

NATIONAL QUALITY FORUM

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

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

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THURSDAY  
APRIL 30, 2015

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

PRESENT:

JOE CALDWELL, PhD, Co-Chair

H. STEPHEN KAYE, PhD, Co-Chair

ROBERT APPLEBAUM, MSW, PhD, Scripps Gerontology  
Center, Miami University

KIMBERLY AUSTIN-OSER, MS, SEIU Healthcare

SUZANNE CRISP, National Resource Center for  
Participant Directed Services

JONATHAN DELMAN, PhD, JD, MPH, University of  
Massachusetts Medical School

CAMILLE DOBSON, MPA, CPHQ, National Association  
of States United for Aging and  
Disabilities

SARA GALANTOWICZ, MPH, Abt Associates Inc.

ARI HOUSER, MA, AARP Public Policy Institute

JAMIE KENDALL, MPP, Administration of Community  
Living

PATTI KILLINGSWORTH, Bureau of TennCare  
 K. CHARLIE LAKIN, PhD, Retired, National  
 Institute on Disability and Rehabilitation  
 Research

CLARE LUZ, PhD, Michigan State University  
 SANDRA MARKWOOD, MA, National Association of  
 Area Agencies on Aging

BARBARA McCANN, MA, Interim Health Care\*  
 SARITA MOHANTY, MD, MPH, MBA, Kaiser Permanente  
 Northern California

GERRY MORRISSEY, MEd, MPA, The MENTOR Network  
 ARI NE'EMAN, Autistic Self Advocacy Network  
 ANDREY OSTROVSKY, MD, Care at Hand  
 MIKE OXFORD, Topeka Independent Living Resource  
 Center

LORRAINE PHILLIPS, PhD, RN, University of  
 Missouri

MARY SMITH, PhD, Illinois Division of Mental  
 Health

ANITA YUSKAUSKAS, PhD, Pennsylvania State  
 University

#### NQF STAFF:

MARCIA WILSON, PhD, MBA, Senior Vice President,  
 Quality Measurement

NADINE ALLEN, Project Analyst

ANDREW ANDERSON, Senior Project Manager

JULIET FELDMAN, Project Manager, Stakeholder  
 Collaboration

SARAH LASH, Senior Director

#### ALSO PRESENT:

ELLEN BLACKWELL

D.E.B. POTTER

\* Present by teleconference

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

Review Results and Themes from Day 1	
Sarah Lash. . . . .	4
Large Group Discussion of Measurement Domains	
Andrew Anderson . . . . .	.14
Opportunity for Public Comment . . . . .	.99
Small Group Work: Defining Measurement Sub-	
Domains for Chosen Domains . . . . .	115
Opportunity for Public Comment . . . . .	165
Committee's Review and Final Refinements to	
Conceptual Framework	
Sarah Lash. . . . .	166
Review the Methodology for Next Steps:	
Environmental Scan and Synthesis of Evidence	
Juliet Feldman. . . . .	179
Round Robin: Identifying Fertile Ground for	
Measurement. . . . .	187
Adjourn	

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

9:02 a.m.

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

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

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

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

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

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

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

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

1 conducting the measurement.

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

8 (Laughter)

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

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

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

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

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



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

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

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

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

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

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

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

22                   And then after lunch we will tackle

1 your input on a sketch of a conceptual framework  
2 that we came up with last evening to see what  
3 enhancements you might be able to offer. We will  
4 review the methodology for the next step in the  
5 project, which is environmental scan and  
6 synthesis of evidence, and we'll close with a  
7 round robin of the full Committee. And we're  
8 trying very hard to end the meeting on time at  
9 3:30 because we know many of you will have travel  
10 plans built around that.

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

13 (No response)

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

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

1 muted and we didn't know that.

2 So I mean, I think you deserve extra  
3 credit for managing to remain silent and calm.

4 So could you introduce yourself?

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

8 (Laughter)

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

21 I know you all by your voices, though.

22 (Laughter)

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

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

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

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

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

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

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

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

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

19 (Simultaneous speaking)

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

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



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

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

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

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

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

20 MR. ANDERSON: Time to another, yes.

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

1 MEMBER YUSKAUSKAS: Anita Yuskas.

2 COURT REPORTER: Thank you.

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

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

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

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

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

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

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

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

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

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

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

9 MEMBER MOHANTY: Yes.

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

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

16 CO-CHAIR KAYE: Right. Yes.

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

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

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

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

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

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

21 Charlie?

22 MEMBER LAKIN: I'd just like to know

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

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

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

14             MR. ANDERSON: Right, to get into that  
15      38, the top 38 sources. I think the other thing  
16      that was helpful to me is there's another thing  
17      that was in the packet that lays out the  
18      different frameworks that were looked at. So  
19      like the NCI and the AHRQ, and DREDF for Steve  
20      Kaye is in that. So I think this was helpful to  
21      me in terms of what they actually looked at, the  
22      different frameworks, and then calculated the

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

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

7 MR. ANDERSON: Oh, yes. Right.

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

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

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

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

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

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



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

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

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

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

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

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

22              MEMBER PHILLIPS: I think if you're

1 going to --

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

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

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

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

10 CO-CHAIR KAYE: Yes.

11 (Laughter)

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

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

18 Andrey?

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

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

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

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

1 think there's so much more beyond care  
2 transitions.

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

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

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

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

2 And then I don't know if --

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

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

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

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

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

22 MEMBER APPLEBAUM: And then I don't

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

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

13 MEMBER APPLEBAUM: Yes.

14 CO-CHAIR KAYE: Okay.

15 MEMBER APPLEBAUM: Correct.

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

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

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

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

19 MEMBER DOBSON: Yes.

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

22 MEMBER OXFORD: It's back on kind of

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

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



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

6 CO-CHAIR KAYE: Okay. Thanks, Mike.

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

11 (No response)

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

19 Andrey?

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

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

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

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

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

21 Go ahead, Barbara.

22 MEMBER McCANN: Perhaps under person-

1 centered?

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

6 MEMBER McCANN: Right.

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

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

13 CO-CHAIR KAYE: Yes.

14 MEMBER McCANN: Okay.

15 CO-CHAIR KAYE: That would be a  
16 separate one. We've got that in a separate one.  
17 Mary?

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

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

1       which means participation in the system, system  
2       participation.

3               MEMBER McCANN:   Okay.

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

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

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

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

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

22              (No response)

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

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

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

13 MEMBER OXFORD: -- system level.

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

16 MEMBER OXFORD: Yes.

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

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

1 CO-CHAIR KAYE: I kind of think so.

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

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

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

9 CO-CHAIR KAYE: Right.

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

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

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

1 are actually in the home and providing supports.

2 CO-CHAIR KAYE: What do you think?

3 Gerry?

4 MEMBER MORRISSEY: Not on that point.

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

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

20 Kimberly?

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

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

17 CO-CHAIR KAYE: Right.

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



1 unless you --

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

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

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

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

8 (No response)

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

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

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

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

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

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

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

22 And so, I think both of those are

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

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

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

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

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

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

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

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

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

4                    CO-CHAIR KAYE:    Okay.    Ari?

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

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

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

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

1 (No response)

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

4 MEMBER AUSTIN-OSER: Actually I do.

5 MEMBER KILLINGSWORTH: I do.

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

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

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



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

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

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

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

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

11 CO-CHAIR KAYE: Right.

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

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

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

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

4 MEMBER OXFORD: It could be  
5 individuals or agencies.

6 CO-CHAIR KAYE: Okay.

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

10 CO-CHAIR KAYE: Clair?

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

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

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

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

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

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

18 (No response)

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

22 MEMBER CRISP: I just wanted to say

1 are we trying to say participant input in  
2 operations?

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

7 CO-CHAIR KAYE: What about consumer  
8 voice?

9 MEMBER CRISP: Yes.

10 CO-CHAIR KAYE: Consumer voice?

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

13 (Simultaneous speaking)

14 CO-CHAIR KAYE: Stakeholder  
15 engagement.

16 (Simultaneous speaking)

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

19 MEMBER MORRISSEY: How about  
20 individual engagement?

21 MEMBER CRISP: What was that?

22 MEMBER MORRISSEY: Individual. Well,

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

8 CO-CHAIR KAYE: Sarita?

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

18 (Simultaneous speaking)

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

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

1 CO-CHAIR KAYE: Consumer/stakeholder  
2 engagement.

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

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

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

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

17 CO-CHAIR KAYE: Consumer and  
18 stakeholder engagement.

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

1 (Laughter)

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

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

10 MEMBER DELMAN: Can I comment on the  
11 last one?

12 CO-CHAIR KAYE: Sure.

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



1 driven and the outcomes of consumers have been  
2 ignored.

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

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

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

1 emphasis on participants or patient engagement.

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

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

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

10 MEMBER DELMAN: Self-determination?

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

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

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

20 DR. MORRISSEY: Yea.

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

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

4 MEMBER APPLEBAUM: How about choice  
5 and control?

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

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

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

13 (No response)

14 CO-CHAIR KAYE: No objection to  
15 collapsing these?

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

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

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

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

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

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

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

21             CO-CHAIR KAYE: Clare?

22             MEMBER LUZ: So the language of choice

1 and control is very individual-oriented.

2 CO-CHAIR KAYE: Yes.

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

9 CO-CHAIR KAYE: Yes.

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

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

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

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

4 CO-CHAIR KAYE: Jon is not happy.

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

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

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

11 CO-CHAIR KAYE: Human rights?

12 MEMBER OXFORD: How about human and  
13 legal rights?

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

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

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

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

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

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

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

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

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

19 MEMBER MORRISSEY: System performance.

20 CO-CHAIR KAYE: Is that okay? Yes?

21 (No response)

22 CO-CHAIR KAYE: Okay. System



1 performance for that.

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

7 DR. MORRISSEY: Inclusion. How about  
8 real lives?

9 CO-CHAIR KAYE: Real lives.

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

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

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

22 MEMBER GALANTOWICZ: Sure, just

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

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

10 Ari is not happy.

11 (Off mic comments)

12 (Laughter)

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

15 MEMBER HOUSER: I was just going to  
16 agree.

17 CO-CHAIR KAYE: Oh.

18 MEMBER HOUSER: Community inclusion.

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

22 MEMBER OSTROVSKY: Can I ask a quick

1 question?

2 CO-CHAIR KAYE: Sure.

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

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

18 CO-CHAIR KAYE: Michael?

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

1 participation.

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

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

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

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

12 MEMBER LAKIN: Sub-domain.

13 CO-CHAIR KAYE: Sub-domain.

14 MEMBER LAKIN: I think full community  
15 inclusion is --

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

18 (Off mic comments)

19 CO-CHAIR KAYE: Ari Houser?

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

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

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

10 MR. NE'EMAN: Inclusion.

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

13 MEMBER OXFORD: Yes.

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

16 (Laughter)

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

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

1 Clare?

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

9 CO-CHAIR KAYE: Yes.

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

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

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

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

3 CO-CHAIR KAYE: You agree with that?

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

6 (Laughter)

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

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

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

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

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

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

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

12              (No response)

13              CO-CHAIR KAYE: Yes? Okay. Good.

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

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

22              CO-CHAIR KAYE: Is there agreement on



1       that?

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

6                   CO-CHAIR KAYE: Quality of care?

7                   MEMBER OXFORD: Yes.

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

10                  MEMBER OXFORD: Right.

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

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

1 kind of performance?

2 Go ahead, Sandy.

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

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

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

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

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

19 CO-CHAIR KAYE: Okay.

20 MEMBER SMITH: I think effectiveness  
21 says something different.

22 CO-CHAIR KAYE: Is that all right?

1 Effectiveness/quality of care as a domain?

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

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

10 MEMBER KILLINGSWORTH: Or just quality  
11 and effectiveness.

12 CO-CHAIR KAYE: Quality of what?

13 MEMBER KILLINGSWORTH: Quality and  
14 effectiveness.

15 CO-CHAIR KAYE: Quality/effectiveness?

16 MEMBER KILLINGSWORTH: Yes.

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

1 services or just quality of services? Quality of  
2 services.

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

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

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

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

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

21 MEMBER OXFORD: I think the --

22 CO-CHAIR KAYE: Who wants to say no?

1 MEMBER SMITH: I do.

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

6 CO-CHAIR KAYE: Right.

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

12 CO-CHAIR KAYE: I think so.

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

15 (Simultaneous speaking)

16 CO-CHAIR KAYE: Is not coordinated?

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

19 (Simultaneous speaking)

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

22 MEMBER AUSTIN-OSER: So, it feels like

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

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

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

3 MEMBER AUSTIN-OSER: I think they are.

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

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

8 CO-CHAIR KAYE: True.

9 MEMBER LUZ: -- different from  
10 quality.

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

17 Ari Houser?

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

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

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

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

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



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

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

13 MEMBER OXFORD: Yes.

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

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

18 CO-CHAIR KAYE: Yes.

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

22 CO-CHAIR KAYE: Do you have another

1 way of phrasing what is in that bucket?

2 MEMBER SMITH: In this bucket?

3 CO-CHAIR KAYE: Yes.

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

6 CO-CHAIR KAYE: Mike does?

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

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

15 MEMBER OXFORD: Well, yes.

16 CO-CHAIR KAYE: Okay. Clare?

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

20 CO-CHAIR KAYE: Of care?

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

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

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

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

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

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

20 (Simultaneous speaking)

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

1 effectiveness and quality of services?

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

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

8 MEMBER MARKWOOD: Well, yes.

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

12 (No response)

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

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

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

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

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

16 (Simultaneous speaking)

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

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

21 CO-CHAIR KAYE: Please.

22 MEMBER DOBSON: Point of order to the

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

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

8 MEMBER DOBSON: But some of these are  
9 --

10 CO-CHAIR KAYE: -- sub-domains.

11 MEMBER DOBSON: -- individual.

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

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

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

18 MEMBER DOBSON: -- individual --

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

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

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

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

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

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

11 CO-CHAIR KAYE: Barbara is agreeing  
12 with that.

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

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



1 intimate relationships with non-family support  
2 providers.

3 CO-CHAIR KAYE: Barbara?

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

10 CO-CHAIR KAYE: Anita?

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

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

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

1 something like equity? Service equity or  
2 something like that?

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

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

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

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

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

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

21 CO-CHAIR KAYE: Equity and fairness?

22 (No response)

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

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

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

19 (No response)

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

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

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

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

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

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

4 CO-CHAIR KAYE: That's not helpful.

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

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

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

12 CO-CHAIR KAYE: Buy-in, yes.

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

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

1 appalled at the stakeholder engagement in  
2 California --

3 (Simultaneous speaking)

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

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

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

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

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

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

2 CO-CHAIR KAYE: Gerry, keep thinking.

3 (Laughter)

4 CO-CHAIR KAYE: Clare?

5 MEMBER LUZ: I'm okay with ownership.

6 I'm not okay with buy-in because I do think the  
7 situation can exist where somebody decides  
8 everything and then gets you to agree to it and  
9 then calls it buy-in.

10 CO-CHAIR KAYE: Okay. Bob?

11 MEMBER APPLEBAUM: I just would agree  
12 with Jon. I really like something like  
13 meaningful involvement in the design, or  
14 something like that. I think the thing I don't  
15 like about ownership is we live in a world where  
16 75 percent of nursing homes are for-profit, 60  
17 percent of home health agencies are for-profit,  
18 and I think ownership can connote something that  
19 I think we don't want to communicate here in this  
20 particular --

21 CO-CHAIR KAYE: Suzanne and Anita and  
22 Sarita.

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

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

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

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

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

18                  CO-CHAIR KAYE: Right.

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

21                  CO-CHAIR KAYE: Anita?

22                  MEMBER YUSKAUSKAS: I think the terms



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

13 CO-CHAIR KAYE: Sarita?

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

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

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

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

11 CO-CHAIR KAYE: Right.

12 MEMBER SMITH: Or accountable to  
13 consumer voice.

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

17 CO-CHAIR KAYE: Sandy?

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

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

22 MEMBER MARKWOOD: Yes.

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

4 (No response)

5 CO-CHAIR KAYE: Consumer  
6 voice/ownership wins.

7 (Laughter)

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

10 (No response)

11 CO-CHAIR KAYE: Thanks, everybody.

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

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

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

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

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

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

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

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

19 MS. BLACKWELL: Okay.

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

22 MS. BLACKWELL: Okay.

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

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

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

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

1 agencies, at a date in June 2012, 600,000 or so,  
2 which is 56 percent, lived in the home of a  
3 family member, 10 percent lived in a home they  
4 owned or leased, and 5 percent lived with a host  
5 family or in a family foster home. The remaining  
6 28 percent lived in a group home or facility.  
7 And so, individuals providing support to people  
8 with IDD is not a small number.

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

12 As an alternative to the term  
13 ownership, responsibility.

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

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

5 Thank you all for those comments.

6 We'll reconvene at 11:00.

7 (Whereupon, the above-entitled matter  
8 went off the record at 10:43 a.m. and resumed at  
9 11:03 a.m.)

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

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

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

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

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

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

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

21 So, with that, here are the group  
22 assignments.



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

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

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

12           Any questions?

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

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

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

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

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

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

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

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

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

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

7                   CO-CHAIR CALDWELL: Gerry?

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

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

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

22                   So, in other words, not a paid worker

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

3                   MEMBER MORRISSEY: Neighbor, natural  
4       supports?

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

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

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

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

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

1 MEMBER MORRISSEY: Family caregivers.

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

22           So, that might help us if we get the

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

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

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

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

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

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



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

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

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

13          Any other questions? Kimberly?

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

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

20          MS. LASH: Yes.

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

1 MS. LASH: Yes.

2 MEMBER AUSTIN-OSER: Okay.

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

4 MEMBER AUSTIN-OSER: More than just  
5 reporting out?

6 MS. LASH: -- about 45 minutes or so  
7 after lunch sharing our results with the larger  
8 committee so that we can have the opportunity for  
9 --

10 MEMBER AUSTIN-OSER: Feedback, okay,  
11 great.

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

14 MEMBER AUSTIN-OSER: Thank you.

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

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

20 Okay, let's do it.

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

1 1:05 p.m.)

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

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

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

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

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

1 Sandy Markwood, Barbara McCann and Mike Oxford.

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

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

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

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

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

6 And Joe will be facilitating you if  
7 you run over.

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

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

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

1 Bob.

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

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

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

22 But there was a lot of discussion

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

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

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

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

12 CO-CHAIR CALDWELL: Yes, I think so.

13 MEMBER APPLEBAUM: Okay.

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

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

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

1 Is this not the time to ask?

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

5 MEMBER DOBSON: It's up to you.

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

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

10 MEMBER APPLEBAUM: Okay, so --

11 MEMBER DOBSON: Program delivery  
12 models, what that meant.

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

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



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

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

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

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

22 And the presence of actually having

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

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

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

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

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

22 So, that was the only thing that was

1 really very different.

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

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

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

12 MEMBER DOBSON: System responsiveness?

13 MEMBER APPLEBAUM: Is that yours?

14 Okay, please.

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

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

1 mechanisms in place to address when this goes  
2 south.

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

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

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

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

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

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

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

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

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

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

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

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

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

18                  Anybody want to add anything to? No?

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

22                  MEMBER YUSKAUSKAS: I just have a

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

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

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

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

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

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

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

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

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



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

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

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

14 CO-CHAIR CALDWELL: Yes, Andrey?

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

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

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

4                   Did you guys speak to that?

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

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

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

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

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

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

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

14 CO-CHAIR CALDWELL: And Sandy, you  
15 wanted?

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

22 MR. NE'EMAN: I would have no

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

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

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

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

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

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

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

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

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

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

1 services, good services, and some are not.

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

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

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

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

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

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

21 MR. NE'EMAN: Eligibility?

22 MEMBER YUSKAUSKAS: Eligibility and

1 scope and --

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

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

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

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

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

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

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



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

4 We had a set of issues relating to the  
5 availability of data and the integrity of data.

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

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

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

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

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

5 MR. NE'EMAN: Next?

6 CO-CHAIR CALDWELL: Andrey wanted to  
7 say something.

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

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

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

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

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

1           That providers be culturally and  
2           linguistically competent, sensitive and mindful.  
3           That providers have adequately compensated  
4           benefits, or are adequately compensated and have  
5           access to benefits.

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

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

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

22                 MEMBER AUSTIN-OSER: So, I probably

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

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

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

22 MEMBER AUSTIN-OSER: I would like to

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

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

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

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

22 CO-CHAIR CALDWELL: John?

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

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

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

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

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

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

16                   MEMBER SMITH: Could I just make a  
17      comment?

18                   CO-CHAIR CALDWELL: Yes.

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



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

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

11 CO-CHAIR CALDWELL: Patti?

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

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

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

3 CO-CHAIR CALDWELL: Okay.

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

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

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

18 CO-CHAIR CALDWELL: Andrey?

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

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

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

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

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

22 I think what we tried to do was

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

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

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

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

22 MEMBER KILLINGSWORTH: I think our

1 other two are --

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

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

19 MEMBER KILLINGSWORTH: Makes sense.

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

22 MEMBER KILLINGSWORTH: I think we're

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

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

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

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

6 MEMBER KILLINGSWORTH: That's the  
7 intent.

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

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

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

1 MEMBER KILLINGSWORTH: It was.

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

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

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



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

5           MEMBER KILLINGSWORTH: Yes, it was.

6           MEMBER HOUSER: Okay.

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

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

19           CO-CHAIR CALDWELL: That's good. Any  
20 comments? Okay. We've got the last group, Group  
21 4.

22           MEMBER CRISP: So, one of the hazards

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

5 So, our first domain that we worked on  
6 was the effectiveness and quality of services.

7 So, we really looked at effectiveness as  
8 achieving outcomes and effective -- a measure of  
9 effectiveness is whether or not you accomplish  
10 what you set out to accomplish. So, you'll see  
11 that we've listed meeting goals, meeting  
12 preferences, health outcome achieved.

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

22 MEMBER LUZ: And I'll add that, like

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

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

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

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

22 The first adjective was service -- it

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

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

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



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

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

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

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

1 continuity?

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

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

22 You know, if you are eligible for a

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

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

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

22 And then we all laughed because really

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

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

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

20                   CO-CHAIR CALDWELL: Okay.

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

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

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

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

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

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

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

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

22          Also, that it would be fairly simple

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

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

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

1                   So, this is the product of some tired  
2                   brains. Last night we had pyramids, we had  
3                   circles for a while. We ended up with this  
4                   arrow. So, we'd like any concrete suggestions  
5                   you have for how this might be able to be  
6                   enhanced. If it's missing the boat entirely, we  
7                   can probably spend until, it is now going to be  
8                   2:30 on this topic, and then this is also  
9                   something that you'll be able to give us written  
10                  email feedback on after the meeting, since we're  
11                  just kind of throwing this out at you without too  
12                  much other preparation. Joe and Steve, did I  
13                  capture that correctly?

