that people do that are considered
3 dangerous, but because they're mentally ill it --
4 --- you know, people are going to deny them, or
5 elderly. Elderly people have the right to
6 skydive. George Bush did it. You know, the
7 problem with this is that families suffer around
8 people who make bad choices. I don't think --- I
9 think that's life. Life is full of suffering and
10 we can't ameliorate that. People who are able to
11 make independent decisions make bad ones. Now,
12 you can get a guardianship, or this or that. I
13 had to deal with this with my father, and it
14 hasn't been easy, but he has the right. He has
15 the right to do what he wants. If he wants to go
16 homeless, I'll try to talk him out of it, but I
17 can't stop him.

18 MEMBER NE'EMAN: So, with respect to
19 the issue of either safety or freedom from abuse,
20 exploitation, and neglect, I would really, again,
21 argue for replacing safety with freedom from
22 abuse, exploitation, and neglect, because to me

1 the issue is what is the duty of care from the
2 provider? And we really want to very explicitly
3 affirm, as Jon is really referencing here, that
4 people have a dignity of risk. People have the
5 right to make bad choices, and the duty of care
6 of the provider is not to intercede when somebody
7 who is fully informed and has full capacity makes
8 a choice that they might disagree with.

9 There's a very significant difference
10 from saying you have a duty to keep people safe
11 versus you have a duty not to abuse, exploit, or
12 neglect people. And the latter seems much more
13 aligned with the values of the community-based
14 system.

15 CO-CHAIR KAYE: And what about people
16 who do ----who value safety as a personal goal,
17 like Anita's mother, or friends of mine with OI
18 who don't want to be dropped.

19 MEMBER NE'EMAN: So, what I would argue
20 is that that speaks to neglect. I mean, if you're
21 dropping some --- if somebody is dropping you,
22 then you're being neglected or abused. If you

1 don't feel safe with your service provider, not
2 because your service provider is going to stop
3 you from making decisions you want to make, but
4 because your service provider is not providing
5 you with a quality of care that you feel like
6 your physical safety, you know, requires, then to
7 my mind that fits under abuse, exploitation, and
8 neglect.

9 CO-CHAIR KAYE: Anita, and then Clare.

10 MEMBER YUSKAUSKAS: With all due
11 respect, I think my sense is that you're looking
12 at this very narrowly, because my mother, given
13 her Parkinson's, has difficulty walking. Her
14 brain and her body don't work together, and so
15 she needs assistance in order to be safe. It's
16 not neglect or abuse. She wants that assistance
17 in order to have her freedom. Without that
18 assistance, she would not have freedom.

19 (Off mic comment)

20 MEMBER YUSKAUSKAS: But that's safety.

21 (Off mic comment)

22 MEMBER DELMAN: I mean, for some people

1 you can't have --- I don't think we have
2 independence in here, our choice. You can't have
3 that without safety. I'm not minimizing that. I
4 think a person --- part of these services --- I
5 mean, I'm not sure how to describe it. We want to
6 help people to feel safe. We can't convince
7 people to feel safe. I mean, you know, we can do
8 what we can, we can reassure them and things like
9 that. But I'm not -- but safety is too broad a
10 term. I mean, you're saying narrow. I think we're
11 thinking too broad.

12 MEMBER YUSKAUSKAS: Honestly, there are
13 so many different diagnostic categories that are
14 attributed to the people who utilize home and
15 community-based services, and what I hear you
16 talking about is paternalism associated with
17 services. Safety for some groups is an end goal
18 in itself, and there are many, many, many, many
19 people that use home and community-based services
20 in addition to the group that I believe you're
21 talking about.

22 MEMBER DELMAN: Fortunately, they get

1 grouped in with the rest of us. We have to find a
2 word ----

3 MEMBER YUSKAUSKAS: Well, everyone is
4 grouped together. It's a needs-based system.

5 MEMBER DELMAN: But we can't use a word
6 that some groups don't like.

7 MEMBER OXFORD: Yes. Safety, where we
8 see it, I guess in my provider hat, as a real big
9 barrier is in housing, and in community
10 integration. So, Ari can't move out of a group
11 home because the only housing is in a bad
12 neighborhood. So, aside from the code words and
13 so on there, it's this idea that he wants to move
14 out. And he knows he's only got SSI income, he
15 knows where the housing is that he can afford, he
16 knows that --- you know, and so on and so on, and
17 so it becomes a real big barrier there, and also
18 in sorts of community integration activities that
19 adults do besides where --- what you think about
20 them, going to the strip bar, getting drunk, you
21 know, having sex. I mean, all these community
22 integration things for safety is the biggest

1 barrier that we run into, and I don't know if
2 it's the old health and safety in Medicaid thing
3 that comes in, but without regard to funding
4 source. Recently, there's been these articles
5 about Florida and Delaware, I've seen them about
6 these gated communities that are being built, a
7 whole community that now we're going to have the
8 same disability, same diagnosis kind of non-
9 integrated housing because relatively well to do
10 parents have figured out how to get money and the
11 tax subsidies and so on to build these gated
12 communities privately and so on. And, again, it's
13 in safety, so I guess with respect to ---

14 everyone wants to be safe as a certain level,
15 and with some disabilities I think it becomes
16 more of a service issue than others, is what
17 you're trying to say. But, boy, it is such ---

18 it's a word that is so loaded with barriers and
19 problems that we've seen, that if we could just
20 figure out a way to maybe satisfy the needs here
21 without getting into safety, because I think it's
22 going to continue to be this problem.