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

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



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

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

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

1 understand HCBS as a construct?

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

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

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

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

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

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

22                   CO-CHAIR KAYE: What if it were

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

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

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

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

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

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

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

11 CO-CHAIR CALDWELL: That's good.

12 Patti?

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

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

22 Now, that doesn't work if you change

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

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

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

17 CO-CHAIR CALDWELL: Sara?

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

1 is one that realizes the outcomes for  
2 individuals.

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

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

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

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

1                   Anita?

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

8                   CO-CHAIR CALDWELL: Mary?

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

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

19                  MEMBER SMITH: I would also agree with  
20 --

21                  MEMBER OXFORD: Human legal rights for  
22 people being served.



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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

22           So, this just is a visual

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

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

9 Our environmental scan and synthesis  
10 of evidence will continue through the fall of  
11 2015 with our second draft report due on the  
12 environmental scan in November.

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

21 So, a lot more to come.

22 So, just -- this slide just shares

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

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

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

16              I'm going to keep going.

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

22              For our next phase, we will be

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

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

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

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

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

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

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

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

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

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

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

4 (Off mic comments)

5 MS. LASH: Thanks, Juliet.

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

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



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

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

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

20 MEMBER HOUSER: Sure. Why not?

21 MS. LASH: Thank you.

22 MEMBER HOUSER: So I think the major

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

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

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

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

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

8               CO-CHAIR CALDWELL: I'll weigh in.

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

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

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

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

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

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

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

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

22 So I really want a comprehensive data

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

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

11 The concept of harmonizing has been  
12 very helpful in health because we can't speak to  
13 each other across settings. So just the idea of  
14 if you're going to look at well-being, function,  
15 whatever, to make it broad enough so that you can  
16 ask those questions or assess it regardless of  
17 the types of services people are receiving, just  
18 start out that way instead of unique as often as  
19 possible to make it similar.

20 IMPACT is an act that people are  
21 involved in, probably more than they ever wanted  
22 to be. But that's part of that: how do we

1        assess disability, function? So I think there's  
2        so much wonderful work going out there that if  
3        you can take advantage of that, how great to do  
4        that.

5                    It would be interesting to look at an  
6        analysis of claims or see if it's even possible  
7        because the Medicaid systems vary so much from  
8        state to state. I'm not sure that they even have  
9        the standardization of HIPAA codes or such other  
10       policies. It gets a little bit crazy. However,  
11       the long-term care measure on using payroll to  
12       look at staffing, accessibility, a lot of that  
13       capacity and who does what, payroll systems are  
14       already talking to CMS about doing that. And so  
15       that may be a way to get that for the variety of  
16       folks out there.

17                   In all the DUALss contracts, we work  
18       in most of the DUALss states, they have specific  
19       outcome measures in there.

20                   HETUS and NQQA for managed care to see  
21       if there's anything that can be pulled  
22       considering the populations, look at the variety

1 of health plans. And PCORI, I mean they just do  
2 incredible research on person-centered.

3 So I guess what I'm saying is there's  
4 so much out there and there is, as we talked,  
5 such similarity regardless of different services.  
6 So not to throw the health side out because of  
7 the word health. They may have processes that  
8 they painfully had to go through under the  
9 Affordable Care Act for five years that might  
10 actually be of help in this process. They have  
11 many scars to share, so. My comments.

12 MEMBER AUSTIN-OSER: Yes, this has all  
13 been good stuff. I mean I don't have a lot to  
14 add as far as like the broader bodies of  
15 knowledge. I think those have, you know, already  
16 been pretty adequately identified.

17 But one of the things I do want to say  
18 is something about some pockets of innovations  
19 that are going on around the country that may not  
20 be, you know, I think we can try to bring some of  
21 that to the surface to be looked at, but that may  
22 not be a part of, for instance, CMMI grant. Some



1 of them are, some of them aren't.

2 But a lot of things that are  
3 happening, especially around work force and  
4 looking at this concept of job quality and work  
5 force quality, which aren't the same thing, job  
6 quality and work force quality, and the impact  
7 on, for instance, the triple aim, so the impact  
8 on health, you know, improved health outcomes,  
9 just improved outcomes let's say for people-  
10 effective training or, excuse me, effective  
11 service delivery, greater levels of satisfaction  
12 and experience of care and then lower cost.

13 I think there are some really  
14 interesting things going on out there in how we  
15 could look at, especially when we get to the work  
16 force side of it. You know, what do we need to  
17 look at and what makes sense, and actually  
18 looking at the job quality, not just the quality  
19 of the work force, looking at those two things.

20 So I think there are -- I just want to  
21 throw that out that there are some things that  
22 may not be widely known but that we probably want

1 to bring up and say, hey, these have been  
2 successful. Are there measures here that we need  
3 to elevate?

4 MS. LASH: And if you have particular  
5 communities in mind you want to email us about we  
6 can make more specific note of that.

7 MEMBER AUSTIN-OSER: Thanks.

8 MS. LASH: And that sort of goes  
9 universally to everyone.

10 Anita?

11 MEMBER YUSKAUSKAS: Yes. Some  
12 promising measurements activities that are taking  
13 place now have to do with some things I was  
14 working on, so I'm going to bring them up.

15 Under the TEFT grant there are two  
16 measurement initiatives, and I think Joe  
17 mentioned one, which is the Experience Survey for  
18 HCBS which is going to eventually have  
19 endorsement and a CAHPS trademark, hopefully.

20 The other one is the CARE Functional  
21 Assessment. And we were looking at the CARE as -  
22 - testing it across not just post-acute care

1 populations but also folks in LTSS, so that as  
2 people move in and out of different environments  
3 we can begin to make some comparisons. So that's  
4 gone through some changes; I'm not quite sure  
5 where it is.

6 But as we develop a truly person-  
7 centered system I think we're going to have to be  
8 able to look at ways that we can compare measures  
9 across settings.

10 The most feasible I would say, I would  
11 really concur with Ari, administrative data  
12 capabilities are a really important area. D.E.B.  
13 Potter who is over there did probably the first  
14 real study that highlighted administrative data  
15 in long-term service and support. And CMS has a  
16 lot of information. I don't think it's even been  
17 closely -- I don't think we've begun to tap it.  
18 And I think there's a lot of information we can  
19 learn.

20 There's also state-collected  
21 information on quality. And I'm thinking  
22 primarily of the 1915 waivers. While we're not

1 going to be able to do a pure comparison because  
2 those measures differ, from an indicator  
3 perspective we'll at least be able to look across  
4 states. And that is all -- well, no it's not.  
5 Never mind. In the design phase it's electronic  
6 but it's not in the back-end, so that will have  
7 some challenges.

8 I think some of the areas that are  
9 going to be most interesting will be to take a  
10 look at larger managed care organizations that  
11 truly have the capacity to do integrated person-  
12 centered care. Once a person has all of their  
13 services coordinated then they are truly person-  
14 centered, then I think we really start to look at  
15 long-term services and supports with a different  
16 set of glasses.

17 Sarita and I were talking about that  
18 in relation to Kaiser, who is really just  
19 starting to touch the tip of the iceberg with  
20 that. I think that's going to be something very  
21 interesting to watch.

22 And finally, I think the area that has

1       been keeping me up at night for a very long time  
2       is the fact that we really don't have true  
3       evidence-based practices in long-term services  
4       and supports. And that's because we have no  
5       standard interventions. We have no standard  
6       service definitions in order to even begin to  
7       look at causality. And I think that's something  
8       we have to do because that's one thing we have  
9       not even talked about here. Other than labeling  
10      it as services and supports we haven't drilled  
11      down on that issue at all.

12               We've talked about who and we've  
13      talked about for what purpose, but we have not  
14      talked about that elephant in the room. And I  
15      think that that's really important.

16               So that's it.

17               MEMBER GALANTOWICZ: I just wanted to  
18      offer a couple of comments and caveats based on  
19      personal experience with some of the initiatives  
20      that have been described so far.

21               First the compendium of HCBS measures  
22      that Potter and I worked on now many years ago

1       because it's been more than just a few.

2               Thinking from a methodological point  
3       of view, when you do your scan we found the vast  
4       majority of what's included in that compendium  
5       not by doing the literature review but more  
6       looking at the gray literature, doing web  
7       searches, but really what we did was reach out to  
8       all of our contacts in the states and ask them  
9       what they were doing. And so I think if you look  
10      just narrowly at what's been published you'll  
11      miss all the richness of what's going on.

12              When I think of the 200-plus measures  
13      in that compendium, most of them came from the  
14      states. So I think that's the first suggestion.

15              With regard to experience surveys, I  
16      worked on the original PES, I worked on the HCBS  
17      experience survey before I switched jobs. I feel  
18      very strongly about the importance of getting  
19      participant feedback. I think so many things  
20      we've been talking about can only be measured by  
21      talking to people who receive services. But it  
22      is really feasible. I think they're the source;

1 I think we have to be honest about that. It's  
2 very expensive to collect that data.

3 It was harder than you think to come  
4 up with a consensus list of things that should be  
5 asked. And for some of that work we started with  
6 asking with individuals in programs what they  
7 thought we should measure. And I think we're  
8 coming at it from one lens of what we think needs  
9 to be measured but a good consumer survey starts  
10 with what people say is important as far as the  
11 research. So I would just add that.

12 On the whole care, LTSS, I was on that  
13 project for a little while too.

14 MEMBER AUSTIN-OSER: You were on all  
15 of them. And I apologize for not bringing that  
16 up. I really do.

17 MEMBER GALANTOWICZ: No, no, no. And  
18 I also, and I'm working on IMPACT Act measures  
19 now. So I think standardization is really  
20 important but we can't lose sight of how  
21 different HCBS is from some of the other post-  
22 acute care settings. So we can only standardize

1       so much. On that care project it was, at least  
2       at the beginning, just getting people to  
3       understand how HCBS is different and what you  
4       assess was a real challenge. So that's the  
5       caveat for that.

6               And finally, on the claims issue I  
7       agree that there is an incredible amount of  
8       administrative data out there. I'm working with  
9       one state right now where we are trying to use  
10      their claims data to look at HCBS participants.  
11      Months of discussion of even which HIPAA codes we  
12      use on the claims to even flag someone as an HCBS  
13      user.

14             So I would just echo what Anita said,  
15      there is no standard definition of what's in  
16      HCBS, and that's just one state that's trying to  
17      come to consensus for what services we put in the  
18      HCBS bucket for the purpose of profiling HCBS  
19      users. And I think it only gets exponentially  
20      more complicated when you're talking about all  
21      the different programs.

22             So not to be a downer, but those are



1 all the caveats.

2 MEMBER MOHANTY: I appreciate what  
3 Sara just said because just in our own system to  
4 code HCBS as a new benefit for Kaiser Permanente  
5 was a bear. And so I can -- and this was just in  
6 certain little pieces of the benefit. I mean we  
7 haven't even expanded it in California yet, so  
8 more to come; it is quite complicated.

9 You know, I think some of, a lot of,  
10 I think pretty much all the things, the themes  
11 have been mentioned. But some of the things I'd  
12 like to highlight that I also believe that the  
13 claims, data there's more than just the claims  
14 data. But you can glean some important  
15 information from the claims data.

16 In our system, for example, what we're  
17 finding is that in our care planning we have  
18 integrated the care plan within our HealthConnect  
19 or Epic system, and there are certain elements of  
20 that care plan that can be pulled out and offer  
21 some information about the long-term services  
22 supports, for example, and some of the home- and

1 community-based service needs or the care  
2 experience. So there's some opportunities there.

3 And, you know, one of the things I,  
4 you know, I think everybody kind of mentioned is  
5 that there are so many assessments, so many care  
6 plans, so many definitions of how things are  
7 measured. What we're trying to do in our own  
8 organization is try to take all that information  
9 from the external entities and trying to  
10 incorporate into one master care plan or trying  
11 to come up with some master assessments.

12 And so it gets back to that comment of  
13 harmonizing. How do we do that? So that I think  
14 going to what I think also Sara said is talking  
15 to some of the delivery systems that are working  
16 on this and exploring with them some of the  
17 approaches they've taken. And I think that will  
18 be very useful in how we, you know, start to  
19 think through measurement a little bit more  
20 carefully.

21 The other thing I just wanted to  
22 highlight is also the use of vendors. There has

1       been a lot of use of vendors in a lot of systems  
2       to help with the LTSS or home- and community-  
3       based service delivery or assessment base. And  
4       I've noticed that some systems have not actually  
5       fully leveraged that information from their  
6       vendors. Their vendors will do these assessments  
7       and then maybe come up with some key themes: oh,  
8       here are some, you know, here is a care plan we  
9       developed for you.

10               But sometimes there's that back-end  
11       data that the vendors have that the system hasn't  
12       necessarily, you know, utilized to the best of  
13       the ability. So I think just another piece of,  
14       another source of information I think is what I'm  
15       getting at.

16               And, you know, I think the other, the  
17       last thing I would probably say, I mean the one  
18       thing, HETUS and NCQA I think is important but  
19       it's lack -- you know, right now we know it's  
20       limited. So it will give us some of our physical  
21       health measures and some access issues but not  
22       fully -- it will be comprehensive.

1                   And then, you know, I had a  
2                   conversation I guess a few days ago. And I think  
3                   pretty much everybody knows that, or most people  
4                   know that SCAN Foundation is also working on some  
5                   home- and community-based measurements. And so  
6                   to the extent that we're partnering or working  
7                   closely with the entities that are also embarking  
8                   on this process I think will be important.

9                   Thank you.

10                  MEMBER CRISP: Well, this is a tough  
11                  act to follow.

12                  Of course I agree with everything that  
13                  everyone has said. And in an effort to come up  
14                  with something new, one of the most promising  
15                  quality measure activities, measurement  
16                  activities I see is that we're disembarking on  
17                  person-centered planning and what that means and  
18                  what is the thinking behind that and what kind of  
19                  changes are being made, how participants are  
20                  going to be educated on person-centeredness. And  
21                  then what are the measurable items that we can  
22                  look at and analyze to see is that really

1       happening, how is it happening, and is it a good  
2       thing?

3               I know a lot of people are working on  
4       this. Michael Small, SCAN, I know our division,  
5       our center is working on this. We're in the  
6       process of interviewing service coordinators now  
7       as to what it used to be and what it is now and  
8       where do you hope it's going to go. So that's a  
9       promising measurement for us.

10              The most feasible in the short term is  
11       data collection, as everyone has said, in  
12       particular service utilization. What services  
13       are being purchased? Who are purchasing those  
14       services? And what happens when they purchase  
15       those services?

16              I think there's a lot of not only data  
17       collection that can happen but also a lot of  
18       analysis, synthesis, and a lot of assumptions can  
19       be drawn from that levy of data.

20              Strongest, of course, in the realm of  
21       personal outcomes; that's a thing that we've been  
22       talking about for years and never quite achieved

1       it. Certainly with the core indicator project  
2       for disabled and elderly, that's going to be a  
3       huge step in the right direction.

4               I also think that there is strong  
5       evidence growing in looking at coordinating not  
6       just care but integrating systems and getting  
7       Medicare to talk to Medicaid, and the Elder  
8       Americans Act to talk to everybody else, and  
9       whatnot. So I look forward to that being strong  
10      in the future.

11             Thank you.

12             MEMBER LAKIN: Well, thanks for  
13      inviting me. I've had an interesting and good  
14      time.

15             You know, when we, when we presented  
16      our system effectiveness list one of the things  
17      that got buried in there and not mentioned was  
18      that, you know, whether we're talking systems  
19      level or intermediary levels we really need to  
20      base our analysis on individual outcomes  
21      whenever, whenever possible. And to not do that  
22      sort of gets us caught up in process measures

1       which I think have at times some connection to  
2       outcomes but not the kinds of connections that we  
3       would like.

4               I guess rather than give answers to  
5       the questions I'd really like to kind of ask  
6       other questions because I'm, I'm really, I'm  
7       aware that we're going to have so many measures  
8       that map up really well with the domains and sub-  
9       domains we've created. And some of them are very  
10      lightly used. But few come anywhere near meeting  
11      the quality that the NQF applies in its standing  
12      committees to other, to the other measures that  
13      are submitted for review.

14             And it is for me a real challenge to  
15      think about how we're going to get to that  
16      standard of quality from where we are today. And  
17      I think we can but it's going to take a very  
18      major investment. And I don't know where that  
19      investment's going to come from but it will need  
20      to be made if any of this will be realized at the  
21      standards that the NQF has applied to other  
22      measures.

1 I'm excited about the widespread use  
2 of measures. I'm excited about the communities  
3 of practice that have developed around the NCI  
4 and other instrumentation. I think when data is  
5 something raised, entities, states, providers get  
6 together to talk about what they're doing, why  
7 they're getting the results they are, what they  
8 can do to improve, it gives you a reason to  
9 collect all this stuff. And I think that's  
10 happening in really important ways.

11 But as Sara mentioned, all of this  
12 stuff is so expensive. And there's a  
13 methodological complexity to it that I think we  
14 often fail to appreciate. We have respondent  
15 problems. We have proxies answering the same  
16 question as we have people with disabilities  
17 answering for themselves. We have response  
18 biases that we know exist, particularly among  
19 people with cognitive limitations. We have  
20 different kinds of interviewers doing these  
21 surveys in different places. They have different  
22 levels of training, if any. And rarely have they



1       been tested to meet some sort of criterion for  
2       the effective implementation of those interviews.

3               So there's just a lot to do. And I  
4       hope that rather than just kind of move items  
5       from all these instruments into boxes, we really  
6       get into the technical quality of what we're  
7       doing. I'm really I'm concerned about people  
8       using claims data without understanding what's  
9       underneath them.

10              I just had an experience in a state  
11       using claims data where I said, Great, this  
12       variable says it measures this and we can use it  
13       for this court-ordered assessment. And they  
14       said, Well, it doesn't really, doesn't really  
15       mean that.

16              And so, you know, just to grab claims  
17       data and think that the HIPAA code is going to  
18       tell you what's happening is really not used.  
19       And so we need to be careful.

20              But anyway, I think we're off to a  
21       good start. I hope we will be serious about the  
22       complexity of what we're taking on.

1                   MEMBER KILLINGSWORTH: Wow, so there's  
2 no one who has spoken thus far that I've not  
3 wanted to say, Yes, I agree with that. And so  
4 lots of great ideas already. So I'll probably  
5 just be reemphasizing a few things.

6                   One, I agree with Sara that there is  
7 a lot of information to be gleaned from states  
8 and work that states have done. I think it would  
9 be interesting to look at the domains most  
10 frequently measured by the states. So I do think  
11 that would be really an interesting exercise as  
12 well.

13                   I do, and I think echoing some of the  
14 things that Ari said and Steve said, I think I  
15 never want us to move far away from the  
16 experience of the consumer. And I think that's  
17 one of the richest areas for development and  
18 exploration. I think we're getting there with  
19 some of the things that are happening. There are  
20 a lot of good tools. That standardization -- and  
21 this harkens back to what Sara said as well -- is  
22 just it's so important for us to be able to

1 compare performance across health plans, across  
2 states, across programs, so I encourage us to do  
3 that.

4 I think, and this is probably jumping  
5 ahead of Andrey just a little bit, there is so  
6 much opportunity with technology. We are -- I  
7 don't even think we can conceive the potential  
8 that is there for us to leverage technology. We  
9 will begin later this fall to collect real-time  
10 quality data from members at the conclusion of  
11 every in-home service that they receive. That's  
12 just such a rich source of data that we'll have  
13 at our fingertips.

14 So I think, you know, we need to, even  
15 though we think it's all expensive, and it's not  
16 always expensive, right? There are, especially  
17 if we design systems with the measurements in  
18 mind -- and we've done that -- it can be  
19 relatively inexpensive to build quality into  
20 something that we're doing anyway, and to be sure  
21 that we can actually measure performance on the  
22 back-end of that.

1           In addition, I think, as Suzanne said,  
2       there are great opportunities with respect to  
3       beginning to measure community inclusion in new  
4       ways and with new expectations. And so even  
5       though it's something that we've often looked at,  
6       I'm not sure that we're looking at it in the same  
7       way every day, as we always have. And I think  
8       the same is true for care giver supports,  
9       whatever we want to call them. I think we've  
10      looked at them for a long time but we're  
11      beginning to look at them differently. So those  
12      are all rich areas for us to explore as we move  
13      forward.

14           MEMBER HOUSER: I can probably echo  
15      what a lot of, a lot of people have said. A few  
16      things that were, that I want to sort of add some  
17      emphasis to. I think the most expensive part of  
18      this is data collection. So, as much as we can,  
19      it's useful to use sources of data that are  
20      already, that already exist. I know there is  
21      incredibly rich state data.

22           I can't count the number of

1 presentations I've been to where someone  
2 presented some very, very rich state data. And  
3 it seems like the bottom line was, you know, we  
4 now have 45,000, you know, people receiving  
5 services in our state and, you know, one or two  
6 other top-line items. It seems that's all the  
7 capacity that this under-staffed state agency had  
8 to analyze this data source. But there's a lot  
9 more that could possibly be done.

10 A number of people I've talked to are  
11 very optimistic about the capacity of T-MSIS to  
12 provide, you know, high quality claims experience  
13 data that could be used. I know second-hand of  
14 at least one effort to link claims data to  
15 functional assessment data so that you can have a  
16 measure of, imperfect perhaps, of services and  
17 some information about the recipient of that  
18 service, which is not in the claims data,  
19 typically.

20 And then the last thing that I would  
21 mention is to keep in mind what the goals of  
22 quality measurements are. And so fertile -ground

1 for measurement can be: where do we think we can  
2 find the data set to measure? And also, the  
3 other question would be is: where is it important  
4 to have measures for positive impacts on the  
5 system?

6 And an analogy would be do we want to  
7 look where the light is, or do we want to look  
8 where we dropped our keys? And where the light  
9 is is where the data is. And where we dropped  
10 our keys is where we can actually effect positive  
11 change. And those are probably different places,  
12 and yes, just another way of thinking about it.

13 MEMBER SMITH: So I guess ditto for a  
14 lot of things that folks have said. But I have a  
15 couple of things that I'd like to mention. And I  
16 think I've mentioned this a couple of times and  
17 keep struggling with the fact that, you know,  
18 this area is so broad and there are so many  
19 populations that are subsumed under it. And  
20 there's a lot of work going on in some of those  
21 other areas that I think we might not pick up  
22 here.

1           You might pick it up. You know, I  
2           thought I heard folks say that you were going to  
3           cast a broader net. You know, instead of looking  
4           at HCBS, perhaps you would look at some of the  
5           domains that we came up with. And so that may  
6           bring in some more initiatives.

7           You know, but it's not lost on me that  
8           in mental health, you know, we've been working  
9           probably for the last 20 years -- maybe more, God  
10          only knows, might be 30 -- but we've been, you  
11          know, putting together our own performance  
12          measurement framework. And, you know, the really  
13          interesting thing is many of the measures that we  
14          talked about here today and the domains, they're  
15          the same ones that we've been looking at in  
16          mental health. And I don't want to speak for  
17          substance abuse because I've been more focused on  
18          mental health.

19          But, you know, not that you would use  
20          the exact same measure across all populations,  
21          but I think that we've come up with definitions  
22          for safety, you know, for well-being, for looking

1 at employment. So I would direct us to look at  
2 some of the things like, you know, at one point  
3 we, there we brought together a large group of  
4 stakeholders.

5 They were providers, policy makers,  
6 consumers, family members, folks from managed  
7 care companies. And we actually put together  
8 something called the Mental Health Quality  
9 Report, which has been around for quite a while.  
10 It had, we actually started doing this kind of  
11 stuff back in '98, when we were looking at like  
12 something called the MHSP Report Card. And then  
13 that kind of rolled into the Mental Health  
14 Quality Report, which was an updated version.

15 So I think we should look at things  
16 like that. Also many of the, well, all of the  
17 states and U.S. territories have been working  
18 with census, mental health, let's see, mental  
19 health services, Center for Mental Health  
20 Services and others to come up with performance  
21 measures. And pretty much every state mental  
22 health authority is reporting what are called



1 National Outcome Measures. You know, they're not  
2 perfect, but they do include a lot of the domains  
3 that we talked about here.

4 And the substance abuse folks are  
5 doing the same kind of reporting. You know, and  
6 it's not like somebody plucked the measures out  
7 of the air. You know, I can tell you that, you  
8 know, if you think these last two days had a lot  
9 of detail, you know, sometimes we spent like a  
10 year talking about how to get to one measure. So  
11 I guess I'm just saying I hope that we can look  
12 at some of those other things.

13 The evidence, I think Mike talked  
14 about, you know, the evidence that one looks at  
15 before adopting NQF measure, I think that's going  
16 to be a challenge. But what we're talking about  
17 are measures that the states already collect,  
18 and that people have spent a lot of time  
19 developing.

20 In terms of consumer evaluation of  
21 care, you know, again I think that is of critical  
22 importance. And, you know, the struggle here for

1 me, even back in Illinois, is that folks have  
2 adopted the CAHPS Survey. And, you know, that's  
3 not particularly a good survey for our  
4 population. You know, we developed a survey in  
5 mental health. You know, again that probably  
6 tracks back to ten years. There's an inpatient  
7 version that was endorsed by NQF already.

8           So, you know, I'm wondering why if we  
9 are -- you know, if we care to look at some  
10 specific populations, why don't we look at some  
11 of these surveys that the states have adopted and  
12 are in use? You know, because some of them those  
13 are some of the same populations. Let's see,  
14 there might be one other point. No, I think  
15 those are the major things. Thanks. Thanks for  
16 inviting me. I enjoyed this.

17           MEMBER MARKWOOD: Well, I'd like to  
18 thank the group as well, and say that through the  
19 robust discussion that we've had over the past  
20 two days, you know, I've learned a lot from  
21 different perspectives that I really value. But  
22 I think from my perspective in representing

1 community-based organizations in this area is  
2 just to reiterate their excitement about  
3 measuring quality, and their commitment to doing  
4 this to the best degree that they can. And I say  
5 that because, echoing Sara and Charlie's comment  
6 about the fact that in an already overstretched  
7 system this is important work, but it also needs  
8 to be invested in.

9 And that being said, recognizing that  
10 the states are doing a lot in this arena, I also  
11 wanted to raise the point though, too, that  
12 especially with the evolution of managed care  
13 that there are also some information lessons that  
14 can be learned both in the managed care front and  
15 also in the care transitions front that are not  
16 necessarily at the state level but more regional  
17 or locally specific. And those, some of the  
18 champions that are leading those efforts, I'd be  
19 happy to forward to you.

20 Additionally, I think that, as Patti  
21 said, that I think that there are things at the  
22 local level that we're trying to do and would

1 welcome more guidance in doing with the resources  
2 that we have. But again, when you're looking at  
3 IT through the ACL business collaborative that  
4 we're doing with the aging and disability  
5 community, that the investment in IT has been  
6 raised as one of the greatest barriers in moving  
7 forward in this regard.

8           So I just think that that needs to be  
9 a recognition as we're looking at collecting more  
10 comprehensive data and being able to analyze and  
11 use it. But that being said, I think that,  
12 again, the commitment on the part of the  
13 community-based organizations is that this is  
14 where they know they need to go, this is where  
15 they want to go, they just need some help in  
16 getting there.

17           MEMBER DOBSON: I echo what Sandy  
18 said. I learned a lot from different  
19 perspectives. It's extremely useful. As --  
20 representing states who are, you know, in the  
21 middle of this, I think there are a couple of  
22 things that I would share that are of importance.

1 One, I can't stress enough the use of consumer  
2 surveys, obviously. Steve and Ari already  
3 mentioned NCI, NCIAD which is going into -- is  
4 going live June 1st with 13 states on our first  
5 year. That's not public but I will make the  
6 survey available to the staff so that you have  
7 it.

8 And so we're excited to see how that  
9 goes. And it really does reflect the nuances of  
10 individuals with physical disabilities and the  
11 elderly that are slightly different, in many  
12 cases very different than individuals with IDD.

13 I would tell you if you're not aware  
14 -- I'm sure you all are aware that, you know, 20  
15 states now are using capitated health plans to  
16 deliver most, if not all, of their HCBS services  
17 to individuals. And so that raises opportunities  
18 and complexities, I think, I would say on both  
19 sides.

20 It is very clear that, I echo Sara  
21 about the level of intensity and the cost for  
22 person-reported outcomes and how hard those are,

1 and so the need to find administrative -- I'd go  
2 beyond claims -- but administrative data, ways to  
3 use administrative data to extract information  
4 from care plans, for example, to assess  
5 timeliness of services. That is a critical part,  
6 or the system will collapse under the weight of  
7 the measurements, I think is really the concern  
8 that we've got.

9           So I would -- I know you're already  
10 pulling out what all the states are doing, so I  
11 don't need to say that already. But I think a  
12 place where maybe you, maybe if you haven't  
13 started is to talk to the health plans  
14 themselves. A number of them even if the states  
15 don't have rigorous quality members around HCBS  
16 performance, that's part of their standard QM  
17 activities, and so I think there are a number of  
18 the duals plans, obviously, several national  
19 health plans, and very significantly, a number of  
20 small, locally-based plans who have been in HCBS  
21 for a long time I think could provide some  
22 lessons.

1           So I can provide those contacts for  
2       some of those national folks that would be useful  
3       to provide you some data. And yes, I think  
4       that's it. I don't have anything else to say.  
5       Other people have stuff to add I'm sure.

6           MEMBER PHILLIPS: Well, I think I'm --  
7       I've really been outdone. I'm not sure I have a  
8       lot more to add about specific measures. But I  
9       would like to see -- and we haven't talked about  
10      the populations of persons with dementia living  
11      in the community and promoting their tenure in  
12      the community.

13           Building dementia-friendly communities  
14      is not quite here yet. There are countries in  
15      Europe who are doing better jobs of that. And  
16      I'm not sure how it's being measured, obviously.  
17      Eliminate or preventing nursing home admission or  
18      other institutionalization. So I would like to  
19      suggest that at some point we explore that  
20      avenue. Along with people ageing with physical  
21      and, you know, mental cognitive disabilities and  
22      keeping them in the community rather than moving

1 to higher levels of care.

2 MEMBER OSTROVSKY: Thank you very much  
3 for having me here. I have a couple of points to  
4 make. One is that my line of work focuses almost  
5 exclusively on home- and community-based service  
6 providers getting reimbursed for the outcomes  
7 that they produce. And this is predominantly  
8 through new lines of service outside of  
9 traditional home- and community-based services,  
10 care transitions being one of them, use of  
11 chronic disease self-management outside of just,  
12 you know, having a CPT code or with having a CPT  
13 code and other ways.

14 Transportation can be, can be a very  
15 valuable service for a managed care entity when a  
16 return on investment can be proven. And I think  
17 it's incredibly challenging to watch particularly  
18 area agencies on ageing now where we're working  
19 with more and more Meals On Wheels programs where  
20 they're really doing -- they're working really  
21 hard to try to show their return on investment.  
22 But the only data they have available is the data



1       that, say, my technology provides which,  
2       fortunately, is getting them closed deals, but I  
3       don't think my technology is going to be great  
4       for every single ACBS provider in the country.

5               So it would be really powerful in  
6       having a way for health systems' preparers to be  
7       able to have a common way to evaluate ACBS  
8       providers in an ROI that is relevant to the payer  
9       and the provider. I know we want to be consumer-  
10      centric here but I think for sustainability  
11      purposes our quality measurement really needs to  
12      take into account how will we demonstrate value  
13      for payers and providers.

14             The other notion I think is really  
15      important is I, as a for-profit technology  
16      vendor, I just hired three salespeople. And I  
17      hired three salespeople because I have to get the  
18      word out. And when I hire people, I hire them  
19      based on their ability to educate rather than to  
20      sell. And I think we need to move away from  
21      salesmanship in the vendor, technology vendor  
22      community and more into how does the technology

1 contribute to improving a validated quality  
2 measure?

3 I think that would take away from the,  
4 you know, the big rah-rah, like, how much money  
5 do you have to spend in marketing, and rather  
6 focus on how does the technology really improve  
7 the quality of home- and community-based  
8 services. So I think that would equalize what we  
9 in the vendor community do.

10 And then the final thing is ONC, I  
11 really commend them because in their language,  
12 and I mentioned this earlier, in their language  
13 in a few of their recent publications they have  
14 specifically called out home- and community-based  
15 services. They have specifically called out  
16 harmonization of quality measurement.

17 I think we need to really heavily  
18 harmonize with those efforts, because if we can  
19 enable data integration to facilitate quality  
20 measurement, not just what an EMR can do but  
21 rather what any other technology, especially  
22 with more innovation, technology innovation

1 hopefully coming to our space, I think that will  
2 facilitate that alignment of where the keys are  
3 and where the light is shining, to borrow Ari's  
4 metaphor.

5 And then I'd like to propose just one  
6 thing that a colleague of mine Mike Doyle says:  
7 return on information. How can we, through  
8 quality measurement, not just show a return on  
9 cash investment, but a return on how many  
10 megabytes do we have to spend of data to actually  
11 get meaningful quality measurement. So, happy to  
12 elaborate on that.

13 MEMBER APPLEBAUM: So, in 1982 when I  
14 was evaluating the Channeling demonstration I did  
15 some interviews as part of the evaluation. And  
16 several people, many people said, we think this  
17 home- and community-based service stuff is a good  
18 idea but we're kind of worried about quality of  
19 what's going on inside the home.

20 And if you think about the many  
21 billions of dollars we now spend on something  
22 that we were worried about in 1982, I think

1 obviously the importance of this activity is  
2 quite obvious.

3 I was thinking back as people went  
4 around the room to the book that some of us read,  
5 some of us who were born before 1982, A Tale of  
6 Two Cities that we used to have to read in high  
7 school and that starts out with It was the best  
8 of times, it was the worst of times, and your  
9 English teacher teaches you about what a paradox  
10 is. So as I sat here listening to what people  
11 said I was listening to the many paradoxes.

12 So we talked about the innovations in  
13 measurement and the excitement about that. And  
14 then I sort of thought about, okay, well what's  
15 one of the oldest measures we have? Sid Katz  
16 came up with the ADL score in 1963. And I can  
17 tell you that that measure actually is not very  
18 good for doing and measuring functioning. I  
19 can't tell you how many times I sat in the homes  
20 of individuals who are getting service and they  
21 ask Can you dress independently? And the one  
22 that lives with her daughter says no, and the

1 person who lives alone says yes. They have  
2 exactly the same functional impairment.

3 So we think we know how to do that.  
4 That's in the books, and it's not. So at one  
5 level we have all these exiting new measures and  
6 at another level this is still hard, which I  
7 think reflects some of the things that Charlie  
8 said.

9 Claims data: we were talking about the  
10 importance of administrative data and claims data  
11 which I use them a lot. It's great. But I will  
12 tell you, and we've mentioned the integrated care  
13 demonstrations, right now at least the data that  
14 we're getting from integrated care  
15 demonstrations, everybody who's in the Medicaid  
16 integrated claims data, they all look the same.  
17 They have the capitated rate, there's no  
18 encounter data, there's nothing.

19 And so the claims data has just gotten  
20 way worse in any of the states doing integrated  
21 care. Now maybe the plans will develop their own  
22 data systems and there will be some way of

1 sharing those data systems with everybody else.

2 But right now that isn't happening.

3 And then finally, we were talking  
4 about nationally unifying measures. But long-  
5 term care and long-term services is a state  
6 system. And at one level it is great to go after  
7 what states are doing. I've been working on a  
8 22-year longitudinal study for the state of Ohio.  
9 We have lots of great data but it's very  
10 difficult to get those centralized all together.  
11 So I think we have some challenges.

12 And that leads me to my two, maybe,  
13 final pieces of this. One is that -- and I  
14 really like what Patti said about being creative  
15 about how we collect data, because the fact of  
16 the matter is that we can think differently about  
17 how we collect data, particularly if we recognize  
18 that this is a state-driven system.

19 And so one example, we had one of the  
20 area agencies that we were working with who  
21 wanted to be able to collect satisfaction data on  
22 all of their 5,000 participants. And if they did

1 a random sample survey of independent data  
2 collection, they couldn't get much sample. And  
3 they wanted to be able to compare across  
4 providers.

5 So what we did was we went in and  
6 trained care managers who were going into the  
7 home anyway and trained them to collect data.  
8 And then we actually validated that with  
9 independent research interviews. And we said,  
10 hey, looks pretty much the same. And that agency  
11 now collects data every time the care manager  
12 walks in the door. And they have tremendous  
13 amounts of quality data that they can use to be  
14 able to compare across providers.

15 So I think in general we have to be  
16 way more creative about how we think about  
17 collecting data. We designed something some  
18 years ago, it was kind of like a Nielsen family  
19 rating. Everybody knows the Nielsens for  
20 television. We had consumers keep a log of  
21 something as simple as home delivery meals. Did  
22 they show up on time? Were the meals good?

1           It was very inexpensive to do. And  
2       people liked doing it. I mean when they didn't  
3       send out -- didn't get their logs they were like  
4       calling up and saying, Hey, where's my log?  
5       Nielsen pays people a dollar to fill out their  
6       little Nielsen form out for two weeks of  
7       recording their T.V. watching every, you know,  
8       half hour.

9           And then finally I just wanted to say  
10      that this is an evolutionary process, and  
11      whatever measures we come up with today, in five  
12      years we'll be going like, Wow, can you believe  
13      we used to measure it that way? And so I think  
14      we have to always remember that this is an ever-  
15      evolving process. Thank you.

16           MEMBER LUZ: I would like to say thank  
17      you, too. I think it's a privilege to be among  
18      this group and to be able to be in active dialog  
19      with you. And I appreciate the staff and the  
20      consensus process. It's really fun and  
21      interesting. Learning a lot.

22           I'm not going to try to add.



1       Everybody has said things very eloquently about  
2       HCBS in general. I'm going to focus just on one  
3       aspect of it which is near and dear to my heart,  
4       which is the work force issues, particularly the  
5       PCAs.

6               In terms of process, I just want to  
7       make sure that, you know, there is a way between  
8       now and our next meeting that we are able to sort  
9       of revisit some of these areas where we weren't -  
10      - maybe didn't have consensus. If there's a way  
11      for us to be in communication and carry on the  
12      dialog before we meet again, that would be really  
13      helpful.

14             And with respect to the, really full  
15      respect for the full range of thoughts and  
16      feelings about training and education of PCAs,  
17      there are some of us in the room who are really  
18      excited about the fact that it's even being  
19      discussed in this meeting. And if we talk about,  
20      you know, identifying fertile ground for  
21      measurement, this is really it. Because right  
22      now there are absolutely zero federal training

1 requirements for PCAs. And so this is a huge  
2 step forward and I am excited about it.

3 And I hope that we have an opportunity  
4 to just really reach some consensus around it  
5 that satisfies everybody and how to measure it.  
6 And it's going to help us establish, you know, a  
7 lot of what everybody else has been talking  
8 about: this association between work force  
9 development and training, and the goals of the  
10 triple aim, and the goals of this group.

11 And it's not just about, it's not just  
12 a work force issue, I think it's a social justice  
13 issue and an economic development issue. So, you  
14 know, we're touching on a lot of ground that  
15 hasn't been measured to date at all. So I'm  
16 excited about this. And I had one question. I  
17 don't know if anybody is interested in this, or  
18 maybe it's already available, but sharing each  
19 other's contact information.

20 MEMBER DELMAN: Well, I'm honored to be  
21 here too. I'm really happy to be at a frontier.  
22 I prefer being at the frontier than at the

1 stayed-at-home, typical place. It's where I'm  
2 most comfortable. And I think we have a lot of  
3 great thinkers here, and everybody is on the  
4 right path.

5 And I have very little to add. So  
6 instead, I did some research and the IOM came up  
7 on a Report on Long-Term Quality care in 2001. I  
8 don't know if people are familiar with that.  
9 Apparently made a lot of great recommendations  
10 that moved the field forward. But of about the  
11 18 or so people, brilliant people, a third of the  
12 people dissented on one point. And I just want  
13 to read from their dissent: If quality of life is  
14 seen as a legitimate goal of long-term care, --  
15 this will be brief, not the whole dissent.

16 (Laughter)

17 MEMBER DELMAN: -- the consumer's view  
18 of quality may sometimes involve conditions and  
19 circumstances that professionals view as a threat  
20 to health or safety. This tradeoff and the  
21 possibility that consumers might knowingly assume  
22 risks in order to maximize other benefits were

1 not expressed in the final version of the report,  
2 yet it is an important reality.

3 Moving on: Consumer-centered care  
4 calls for the consumer, or his or her agent, to  
5 be involved to the extent desired and practical  
6 in all goal-setting and planning for care, and to  
7 have direct input into the evaluation of his or  
8 her care.

9 One more part from this dissent. The  
10 report marginalizes 'consumer-centered care,'  
11 stating that it is not for all people. This, we  
12 believe, is a misunderstanding of the concept.  
13 The principle of consulting consumer preferences  
14 directly or through their agents has widespread  
15 applicability to people of all ages in all  
16 settings, including nursing homes. It has been  
17 applied to people with cognitive impairment,  
18 including Alzheimer's disease, and developmental  
19 disability. The emergence of new models of care,  
20 including client-directed home and community  
21 assisted living is a direct result of consumer  
22 choice about how they want to live while needing

1       care.

2                   And this was written by smart people,  
3       and I think their view has prevailed. My only,  
4       and just referring to what Bob said, people --  
5       technology really is cheap. And I work with a  
6       lot of young adults. Think text messaging. I  
7       mean that's -- people are knocking data all over  
8       the place. And we have things available. And  
9       the young people, you know, half the people, or  
10      more, of age groups use the internet now. And I  
11      see a lot of people here text messaging so, you  
12      know, think about it.

13                   MEMBER MORRISSEY: Jon, that's because  
14      we're young too. I'll, like everybody, just  
15      maybe add a few points. So I appreciate being  
16      part of the group and learning and listening.  
17      And to the NQF staff, thank you very much for  
18      facilitating 25 individuals who have a lot of  
19      different views and converging that into arrows  
20      and pie charts and pretty cool things.

21                   I guess in terms of adding a couple of  
22      things, I'd just say one is the best practices

1 really occur at the state level in the state  
2 systems. And I really think that we, we believe  
3 we know where those best practices are, but I  
4 think we need to figure out really using the  
5 state, the national state organizations, I think,  
6 could help facilitate some of that discovery in  
7 terms of best practices, number one.

8           Number two would be the NCI. I think  
9 you know I'm a pretty big fan of that. Been  
10 around for 18 years. And this gets to there's an  
11 awful lot of quality frameworks and measures that  
12 are already under way. So I hope we're not  
13 starting with, you know, whole cloth. I think  
14 we, to do something for 18 years it's evolved.  
15 And there's, you know, many, many states involved  
16 now. And with the seniors now joining I think  
17 the beauty of that is that we're all about  
18 relationships and partnerships, and everybody  
19 working together. And I think that gets to  
20 alignment.

21           Third is while we can come up with  
22 maybe 152 domains and sub-domains, I think one of

1 the things it really is about the people we  
2 serve. It's about relationships. It's about --  
3 I'll use my word -- safety. It's about health  
4 and safety and relationships and living in the  
5 community in a very thoughtful way and in a  
6 prosperous way.

7 So we are not very good at investing  
8 in those kinds of things as much as we need to.  
9 And I'm very concerned about our zeal for  
10 technology without financing some of that  
11 technology.

12 And then I think we're building, we're  
13 trying to build an architecture for 10 to 15  
14 years from now, not today. So I think we need to  
15 be bold and we need to kind of really think about  
16 what is the system for individuals and families  
17 and providers and the work force 10 to 15 years  
18 from today, not think about it in terms of  
19 today's view.

20 And then I think I didn't hear much,  
21 I know we didn't talk much about certain  
22 populations, but the ABI population in the

1 veterans are an emerging population. And I think  
2 we need to be thinking from the representation  
3 point of view, if not seeking out some  
4 information about the emergence of the ABI waiver  
5 and how the veterans in the company are going to  
6 be supported in the community long term. So  
7 those would be my additional thoughts. Thank  
8 you.

9 MEMBER OXFORD: Yes, well I don't know  
10 what I would add after all that. But I do want  
11 to thank everybody for working with me and I  
12 appreciate being here. I particularly want to  
13 thank the staff who have worked hard behind the  
14 scenes and so on. And I know, speaking  
15 personally, they, you know, did some extra stuff  
16 to accommodate me and help me out. And I  
17 appreciate that very much.