1 MEMBER YUSKAUSKAS: I agree it's a
2 semantic issue, because I think what you're
3 talking about is paternalism. But I also have
4 some difficulty putting it with abuse, neglect,
5 and exploitation, because I think safety in many
6 regards is an end in and of itself for some
7 people.

8 MEMBER NE'EMAN: So, let's instead of
9 saying abuse, and neglect, and exploitation,
10 let's add to that inadequate support. I mean, to
11 my mind you've made a compelling argument that
12 there are subgroups within the HCBS eligible
13 population that look at safety as an important
14 value. But at the same time, it's also been made
15 very clear that there are other subgroups, and we
16 can argue about who's the majority or what have
17 you. I don't know that that's particularly
18 productive for whom safety as a crosscutting
19 quality characteristic would be actively harmful.
20 To me, the point ---

21 CO-CHAIR KAYE: Ari, you're not going
22 to satisfy Anita with that change. I don't think

1 that's going to --- I cut you off because Clare
2 and Mary have had their cards up for a very long
3 time. So, Clare first.

4 MEMBER LUZ: So, we have several
5 concepts of safety going on, and one of them is
6 the right to a sense of safety, to feel safe. To
7 me, that falls under emotional health,
8 psychological and emotional health. That's a key
9 part of feeling emotionally healthy is to feel
10 safe. So, maybe if we clarify it under there,
11 that that's included there.

12 In terms of supports and services
13 being provided in a safe way, I see that falling
14 under workforce, because part of workforce is
15 making sure we have a qualified, trained
16 workforce. And when we train our workforce, we're
17 training them how to deliver supports and
18 services in a safe way. It's a key part of
19 workforce.

20 In terms of choice, whether you want
21 to take risks or not, it seems like that falls
22 under choice, person-driven choice includes the

1 right to make bad choices, or risky choices.

2 CO-CHAIR KAYE: Yes. I was thinking of
3 trying to propose something to the effect of
4 changing safety --- right, taking out the sense
5 of safety and the services safely delivered, and
6 then safety in the bullet by itself could be
7 changed something like control over your level of
8 risk or, you know, control over how safe you are.

9 (Off mic comment)

10 CO-CHAIR KAYE: That satisfies Jon, but
11 I have a feeling it might not satisfy anybody
12 else in the room. Anita is looking unhappy.

13 (Off mic comment)

14 CO-CHAIR KAYE: Microphone, please.

15 MEMBER DELMAN: I guess I'm trying to
16 look up something and it does say in this of many
17 things, safety is defined as the control of
18 recognized hazards to achieve an acceptable level
19 of risk. But I do think the person has the right
20 --- is the control --- I mean, to control
21 hazards. I don't know. I agree. I want people to
22 have a right to safety as they have the right to

1 the dignity of risk. I'm not sure, though.

2 CO-CHAIR KAYE: What about balancing
3 safety against dignity of risk? Would that be a
4 way of changing that bullet?

5 MEMBER DELMAN: No. Dignity of risk
6 stands on its own.

7 CO-CHAIR KAYE: But we don't have
8 dignity of risk.

9 MEMBER DELMAN: You're right.

10 MEMBER MORRISSEY: We have dignity on
11 three, and I guess one of the things if we're
12 talking about characteristics of a system, number
13 two, the second bullet there, we have that
14 bullet, and then all of a sudden we talk about
15 all those things in that bullet elsewhere. When
16 we talk about choice, it's the individual's
17 choice to make good decisions, or poor decisions.
18 Right? When we talk about person-driven, we're
19 talking about culturally people making choices
20 about who their care givers are. When we talk
21 about consumer-directed and control, we're
22 talking about what are the choices they want to

1 have over their resources. So, I think that is a
2 pretty inclusive bullet that can deal with the
3 issues of safety, and also can deal with the
4 issues of workforce. Right?

5 CO-CHAIR KAYE: So what do we do about
6 safety then? Leave it as it is?

7 MEMBER SMITH: My proposal, and
8 probably nobody will like this either, but I
9 would say safety from the perspective of the
10 consumer, or the individual. Because I really
11 think that's what we're talking about.