18 Just some random thoughts. I mean I'm  
19 not a researcher, I'm an advocate. So just some  
20 perhaps random thoughts -- but I also am a  
21 provider; I run a program in my agency -- is I  
22 hope we think about whatever we do and as this



1 work goes forward, which is incredibly important,  
2 to think about utility for hands-on, kind of, on-  
3 the-ground application so that people that are  
4 perhaps running a program, providing services  
5 and, you know, providers, and I mean agencies,  
6 are so varied these days, little bitty company  
7 serving just their family, to just a few people,  
8 to just a certain area, and so on.

9 And I know across all these different  
10 kinds of providers there is a lot of interest I  
11 think, genuine interest in doing the best job  
12 possible. And quality is important. And so  
13 tools, ideas, information that can be useful at  
14 that level, I think, would be very much a good  
15 idea and needed.

16 I appreciate, you know, in terms of  
17 being an advocate how, you know, it wasn't that  
18 long ago that there would have been quite an  
19 uproar over consumer control and, you know, some  
20 of these things. But now it's like ho-hum, yes,  
21 yes, you know, everybody's in agreement. And  
22 that's, that's definitely rewarding to see over

1 time.

2 One of the things that I'm worried  
3 about that I noticed is, you know, access to data  
4 and need for data. And I am concerned with  
5 moving around into different kinds of  
6 environments that we're getting into with 1115  
7 waivers and so on, about transparency of data,  
8 about privatization of data and so on and that  
9 that needs to be addressed so advocates,  
10 researchers and so on have access to the same  
11 level of information that, you know, that they  
12 need, whether the state is ultimately providing  
13 this service, or that's been to privatized.

14 And thinking ahead about perhaps some  
15 of the political outcomes that are being tossed  
16 around here in this town, that may be even more  
17 important but that we don't, you know, we don't  
18 want to block grant and privatize data.

19 Let's see. Just another thought that  
20 I heard kind of addressed that I think is real,  
21 real important in terms of, you know, ultimate  
22 goals around quality is that other environmental

1 issues really, really are going to need to be  
2 addressed. They need to be considered, or we're  
3 never going to get to where we want to go. And  
4 those came up in several places I just kind of  
5 want to kind of reiterate in particular: housing  
6 and transportation.

7 I mean unless those are addressed on  
8 a real systematic basis, you know, we can have  
9 the most self-directed, best training, best  
10 services in the world and people are just going  
11 to be stuck, you know, in their house and not  
12 being able to get where they want to go. And it  
13 seems to me like a lot of the goals that we're  
14 all trying to achieve are not going to be met  
15 unless these real critical linkages are also  
16 addressed along the way.

17 Finally, I just want to say and just  
18 remind everyone, this is not a scold, just a  
19 reminder, that I appreciate the sensitivity that  
20 people have shown around the fact that at the end  
21 of the day these programs, you know, these are  
22 real people with real lives and people with

1 disabilities, and there's all sorts of curve  
2 balls and stressors and things that you go  
3 through in dealing with a disability and that,  
4 you know, people, you know, aren't experiments  
5 and don't need to be objects of anything. And,  
6 you know, again that's kind of another thing that  
7 I think, you know, folks are sensitive to and I  
8 appreciate hearing that. That's it.

9 MS. LASH: Thank you, Mike, and thank  
10 you, everyone. I want to ask Jamie, since she  
11 has been listening so intently over the course of  
12 this meeting but not said much, as one of our  
13 project sponsors, if she'd like to add anything.

14 MEMBER KENDALL: Thank you, Sarah. So  
15 I have a few things to say. First and foremost  
16 is thank you, everyone for coming here and  
17 showing up and actually being present and focused  
18 and committed and engaged throughout these two  
19 days. And I know that you all have very busy  
20 lives and multiple competing priorities in our  
21 work life.

22 And to have all of you here as part of

1 the stakeholder committee and really bringing  
2 your subject matter expertise is just extremely  
3 valuable to the Department of Health and Human  
4 Services. So we were very thoughtful with the  
5 approach and structure of this stakeholder group,  
6 because all of you bring a very unique, valuable  
7 contribution. And with that said, the whole is  
8 greater than the sum of our parts. And I think  
9 that throughout this couple days it's been a  
10 little messy. Collaboration, when you do it and  
11 do it in a genuine way, usually is. And very  
12 thoughtful.

13 And so to the stakeholder, thank you  
14 very much. I'd also like to thank NQF. You have  
15 kept us organized and on track and worked to  
16 really create a great structure for the  
17 stakeholder group to thrive. So I really  
18 appreciate all those efforts.

19 And then I also want to say thank you  
20 to my federal colleagues. So we have a great  
21 group. There has been multiple federal staff in  
22 listening mode. We are listening to you

1 throughout this couple days. So D.E.B. Potter  
2 and Ellen Blackwell, Mike Smith, Shawn Terrell,  
3 thank you for being here throughout the meeting  
4 and being here to listen and engage. And we will  
5 take all of this back and continue to think  
6 through how to support this task order most  
7 appropriately.

8 I know the NQF is going to be sending  
9 you out some documents that reflect this  
10 conversation. I just want to encourage you all  
11 to comment on them. I don't think that will be a  
12 problem, given this group.

13 (Laughter)

14 But we really do want to hear from  
15 you. So with that I will turn it back over to  
16 the co-chairs and to Sarah.

17 CO-CHAIR KAYE: Just to add my thanks  
18 to everyone for their very thoughtful  
19 presentation and contributions. We got off to a  
20 kind of slow and rocky start I thought, but in  
21 the end we've pretty much done what we were --  
22 what was on the agenda, which is pretty amazing.

1           I think we forgot to say that we  
2       decided not to show you the definition again  
3       today, but the staff are going to try to combine  
4       some of those really terse basic HCBS definitions  
5       and then use our characteristics, our now 11  
6       characteristics and write them up as, you know,  
7       with actual verbs in them, and circulate that  
8       along with a list of domains and sub-domains,  
9       whatever else, and the picture. And so there  
10      will be lots of stuff to comment on.

11           And as Jamie said, I don't think we  
12      really need to encourage you to do that. But I  
13      really appreciate everybody's very thoughtful  
14      participation.

15           CO-CHAIR CALDWELL: I'd just echo  
16      that. I've just really enjoyed the last two days  
17      and just being with all of you and hearing all  
18      these ideas. And, amazingly, I think we did meet  
19      our objectives. If you look, you know, at the  
20      objectives of the meeting at the outset, somehow  
21      we got there and we've got a lot more work to do,  
22      so. So thank you.

1           MEMBER OXFORD: Joe or maybe staff, is  
2           there -- I forget who said it, I think it's a  
3           good idea, is there any way, I mean what do we  
4           need to do to get a list of contact information?

5           MS. LASH: We have that, definitely  
6           your emails, and I don't know if you want to  
7           exchange phone numbers as well. I think we  
8           collected most of those through the nomination  
9           process. So we'll quickly pull that together and  
10          put it up on your SharePoint site --

11          MEMBER OXFORD: Super.

12          MS. LASH: -- where you downloaded  
13          today's meeting materials.

14          MEMBER OXFORD: Thank you.

15          MS. LASH: You can look for that next  
16          week some time.

17          MEMBER OXFORD: All righty.

18          MS. LASH: Thank you all.

19          (Whereupon, the above-entitled matter  
20          went off the record at 3:34 p.m.)  
21  
22



A			
<b>a.m</b> 1:12 4:2 103:8,9 114:22	129:21 <b>accommodation</b> 16:3 83:13	<b>Additionally</b> 219:20 <b>additions</b> 135:19 <b>address</b> 27:12 28:10	231:10 240:21 <b>agenda</b> 4:17 11:9 246:22
<b>AARP</b> 1:21	<b>accompanied</b> 179:20	31:15 45:19 49:12	<b>agent</b> 236:4
<b>ABI</b> 239:22 240:4	<b>accomplish</b> 4:15 154:9 154:10	52:12,21 83:8 124:1 134:16 138:13 152:18	<b>agents</b> 236:14
<b>abilities</b> 145:7 152:20	<b>account</b> 185:10 225:12	<b>addressed</b> 7:13,20	<b>ages</b> 5:2 236:15
<b>ability</b> 62:7 136:20 147:11 150:22 152:11 162:10,11 172:16 203:13 225:19	<b>accountability</b> 19:1 97:21 98:9 104:19 118:11 167:21	40:15 78:22 85:6 156:2 242:9,20 243:2 243:7,16	<b>aging</b> 1:19 2:4 147:2 220:4
<b>able</b> 4:15 12:3 32:13 45:19 47:7 84:19 111:9 113:21 121:12 127:20 131:21 160:7 167:15 168:5,9 169:22 183:15 195:8 196:1,3 210:22	<b>accountable</b> 10:6 87:21 98:7,12,15	<b>ADDRESSING</b> 1:5 <b>adequacy</b> 139:8	<b>ago</b> 197:22 204:2 231:18 241:18
<b>above-entitled</b> 103:7 114:21 248:19	<b>accreditation</b> 7:20	<b>adequate</b> 5:19 46:7 63:21 122:20	<b>agree</b> 5:18 42:14 46:5 51:12 66:16 71:3 73:11 86:22 94:17 95:8,11 134:11
<b>absence</b> 26:8,12 156:7	<b>accredited</b> 44:9	<b>adequately</b> 9:14 140:3 140:4 192:16	135:10 172:21 176:19 189:9 200:7 204:12 210:3,6
<b>absolute</b> 51:20 71:21	<b>accurate</b> 165:16	<b>adjective</b> 159:22 161:15	<b>agreed</b> 141:13
<b>absolutely</b> 136:16 156:11 233:22	<b>accurately</b> 141:19 142:10	<b>Adjourn</b> 3:22	<b>agreeing</b> 88:11
<b>Abt</b> 1:20	<b>achieve</b> 243:14	<b>ADL</b> 32:10 228:16	<b>agreement</b> 46:19 47:9 72:22 85:18 241:21
<b>abuse</b> 10:21 91:12 125:11 153:16 215:17 217:4	<b>achieved</b> 154:12 205:22	<b>administered</b> 131:4	<b>ahead</b> 34:21 53:18 58:12 74:2 92:22 112:2 211:5 242:14
<b>ACA</b> 58:3	<b>achieving</b> 56:7 154:8 159:9,10	<b>Administration</b> 1:21	<b>AHRQ</b> 22:19
<b>ACBS</b> 225:4,7	<b>acknowledge</b> 12:20 179:9	<b>administrative</b> 56:22 195:11,14 200:8 222:1,2,3 229:10	<b>aim</b> 9:18 193:7 234:10
<b>accepting</b> 97:21	<b>acknowledged</b> 156:2	<b>admission</b> 223:17	<b>air</b> 217:7
<b>access</b> 15:22 16:2 76:13 83:12 103:3 120:15 128:19,22 129:6,11 130:10 131:7,20 133:2,3 134:4,7,9,17,20,20 135:7,10,18,19 136:9 139:10 140:5 150:10 150:15 152:11 160:7 203:21 242:3,10	<b>ACL</b> 220:3	<b>admits</b> 173:14	<b>aligned</b> 29:13 160:17 160:19,20
<b>access/accessibility</b> 83:10	<b>act</b> 6:22 57:22 66:8 190:20 192:9 199:18 204:11 206:8	<b>adopted</b> 218:2,11	<b>alignment</b> 130:8 227:2 238:20
<b>accessibility</b> 16:3 79:7 82:22 83:6,13,17 132:10 148:16 160:1 160:3,4,4,5 191:12	<b>action</b> 164:2 167:20	<b>adopting</b> 217:15	<b>Allen</b> 2:14 115:21
<b>accessible</b> 28:18 29:7 43:2 44:4 76:10,18 78:7 79:13 80:15 81:21 82:10 128:20 133:3 148:14 149:3 160:14	<b>actionable</b> 175:14	<b>adults</b> 4:22 237:6	<b>alliance</b> 187:22
<b>accessing</b> 134:15	<b>active</b> 94:11,15 232:18	<b>advantage</b> 191:3	<b>allocated</b> 18:6 64:6 73:18
<b>accommodate</b> 240:16	<b>activities</b> 185:8 194:12 204:15,16 222:17	<b>advice</b> 39:14 53:6	<b>allocation</b> 128:13 137:7
<b>accommodating</b>	<b>activity</b> 228:1	<b>advise</b> 39:9	<b>allow</b> 17:2 111:17
	<b>actual</b> 49:13,14 177:17 247:7	<b>advisors</b> 24:3	<b>allows</b> 89:7
	<b>actualized</b> 70:21	<b>advisory</b> 35:8	<b>alternative</b> 102:12
	<b>acumen</b> 147:6	<b>advocacy</b> 2:6 149:10 241:17	<b>Alzheimer's</b> 236:18
	<b>acute</b> 29:14 199:22	<b>advocate</b> 55:11 240:19 241:17	<b>amazing</b> 246:22
	<b>AD</b> 131:3	<b>advocates</b> 242:9	<b>amazingly</b> 247:18
	<b>ADA</b> 160:6	<b>advocating</b> 70:11	<b>Americans</b> 66:8 206:8
	<b>add</b> 11:18 23:18 26:16 31:14 51:1 88:21 119:9 123:11 125:11 126:18 133:6 134:19 146:15 158:22 192:14 199:11 212:16 223:5 223:8 232:22 235:5 237:15 240:10 244:13 246:17	<b>affordability</b> 8:20 9:10 16:2 83:1,13 132:9	<b>amount</b> 57:22 112:6 128:7 130:3 200:7
	<b>added</b> 25:9 26:15 124:6 124:7 125:11 147:21	<b>affordable</b> 9:5 57:21 128:20 132:7 133:3 192:9	<b>amounts</b> 231:13
	<b>adding</b> 28:20 132:2 134:9 237:21	<b>afraid</b> 50:4 52:10 62:12 71:8 92:21	<b>analogy</b> 214:6
	<b>addition</b> 71:15 122:17 212:1	<b>afternoon</b> 24:13	<b>analysis</b> 10:2 17:16 22:6 104:2 112:12,22 113:4 116:8 189:19 191:6 205:18 206:20
	<b>additional</b> 44:11 240:7	<b>age</b> 237:10	<b>Analyst</b> 2:14
		<b>ageing</b> 223:20 224:18	<b>analyze</b> 204:22 213:8 220:10
		<b>agencies</b> 2:4 51:5,19 95:17 102:1 140:17 145:17 146:22 147:1 147:11 224:18 230:20 241:5	<b>and/or</b> 166:5
		<b>agency</b> 52:4 108:11 121:6 140:15 213:7	<b>Anderson</b> 2:14 3:4 14:3 16:18,22 17:12,20 18:10,17 22:7,14 23:7

23:10 83:11 93:1,5  
99:12 103:14 115:12  
**Andrew** 2:14 3:4 115:11  
**Andrew's** 136:19  
**Andrey** 2:7 25:7 26:18  
28:16 33:19 45:12  
76:15 115:8 129:14  
138:6 146:18 171:2  
211:5  
**Angeles** 131:10  
**angles** 9:8  
**angular** 174:10  
**Anita** 2:10 18:1 89:10  
95:21 96:21 115:13  
126:21 176:1 194:10  
200:14  
**announcement** 113:7  
**answer** 79:18 101:11  
**answering** 208:15,17  
**answers** 207:4  
**anxious** 178:12  
**anybody** 42:18 47:21  
107:21 119:8 123:10  
126:18 140:8 146:14  
159:11 178:2 189:3  
234:17  
**anyway** 26:16 111:2  
209:20 211:20 231:7  
**apologize** 199:15  
**appalled** 94:1  
**Apparently** 235:9  
**applause** 4:8  
**Applebaum** 1:15 28:15  
29:22 30:13,15 59:4,8  
61:3 76:16 91:15  
95:11 115:8 118:2  
119:13,17 120:10,13  
122:7 123:13 124:3  
125:5,15 155:8 171:3  
172:4 227:13  
**applicability** 236:15  
**applicable** 182:11  
**application** 241:3  
**applied** 18:5 128:17  
207:21 236:17  
**applies** 36:16 62:5  
207:11  
**apply** 18:8 50:6 70:17  
**appreciate** 201:2  
208:14 232:19 237:15  
240:12,17 241:16  
243:19 244:8 245:18  
247:13  
**appreciated** 136:20  
**approach** 14:20 166:4  
176:6 179:7 181:1  
245:5  
**approaches** 202:17

**appropriate** 28:18 29:7  
43:2 76:10 78:7 80:15  
81:20 82:10,17 91:3  
140:13 141:5 142:5  
145:1 148:5 156:10  
160:16,18,20 161:1  
**appropriately** 47:20  
129:21 139:10 246:7  
**appropriateness** 81:6  
81:12,17  
**approximately** 69:2  
**APRIL** 1:9  
**arbitrarily** 91:8  
**architecture** 239:13  
**area** 2:4 13:7 15:6  
36:16 122:9 125:13  
147:1 160:11,15  
195:12 196:22 214:18  
219:1 224:18 230:20  
241:8  
**areas** 27:21 119:2  
128:11 163:7 196:8  
210:17 212:12 214:21  
233:9  
**arena** 219:10  
**argue** 28:8 57:15 71:12  
88:19  
**arguing** 82:13  
**Ari** 1:21 2:6 45:12 46:4  
47:18 60:8 66:10  
68:19 69:8 79:17 88:4  
89:17 105:22 110:14  
115:8,13 141:3  
146:12 172:18 185:18  
188:1 189:9 195:11  
210:14 221:2  
**Ari's** 107:8 134:2  
152:18 164:8 227:3  
**arose** 6:11  
**arrangements** 88:22  
**array** 157:2  
**arrived** 104:8  
**arrow** 168:4 173:16,18  
174:5,10 176:10  
**arrows** 237:19  
**art** 157:12  
**articulate** 125:17  
**articulated** 170:7  
186:11  
**articulation** 186:19  
**asked** 34:10 48:11  
101:7 128:3 186:14  
199:5  
**asking** 142:17 189:13  
189:14 199:6  
**aspect** 61:6 83:22  
147:10 233:3  
**aspects** 7:18 21:11

70:6 97:17 98:3 148:4  
**assertive** 97:11  
**assess** 130:14 157:20  
175:18 190:16 191:1  
200:4 222:4  
**assessed** 150:22 151:4  
160:22  
**assessment** 129:2  
150:13,20 151:9,11  
151:13,14 152:6  
163:9 194:21 203:3  
209:13 213:15  
**assessments** 150:21  
202:5,11 203:6  
**assigned** 34:9 41:17  
116:8 121:21 122:2  
**assignments** 104:22  
**assist** 151:1  
**assistance** 32:22  
**assisted** 236:21  
**Associates** 1:20  
**association** 1:19 2:3  
234:8  
**assume** 235:21  
**assumed** 58:15 118:12  
**assumptions** 205:18  
**Atlanta** 13:7  
**attainable** 165:18  
**attention** 14:7 179:10  
**audience** 165:1  
**August** 117:14 183:10  
183:10  
**Austin** 115:7  
**AUSTIN-OSER** 1:16  
21:5 29:18 39:21  
40:18 42:13 48:4  
77:22 79:3 84:15,21  
109:21 113:14,21  
114:2,4,10,14 123:15  
124:19 140:22 141:22  
146:4 192:12 194:7  
199:14  
**authority** 39:13,14  
216:22  
**Autistic** 2:6  
**availability** 16:3 46:10  
47:11 83:12 129:1  
137:5  
**available** 46:12 161:6  
221:6 224:22 234:18  
237:8  
**avenue** 223:20  
**avoid** 130:8  
**avoidable** 10:22  
**aware** 160:12 207:7  
221:13,14  
**awareness** 160:9  
**awful** 238:11

**axe** 118:20

## B

**back** 4:3 11:7 31:22  
39:5 41:4 57:4 58:7  
67:14 69:18 70:2 74:4  
79:21 81:9 86:15 88:4  
92:8 99:16 103:20  
104:7 105:16 107:8  
109:11 111:17 113:19  
120:4,7 145:21 149:3  
150:1 156:19 158:16  
164:2 202:12 210:21  
216:11 218:1,6 228:3  
246:5,15  
**back-end** 196:6 203:10  
211:22  
**backward** 72:2  
**balanced** 155:4  
**balls** 244:2  
**bar** 6:7  
**Barbara** 2:4 12:20  
34:21 72:6 88:11 89:3  
116:1  
**barriers** 50:6 128:19,22  
131:20 182:16 220:6  
**base** 156:15 203:3  
206:20  
**based** 8:18,22 14:16  
23:16 54:13 87:16  
124:8 146:8 155:20  
156:5 157:20 171:18  
177:14 181:15 183:2  
183:7 197:18 203:3  
225:19  
**basic** 49:5 139:8 162:9  
247:4  
**basically** 148:1  
**basis** 9:22 156:8 163:4  
243:8  
**bath** 72:20,20  
**bear** 201:5  
**beauty** 238:17  
**bed** 32:11  
**beginning** 164:2 169:22  
186:19 200:2 212:3  
212:11  
**begs** 21:6 88:8  
**begun** 195:17  
**believe** 54:3,4 201:12  
232:12 236:12 238:2  
**belongs** 64:18 148:9  
**benefit** 201:4,6  
**benefits** 122:20 140:4,5  
152:9 235:22  
**benefitted** 136:19  
**best** 10:6 39:17 151:20  
156:6,7 174:5 203:12

219:4 228:7 237:22  
 238:3,7 241:11 243:9  
 243:9  
**better** 7:19 40:19 52:15  
 52:20 72:18,21 75:7  
 95:1 110:11 134:22  
 168:19 169:5,15  
 174:9 186:19 223:15  
**beyond** 28:1 44:13 49:6  
 100:10 102:10 106:8  
 135:18 148:17 149:6  
 222:2  
**biases** 208:18  
**big** 9:19 18:10 58:7  
 188:16,18 226:4  
 238:9  
**bigger** 103:22 190:4  
**billions** 227:21  
**bit** 4:11 6:3 25:2 45:9  
 78:15 100:8 107:19  
 108:10 125:16 127:2  
 144:21 150:7 154:14  
 166:9,21 191:10  
 202:19 211:5  
**bitty** 241:6  
**Blackwell** 2:18 99:15  
 99:17,21 100:7,19,22  
 246:2  
**blend** 73:18  
**blended** 71:22  
**blending** 72:2  
**block** 242:18  
**board** 35:8  
**boat** 168:6  
**Bob** 25:7 28:13 31:4  
 76:14 94:8 95:10  
 118:1,3,3 171:2 237:4  
**bodies** 192:14  
**body** 15:6  
**bogged** 112:13  
**bold** 239:15  
**book** 228:4  
**books** 229:4  
**born** 228:5  
**borrow** 227:3  
**bottom** 10:14 25:21  
 29:7 213:3  
**boundaries** 139:16  
**box** 171:6,20,21 173:4  
 173:5,7 174:15  
 177:16  
**boxes** 169:2 172:22  
 173:1 209:5  
**brain** 32:16 124:16  
**brains** 168:2  
**breadth** 126:7  
**breadths** 14:14,17  
**break** 11:17,18,20 34:8