12 CO-CHAIR KAYE: Safety as defined by
13 the consumer.

14 MEMBER SMITH: And that's, you know,
15 that's different than this perspective of
16 delivering services safely, et cetera. So, that's
17 my proposal for that.

18 CO-CHAIR KAYE: Let's see. Safety from
19 the perspective of the consumer. Does that help
20 anybody? Does that sound good? Jon is happy.
21 Anybody seriously object?

22 (Off mic comment)

1 CO-CHAIR KAYE: As a separate thing, or
2 semicolon, dignity of risk? What do you say,
3 safety from the perspective of the consumer.

4 MEMBER AUSTIN-OSER: What's the problem
5 with dignity of risk? What's the problem with
6 that?

7 CO-CHAIR KAYE: I don't think anybody
8 objects to it.

9 MEMBER AUSTIN-OSER: Oh, okay.

10 CO-CHAIR KAYE: The question is should
11 it be a separate bullet.

12 MEMBER AUSTIN-OSER: Oh, should it be
13 a separate bullet.

14 CO-CHAIR KAYE: Does anybody object to
15 dignity of risk? Should that be ---

16 (Off mic comment)

17 MEMBER SMITH: I don't think it's the
18 same. It's not the same.

19 (Off mic comment)

20 CO-CHAIR KAYE: What if we had a bullet
21 that was dignity of risk, safety from the
22 perspective of the consumer?

1 MEMBER OXFORD: Could we add like
2 informed ----no, never mind.

3 CO-CHAIR KAYE: No, let's just leave
4 it. All right. It's not going to be perfect. We
5 don't have to wordsmith now. Okay. So, I would
6 like ---

7 MEMBER SMITH: Wait, I wasn't finished.
8 Can I ---

9 CO-CHAIR KAYE: Can you hold for a
10 second, because I want to ask Drew to add ---
11 okay. You have physical/emotional health,
12 including sense of safety. That's one thing. And
13 the other thing is we took off all the stuff
14 about workforce because there wasn't room, and
15 now that there is room, I want to --- so, we had
16 with workforce, we had trained, cultural
17 competence, and safely delivered services,
18 something like that. I mean, it's not quite what
19 we want, but at least it captures those concepts.
20 So, could you put those after workforce?

21 MEMBER DELMAN: I don't think ---
22 dignity of risk and safety should not be in the

1 same line. Dignity of risk should be under
2 choice. You can't --- I mean, they contradict
3 each other. Dignity of risk is the right to
4 damage yourself.

5 CO-CHAIR KAYE: All right. So, can we
6 put dignity of risk under choice, and then take
7 it out of safety?

8 MEMBER DELMAN: I mean, I don't ---

9 CO-CHAIR KAYE: Or do we not need to
10 put --- do we need not to mention dignity of risk
11 at all?

12 (Off mic comment)

13 CO-CHAIR KAYE: All right. So, under --
14 - sorry to keep --- dignity of risk under choice,
15 and safety from the perspective of the consumer
16 is a separate item. Is that right? I think that's
17 the best we're going to do.

18 MEMBER DELMAN: That's great.

19 CO-CHAIR KAYE: All right. This is
20 supposed to be --- so trained, culturally
21 competent --- workforce trained, culturally
22 competent, adequate and ---

1 (Off mic comment)

2 CO-CHAIR KAYE: Sufficient numbers of
3 people. All right. And we'll remember that we
4 might want to put items about safely delivered
5 services in there. All right. Can we go on,
6 please? Okay.

7 (Off mic comment)

8 CO-CHAIR KAYE: Oh, I'm sorry. I'm
9 sorry, Mary.

10 MEMBER SMITH: That's all right. I was
11 patient. So, I was a little bit, or am a little
12 concerned that, you know, eight people voted for
13 those improved outcomes, but when we've talked
14 about it, people say they don't know what it
15 means. So, I'm actually wondering if improved
16 outcomes is really that dot with community
17 engagement all of that other stuff. And that the
18 delivery of effective treatment is really a
19 separate thing.

20 CO-CHAIR KAYE: I think so. I wonder if
21 Andrey would be willing to take out improved
22 outcomes and just put effectiveness and quality

1 of care.

2 MEMBER OSTROVSKY: I think that's
3 totally fine. I think it will be important to
4 keep in mind, and we actually may cover it with
5 integrated --- the part about integrated system.

6 CO-CHAIR KAYE: Right.

7 MEMBER OSTROVSKY: I just want to make
8 sure that we can have a clear bridge between what
9 home and community-based services can do and its
10 impact on morbidity, mortality, and other valued
11 outcomes that the medical provider/payer systems
12 look at as valuable. Because I don't want to
13 disconnect us from that, because I do think that
14 would be a really important key to
15 sustainability. So, I think the way you framed it
16 is great. And a lot of these things are outcomes,
17 I mean in many cases outcomes focused, so that's,
18 I think very appropriate.

19 MEMBER SMITH: Us behavioral health
20 people have that mortality and morbidity concern
21 to them.

22 (Off mic comment)

1 CO-CHAIR KAYE: Oh, I'm sorry. Mary,
2 since I cut you off before, are you done? I
3 apologize for forgetting.

4 MEMBER SMITH: Well, let me think. Yes.

5 CO-CHAIR KAYE: Okay, thank you. And
6 sorry for not getting back to you. Okay. Mike, do
7 you have to say something now, or can you wait
8 until --- okay, wait until -- Patti and Sandy
9 have their cards up.

10 MEMBER KILLINGSWORTH: Now that we've
11 agreed to delete something from the list, I just
12 --- I'm a little concerned about us taking out
13 the whole notion that a high quality system
14 should not result in people achieving the
15 outcomes that are important to them. Right? And
16 I'm not sure that's implicit in all of these
17 other things.

18 CO-CHAIR KAYE: Focused on individual
19 goals ---

20 MEMBER KILLINGSWORTH: We talk about
21 being focused on individual goals, but being
22 focused on them and achieving them are two very

1 different things. So, I am a little worried about
2 that. Just want us to think that through before
3 we drop it off the list.

4 MEMBER OSTROVSKY: What if you just
5 call it achieving individual goals, because
6 that's measurable, or we could create measures
7 around that. It's not just how well are we
8 focusing on it, but how well are we actually
9 helping people achieving ---

10 MEMBER KILLINGSWORTH: I agree. I like
11 that better.

12 (Off mic comment)

13 MEMBER KILLINGSWORTH: I just don't
14 want to lose the notion that what we really want
15 to get to is not just that we focus on them, but
16 we actually achieve them.

17 MEMBER OXFORD: I was actually thinking
18 improved outcomes was more of a system thing. So,
19 you go to the emergency room less, you get sick,
20 your weight gain, or your weight loss gets
21 better, those kinds of things, that's what --- I
22 mean, heck, I thought I knew what it meant, but

1 apparently --- so, I was not thinking of like
2 that on the individual level at all. I was
3 thinking of that whole line as a system.

4 MEMBER OSTROVSKY: I think that's
5 covered under --- alluded to in quality of care
6 and effectiveness, and also under achieving
7 individual goals, because we're getting at
8 systems and individual levels. And, I mean,
9 outcomes I think really it's just a distinction.
10 Like are we talking about structural measures,
11 process measures, outcome measures, and then a
12 lot of these do fall under the outcome domain.
13 And I think to put it into context, this is the
14 high level framework. Whatever quality measures
15 get developed can get at the issues you're
16 addressing, which I think is important. Like ED
17 utilization may be, or some reference to it could
18 be very important to measure as part of HCBS
19 quality measurement, but it will be --- it has to
20 be appropriately contextualized. And I think we
21 speak to that --- those types of --- we leave
22 room for those types of measures the way this is

1 set up.

2 MEMBER OXFORD: So, you're talking
3 about like the chart that we're going to draw,
4 and I was actually thinking about the services.

5 CO-CHAIR KAYE: Right. So, we're taking
6 out improved outcomes. Right? All right. So, got
7 it. Who else has their --- Sandy, do you still?
8 Yes. Patti, are you still waiting?

9 MEMBER KILLINGSWORTH: No, sorry.

10 MEMBER MARKWOOD: On the
11 physical/emotional health, I would include and
12 well-being, because that was --- I think that
13 that needs to be in there. Also, back on the next
14 to the last bullet on health disparities, I still
15 believe it should read equitable system, fairness
16 of resources, and eliminate disparities, and
17 disparities period, not just health disparities.

18 CO-CHAIR KAYE: Okay. Equitable system,
19 fairness of resources, eliminate disparities.
20 Yes.

21 MEMBER MARKWOOD: Yes, fairness of
22 distribution of resources, eliminate disparities.

1 CO-CHAIR KAYE: Okay. Is wellness okay
2 for the --- I mean, we took out well-being
3 before, and now we're putting it back in, but in
4 a different place. Is this okay? Anybody object
5 to that? Thumbs up from Gerry. Nobody is saying
6 no. Ari, do you still want to comment?

7 MEMBER NE'EMAN: Oh, no. I'm fine.

8 CO-CHAIR KAYE: Lorraine wanted to ---
9 has her card up.

10 MEMBER PHILLIPS: Yes. And I'm not sure
11 exactly where this should go, but I appreciate
12 the long conversation on safety. I agree with
13 what's on the screen. I'm not sure it encompasses
14 safety in the sense that --- from the perspective
15 of the consumer. The consumer may not recognize
16 when there is an omission, or error in care. And
17 the event occurs, and then the realization comes
18 that they were not safe. I'm not sure how to
19 include that, but I think safety is a bigger
20 issue than is portrayed.