86:5,6 87:15 101:4  
 103:15 105:14,14  
 109:16 110:18 113:11  
 115:2 166:10 178:11  
**breaks** 14:13 23:13  
**brief** 34:1 117:15  
 235:15  
**briefly** 139:7 164:18  
**brilliant** 235:11  
**bring** 14:7 105:16 186:8  
 192:20 194:1,14  
 215:6 245:6  
**bringing** 158:19 165:4  
 199:15 245:1  
**brings** 163:10  
**bristle** 52:4 53:11  
**bristled** 53:17  
**broad** 14:18,19 70:22  
 71:2 102:10 109:15  
 141:8 150:10 166:19  
 190:15 214:18  
**broaden** 106:8  
**broader** 35:10 59:3  
 63:6 70:17 88:19  
 101:12 121:17 130:12  
 132:20 147:7 192:14  
 215:3  
**broadly** 108:9 137:1  
 148:17 149:14 183:5  
**broken** 18:13  
**brought** 216:3  
**bubbled** 5:8  
**bucket** 8:4 16:1 18:11  
 18:12 27:11 58:7 82:1  
 82:2 100:17 108:2  
 109:20 200:18  
**bucketing** 59:2  
**buckets** 15:18 16:5  
 17:7 103:22 168:22  
 179:1  
**budget** 128:14  
**build** 5:4 11:13 137:9  
 149:3 179:16 211:19  
 239:13  
**building** 150:9 223:13  
 239:12  
**built** 12:10 148:13,14  
 149:11  
**bullet** 11:2 124:14  
 132:6,16 135:2,4  
 164:1  
**bulleted** 34:2  
**bullets** 136:12  
**bundle** 132:5  
**burden** 29:15  
**burdens** 152:13  
**Bureau** 2:1  
**burgeoning** 27:21

**buried** 206:17  
**business** 147:5 220:3  
**busy** 244:19  
**Buy** 94:16  
**buy-in** 93:11,12,16 94:4  
 94:9 95:6,9 114:13

# C

**C-O-N-T-E-N-T-S** 3:1  
**CAHPS** 194:19 218:2  
**calculated** 22:22  
**Caldwell** 1:12,14  
 105:13 106:18 107:3  
 107:7 109:18 111:13  
 115:7 117:8 119:12  
 119:14 120:2,6 122:5  
 124:11 125:3,10  
 126:19 127:4 128:1  
 129:14 131:14 133:5  
 135:1 137:12 138:3,6  
 140:20 142:22 144:7  
 144:18 145:11 146:3  
 146:11,18 147:15  
 148:20 149:20 151:21  
 152:2 153:19 156:13  
 157:3 158:7 159:11  
 164:6,20 168:14  
 170:20 172:17 173:11  
 174:4,17 175:20  
 176:8 178:1 187:8  
 247:15  
**California** 2:5 94:2  
 201:7  
**call** 10:17 12:19 20:15  
 20:18 36:8 44:17  
 45:10 55:13 58:9 72:5  
 72:6,16 81:5 90:6,11  
 110:13 118:18 121:8  
 176:11,12 212:9  
**called** 28:12 56:9 57:21  
 71:17 77:8 131:17  
 155:17 216:8,12,22  
 226:14,15  
**calling** 71:14 81:16  
 109:9 138:16 189:12  
 232:4  
**calls** 95:9 236:4  
**calm** 13:3,6  
**Camille** 1:19 31:2 34:13  
 84:5 85:17 115:22  
**capabilities** 41:9 44:2  
 44:11 195:12  
**capacities** 146:22  
**capacity** 41:9,11 44:2,6  
 44:14 147:3,5 161:6  
 191:13 196:11 213:7  
 213:11  
**capitated** 221:15

229:17  
**capture** 44:1 87:15  
 101:12 158:3,5  
 168:13  
**captured** 148:4  
**captures** 84:20 96:3  
**card** 31:1 216:12  
**care** 2:4,7 7:19 9:5,6  
 13:11 16:6 19:19,21  
 20:4,12,22 21:6 26:22  
 27:7,8,17,19,19 28:1  
 28:5,6 32:1,20 39:10  
 45:8,22 46:21 48:13  
 57:21,22 72:15,17,21  
 73:6,9,14,19,20 74:12  
 74:12,18 75:1,3 78:10  
 78:21 79:14 82:20,21  
 83:12 106:12 111:8  
 113:16 135:12 151:1  
 151:2,14,16,18  
 152:12 158:13 160:12  
 163:13,17 191:11,20  
 192:9 193:12 194:20  
 194:21,22 196:10,12  
 199:12,22 200:1  
 201:17,18,20 202:1,5  
 202:10 203:8 206:6  
 212:8 216:7 217:21  
 218:9 219:12,14,15  
 222:4 224:1,10,15  
 229:12,14,21 230:5  
 231:6,11 235:7,14  
 236:3,6,8,10,19 237:1  
**careful** 209:19  
**carefully** 202:20  
**caregiver** 15:20 30:5  
 31:6 72:8,10 76:12  
 79:22 81:10 88:6  
 105:21 106:2,3,3  
 109:9 111:19 115:16  
 150:7,20 151:9,10,11  
 151:13,16,19 152:6  
 152:18  
**caregivers** 46:17 69:21  
 69:22,22 72:4,5,6,9  
 79:20,22 80:2,7,10,12  
 88:7,10 89:7 102:10  
 106:5,11,16,19,20  
 109:1,4,6,15 110:7,21  
 111:1,2 112:5 150:22  
 151:3,3 152:10  
**caregiving** 150:17  
**carried** 178:19  
**carry** 8:8 233:11  
**carryover** 150:19  
 177:16  
**case** 5:20 32:3 151:12  
**cases** 120:19 143:12

221:12  
**cash** 127:13 227:9  
**cast** 215:3  
**catalysts** 57:7  
**catch** 113:11  
**categories** 10:15 30:6  
 84:18 104:13 153:13  
**category** 30:3 56:17  
 70:12 81:17 87:5  
 110:12  
**caught** 206:22  
**causal** 167:17  
**causality** 197:7  
**cause** 65:16  
**caution** 47:13  
**caveat** 77:3 200:5  
**caveats** 197:18 201:1  
**census** 216:18  
**center** 1:16,17 2:8  
 189:12 205:5 216:19  
**centered** 35:1 157:10  
 195:7 196:12,14  
**centeredness** 49:1  
**centralized** 230:10  
**centric** 225:10  
**certain** 6:3 9:16 10:3,5  
 34:10 57:8 81:1  
 130:10 134:5,11  
 139:18 142:5 147:5  
 201:6,19 239:21  
 241:8  
**certainly** 30:1 46:18  
 79:6 90:6 136:19  
 171:15 177:19 189:4  
 206:1  
**cetera** 76:18 79:13  
 109:17 113:12,12  
 176:18,18  
**challenge** 200:4 207:14  
 217:16  
**challenges** 171:4 196:7  
 230:11  
**challenging** 224:17  
**champions** 219:18  
**chance** 144:12  
**change** 7:15 17:19 18:8  
 48:3 51:2 57:7,14  
 124:20 166:6 173:22  
 174:14 214:11  
**changes** 7:21 195:4  
 204:19  
**changing** 15:7 42:1  
**Channeling** 227:14  
**characteristics** 4:16  
 10:12 11:8 19:7 33:8  
 92:6 103:21 247:5,6  
**Charlie** 2:1 21:21 68:10  
 68:17 115:12 229:7

**Charlie's** 23:19 219:5  
**chart** 14:6 18:12,15  
 23:1 104:14 112:11  
 148:3  
**charts** 86:15 105:7  
 237:20  
**chat** 101:5  
**cheap** 237:5  
**check** 25:5 164:2  
**checked** 24:2  
**checking** 7:5  
**checklist** 81:4  
**checkmark** 180:2  
**choice** 6:12,13 9:6 11:6  
 56:6 58:8,14,17,18  
 59:4,19 60:5,13,15,18  
 61:4,14,14,17,20,22  
 62:8,12 100:17  
 118:15,18 120:9  
 121:2,20 122:1,4,8  
 148:7 171:10 236:22  
**choose** 61:5 103:18  
 120:20  
**choosing** 121:18  
**chose** 61:1,16 115:6  
**Chosen** 3:7  
**chronic** 4:22 224:11  
**circle** 37:9  
**circled** 74:4  
**circles** 35:20 168:3  
**circulate** 247:7  
**circumstances** 235:19  
**cited** 15:13,14,15,16  
 23:2,3 30:3 41:8  
**cities** 48:10 228:6  
**claims** 186:12,17 190:3  
 190:4 191:6 200:6,10  
 200:12 201:13,13,15  
 209:8,11,16 213:12  
 213:14,18 222:2  
 229:9,10,16,19  
**Clair** 51:10  
**Claire** 133:10  
**Clare** 2:3 28:14 31:1  
 61:21 70:1 77:20 79:5  
 82:16 90:15 94:8 95:4  
 115:22  
**clarification** 17:6 18:4  
 42:22 51:13  
**clarified** 45:2  
**clarify** 23:4 52:9 69:4  
 89:16  
**clarifying** 12:11  
**classic** 164:1  
**clear** 67:11 130:15  
 141:11 174:13 186:10  
 221:20  
**clearly** 27:12 57:9 77:8

**Cleveland** 131:9  
**cliche** 7:18  
**client** 158:4,5  
**client-directed** 236:20  
**close** 9:21 12:6 188:4  
**closed** 225:2  
**closely** 195:17 204:7  
**closer** 28:9 105:6  
 111:11  
**closing** 90:11 184:7,8  
**cloth** 238:13  
**CMMI** 192:22  
**CMS** 191:14 195:15  
**co-branded** 173:1  
**Co-Chair** 1:14,15 12:16  
 14:1 16:16,20 18:3,14  
 18:19 20:7,10,16 21:3  
 21:19 23:4,8 24:18  
 25:15,20 26:2,6,10,15  
 28:13 29:3,20 30:10  
 30:14,16 31:17,20  
 33:6,12 34:3 35:2,7  
 35:13,15,20 36:4,8,20  
 37:1,11,14,17 38:1,5  
 38:9,15 39:2,18 40:17  
 42:4,9,16 44:15 45:12  
 46:4 47:16 48:2,6  
 49:10 50:11,21 51:6  
 51:10 52:7,19 53:7,10  
 53:14,17 54:8,19 55:1  
 55:17 56:2,12 58:6,11  
 58:17,21 59:6,11,14  
 60:8 61:21 62:2,9,14  
 63:4,8,11,14 64:3,12  
 64:17,20,22 65:9,14  
 66:7,13,17,19 67:2,18  
 68:4,10,13,16,19 69:6  
 69:11,14,17 70:9,15  
 71:3,19 72:10,13,22  
 73:6,8,15 74:9,14,19  
 74:22 75:8,12,15,17  
 76:7,19,22 77:6,12,16  
 77:20 79:1,4,8,11  
 81:5,14,18,22 82:3,6  
 82:13,16,20 83:3,21  
 84:4,9,13,17 85:17,21  
 86:6,10,12,16,19 88:1  
 88:11 89:3,10,16 90:5  
 90:13,21 91:1,17,20  
 92:17 93:4,7,12,22  
 94:7,19 95:2,4,10,21  
 96:6,12,18,21 97:13  
 98:5,11,17,20 99:1,5  
 99:8,11,19 100:3,16  
 100:20 101:1 105:13  
 106:18 107:3,7,17  
 108:5,21 109:2,8,18  
 110:14 111:13 112:9

117:8 119:12,14  
 120:2,6 122:5 124:11  
 125:3,10 126:19  
 127:4 128:1 129:14  
 131:14 133:5 135:1  
 136:11,15 137:12  
 138:3,6 140:20  
 142:14,22 143:1  
 144:7,18 145:11  
 146:3,11,18 147:15  
 148:20 149:20 151:21  
 152:2 153:19 156:13  
 157:3 158:7 159:11  
 164:6,20 168:14  
 169:9 170:20 171:22  
 172:17 173:11 174:4  
 174:17 175:20 176:8  
 178:1 187:8 188:7  
 246:17 247:15  
**co-chairs** 1:12 4:7  
 12:19 24:4 246:16  
**code** 201:4 209:17  
 224:12,13  
**codes** 191:9 200:11  
**cognitive** 62:6 208:19  
 223:21 236:17  
**collaboration** 2:15  
 140:16 245:10  
**collaborative** 220:3  
**collapse** 10:14 30:6,11  
 59:11 62:17 78:19  
 84:18 222:6  
**collapsed** 15:17  
**collapsible** 30:8 59:19  
**collapsing** 36:19 59:15  
 76:20  
**colleague** 227:6  
**colleagues** 245:20  
**collect** 199:2 208:9  
 211:9 217:17 230:15  
 230:17,21 231:7  
**collected** 182:21 248:8  
**collecting** 220:9 231:17  
**collection** 205:11,17  
 212:18 231:2  
**collects** 231:11  
**colorfully** 170:12,12  
**colors** 170:13  
**Columbus** 131:8,10  
**column** 26:13 33:18  
**columns** 30:11,20  
**combine** 90:10 91:4  
 247:3  
**combined** 91:7 158:21  
**come** 16:8 31:11 33:14  
 52:20 56:16 84:19  
 85:11 102:22 104:7  
 111:17 112:20 113:19

139:5 145:3 161:20  
 169:1 175:4 180:21  
 188:5 199:3 200:17  
 201:8 202:11 203:7  
 204:13 207:10,19  
 215:21 216:20 232:11  
 238:21  
**comes** 111:16 152:10  
 186:1  
**comfortable** 185:18  
 235:2  
**coming** 9:1 24:16 45:4  
 48:17 120:4 125:18  
 178:16 187:17 199:8  
 227:1 244:16  
**commend** 226:11  
**comment** 3:5,9 11:16  
 26:20 37:18 40:20,22  
 42:5,6 51:12 56:10  
 79:5 88:5 99:9,13,14  
 102:14 133:11 138:8  
 144:17 146:20 154:21  
 155:7 158:10 164:18  
 165:7,9,15 170:14  
 175:9 183:15,19  
 202:12 219:5 246:11  
 247:10  
**commented** 101:7,20  
**commenter** 165:14  
**commenting** 181:6  
**comments** 28:16 39:22  
 66:11 68:18 101:4  
 102:9 103:5 140:20  
 148:21 152:5 153:20  
 156:17 164:6,14  
 165:10 174:18 184:4  
 192:11 197:18  
**Commission** 13:16  
**commitment** 125:18  
 219:3 220:12  
**committed** 244:18  
**committee** 1:3,11 7:16  
 12:7 24:2 56:15 100:1  
 103:16,17 114:8  
 116:15 180:13 181:3  
 181:19 183:1,9,11,16  
 183:22 184:2 245:1  
**committee's** 3:11 182:8  
 182:15 183:4  
**committees** 207:12  
**common** 87:12 150:21  
 170:14 225:7  
**communicate** 95:19  
**communicating** 102:17  
 142:10  
**communication** 233:11  
**communities** 101:18  
 139:11,12 194:5

208:2 223:13  
**community** 1:6,21 8:12  
 8:17 22:3 31:12 34:20  
 35:22 43:20 45:6  
 54:13 65:2 66:2,3,18  
 66:19,20 67:4,8,17,22  
 68:14 69:18 70:5,14  
 70:17 71:15 89:13  
 101:15 103:3 115:16  
 124:8 133:4 147:19  
 148:16 171:18 177:9  
 203:2 212:3 220:5  
 223:11,12,22 225:22  
 226:9 236:20 239:5  
 240:6  
**community-based** 1:3  
 1:6 13:13 22:12 27:21  
 167:20 202:1 204:5  
 219:1 220:13 224:5,9  
 226:7,14 227:17  
**companies** 216:7  
**company** 240:5 241:6  
**comparatively** 130:16  
**compare** 147:11 195:8  
 211:1 231:3,14  
**compared** 32:21 108:17  
 172:15  
**comparison** 196:1  
**comparisons** 195:3  
**compendium** 197:21  
 198:4,13  
**compensated** 140:3,4  
**compensation** 150:15  
 152:8,9  
**competence** 154:17  
**competencies** 139:20  
 139:22 140:14 141:6  
 141:10 142:15 143:7  
 143:8,10 144:1 145:1  
**competency** 130:9  
 162:5,6,9  
**competent** 62:4 140:2  
 156:10 162:15,17  
 165:16  
**competing** 244:20  
**compiled** 182:21  
**compiles** 186:21  
**completely** 87:1 91:22  
 184:22  
**complex** 167:1  
**complexities** 221:18  
**complexity** 208:13  
 209:22  
**complicated** 200:20  
 201:8  
**compliment** 188:15  
**component** 90:10  
 162:17

**components** 98:1  
 116:14 161:18  
**composition** 159:4  
**comprehensive** 15:2  
 23:20 101:10 163:10  
 163:16 189:22 203:22  
 220:10  
**comprehensively**  
 101:13  
**comprised** 103:17  
**comprises** 16:1  
**compromised** 109:5  
**computer** 92:17,21  
**conceivably** 90:10  
**conceive** 211:7  
**concept** 9:10 28:6 38:8  
 38:11,14 71:8,10 79:7  
 81:7 82:22 84:19 93:9  
 181:14 190:8,11  
 193:4 236:12  
**conception** 97:3  
**concepts** 8:20 9:17  
 10:18 11:5 71:16 83:7  
 90:5 91:7 101:19  
 126:7 128:10 167:10  
 167:11 170:6 182:18  
**conceptual** 3:12 12:1  
 164:13,16,18 165:3  
 166:14 167:4 181:12  
 182:12  
**conceptualizing** 24:17  
**conceptually** 79:2,15  
 87:14 112:14,17  
**concern** 46:16 88:21  
 102:15 108:8 134:16  
 142:9 222:7  
**concerned** 44:21 209:7  
 239:9 242:4  
**concerns** 97:18 152:18  
**concludes** 179:18  
**conclusion** 211:10  
**concrete** 168:4  
**concur** 195:11  
**conditions** 4:22 235:18  
**conducting** 7:1 182:1  
**Conference** 1:11  
**confident** 5:19  
**conflate** 38:6  
**conflating** 78:1  
**conflicting** 9:12  
**confused** 20:13 51:7  
 94:22  
**confusion** 44:22  
**connect** 131:21  
**connection** 21:13 33:5  
 160:13 207:1  
**connections** 207:2  
**connectiveness** 65:5

**connector** 21:11  
**connote** 95:18  
**consensus** 88:3 117:10  
 199:4 200:17 232:20  
 233:10 234:4  
**consider** 19:17 20:20  
 41:6,7 57:8 101:14  
**consideration** 145:13  
 187:1  
**considerations** 179:7  
**considered** 159:19  
 180:20 243:2  
**considering** 150:14  
 191:22  
**consistency** 129:4,16  
 129:17,18 130:1,19  
 133:14,20 134:3,3,9  
 134:17 135:5,7 136:9  
 145:18 162:4  
**consistent** 58:3 135:19  
 142:2  
**consistently** 41:17  
**constantly** 15:7  
**constitutes** 9:4  
**constrain** 46:3  
**construct** 170:1,3  
**constructed** 187:2  
**consult** 55:7  
**consultation** 55:10  
**consulted** 181:17  
**consulting** 236:13  
**consumer** 7:22 8:9 9:15  
 15:19 20:11 30:5 31:6  
 36:7,14 40:5 49:3,4  
 49:18 53:7,10,18  
 54:11,14 55:4,4,10,14  
 55:17,21 56:7 76:12  
 76:14 87:22 91:11  
 96:7 98:13,15,19,20  
 99:1,5,17,19 100:1,5  
 101:1 115:5 118:13  
 122:18 125:21 127:2  
 156:19,20 167:4  
 173:6 174:1,11  
 175:21,22 176:12,13  
 178:8 187:22 189:8  
 189:10 199:9 210:16  
 217:20 221:1 225:9  
 236:4,13,21 241:19  
**consumer's** 6:13  
 235:17  
**consumer-centered**  
 236:3,10  
**consumer-directed**  
 31:10  
**consumer-experience**  
 31:11  
**consumer/patient** 58:5

**consumer/self-deter...**  
100:2  
**consumer/stakeholder**  
55:1,13  
**consumers** 9:2,2 10:19  
35:8 47:2 53:5 54:5  
54:20 56:17,19,21  
57:1,4,5,5,10,15,18  
98:7,9 127:5,9,10  
137:3 139:17 159:6  
171:8 172:1,2,22  
174:15 188:12 216:6  
231:20 235:21  
**contact** 234:19 248:4  
**contacts** 198:8 223:1  
**contain** 14:10 22:8,8  
**content** 49:14 164:22  
**context** 45:16 46:2,7  
51:15 135:6 138:1,2  
142:21 187:5  
**continual** 181:2  
**continue** 113:9 180:10  
183:1 246:5  
**continuity** 162:1  
**continuous** 184:2  
**continuum** 6:19 8:13  
**contracting** 6:14  
**contracts** 191:17  
**contribute** 152:21  
161:2 226:1  
**contribution** 245:7  
**contributions** 246:19  
**control** 31:10 53:6  
58:14,18,19 59:5,19  
60:6,13 61:4,5,10  
62:1,8,13 93:14,16  
95:1 97:9 100:17  
101:2 115:6 118:15  
118:19 148:18 171:10  
241:19  
**controlled** 49:19 56:8  
**controversial** 117:18  
**controversy** 65:17  
**convenience** 60:19  
**converging** 237:19  
**conversation** 4:11,15  
5:12 21:18 78:3 85:3  
87:11 113:19 123:16  
126:3 140:6 141:1,8  
142:6 145:2,10 204:2  
246:10  
**conversations** 8:19  
86:2 116:22 130:13  
**cool** 237:20  
**coordinate** 21:8 160:12  
**coordinated** 20:5,12  
28:20,22 29:8,12 43:3  
76:11 77:16 196:13

**coordinating** 206:5  
**coordination** 8:14  
19:19,21 20:4,22 21:6  
21:14 26:22 27:8,17  
28:7,21 32:1,20,21  
45:22 77:3,9 80:22  
81:2 139:3 158:13  
163:6,12,18  
**coordinator** 21:16  
**coordinators** 205:6  
**copies** 18:15,18  
**copy** 16:17  
**core** 113:3 186:6,19  
188:13 206:1  
**corner** 105:3  
**Correct** 30:15  
**correctly** 168:13  
**correlates** 63:2  
**correlation** 175:15  
**correspondence** 19:3  
24:20  
**cost** 193:12 221:21  
**costs** 160:5  
**Counseling** 127:13  
**count** 161:19 212:22  
**counterclockwise**  
187:7  
**countries** 223:14  
**country** 13:19 44:9  
192:19 225:4  
**county** 129:7 131:5  
**county-based** 129:5  
**couple** 37:2 39:21  
145:12 166:11 175:10  
185:12 187:14 188:20  
197:18 214:15,16  
220:21 224:3 237:21  
245:9 246:1  
**course** 32:8 56:16 59:2  
184:12 204:12 205:20  
244:11  
**court** 17:21 18:2 184:13  
**court-ordered** 209:13  
**cover** 50:16 70:12  
**coverage** 161:20  
**covered** 157:11,11  
**covers** 68:2  
**CPHQ** 1:19  
**CPR** 49:6  
**CPT** 224:12,12  
**CQI** 164:1  
**crazy** 99:21 191:10  
**create** 127:18 245:16  
**created** 162:19 207:9  
**creative** 172:20 230:14  
231:16  
**credit** 13:3 147:12  
**Crisp** 1:17 37:19 38:2,7

38:10 52:22 53:9,11  
53:21 58:13 72:17  
96:1,9,15,19 106:13  
107:1,5 112:3 115:18  
153:22 155:11 204:10  
**criteria** 14:13,17 23:17  
**criterion** 209:1  
**critical** 24:1 27:22  
143:6 184:10 217:21  
222:5 243:15  
**critically** 8:1 43:11  
**crosses** 100:12  
**crosswalk** 5:10  
**crosswalked** 16:9  
**crystalize** 113:2  
**cultural** 130:8 165:18  
**culturally** 140:1 165:16  
**culture** 140:15  
**curious** 17:10 22:5  
54:17  
**currency** 14:15  
**current** 8:14 15:8 79:12  
127:21  
**curve** 244:1  
**cut** 23:21 55:19 119:1  
145:3  
**cutting** 121:6

## D

**d'etre** 4:20  
**D.C** 1:12  
**D.E.B** 2:19 195:12  
246:1  
**daily** 9:22  
**data** 64:6 78:13 101:21  
137:5,5 138:13  
180:20 186:13,17  
189:10,19,22 190:3,4  
195:11,14 199:2  
200:8,10 201:13,14  
201:15 203:11 205:11  
205:16,19 208:4  
209:8,11,17 211:10  
211:12 212:18,19,21  
213:2,8,13,14,15,18  
214:2,9 220:10 222:2  
222:3 223:3 224:22  
224:22 226:19 227:10  
229:9,10,10,13,16,18  
229:19,22 230:1,9,15  
230:17,21 231:1,7,11  
231:13,17 237:7  
242:3,4,7,8,18  
**date** 102:1 180:15  
234:15  
**daughter** 228:22  
**day** 3:2 7:4,6,10 12:22  
62:22 88:18 163:4,4

187:5 212:7 243:21  
**days** 182:4 204:2 217:8  
218:20 241:6 244:19  
245:9 246:1 247:16  
**DD** 44:8 131:3 188:17  
**deal** 5:13 9:9 29:1  
**dealing** 22:3 162:5  
244:3  
**deals** 225:2  
**dear** 13:18 233:3  
**debrief** 10:13  
**debriefing** 116:3  
**decide** 9:9 33:15  
**decided** 86:19 122:9  
150:9 247:2  
**decides** 95:7  
**decision** 94:13  
**decisions** 6:14  
**deconstructing** 85:9  
**deeper** 179:3  
**default** 45:17  
**define** 46:3 51:9 52:1  
**defined** 8:22 102:16  
108:9 153:13 157:14  
**Defining** 3:6  
**definitely** 46:5 55:4  
142:11 144:13 241:22  
248:5  
**definition** 20:20 26:21  
26:22 32:2 45:1,3  
89:6 97:15,20 98:4  
116:13 170:4 180:8  
181:12 182:2 183:13  
200:15 247:2  
**definitions** 61:9 180:4  
186:20 187:3 197:6  
202:6 215:21 247:4  
**defray** 150:16  
**degree** 65:3 128:18  
219:4  
**degrees** 7:4,7  
**delegates** 56:19  
**deliberate** 116:18  
**delimit** 22:1  
**deliver** 78:6 138:19  
157:8,9 221:16  
**delivered** 27:10 156:11  
157:13  
**delivering** 43:19,20  
51:19 78:5 154:18  
**delivery** 61:6 120:9,11  
121:19 122:14 137:11  
154:20 155:10 156:9  
157:18 193:11 202:15  
203:3 231:21  
**Delman** 1:18 56:10,13  
58:10 63:5 94:9,21  
115:12 143:3 234:20

235:17  
**demand** 161:8,12  
**dementia** 62:5 223:10  
**dementia-friendly**  
 223:13  
**demonstrate** 38:12  
 167:5 225:12  
**demonstrated** 139:20  
 139:22 140:13 142:15  
 144:22 147:2,4  
**demonstrates** 185:14  
**demonstrating** 141:5  
 143:6,7  
**demonstration** 227:14  
**demonstrations** 229:13  
 229:15  
**denotes** 97:9 165:17  
**Department** 245:3  
**dependability** 161:16  
 161:18 162:19  
**dependable** 28:19 29:8  
 43:3 44:5 76:10 78:8  
 80:16 82:10,18  
 139:14 161:21  
**dependably** 162:7  
**dependent** 186:13  
**depending** 130:11  
 136:4  
**depends** 88:18  
**depth** 126:7  
**described** 197:20  
**description** 52:9 89:17  
 144:6  
**descriptive** 18:22  
**deserve** 4:7 13:2 62:11  
**design** 7:22 34:18 35:4  
 52:16 54:15 95:13  
 196:5 211:17  
**designed** 6:11 161:2  
 170:4 231:17  
**designer** 169:11  
**designing** 16:15  
**desired** 80:21 163:2  
 236:5  
**desperately** 13:20  
**destroying** 85:10,14  
**detail** 87:18 119:11  
 217:9  
**detailed** 112:7  
**details** 4:9  
**detect** 6:16  
**determination** 118:17  
**determined** 151:17  
**develop** 89:13 153:2  
 172:14 195:6 229:21  
**developed** 182:19  
 203:9 208:3 218:4  
**developing** 50:4 217:19

**development** 163:15  
 181:11 188:11 210:17  
 234:9,13  
**developmental** 236:18  
**devoting** 179:10  
**diagram** 167:18 170:18  
**dialog** 232:18 233:12  
**dialogue** 8:7 114:12  
**dialoguing** 5:8  
**differ** 196:2  
**difference** 32:1,2 59:9  
 76:17 110:3 128:9  
 144:22  
**differences** 6:17,22  
 7:12 27:13  
**different** 9:2,3,4,14  
 10:3,7 17:17 20:21  
 21:17 22:18,22 40:4  
 41:15 50:14 57:16  
 59:20 60:4,11 74:21  
 79:9 81:7,9 82:22  
 83:5 103:1 104:1  
 108:10,16 121:12  
 122:12 123:1 126:2  
 127:21 129:6,20  
 130:10 131:7 133:15  
 145:8 147:11 148:4  
 150:11 153:17 158:15  
 159:18,19 160:2  
 162:12 167:2 169:4  
 175:4,10 186:20  
 189:1 192:5 195:2  
 196:15 199:21 200:3  
 200:21 208:20,21,21  
 214:11 218:21 220:18  
 221:11,12 237:19  
 241:9 242:5  
**differentiate** 46:9 63:17  
 108:19 186:17  
**differentiating** 106:14  
**differentiation** 39:7  
**differently** 8:22 167:16  
 212:11 230:16  
**difficult** 130:14 230:10  
**difficulties** 62:6  
**digest** 79:20  
**dignity** 30:4 31:11 56:8  
 58:22 60:21 61:8,18  
 62:4,11  
**dimensions** 162:6  
**direct** 106:12 121:6,6  
 216:1 236:7,21  
**directed** 1:17 56:8  
 58:14  
**directing** 121:20  
**direction** 5:17 31:4  
 36:15 39:15,19 49:3,4  
 53:6 81:12 84:14

120:17 206:3  
**directive** 71:9  
**directly** 138:16 181:11  
 186:12 236:14  
**Director** 2:16  
**disabilities** 1:20 5:1  
 57:6 66:6,8 188:14  
 208:16 221:10 223:21  
 244:1  
**disability** 2:2 35:21  
 102:19 191:1 220:4  
 236:19 244:3  
**disabled** 206:2  
**disagreement** 105:20  
**disappear** 40:15  
**disbursed** 139:10  
**disciplines** 159:5  
**discovery** 238:6  
**discuss** 54:6  
**discussed** 6:18 174:19  
 185:3 233:19  
**discussing** 104:20  
 180:16 182:3 183:8  
**discussion** 3:3 4:13  
 10:17 11:7,12 12:12  
 17:2 56:21 80:14  
 87:17 91:3 101:15  
 104:6 105:15 116:5  
 117:12 118:22 123:5  
 127:3 129:17 133:13  
 133:19 135:11 139:21  
 140:9 143:17 145:14  
 156:12 157:6,15  
 158:11,20 168:15  
 178:14 182:16 184:8  
 184:19 200:11 218:19  
**discussions** 141:20  
**disease** 224:11 236:18  
**disembarking** 204:16  
**disparities** 89:21 90:4,7  
 90:8,12,18 128:12  
 129:10  
**dissent** 235:13,15  
 236:9  
**dissented** 235:12  
**distill** 34:1  
**distinct** 37:15 47:4  
 71:14,16 73:14 79:2,7  
 79:15 87:14  
**distinction** 28:4 37:22  
 40:22 45:10 109:22  
 110:7  
**distinctions** 179:9  
**distribution** 89:20  
 102:17  
**ditto** 131:9 214:13  
**dive** 179:3  
**diverge** 50:18

**divergence** 49:18  
**diverse** 9:15  
**diversity** 158:11 159:5  
**divide** 33:16  
**dividing** 111:11  
**division** 2:9 205:4  
**Dobson** 1:19 31:3,19  
 85:19,22 86:8,11,14  
 86:18,21 115:22  
 119:21 120:5,8,11  
 123:12 220:17  
**document** 23:12,13,15  
**documentation** 27:16  
**documents** 24:5 118:10  
 246:9  
**doing** 38:13 40:8 60:7  
 71:10 84:16 92:22  
 111:6 127:13 173:19  
 174:3 191:14 198:5,6  
 198:9 208:6,20 209:7  
 211:20 216:10 217:5  
 219:3,10 220:1,4  
 222:10 223:15 224:20  
 228:18 229:20 230:7  
 232:2 241:11  
**dollar** 232:5  
**dollars** 134:16 227:21  
**domain** 11:7 12:12 14:4  
 18:11 20:15 21:14  
 28:12 31:12 40:12,13  
 41:7 49:14 64:10 75:1  
 78:17 85:12 87:13  
 90:8 101:12 105:21  
 106:11,21 108:22  
 109:15 113:3 117:2  
 118:15,18 125:13  
 126:11 148:2 154:5  
 159:20 174:20,21  
**domains** 3:3,7,7 4:14  
 5:3 11:13,19 14:10,11  
 15:12 19:8,9 22:8  
 23:14 24:10 25:3  
 27:14 30:19 31:10,15  
 33:9 34:10 40:2 49:13  
 58:4 67:9,12 76:20  
 87:7 91:21 101:9,18  
 103:21 104:8,15,16  
 105:10,15 112:11  
 113:17 117:2 137:18  
 137:21,22 154:4  
 159:21 167:8,14  
 169:4 175:5 182:2,12  
 183:2,8 184:18 186:3  
 186:10 189:1 207:8,9  
 210:9 215:5,14 217:2  
 238:22 247:8  
**dominate** 107:10  
**door** 48:20 231:12

**downer** 200:22  
**downloaded** 248:12  
**Doyle** 227:6  
**DR** 58:20 65:7  
**draft** 116:12 165:3  
 180:7,11 183:13,18  
**drastically** 130:10  
 131:7  
**draw** 148:1  
**drawn** 205:19  
**dream** 32:14  
**DREDF** 22:19  
**dress** 228:21  
**dressed** 32:11  
**Drew** 12:14 14:2 19:12  
 83:9 92:22 103:12  
 165:2  
**Drew's** 25:3  
**drilled** 197:10  
**drive** 6:11 21:12  
**driven** 57:1  
**driver** 25:11  
**dropped** 214:8,9  
**dropping** 76:5  
**duals** 222:18  
**DUALs** 191:17,18  
**due** 180:7,11 183:18  
**duplication** 25:2 153:14  
**duplicative** 154:2 163:7  
**dynamic** 108:11,16

## E

**earlier** 96:7 145:22  
 150:4 226:12  
**early** 24:3  
**easier** 12:19  
**echo** 146:4 152:4  
 200:14 212:14 220:17  
 221:20 247:15  
**echoing** 210:13 219:5  
**economic** 68:6 160:4  
 234:13  
**edit** 141:16  
**editing** 114:15  
**educate** 225:19  
**educated** 204:20  
**education** 139:20 141:4  
 141:9 142:7 143:14  
 143:21 144:3 145:6  
 166:2 233:16  
**effect** 92:15 160:14  
 214:10  
**effective** 6:21 28:6  
 72:18 73:13 82:9  
 154:8 155:2 166:3  
 174:22 193:10,10  
 209:2  
**effectiveness** 72:14,16

73:12 74:20 75:11,14  
 76:6,17 78:4,9 80:19  
 81:1,8,12,16 84:1  
 154:6,7,9 174:20  
 177:2 206:16  
**effectiveness/quality**  
 74:17 75:1,22 76:4,8  
 115:20  
**efficiency** 43:5 64:7  
 84:2 90:11  
**efficient** 9:5 18:5 44:3  
 64:5 73:17 78:12  
**effort** 204:13 213:14  
**efforts** 5:11 167:22  
 179:11,13 180:1  
 183:7 219:18 226:18  
 245:18  
**eight** 15:16,16 117:4  
**either** 32:4 38:4 54:3  
 87:2 122:4 138:17  
 142:13 173:14  
**elaborate** 227:12  
**Elder** 206:7  
**elderly** 188:14 206:2  
 221:11  
**electronic** 117:13 196:5  
**element** 29:11 163:6  
**elements** 31:5 87:3  
 201:19  
**elephant** 197:14  
**elevate** 194:3  
**eligibility** 135:21,22  
 136:9  
**eligible** 162:22  
**eliminate** 89:21 223:17  
**eliminated** 143:13  
**Ellen** 2:18 99:17 246:2  
**eloquently** 233:1  
**eLTSS** 138:15  
**email** 113:11 116:16  
 117:13 168:10 194:5  
**emailed** 165:2  
**emailing** 189:12  
**emails** 248:6  
**embarking** 204:7  
**embodied** 63:18  
**emergence** 236:19  
 240:4  
**emerging** 185:15 187:4  
 240:1  
**emotional** 10:20 91:14  
 91:16,18 101:17  
 115:15 153:9 176:17  
 177:8  
**emphasis** 49:20 58:1,4  
 90:3,17 106:9 138:14  
 182:11 212:17  
**emphasize** 101:5 179:8

184:3  
**employer** 49:22  
**employment** 65:4 68:3  
 121:9 187:4 216:1  
**EMR** 226:20  
**enable** 226:19  
**enables** 111:8  
**encapsulate** 67:4  
**encompasses** 165:21  
 166:20  
**encounter** 152:15  
 229:18  
**encourage** 8:1 134:13  
 211:2 246:10 247:12  
**end-all-be-all** 24:14  
**ended** 168:3  
**endorsed** 218:7  
**endorsement** 188:6  
 194:19  
**engage** 54:6 246:4  
**engaged** 54:20 244:18  
**engagement** 16:14  
 31:12 34:17,19,20,20  
 35:3 36:14 39:13  
 40:10,12 42:7 53:15  
 53:20 54:10,16 55:2  
 55:15,18 58:1 65:2  
 68:22 92:9,12 93:17  
 94:1 137:2  
**English** 228:9  
**enhanced** 168:6  
**enhancements** 12:3  
**enhancing** 5:17  
**enjoyable** 72:20  
**enjoyed** 218:16 247:16  
**enjoyment** 147:21  
**enormous** 112:6  
**ensure** 141:17  
**ensuring** 6:4  
**entire** 56:4  
**entirely** 143:14 168:6  
**entities** 202:9 204:7  
 208:5  
**entity** 17:14 47:6 87:21  
 224:15  
**environment** 148:14  
 149:3,11  
**environmental** 3:16  
 12:5 156:15 180:9,12  
 182:9 187:13 242:22  
**environments** 195:2  
 242:6  
**Epic** 201:19  
**equal** 134:6,20  
**equalize** 226:8  
**equate** 166:2  
**equitable** 18:6 66:4  
 89:20,22 102:15,17

102:20 135:13 137:6  
**equitably** 128:17  
**equity** 16:12 19:2 90:1  
 90:1,4,10,14,17,20,21  
 115:11 128:6,9 131:6  
 133:13 166:2  
**especially** 138:14  
 156:14 185:4 193:3  
 193:15 211:16 219:12  
 226:21  
**essence** 85:8  
**essentially** 14:17  
 116:10 128:14 150:15  
 167:16 175:18  
**establish** 234:6  
**established** 5:2 33:22  
 117:2  
**et** 76:18 79:13 109:17  
 113:11,12 176:18,18  
**ethnicity** 165:22  
**Europe** 223:15  
**evaluate** 225:7  
**evaluated** 14:16 163:21  
**evaluating** 5:3 158:5  
 227:14  
**evaluation** 34:18 35:4  
 35:11 40:6 52:16  
 129:2 156:20 158:4  
 172:7 175:21 217:20  
 227:15 236:7  
**evening** 12:2  
**eventually** 194:18  
**everybody** 12:17 26:16  
 37:20 49:4 91:9,22  
 99:11 116:2 202:4  
 204:3 206:8 229:15  
 230:1 231:19 233:1  
 234:5,7 235:3 237:14  
 238:18 240:11  
**everybody's** 241:21  
 247:13  
**evidence** 3:16 12:6  
 14:15,22 15:6 24:9  
 155:20 156:5,8,15  
 157:20 179:3 180:10  
 181:10 182:21 185:13  
 206:5 217:13,14  
**evidence-based** 197:3  
**evolution** 219:12  
**evolutionary** 232:10  
**evolved** 238:14  
**evolving** 232:15  
**exact** 215:20  
**exactly** 32:15 34:5  
 118:11,14 136:12  
 147:9 229:2  
**examined** 30:4  
**example** 7:2 19:18 27:7



111:18 124:9 131:2,9  
 147:1 152:11 171:5  
 201:16,22 222:4  
 230:19  
**examples** 124:3 182:14  
**excellence** 44:10  
**exchange** 248:7  
**exchanged** 163:16  
**excited** 208:1,2 221:8  
 233:18 234:2,16  
**excitement** 219:2  
 228:13  
**exclusive** 101:10,13  
 154:3  
**exclusively** 167:10  
 224:5  
**excuse** 166:11 193:10  
**exercise** 10:11 41:3  
 62:8 87:2 116:9  
 154:14 210:11  
**exhaustive** 189:5  
**exist** 5:4 83:2 95:7  
 139:9 208:18 212:20  
**existence** 47:13  
**existing** 5:11,14 161:8  
 179:4,14 180:4  
 182:10 186:22  
**exists** 8:10  
**exiting** 229:5  
**expanded** 201:7  
**expectations** 212:4  
**expected** 163:19  
**expensive** 199:2  
 208:12 211:15,16  
 212:17  
**experience** 15:20,22  
 30:5 31:7 48:13 76:12  
 76:14 88:14 171:8,17  
 175:11,13,17,22  
 188:4,18,19 193:12  
 194:17 197:19 198:15  
 198:17 202:2 209:10  
 210:16 213:12  
**experimentation** 130:8  
**experiments** 244:4  
**expertise** 144:12 245:2  
**experts** 185:1  
**explain** 56:15 127:1  
**explanatory** 16:5  
**explicitly** 19:20 25:2  
**exploitation** 10:21  
 91:12 153:16  
**exploration** 210:18  
**explore** 138:21 212:12  
 223:19  
**exploring** 202:16  
**exponentially** 200:19  
**express** 141:15

**expressed** 142:3 236:1  
**extent** 24:19 204:6  
 236:5  
**external** 47:6 202:9  
**extra** 13:2 18:18 31:8  
 116:19 118:20 240:15  
**extract** 222:3  
**extraction** 15:12  
**extremely** 220:19 245:2

## F

**faced** 110:22  
**faces** 40:4  
**facets** 16:2 83:11 179:8  
**facilitate** 226:19 227:2  
 238:6  
**facilitating** 117:6  
 237:18  
**facilitator** 104:5  
**facility** 102:6  
**fact** 9:11 65:16 87:3  
 122:17 141:17 197:2  
 214:17 219:6 230:15  
 233:18 243:20  
**factors** 179:8  
**fail** 208:14  
**failed** 97:7  
**fair** 128:7  
**fairly** 166:22  
**fairness** 18:6 90:13,14  
 90:14,20,21 115:11  
 128:7,9 131:20  
**fall** 65:11 77:11 109:20  
 155:17 180:10 211:9  
**falls** 55:4 78:17 110:9  
**familiar** 235:8  
**families** 239:16  
**family** 46:17 47:3 69:20  
 69:22 72:4,5,9 79:20  
 79:22 80:2,5,9,12  
 81:10 87:22 88:6,10  
 88:16,17 89:6,9,15  
 101:15 102:3,5,11  
 103:3 106:3,5,8,15,19  
 106:20,22 107:1,9,13  
 107:19,20 108:9,10  
 108:14,15 109:1,4,6  
 109:16,19 110:7,11  
 110:21 111:1,19  
 150:19 152:14,18  
 174:12 216:6 231:18  
 241:7  
**family's** 107:10  
**fan** 238:9  
**far** 4:6 14:14 97:2 105:3  
 105:4 131:21 192:14  
 197:20 199:10 210:2  
 210:15