21 CO-CHAIR KAYE: So, we have --- we
22 explicitly have safety twice, and we implicitly

1 have it a third time. The third being workforce -

2 --

3 MEMBER PHILLIPS: Right.

4 CO-CHAIR KAYE: You know, to safe
5 services, but that's still different --- I mean,
6 you're talking about safety as kind of a subset
7 of quality of care, so that the care is ---

8 MEMBER PHILLIPS: I am, so maybe that's
9 where it needs to come later.

10 CO-CHAIR KAYE: Is that --- is it okay
11 to leave it like that and make a mental note that
12 it's ---

13 MEMBER PHILLIPS: Yes.

14 CO-CHAIR KAYE: That we want, you know,
15 safety in the sense of care --- and that's also
16 neglect kind of thing, too.

17 MEMBER PHILLIPS: Well, it's also
18 workforce training, and accountability, and
19 responsibility.

20 CO-CHAIR KAYE: Okay. Kimberly, do you
21 ---

22 MEMBER AUSTIN-OSER: So, I have a

1 question. I'm looking over this, "A high quality
2 HCBS system has the following characteristics."
3 And we don't actually have any kind of verbs or
4 whatever, but it's kind of like a system that
5 honors or is centered around choice, person-
6 driven, focused, that sort of thing. One of the
7 things I don't see, and maybe it's just kind of
8 implicit, and that is that --- has the following
9 characteristics of delivering the right service
10 at the right time, and the right place. And all
11 this stuff is really talking about service
12 delivery, how it gets delivered, but we don't say
13 anything about the service delivery. And maybe
14 that doesn't matter, but to me, if I'm kind of a
15 lay person, I'm not familiar, I'm looking at a
16 high quality HCBS has the following
17 characteristics, has all these characteristics,
18 but it doesn't say anything about the actual
19 service delivery, which to me is --- when you
20 were talking, Anita, about safety, that's what
21 your mother needs. She needs services that keep
22 her safe, that keep her from falling, that keep

1 her -- and that's a part of her plan. It should
2 be a part of a person-centered plan that's built
3 around her needs. But when I was looking on here,
4 I'm like I don't see it anywhere, and maybe it's
5 just a given, but --- and then the other thing is
6 around workers. I'm not necessarily saying that
7 it's on here, but we're very consumer-focused,
8 and I think that's important. But we have kind of
9 another group of folks in this picture, and I'm
10 hoping that we'll be able to deal with it in the
11 workforce relation, or the workforce component,
12 about them being well supported, or whatever.

13 We're also talking about in many ways
14 whether it's a family care giver or a workforce,
15 kind of a marginalized group of people, and it's
16 not always safe for them either. So, we're
17 talking about safety for mom, but the training is
18 so important so workers have some safety, some
19 safeguards in place for them, as well. And that's
20 just something that's been stuck in craw, I want
21 to get out there.

22 CO-CHAIR KAYE: Patti, could you turn

1 your microphone off, please. So, do we want to
2 add safe after the colon in workforce, or injury,
3 you know, injury prevention, or something?

4 MEMBER AUSTIN-OSER: I mean, we could,
5 but then I feel like we're starting to get really
6 specific.

7 CO-CHAIR KAYE: Yes, I know. I do, too.

8 MEMBER AUSTIN-OSER: I'm fine saying
9 like a well supported, adequate workforce,
10 because then I feel like when we start having the
11 conversation, what does that mean?

12 CO-CHAIR KAYE: Okay.

13 MEMBER AUSTIN-OSER: And we can --- we
14 get into things like wages, and safety, and
15 training, and you know, that sort of thing for
16 them, so I don't feel like we have to get that
17 detailed. But I love culturally competent
18 workforce, that goes to training, in my opinion,
19 also goes to reflecting the cultural diversity of
20 our workforce, as well as the cultural and other
21 diversity, you know, other aspects of diversity
22 of the folks that we're supporting, and all that

1 sort of thing.

2 CO-CHAIR KAYE: All right. Ari Houser,
3 and then Ari Ne'eman, and then Anita.

4 MEMBER HOUSER: To answer the issue
5 that was recently brought up, there actually are
6 two bullet points that are about services which
7 don't have services written in. In the middle
8 where it says accessible, sufficient, and
9 dependable we might want to say services are
10 accessible, sufficient, appropriate, and
11 dependable.

12 CO-CHAIR KAYE: I support that. Any
13 objections to that? So, services are appropriate,
14 accessible, sufficient, and dependable, or you
15 had --- no, no, not a separate bullet. Under
16 where it says accessible down below. Services are
17 at the beginning, no, at the beginning. Services
18 are accessible, appropriate. Okay. And what else
19 were you going to say?