**avored** 15:1,3,7  
**Fay** 101:20  
**fear** 37:5  
**feasibility** 180:19  
**feasible** 185:11 187:10  
 195:10 198:22 205:10  
**federal** 233:22 245:20  
 245:21  
**federally** 49:21  
**feedback** 114:10  
 137:16 168:10 198:19  
**feel** 17:7 19:16 40:1,3  
 56:16 67:7 78:2,15,20  
 85:9,14 94:19 132:1  
 134:22 135:3 140:10  
 141:14,15 166:10  
 171:9 198:17  
**feelings** 233:16  
**feels** 77:22 78:14  
 146:15  
**Feldman** 2:15 3:17  
 115:7 165:14 178:20  
**felt** 91:6 127:5 162:11  
**fertile** 3:19 213:22  
 233:20  
**fewer** 92:15  
**fewest** 91:5  
**field** 235:10  
**figure** 43:6 125:1 133:7  
 148:8 171:12 172:7  
 238:4  
**figuring** 83:17  
**fill** 232:5  
**final** 3:11 71:21 88:4  
 154:21 169:14 179:18  
 226:10 230:13 236:1  
**finally** 102:14 196:22  
 200:6 230:3 232:9  
 243:17  
**financial** 46:11 101:16  
 150:16  
**financing** 137:10  
 239:10  
**find** 7:6,12 16:11 97:9  
 184:20 214:2 222:1  
**finding** 201:17  
**fine** 38:17 55:14 77:5  
 77:18 85:2 90:19  
**fingertips** 211:13  
**finish** 80:14 178:13  
**finished** 91:22 164:15  
 183:14  
**first** 8:8 10:18 12:16  
 15:19 22:7 23:21 25:6  
 31:2 36:9 37:19 43:9  
 44:9 60:8 76:14 77:21  
 99:13 112:14 120:7  
 122:13 124:14 135:2

135:4 137:8 144:20  
 147:19 150:1,6 154:5  
 159:22 163:9 166:13  
 180:7 195:13 197:21  
 198:14 221:4 244:15  
**first-aid** 49:6  
**fit** 10:6 50:9 60:5 97:10  
 174:10  
**fits** 28:16 32:16 110:11  
 112:21 158:13  
**five** 16:2 83:9,11 103:15  
 104:11,12 113:2  
 159:18,18 192:9  
 232:11  
**flag** 200:12  
**flagged** 31:5  
**fleshed** 167:8  
**flip** 98:6 105:7  
**Floor** 1:11  
**flows** 177:18  
**fluctuation** 7:7  
**focus** 89:11 100:14  
 127:14 180:15 226:6  
 233:2  
**focused** 56:7 180:7  
 215:17 244:17  
**focuses** 224:4  
**Focusing** 102:21  
**folded** 40:16  
**folks** 40:2 54:17 141:2  
 177:5 188:2 191:16  
 195:1 214:14 215:2  
 216:6 217:4 218:1  
 223:2 244:7  
**follow** 11:6 204:11  
**follow-up** 178:21  
 188:22  
**following** 11:10 115:2  
**Follows** 188:21  
**for-profit** 95:16,17  
 97:18 225:15  
**force** 44:14 45:11 49:7  
 50:9 51:1 52:6 101:16  
 193:3,5,6,16,19 233:4  
 234:8,12 239:17  
**force/providers** 52:8  
**forceful** 96:1 126:4  
**foremost** 8:9 244:15  
**forget** 143:13 248:2  
**forgot** 247:1  
**form** 11:20 232:6  
**formal** 60:1 97:20  
 179:21  
**formally** 56:14  
**forth** 129:11 139:15  
 164:3  
**Fortunately** 225:2  
**Forum** 1:1,11

**forward** 6:8 8:8 178:19  
206:9 212:13 219:19  
220:7 234:2 235:10  
241:1  
**foster** 102:5  
**fought** 89:5  
**found** 5:10 11:14 14:10  
16:9 19:12 23:15  
180:17 198:3  
**foundation** 169:21  
204:4  
**foundational** 6:6  
**four** 75:9 103:15 105:5  
160:2 177:17  
**framework** 3:12 5:7,7  
9:14 12:1 164:13,19  
165:3 166:14,19  
167:4 169:21 173:9  
174:13 180:8 181:12  
182:2 183:2,13  
215:12  
**frameworks** 5:2,11  
22:18,22 180:5  
182:12 238:11  
**framing** 129:17  
**frankly** 57:12  
**fraught** 70:16  
**free** 17:7 141:15 166:10  
**freedom** 10:21 62:4  
91:11 125:11 153:16  
**freedom/independen...**  
59:1  
**freehold** 93:2  
**frequency** 14:6 18:11  
23:1 148:2  
**frequently** 55:7 210:10  
**friends** 80:3 103:3  
**front** 219:14,15  
**frontier** 234:21,22  
**frowning** 38:16  
**fruitful** 188:3  
**fudge** 107:18  
**full** 12:7 66:2,4,7,19,20  
66:20 67:3,16,20,21  
68:14 69:18 70:3  
71:15 115:16 141:21  
144:10 146:7 147:19  
149:10 177:9 233:14  
233:15  
**fully** 203:5,22  
**fun** 65:5 67:5,6 69:19  
70:7,11,13 147:20  
232:20  
**function** 159:7 190:14  
191:1  
**functional** 25:9,11,19  
26:13 27:4 172:16  
194:20 213:15 229:2

**functioning** 153:10  
159:8 228:18  
**funded** 52:1 138:18  
**funding** 47:11  
**further** 11:18 42:21  
114:12 164:22 182:18  
185:10  
**furthermore** 49:20  
**future** 145:13 161:8  
182:19 188:6 206:10

## G

**Galantowicz** 1:20 65:22  
115:22 156:3 157:16  
159:15 174:18 197:17  
199:17  
**GAPS** 1:5  
**general** 49:7 50:9 63:19  
64:1 69:1 106:1  
109:15 231:15 233:2  
**generally** 33:7 110:17  
153:11 162:16  
**generation** 6:8  
**genuine** 241:11 245:11  
**geographic** 160:3  
**Gerontology** 1:15  
**Gerry** 2:6 39:3 52:13  
64:13 92:1 93:8 95:2  
107:7 115:18  
**Gerry's** 66:1  
**getting** 9:20 19:3 60:17  
62:22 70:22 71:8  
80:17,18 100:11  
104:12 110:6 133:17  
133:22 135:4 166:9  
172:8 177:12 188:4  
198:18 200:2 203:15  
206:6 208:7 210:18  
220:16 224:6 225:2  
228:20 229:14 242:6  
**give** 30:20 72:19 103:11  
110:14 113:5 116:14  
147:12 166:10 168:9  
203:20 207:4  
**given** 46:16 47:1 60:1  
62:14 94:12 128:21  
151:18 187:1 246:12  
**giver** 212:8  
**gives** 208:8  
**glasses** 196:16  
**glean** 201:14  
**gleaned** 210:7  
**go** 4:18 10:3,4 14:4  
29:20 31:7,13 33:13  
34:21 46:13 53:18  
58:12 74:2 76:3 86:20  
88:4 92:22 97:2  
106:21,21 111:14,20

111:20 112:1,9  
119:10 120:7 128:2  
149:3,20 150:4  
156:18 158:7,16  
159:12 164:2,18  
166:12 169:20 171:2  
172:18 184:15,16  
185:17 192:8 205:8  
220:14,15 222:1  
230:6 243:3,12 244:2  
**goal** 143:21 161:1  
235:14  
**goal-setting** 236:6  
**goals** 32:13 56:7  
154:11 160:22 166:5  
213:21 234:9,10  
242:22 243:13  
**God** 215:9  
**goes** 21:1 90:14 100:10  
124:1 135:18 145:21  
170:5 194:8 221:9  
241:1  
**going** 6:1 7:19 8:21  
11:10,17 14:3,4 16:22  
17:1 26:1,7 27:22  
28:17,19 30:10 34:4,8  
37:20 39:19 42:4,6  
44:17,22 47:21 49:11  
49:16 50:6,13,16,18  
52:11 56:13 57:14,15  
59:17,17 66:15 67:20  
78:5,6 79:5 81:11  
86:4,7,12,21 88:2  
91:9 93:6 99:12,14  
103:14,16,19 104:10  
104:15,16,17 105:2,2  
109:12,20 112:7,15  
113:18 114:3 121:16  
132:20 138:4,11  
150:4 153:4 154:1,1  
161:4,11 164:10,12  
164:13,16 166:9  
168:7 169:10,20  
172:19 173:16 175:3  
178:12 181:1,16,16  
183:1,6,14 184:1  
185:11 187:7 190:14  
191:2 192:19 193:14  
194:14,18 195:7  
196:1,9,20 198:11  
202:14 204:20 205:8  
206:2 207:7,15,17,19  
209:17 214:20 215:2  
217:15 221:3,4 225:3  
227:19 231:6 232:12  
232:22 233:2 234:6  
240:5 243:1,3,10,14  
246:8 247:3

**good** 4:4 5:13 8:6 21:20  
29:20 31:16 34:16  
36:5 44:5 47:20 58:6  
64:16,18 72:13 85:3  
97:1 117:21 125:2  
130:22 134:1 137:13  
137:18 139:1 140:20  
146:9 148:20 153:19  
168:18 170:21 171:1  
173:11 174:4 176:6  
178:1,3 186:17  
187:17 189:1 192:13  
199:9 205:1 206:13  
209:21 210:20 218:3  
227:17 228:18 231:22  
239:7 241:14 248:3  
**Google** 184:20  
**gotten** 75:8 122:21  
229:19  
**government** 15:3  
189:13  
**grab** 209:16  
**grant** 192:22 194:15  
242:18  
**granular** 14:20 27:9  
**granularity** 33:22  
**graphic** 169:10  
**graphically** 178:7  
**gray** 198:6  
**great** 77:18 114:11  
130:2 135:8 191:3  
209:11 210:4 212:2  
225:3 229:11 230:6,9  
235:3,9 245:16,20  
**greater** 89:8 103:3  
193:11 245:8  
**greatest** 43:18 220:6  
**green** 25:19  
**ground** 3:19 110:11  
188:3 213:22 233:20  
234:14  
**group** 3:3,6 5:14 9:1  
11:12 13:11 26:21  
27:11 28:10 34:9,10  
80:4 87:12 102:6  
103:12,16 104:7,15  
104:21 105:2,3,4,5,9  
109:7 112:5 115:5,10  
115:15,20 117:4  
119:8 122:9 123:10  
127:14 128:2,5 132:1  
135:15 141:7,13,14  
141:21 142:1,11,12  
144:10 146:13,15  
147:9,16,18 149:4  
150:2 153:20,20  
155:6,20 159:1  
166:17 168:19 170:6

170:8 174:19 216:3  
 218:18 232:18 234:10  
 237:16 245:5,17,21  
 246:12  
**groupings** 50:16  
**groups** 11:18 34:4,9  
 87:15 103:15 113:7  
 115:3 116:4,11,22  
 237:10  
**growing** 185:13 206:5  
**guard** 8:16  
**guess** 37:4 40:21 43:3  
 44:20 45:4,8 74:11  
 82:8 85:2 92:12 98:2  
 100:7 108:7 109:10  
 109:12 110:16 118:6  
 120:6 128:1 155:12  
 169:19 170:13 172:5  
 187:6 192:3 204:2  
 207:4 214:13 217:11  
 237:21  
**guidance** 220:1  
**guide** 170:8 182:15  
**guided** 24:9 182:1  
**guys** 14:9 16:8 17:2  
 91:4 104:4,6,10  
 129:16 130:4 188:15

## H

**H** 1:12,15  
**half** 232:8 237:9  
**hall** 166:12  
**hammer** 4:9 7:17  
**hand** 2:7 17:8 27:8 60:9  
 65:20 98:10 104:17  
 105:3  
**handed** 14:7  
**handful** 121:18  
**handle** 28:4 141:2  
**hands-on** 241:2  
**happen** 27:6 205:17  
**happened** 150:3  
**happening** 74:7 138:10  
 149:13 187:12 190:7  
 193:3 205:1,1 208:10  
 209:18 210:19 230:2  
**happens** 172:9 205:14  
**happy** 63:4 66:10 91:9  
 91:21 92:2,4 219:19  
 227:11 234:21  
**hard** 12:8 89:5 221:22  
 224:21 229:6 240:13  
**harder** 175:14 199:3  
**harkens** 210:21  
**harm** 10:22  
**harmonization** 226:16  
**harmonize** 226:18  
**harmonizing** 190:9,11

202:13  
**hash** 142:5  
**hazards** 153:22  
**HCBS** 4:16,20,21 5:3,20  
 6:19 8:15 9:15 10:11  
 14:11 21:8,10,15 22:9  
 29:15 32:6 33:4 45:16  
 45:17 46:2 51:2 65:3  
 75:18 78:5 129:11  
 148:18 154:15 163:11  
 170:1,3,7 179:9,12  
 180:5 182:2,11,15  
 185:15 186:18,20  
 187:5,15 188:3,17  
 189:20 194:18 197:21  
 198:16 199:21 200:3  
 200:10,12,16,18,18  
 201:4 215:4 221:16  
 222:15,20 233:2  
 247:4  
**headers** 33:18  
**heading** 31:3  
**heads** 9:12 132:3  
**health** 2:4,10 8:15  
 10:20 13:11,17 17:14  
 25:10 57:6,9,19 87:21  
 89:21 90:4,7,8,12,18  
 91:10,14 95:17  
 101:17 128:12 144:4  
 152:12 153:11 154:12  
 163:13 190:6,8,12  
 192:1,6,7 193:8,8  
 203:21 211:1 215:8  
 215:16,18 216:8,13  
 216:18,19,19,22  
 218:5 221:15 222:13  
 222:19 225:6 235:20  
 239:3 245:3  
**healthcare** 1:16 27:4,4  
 45:4  
**HealthConnect** 201:18  
**hear** 41:10 76:20 116:3  
 142:1 143:4 184:7  
 239:20 246:14  
**heard** 4:10 8:8 11:13  
 29:9 146:21 149:5  
 166:18 168:15 170:14  
 215:2 242:20  
**hearing** 40:1 100:8  
 244:8 247:17  
**heart** 13:18 185:5 233:3  
**heavily** 226:17  
**help** 7:11 111:22 112:1  
 113:8 172:2 181:8  
 185:1 192:10 203:2  
 220:15 234:6 238:6  
 240:16  
**helpful** 22:16,20 33:18

42:14 93:4 124:21  
 178:4 187:20 190:12  
 233:13  
**helping** 160:12  
**helps** 21:12 170:2  
**heterogeneous** 129:20  
**HETUS** 191:20 203:18  
**hey** 194:1 231:10 232:4  
**HHS** 24:4 103:18  
 181:19  
**hi** 96:15  
**hide** 25:13  
**high** 4:20 72:19 122:18  
 130:20 140:19 166:20  
 213:12 228:6  
**high-level** 8:20 15:18  
**high-quality** 4:16 10:11  
**higher** 28:6 224:1  
**highlight** 201:12 202:22  
**highlighted** 128:11  
 195:14  
**highly** 23:2 123:20  
**hints** 33:18  
**HIPAA** 191:9 200:11  
 209:17  
**hire** 111:7 143:11,12  
 144:6 225:18,18  
**hired** 225:16,17  
**hiring** 108:11  
**historical** 165:20  
**hit** 48:14  
**ho-hum** 241:20  
**hold** 9:12 77:20 84:6  
**hole** 50:19  
**holistic** 21:10  
**home** 1:3,6 8:17 13:12  
 13:17 22:3,11 27:21  
 39:1 40:21 43:19 45:8  
 45:11 48:17 74:7 78:4  
 95:17 100:12 102:2,3  
 102:5,6 121:5 124:8  
 167:19 171:18 201:22  
 203:2 204:5 223:17  
 224:5,9 226:7,14  
 227:17,19 231:7,21  
 236:20  
**homes** 88:21 95:16  
 228:19 236:16  
**homogenize** 130:7  
**honest** 199:1  
**honestly** 51:21 67:5  
**honored** 234:20  
**hope** 4:4 149:14 186:21  
 205:8 209:4,21  
 217:11 234:3 238:12  
 240:22  
**hopefully** 156:2 194:19  
 227:1

**host** 88:21 102:4  
**hour** 127:16 232:8  
**house** 89:5 243:11  
**Houser** 1:21 60:9,10  
 61:12 66:15,18 68:19  
 68:20 79:17,18  
 105:22 110:16 115:9  
 121:16 132:5 150:18  
 151:8 153:1,6 172:19  
 185:20,22 212:14  
**Houser's** 88:5  
**housing** 63:21 128:20  
 128:21,21 131:17  
 132:6,7,12,15,22  
 133:3 243:5  
**huge** 16:5 206:3 234:1  
**human** 63:6,8,11,12,14  
 63:15,18,20 64:1  
 115:6 123:17 176:21  
 177:9 245:3  
**Human/legal** 64:3  
**humility** 165:19

## I

**iceberg** 196:19  
**IDD** 101:22,22 102:8  
 221:12  
**idea** 33:8 46:6 47:10  
 117:19 120:14 127:22  
 160:6 190:13 227:18  
 241:15 248:3  
**ideally** 151:9,13 156:4  
**ideas** 10:6 11:4 108:10  
 169:15 181:14 182:18  
 210:4 241:13 247:18  
**identified** 31:6 179:19  
 181:18 192:16  
**identify** 33:9 34:11  
 112:19 126:6 182:10  
 182:14,17  
**identifying** 3:19 163:12  
 181:14 233:20  
**identities** 101:12  
**ignored** 57:2  
**ignoring** 80:9,11  
**Illinois** 2:9 218:1  
**illness** 62:7  
**imagine** 184:19  
**immediately** 153:2  
**impact** 43:18 94:14  
 147:8 190:20 193:6,7  
 199:18  
**impacts** 132:21 214:4  
**impairment** 134:15  
 229:2 236:17  
**imperative** 9:11  
**imperfect** 190:7 213:16  
**implementation** 34:18

35:4 52:16 182:16  
209:2  
**implemented** 156:6,7  
163:20  
**implications** 67:16  
**imply** 29:15  
**importance** 25:14 44:2  
140:14 185:14 198:18  
217:22 220:22 228:1  
229:10  
**important** 5:21 6:2 8:16  
10:18 15:10 16:13  
19:4,14,22 20:15 28:7  
28:8 32:6,19 37:15  
41:14 43:12,15 44:1  
48:12 49:9 60:22  
67:13 85:8,15 97:8,22  
113:18 117:19 119:5  
120:17 125:8 126:5  
126:16 132:11 138:12  
138:21 144:5 145:15  
148:10 156:14 157:17  
172:12 184:3 195:12  
197:15 199:10,20  
201:14 203:18 204:8  
208:10 210:22 214:3  
219:7 225:15 236:2  
241:1,12 242:17,21  
**importantly** 151:10  
**imposing** 46:20  
**impressed** 169:12  
188:10  
**improve** 179:12 208:8  
226:6  
**improved** 11:9 193:8,9  
**improvement** 6:12 8:5  
147:3 167:22 188:16  
188:18  
**improving** 226:1  
**in-home** 211:11  
**IN-PERSON** 1:3  
**inaccurately** 146:16  
**include** 54:11,12 62:10  
120:17 124:22 133:2  
160:5 182:5 217:2  
**included** 14:13 18:13  
67:8 98:4 123:2  
147:20 155:9 198:4  
**includes** 68:5 83:1  
107:20 155:15 161:5  
**including** 24:3 27:3  
32:2 108:9,16 116:12  
127:9 163:17 236:16  
236:18,20  
**inclusion** 8:11 31:13  
65:2,7 66:2,3,7,18,20  
66:20,21 67:4,17,20  
67:22,22 68:15,22

69:8,10,12,18 70:3,5  
70:17 71:15,17  
115:17 147:19 148:13  
177:10 212:3  
**inclusive** 14:19  
**income** 139:11  
**incorporate** 152:7  
202:10  
**incorporated** 186:8  
**increases** 167:21  
**incredible** 147:3,4  
192:2 200:7  
**incredibly** 212:21  
224:17 241:1  
**independence** 59:3  
101:16  
**independent** 2:7 231:1  
231:9  
**independently** 228:21  
**indicator** 196:2 206:1  
**indicators** 146:9 186:6  
188:13  
**individual** 21:1 25:12  
32:13 35:11 36:17  
39:12 40:9,12 53:20  
53:22 56:7 67:12 74:8  
74:13 78:1,9,11,18  
82:11 86:3,11,18 87:9  
100:15 104:19 130:15  
138:1 146:22 160:11  
160:19 162:3,4,8,16  
166:1 175:7 206:20  
**individual's** 39:14  
**individual-oriented**  
62:1  
**individually-based** 70:7  
**individuals** 9:21 39:8  
51:5 53:5 92:11 102:7  
163:18 175:2 199:6  
221:10,12,17 228:20  
237:18 239:16  
**inequitable** 135:16  
**inevitable** 137:20  
**inexpensive** 211:19  
232:1  
**influenced** 8:3  
**influences** 167:12,12  
**influencing** 6:15  
**influential** 24:6  
**inform** 6:12 184:16  
**informant** 182:5  
**information** 127:10,16  
127:19 156:21 163:16  
182:6 186:22 195:16  
195:18,21 201:15,21  
202:8 203:5,14 210:7  
213:17 219:13 222:3  
227:7 234:19 240:4