20 MEMBER HOUSER: I think in the top
21 bullet when it says effectiveness, that's
22 actually effectiveness of services.

1 CO-CHAIR KAYE: Why don't we change
2 that, effectiveness of services, quality of care.
3 Okay. And Ari Ne'eman. You're done, right?

4 MEMBER HOUSER: Yes.

5 CO-CHAIR KAYE: Okay. Ari Ne'eman.

6 MEMBER NE'EMAN: Let me just pause
7 briefly to communicate in response to Kimberly's
8 point. I certainly agree that the quality and
9 adequacy of the workforce is an important sort of
10 instrumental issues towards insuring other
11 quality outcomes that we care about. At the same
12 time, I want to express sort of preemptively,
13 because I'm sure we're going to have this
14 discussion down the line, that I would be very
15 concerned, and I think a number of other people
16 would be very concerned about looking at
17 workforce outcomes, or worker outcomes as
18 measures of HCBS quality, particularly if it
19 involves minimum training requirements, or a set
20 of requirements around worker safety that would
21 seem to subject people's homes or residences to a
22 set of rules that, you know, are perhaps

1 appropriate for a workplace, but don't
2 acknowledge that at the end of the day people
3 live there. So, I mean, I think there is always a
4 natural tension between disability and labor
5 advocates on this issue, and I'm sure we'll have
6 the opportunity to engage and find appropriate
7 middle ground. I just want to express the
8 likelihood of us needing to reconcile that down
9 the road.

10 CO-CHAIR KAYE: Yes. Could we please
11 not get into that debate now. And Anita, and I
12 wonder, Clare, are you still waiting, or is that
13 from before? Okay. No, first, Anita.

14 COURT REPORTER: I'm sorry, ma'am, your
15 microphone isn't working.

16 MEMBER YUSKAUSKAS: I'd like to propose
17 a change based on what Kimberly said before,
18 which is a high quality HCBS system provides the
19 right services to the right person at the right
20 time, every time, and has the following
21 characteristics. Is that where you were going
22 with that, because that's sort of how I heard it.

1 And it seems like that might be a really sort ---

2

3 CO-CHAIR KAYE: No.

4 MEMBER YUSKAUSKAS: No? You don't like
5 that.

6 CO-CHAIR KAYE: No. I mean, we could
7 put --- we could have it in there, but I don't
8 want to just, you know ---

9 MEMBER YUSKAUSKAS: Okay.

10 CO-CHAIR KAYE: I'm not sure that's the
11 top thing. I mean, that gives it a huge heft.

12 MEMBER YUSKAUSKAS: Well, yes. And I
13 think the reason that I did suggest that is
14 because we're still keeping high quality in
15 there, so that's a high bar to meet.

16 MEMBER AUSTIN-OSER: While I appreciate
17 that, I wasn't suggesting that it change the kind
18 of the top header. And I'm not even necessarily
19 thinking that we have to have it in as a bullet.
20 And I feel like services are accessible,
21 appropriate, sufficient, dependable, effective,
22 and high quality. I'm not sure what quality of

1 care means. I like right services, right time,
2 right place, but that means different things to
3 different people. And I'm thinking about it very
4 broadly, but I think that we probably have the
5 essence of what I was talking about covered. But
6 I also --- I see where you're coming from.

7 CO-CHAIR KAYE: Okay. Clare.

8 MEMBER LUZ: So, right services would
9 be appropriate, appropriate covers that. Right?
10 Right time, could we just add the word time,
11 services are accessible, appropriate, timely?

12 CO-CHAIR KAYE: Yes.

13 (Off mic comment)

14 MEMBER LUZ: Okay. And then back to
15 your point about workforce, and I really respect
16 Ari and Mike's viewpoint over here, but I would
17 like to see, or have the group entertain a
18 thought of having workforce training, culturally
19 supported, adequate and supported, because we
20 don't want them getting hurt, or working for \$6
21 an hour.

22 CO-CHAIR KAYE: Is that okay,

1 culturally --- trained, culturally competent,
2 adequate and supported?

3 MEMBER LUZ: I think you said well
4 supported, adequate numbers and supported, you
5 know.

6 (Off mic comment)

7 CO-CHAIR KAYE: Same as it was --- same
8 as it is already, workforce: trained, culturally
9 competent, adequate, and supported.

10 MEMBER LUZ: I mean, I think if we're
11 going to look for social justice, or equitable
12 system, social justice for consumers we want
13 social justice for everybody.

14 CO-CHAIR KAYE: Right. But you know
15 there's an ongoing war about this.

16 MEMBER LUZ: Yes, I know that.

17 CO-CHAIR KAYE: Right.

18 MEMBER LUZ: And it's --- I'm sorry. I
19 don't want to ---

20 CO-CHAIR KAYE: I'm fine with
21 everything in there except for trained. And if we
22 define that a little bit more, I'd feel more

1 comfortable with it.

2 MEMBER LUZ: Well, that's ---

3 CO-CHAIR KAYE: All right. Well, you --
4 - okay. I understand, but let's not address this
5 now.

6 MEMBER LUZ: So, just one last thought.
7 I think it's implied in all of this, but all of
8 our discussions have been around people who are
9 capable of making decisions on their own, and I
10 don't know if we need to more blatantly address
11 people with dementia, or people who are not able
12 to make decisions on their own?

13 CO-CHAIR KAYE: And how would you do
14 that?

15 MEMBER LUZ: I'm not sure. Maybe, you
16 know ----in the earlier rendition of this we said
17 these services would be for everybody regardless
18 of age, or mental cognition. We had some
19 qualifiers in there, and if we just added
20 something like that.

21 CO-CHAIR KAYE: Right, and we probably
22 will have that in the --- I mean, this is --- so,

1 one of the purposes of this is to have this below
2 the general definition of what HCBS is. And I
3 think we probably will have the different types
4 of disabilities that are served. Right? But that
5 may not fully address what your concern is.

6 MEMBER LUZ: Well, I think if --- I
7 think somewhere we said individuals of their
8 proxy was in there somewhere.

9 CO-CHAIR KAYE: Right. Okay.

10 MEMBER LUZ: Which sort of covered it,
11 didn't it?

12 CO-CHAIR KAYE: Can we put that in the

13 ---

14 MEMBER LUZ: I don't know if it covered
15 it sufficiently enough for everybody, but that's
16 one way of at least addressing it.

17 CO-CHAIR KAYE: Okay. So, now there's
18 the question, we have, I believe, 13 bullets
19 here. And 13 bullets is not necessarily too much.
20 I would prefer half that many, something like
21 that but, I mean, that's just me. Do we --- I
22 mean, as Sarah Lash said, I mean, we seem pretty

1 wedded to most of these. Do we need to --- should
2 we vote? If we voted we would be effectively
3 prioritizing them, and that might be useful for
4 our later --- for later use. I mean, we could
5 list them in order of priority, if we wanted to.
6 If we don't vote then that's the statement that
7 we're pretty happy with these 13. Ari.

8 MEMBER HOUSER: I think that it would
9 be a useful exercise to vote, whether or not we
10 decide to include all 13, just to get a sense
11 from ourselves, you know, if --- you know, right
12 now we have 13, and clearly some are higher
13 priority than others in general.

14 CO-CHAIR KAYE: Right.

15 MEMBER HOUSER: But we don't
16 necessarily know --- we may have a vague sense,
17 but not a statistical sense, and it may be that
18 there's, you know, a clear dividing line on some
19 subset, or there may not be.

20 CO-CHAIR KAYE: Okay, I kind of agree
21 with you. What do you think, Sandy?

22 MEMBER MARKWOOD: I'm just wondering --

1 -

2 CO-CHAIR KAYE: Can you use the
3 microphone? Turn off your microphone, please,
4 Mary.

5 MEMBER MARKWOOD: If we want to vote on
6 these or if there is a way just to do something
7 so we're prioritizing them.

8 CO-CHAIR KAYE: That's what we're going
9 to --- we're going to put stickers on the ---

10 MEMBER MARKWOOD: Okay.

11 CO-CHAIR KAYE: --- board up there, and
12 you can put as many stickers as you want as
13 indication of your priority. And we may decide
14 to cut or consolidate the ones that are less,
15 that are lower priority, or maybe decide to list
16 --- you know, maybe we'll --- I mean, this could
17 be --- in addition to having these as
18 characteristics of the system, we might --- the
19 idea would be to start to use this to help us
20 form what the domains of quality are, and we may
21 decide that some of these don't belong there, or
22 some of these get wrapped up into other things,

1 or something like that. So, we may not want 13
2 high-level quality domains. Mary.

3 MEMBER SMITH: So, I'm going to present
4 the other side. It seems to me that we've spent
5 like three hours wordsmithing each and every one
6 of these. I don't think there's not one that
7 we've talked about in excruciating detail
8 sometimes. So, I guess I'm really not sure again
9 why we ---you know, we can't just go with these
10 as critical things that this group sees as
11 important to HCBS services.

12 CO-CHAIR KAYE: Well ---

13 MEMBER SMITH: I mean, what's the
14 burning need to prioritize them?

15 MEMBER OXFORD: Well, in a little bit
16 different angle, I'm sensing there's also a
17 certain level of frustration and feeling like we
18 just need to move, to move with some of this in
19 terms of finalizing things. And maybe it would be
20 best just to say, you know what, that's a good
21 list, we've worked it real hard. Maybe it should
22 just simmer a little while and this, I think,

1 captures --- I agree with Mary, including the
2 fact that continuing to work this thing after all
3 this time, and including with the frustration I'm
4 beginning to sense around maybe wouldn't be
5 helpful.

6 CO-CHAIR KAYE: Okay. I mean, we're
7 only talking about taking five minutes and
8 everybody get up to the board and vote, so it's
9 not a big deal.

10 (Off mic comment)

11 CO-CHAIR KAYE: Let's just do it? Okay.
12 So, take --- so, you have 10 --- so use 10
13 stickers, use them any way you want. The colors
14 don't mean anything. Stick them on to the items
15 that are up there.

16 MS. LASH: Ten dots, no more, no less.

17 CO-CHAIR KAYE: Okay. Please use 10
18 stickers. You don't want to use all 10 of your
19 stickers, that's fine, but try not to use 15 of
20 them, Ari Ne'eman.

21 (Whereupon, the above-entitled matter
22 went off the record at 4:12 p.m. and resumed at

1 4:22 p.m.)

2 CO-CHAIR KAYE: Okay. Well, we've got
3 quite a range. There are two items that have ---
4 two bullets that have 23 votes, one that has 22,
5 and that at the other extreme there's one that
6 only has five, so there's quite a range of stuff.
7 And I think we'll talk about that tomorrow
8 morning, and you're going to go to public
9 comment. Right?

10 MS. LASH: Right. So, thank you,
11 everyone, for a very productive and long day.
12 We're going to redo some of the agenda so that we
13 begin tomorrow with a thorough recap of some of
14 the things we've decided on today, including sort
15 of the results of this prioritization exercise,
16 and what we think it tells us about potential
17 measurement domains.

18 A reminder that there is a dinner
19 reservation made on behalf of the Committee
20 tonight at 6:00. You can speak to Nadine for more
21 details. And we will take one last round of
22 public comment before we adjourn for the day.

1 Anyone in the room?

2 MS. BOGENREIF: Hi, my name is Jennifer
3 Bogenreif, and I work for the American
4 Occupational Therapy Association in their
5 Regulatory Affairs Department. And I just ---

6 it's been very interesting discussion, and the
7 whole issue about safety, it seems to be a hot
8 topic. I just --- the huge problem with falls
9 risk that we see as occupational therapists is so
10 huge, and it leads to re-admissions and re-
11 hospitalizations, and it would prevent people
12 from being able to be in their home, which is
13 what they truly want. So, I just urge everyone to
14 really think about safety in that way, because
15 it's extremely important in this setting, in this
16 whole area. Thanks.

17 MS. LASH: Any public comments from the
18 phone?

19 OPERATOR: Okay. Once again, to make a
20 public comment please press star one. You have a
21 comment from the line of James Gallant.

22 MS. LASH: James, if you could be

1 brief, please go ahead.

2 MR. GALLANT: Yes, James Gallant,
3 again. Actually, under the part about --- you
4 were talking about the abuse, neglect, and
5 exploitation part, I would recommend you use
6 actually the quote out of the Developmental
7 Disabilities Act of 2000. And it says that, "A
8 person should live free of abuse, neglect,
9 exploitation, and violations of their legal and
10 human rights," which kind of covers the whole
11 gamut of all of it. And because, you know, the
12 example that I gave about the family and custody
13 and parenting rights that, you know, it's a human
14 right, a child has a human right to their family
15 and people, to their family, they have a human
16 right to that. That's under the UN Conventions,
17 and their legal rights, and it kind of wraps it
18 all up there.

19 And, also, I would ask you to please
20 come together as a group and contact the author
21 of a book called, "Roberts Rule of Order for
22 Dummies," and he's a qualified parliamentarian.

1 He's the Louisiana Senate's parliamentarian. And
2 in the book, the back of the book he's got his
3 telephone number. And I've already contacted him,
4 and he said yes, he'd give you a free quote on
5 writing a report, and figure out where you're at
6 now on the parliamentary part of it, you know. I
7 mean, somebody appointed this group. There are
8 some rules, and you could just lay it out. And
9 like you said about the nominating committee, to
10 have the stakeholder missing from this meeting,
11 and like the Action Alliance for Suicide
12 Prevention is also missing, as a parliamentarian,
13 somebody keep track. So, it's not --- you know,
14 and you get sidetracked here and there, and
15 different opinions, to get an actual opinion of a
16 qualified parliamentarian would be important. And
17 I'm assuming that it would probably, you know,
18 change the face of what's happening here before
19 you get too far into it. And thank you very much.

20 MS. LASH: Any other comments from the
21 phone?

22 OPERATOR: There are no comments at

1 this time.

2 MS. LASH: All right. And we thank
3 everyone that submitted written comments on the
4 web. We'll be making a summary of those for the
5 Committee's review. We appreciate everyone's
6 attention and efforts today, and we'll see you in
7 the morning.

8 (Whereupon, the above-entitled matter
9 went off the record at 4:27 p.m.)

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