241:13 242:11 248:4  
**informed** 9:6 181:11  
**infuse** 140:18  
**initial** 117:17  
**initiation** 162:20 163:5  
**initiatives** 8:5 194:16  
197:19 215:6  
**innovation** 226:22,22  
**innovations** 192:18  
228:12  
**inpatient** 218:6  
**input** 7:22 12:1 39:14  
53:1 96:4 116:19  
117:13 182:8,22  
236:7  
**inputs** 176:5  
**inside** 227:19  
**instance** 192:22 193:7  
**Institute** 1:21 2:2  
**institutional** 186:18  
**institutionalization**  
223:18  
**instructions** 103:11  
**instrumentation** 208:4  
**instruments** 209:5  
**integrate** 21:8  
**integrated** 20:1,6 26:21  
27:2,3,5 28:5 29:13  
64:6 73:18 78:13  
196:11 201:18 229:12  
229:14,16,20  
**integrating** 206:6  
**integration** 8:15 20:22  
45:21 70:14 226:19  
**integrity** 64:7 78:13  
137:5 138:13  
**intended** 183:21 184:16  
**intending** 167:19  
**intensity** 221:21  
**intensive** 134:12  
**intent** 151:7,22  
**intentionally** 92:10  
**intently** 244:11  
**intents** 135:13  
**interact** 44:12  
**interest** 116:20 119:19  
241:10,11  
**interested** 50:1 101:8  
121:9 234:17  
**interesting** 27:15 39:19  
111:15 112:10 137:16  
138:20 164:7 189:3  
191:5 193:14 196:9  
196:21 206:13 210:9  
210:11 215:13 232:21  
**Interim** 2:4 13:11  
**intermediary** 206:19  
**intermediate** 17:14

87:20 104:18  
**internet** 237:10  
**interoperability** 138:11  
138:15 139:3  
**interpret** 17:10 167:1  
**interpretation** 102:10  
**intersection** 138:17  
**intervention** 172:8  
**interventions** 197:5  
**interviewers** 208:20  
**interviewing** 205:6  
**interviews** 182:6 209:2  
227:15 231:9  
**intimate** 89:1  
**intrinsically** 177:14  
**introduce** 13:4  
**introducing** 93:8  
**intuitive** 148:6  
**invested** 6:3 219:8  
**investing** 239:7  
**investment** 207:18  
220:5 224:16,21  
227:9  
**investment's** 207:19  
**invite** 97:5  
**inviting** 206:13 218:16  
**involve** 190:5 235:18  
**involved** 37:8 56:18  
121:7 125:19 127:5  
159:6 190:21 236:5  
238:15  
**involvement** 95:13  
125:21  
**IOM** 235:6  
**issue** 28:21 39:5 45:20  
55:6 56:16 74:4  
106:19 111:19 130:9  
137:8 139:8 140:17  
197:11 200:6 234:12  
234:13,13  
**issues** 50:13 106:7  
131:18 136:22 137:2  
137:4,6,8 152:16  
158:18 165:21 180:19  
203:21 233:4 243:1  
**It'd** 111:15  
**item** 122:13 123:3  
127:3 136:14  
**items** 30:2 79:12  
204:21 209:4 213:6  
**iteration** 24:8 166:13  
**iterations** 170:21  
**iterative** 181:1

---

**J**

---

**Jamie** 1:21 244:10  
247:11  
**JD** 1:18

**Jennifer** 101:7  
**job** 21:7 32:14 47:7  
 131:8 137:18 144:5  
 193:4,5,18 241:11  
**jobs** 198:17 223:15  
**Joe** 1:12,14 109:10  
 115:7 117:6 119:11  
 168:12 170:11 187:7  
 194:16 248:1  
**John** 142:22  
**join** 33:16  
**joined** 12:21  
**joining** 238:16  
**Joint** 13:15  
**Jon** 58:6,18 63:4 94:7  
 95:12 237:13  
**Jonathan** 1:18 115:12  
**journal** 15:5  
**journals** 22:3  
**judgment** 10:19  
**Juliet** 2:15 3:17 115:7  
 165:2 166:7 178:15  
 184:5  
**jump** 85:19  
**jumping** 211:4  
**June** 102:1 221:4  
**jurisdiction** 133:16,22  
**jurisdictions** 129:4  
 130:17 134:10,18,21  
 135:8 136:3,7,10  
**justice** 234:12

---

**K**


---

**K** 2:1  
**Kaiser** 2:5 196:18 201:4  
**Katz** 228:15  
**Kaye** 1:12,15 12:16  
 14:1 16:16,20 18:3,14  
 18:19 20:7,10,16 21:3  
 21:19 22:20 23:4,8  
 24:18 25:15,20 26:2,6  
 26:10,15 28:13 29:3  
 29:20 30:10,14,16  
 31:17,20 33:6,12 34:3  
 35:2,7,13,15,20 36:4  
 36:8,20 37:1,11,14,17  
 38:1,5,9,15 39:2,18  
 40:17 42:4,9,16 44:15  
 45:12 46:4 47:16 48:2  
 48:6 49:10 50:11,21  
 51:6,10 52:7,19 53:7  
 53:10,14,17 54:8,19  
 55:1,17 56:2,12 58:6  
 58:11,17,21 59:6,11  
 59:14 60:8 61:21 62:2  
 62:9,14 63:4,8,11,14  
 64:3,12,17,20,22 65:9  
 65:14 66:7,13,17,19

67:2,18 68:4,10,13,16  
 68:19 69:6,11,14,17  
 70:9,15 71:3,19 72:10  
 72:13,22 73:6,8,15  
 74:9,14,19,22 75:8,12  
 75:15,17 76:7,19,22  
 77:6,12,16,20 79:1,4  
 79:8,11 81:5,14,18,22  
 82:3,6,13,16,20 83:3  
 83:21 84:4,9,13,17  
 85:17,21 86:6,10,12  
 86:16,19 88:1,11 89:3  
 89:10,16 90:5,13,21  
 91:1,17,20 92:17 93:4  
 93:7,12,22 94:7,19  
 95:2,4,10,21 96:6,12  
 96:18,21 97:13 98:5  
 98:11,17,20 99:1,5,8  
 99:11,19 100:3,16,20  
 101:1 107:17 108:5  
 108:21 109:2,8  
 110:14 112:9 115:17  
 136:11,15 142:14  
 143:1 169:9 171:22  
 188:7 246:17  
**keep** 28:11 38:5 39:22  
 40:1 45:18 95:2 104:5  
 112:16 114:17 117:15  
 122:10 144:8 150:4,9  
 168:15 172:17 178:12  
 181:16 213:21 214:17  
 231:20  
**keeping** 50:2 177:12  
 197:1 223:22  
**keeps** 187:17  
**KENDALL** 1:21 244:14  
**kept** 125:18 245:15  
**key** 25:11 94:13 182:5  
 203:7  
**keys** 214:8,10 227:2  
**Killingsworth** 2:1 36:11  
 38:17 41:2 43:8 48:5  
 48:8 51:18 75:10,13  
 75:16 115:18 145:12  
 147:17 148:22 149:19  
 149:22 151:6 152:1  
 152:17 153:5,7  
 173:13 210:1  
**Kim** 87:1  
**Kimberly** 1:16 21:4  
 29:9 36:10 39:20  
 42:11 77:21 84:5,14  
 113:13 115:7  
**kind** 9:18 14:5,6,13  
 17:2 18:12 19:10 21:6  
 21:14,17 25:5 27:16  
 28:5,11 29:4,12 31:22  
 35:8 37:6,7,11,14,15

38:1 45:17,17 50:2,12  
 50:18 52:14 54:2,6,16  
 61:13,13 65:15 69:6  
 71:2,13 74:1 80:19  
 83:6 85:9 93:8,9,9  
 96:3 97:16,17,19  
 103:22 110:12 119:15  
 121:6 149:2,12 167:1  
 167:17 168:11 169:1  
 170:14 177:2 180:2  
 183:22 189:15 202:4  
 204:18 207:5 209:4  
 216:10,13 217:5  
 227:18 231:18 239:15  
 241:2 242:20 243:4,5  
 244:6 246:20  
**kinds** 33:3 122:20  
 127:17 130:11 150:11  
 186:2,20 187:2 207:2  
 208:20 239:8 241:10  
 242:5  
**knocking** 237:7  
**know** 5:2 6:1 8:21 10:12  
 12:9 13:1,7,21 20:2  
 20:12 21:22 28:3,9,15  
 29:2 30:1,5,8,21  
 32:15 34:17 36:5  
 48:21 49:6 50:15 52:3  
 54:15 60:6 62:19 64:8  
 70:21,22 72:21 75:5  
 80:6 85:13 92:20 93:6  
 96:5,9 97:7 104:8,20  
 105:22 106:10,21  
 110:7 111:17 112:7  
 116:21 117:9,16,17  
 120:8 123:10 124:18  
 127:8 129:8 130:1,6  
 131:9,17 132:9,21  
 134:5,14 136:5  
 137:15 138:18 140:9  
 144:8,9,9,11,14,21  
 145:2,6,9 146:6,9  
 147:9,14 148:10  
 149:4,12,13 150:11  
 151:17 152:12,13,21  
 156:20 157:8,14  
 161:5 162:22 163:1,3  
 163:19 164:1,12  
 168:15,16 169:13  
 170:2,8 171:1 174:7,8  
 174:11 175:3,5  
 176:14 178:8,12  
 179:12 184:11 185:2  
 185:5,8 186:16 187:9  
 187:13,15,21 188:2,5  
 188:22 189:4,11,13  
 189:16,17,20 190:1  
 192:15,20 193:8,16

201:9 202:3,4,18  
 203:8,12,16,19,19  
 204:1,4 205:3,4  
 206:15,18 207:18  
 208:18 209:16 211:14  
 212:20 213:3,4,5,12  
 213:13 214:17 215:1  
 215:3,7,8,11,12,19,22  
 216:2 217:1,5,7,8,9  
 217:14,21,22 218:2,4  
 218:5,8,9,12,20  
 220:14,20 221:14  
 222:9 223:21 224:12  
 225:9 226:4 229:3  
 232:7 233:7,20 234:6  
 234:14,17 235:8  
 237:9,12 238:3,9,13  
 238:15 239:21 240:9  
 240:14,15 241:5,9,16  
 241:17,19,21 242:3  
 242:11,17,21 243:8  
 243:11,21 244:4,4,6,7  
 244:19 246:8 247:6  
 247:19 248:6  
**knowing** 162:14 167:12  
 168:22  
**knowingly** 235:21  
**knowledge** 24:5 192:15  
**known** 193:22  
**knows** 162:7 204:3  
 215:10 231:19

---

**L**


---

**label** 34:17 97:4,11  
**labeled** 91:8 174:15  
**labeling** 173:8 197:9  
**lack** 128:21 155:21  
 203:19  
**Lakin** 2:1 21:22 22:11  
 68:12,14 115:12  
 206:12  
**language** 61:22 71:9  
 140:8 141:13,18  
 142:19 153:2 165:20  
 226:11,12  
**large** 3:3 11:12 13:11  
 216:3  
**largely** 46:19  
**larger** 80:8 104:7 114:7  
 122:9 149:11 196:10  
**Lash** 2:16 3:2,13 4:3  
 7:9 12:14 23:18 87:10  
 101:3 103:10 112:20  
 113:20 114:1,3,6,12  
 114:15 115:17 116:2  
 164:17,21 165:12  
 166:7 170:2 174:7  
 178:10 184:5 185:21

187:6 194:4,8 244:9  
248:5,12,15,18  
**late** 4:8  
**lately** 188:11  
**laughed** 163:22  
**Laughter** 7:8 13:8,22  
26:11 56:1 66:12  
69:16 71:6 95:3 99:7  
235:16 246:13  
**launch** 184:6  
**laundry** 19:10  
**law** 63:18,19,21  
**lawyers** 149:10  
**lays** 22:17  
**lead** 90:18 152:8  
**leadership** 140:16  
**leading** 118:5 174:14  
219:18  
**leads** 230:12  
**learn** 49:22 195:19  
**learned** 218:20 219:14  
220:18  
**learning** 232:21 237:16  
**leased** 102:4  
**leave** 52:19 74:17 80:10  
109:11 111:14  
**leaving** 81:16  
**led** 117:22 118:3  
**Lee** 101:20  
**left** 56:21 59:17 91:4  
104:17 105:3 121:2  
146:16 167:17  
**legal** 59:1,17 60:4 62:21  
63:13,14,17,22 64:2  
89:6,9 97:17 115:6  
123:18 176:21 177:9  
**legitimate** 235:14  
**lend** 173:4,6,7  
**lens** 41:4 199:8  
**lessons** 219:13 222:22  
**let's** 29:5 42:9 48:2  
50:21 52:12,19 71:19  
74:14 85:11 114:20  
133:8 135:6 136:13  
146:11 147:15 158:7  
159:12 164:17 178:10  
178:12 184:6 185:17  
193:9 216:18 218:13  
242:19  
**level** 9:17 11:3 17:14  
21:2 27:1,9,9 28:6,9  
36:17,17 37:13 40:9  
51:17 53:4 66:5 74:8  
74:13,13 82:11 86:4  
87:7,8,9,18,20,22  
93:16 94:6 100:15  
102:18 104:19,19  
112:11 128:15 130:15

131:5 137:2 140:15  
155:1,5 162:21  
165:17 166:20 167:10  
167:11 173:20,20  
175:6 189:17 206:19  
219:16,22 221:21  
229:5,6 230:6 238:1  
241:14 242:11  
**levels** 10:1,3 17:15,17  
20:21 41:19 46:13  
103:1 104:1 112:22  
113:4 116:8 129:6  
130:10 134:15 147:5  
193:11 206:19 208:22  
224:1  
**leverage** 211:8  
**leveraged** 203:5  
**levy** 205:19  
**liability** 50:13  
**lien** 99:13  
**life** 16:6 32:11 49:5  
65:12,17 67:10,10,15  
70:4,6,13,16 88:21  
133:4 235:13 244:21  
**light** 214:7,8 227:3  
**lightly** 145:9 207:10  
**liked** 101:6 232:2  
**limit** 104:11  
**limitations** 174:8  
208:19  
**limited** 32:20 203:20  
**line** 12:22 26:14 28:17  
28:20 33:2 111:12  
120:18 121:3 129:8  
213:3 224:4  
**linear** 167:17  
**lines** 10:16 224:8  
**linguistic** 165:18  
**linguistically** 140:2  
**link** 161:9 213:14  
**linkages** 149:7 243:15  
**lip** 125:20  
**list** 11:4 15:15 23:5  
24:22 25:3 31:9 33:14  
48:15,16 71:21 85:12  
88:4 103:20 105:1  
112:10 128:19 132:19  
133:1 138:22 148:1  
179:18 181:18,20  
189:5 199:4 206:16  
247:8 248:4  
**listed** 104:15,16 105:11  
154:11  
**listen** 246:4  
**listening** 228:10,11  
237:16 244:11 245:22  
245:22  
**listing** 43:2 69:4

**lists** 19:10,10 34:7  
156:1  
**literature** 5:10 11:15  
16:10 19:13,15 24:8  
27:16 41:8 181:15  
182:1 198:5,6  
**little** 4:11 20:13 25:2  
40:19 44:20 45:9  
78:15 94:22 96:11  
100:8 108:10 125:16  
127:2 141:2 144:21  
150:7 154:2,14 166:9  
167:16 169:6 175:21  
176:13 191:10 199:13  
201:6 202:19 211:5  
232:6 235:5 241:6  
245:10  
**live** 32:14 33:3 95:15  
114:15 130:11 148:11  
148:15 221:4 236:22  
**lived** 102:2,3,4,6  
**lives** 65:8,9 173:21  
228:22 229:1 243:22  
244:20  
**living** 1:6,22 2:7 9:21  
223:10 236:21 239:4  
**loaded** 92:10  
**local** 219:22  
**locality** 129:19  
**locally** 219:17  
**locally-based** 222:20  
**located** 160:15  
**location** 129:22  
**log** 231:20 232:4  
**logic** 107:16 109:17  
172:5 176:5,6 177:18  
**logical** 110:1  
**logs** 232:3  
**long** 10:13 23:13 27:12  
28:12 54:1 56:5 74:18  
77:7 85:3 112:19  
118:20 125:20 135:11  
136:6 139:21 140:9  
145:1,10 157:5 197:1  
212:10 222:21 230:4  
240:6 241:18  
**long-term** 22:12 191:11  
195:15 196:15 197:3  
201:21 230:5 235:7  
235:14  
**longer** 23:12 75:9  
**longitudinal** 230:8  
**look** 5:6,7 17:3 18:11  
41:4 43:16 66:14  
92:18 103:20 104:1  
105:1 131:1 132:12  
137:16,20 138:1  
145:6 149:14 157:18

169:14 171:5 176:4  
190:14 191:5,12,22  
193:15,17 195:8  
196:3,10,14 197:7  
198:9 200:10 204:22  
206:9 210:9 212:11  
214:7,7 215:4 216:1  
216:15 217:11 218:9  
218:10 229:16 247:19  
248:15  
**looked** 7:3 14:21 17:13  
22:18,21 23:5 148:2  
154:7 173:15 192:21  
212:5,10  
**looking** 14:21 18:7  
19:18 30:3 37:3 38:21  
40:6 41:19 43:9 46:6  
46:13 57:17 97:15  
104:17 105:10 123:22  
130:16 147:13 149:6  
149:17 184:22 187:14  
193:4,18,19 194:21  
198:6 206:5 212:6  
215:3,15,22 216:11  
220:2,9  
**looks** 7:17 21:10  
148:20 217:14 231:10  
**Lorraine** 2:8 25:6  
115:19 158:8  
**Los** 131:10  
**lose** 33:21 37:9 54:1  
60:11 62:12 77:3 91:6  
108:13 122:16 199:20  
**losing** 76:5 87:4  
**lost** 37:6 122:21 123:5  
150:16 158:14 215:7  
**lot** 4:9 9:16 11:6 23:5  
29:5 31:9 32:9,18  
34:6 37:2 41:10 48:15  
48:16,21,22 49:1,20  
54:12 60:11 75:4 85:4  
86:2 92:16 100:8,13  
100:18 105:19 109:3  
110:21 116:11 117:11  
118:16,22 125:14  
126:10 137:14 147:1  
152:15 156:8 158:18  
164:7,8,21 171:7  
172:13 175:14 180:21  
186:8 190:4 191:12  
192:13 193:2 195:16  
195:18 201:9 203:1,1  
205:3,16,17,18 209:3  
210:7,20 212:15,15  
213:8 214:14,20  
217:2,8,18 218:20  
219:10 220:18 223:8  
229:11 232:21 234:7

234:14 235:2,9 237:6  
 237:11,18 238:11  
 241:10 243:13 247:21  
**lots** 145:4 210:4 230:9  
 247:10  
**love** 26:4 124:13  
**lovely** 7:9  
**low** 7:12 139:11  
**low-quality** 77:13  
**lower** 193:12  
**LTSS** 5:3 14:11 22:9  
 186:18 189:20 195:1  
 199:12 203:2  
**lump** 11:4  
**lunch** 11:21,22 113:7,8  
 114:7  
**Luz** 2:3 51:11 52:3  
 61:22 62:3,10 70:2,10  
 79:6,9 82:17,21 83:8  
 83:15 84:2 90:16 95:5  
 115:22 124:13 133:12  
 134:19 157:5 158:3  
 158:22 232:16

# M

**MA** 1:21 2:3,4  
**macro** 9:19  
**magnitude** 11:3  
**main** 23:9 170:15 178:8  
**major** 179:1 185:22  
 207:18 218:15  
**majority** 198:4  
**makers** 216:5  
**making** 6:13 14:18  
 21:20 32:22 44:3  
 94:14 123:21 132:18  
 150:13 152:6  
**managed** 191:20  
 196:10 216:6 219:12  
 219:14 224:15  
**management** 32:3  
 41:12 43:15 186:9  
**manager** 2:14,15  
 231:11  
**managers** 231:6  
**managing** 13:3 152:14  
**manner** 157:10  
**map** 182:12 207:8  
**March** 180:14  
**MARCIA** 2:13  
**marginalizes** 236:10  
**marketing** 75:3 226:5  
**Markwood** 2:3 42:20  
 74:3,11 84:8 98:18,22  
 116:1 131:16 158:17  
 218:17  
**Mary** 2:9 35:17 74:14  
 79:4 81:14 101:20

115:13 176:8  
**Mary's** 175:20  
**Massachusetts** 1:18  
**massive** 184:22  
**master** 202:10,11  
**mastery** 165:17  
**match** 16:12  
**matched** 17:4  
**material** 25:3  
**materials** 248:13  
**matrix** 141:18  
**matter** 61:15 103:7  
 114:21 230:16 245:2  
 248:19  
**matters** 96:2,10,12  
 175:17  
**maximize** 8:11 235:22  
**MBA** 2:5,13  
**McCANN** 2:4 12:21  
 13:5,9 20:19 34:22  
 35:6,10,14 36:3,6  
 72:7 89:4 116:1 190:5  
**MD** 2:5,7  
**meals** 224:19 231:21,22  
**mean** 13:2 14:14 17:7  
 19:2,5,21 24:22 29:9  
 30:17 31:4,17 34:19  
 34:20 37:4,9 38:10  
 44:8 48:9,18 49:16  
 51:7,8 54:12 55:3  
 58:13 59:21 61:4,5,8  
 61:8 62:15,21 63:17  
 65:19 68:20 69:5 70:5  
 70:10,19 71:4,10,20  
 71:21 72:19 73:3  
 74:18 76:14 79:14  
 81:9 82:7,12 85:4  
 86:15 88:14 91:21  
 92:5 93:14,22 94:22  
 96:6 98:1 100:13  
 106:18 107:5 109:17  
 119:22 121:5 128:14  
 131:1 135:15 137:14  
 137:20 143:12,18  
 156:5 157:7 164:9  
 169:11 172:4,15  
 176:12,14 178:5  
 184:1 188:16 189:19  
 192:1,13 201:6  
 203:17 209:15 232:2  
 237:7 240:18 241:5  
 243:7 248:3  
**meaning** 92:14 94:12  
 161:18  
**meaningful** 6:16,16,21  
 9:20 55:10 94:11,16  
 95:13 97:1 125:18  
 227:11

**meanings** 69:1  
**means** 32:7 35:21 36:1  
 37:7 49:21 61:4 75:4  
 80:3 81:20 94:5  
 124:17 141:10 204:17  
**meant** 120:9,12 122:19  
 150:19  
**measurable** 204:21  
**measure** 1:5 9:7 46:14  
 47:10,12,15 48:13  
 67:6 77:9 87:7 112:15  
 147:11 154:8 155:5  
 162:21 179:11 182:17  
 182:22 189:5 191:11  
 199:7 204:15 211:21  
 212:3 213:16 214:2  
 215:20 217:10,15  
 226:2 228:17 232:13  
 234:5  
**measured** 77:8 87:8  
 181:15 198:20 199:9  
 202:7 210:10 223:16  
 234:15  
**measurement** 2:13 3:3  
 3:6,20 4:14 5:22 6:2,9  
 6:10,15,20 7:1,15 8:3  
 9:13 10:2,5 11:12,19  
 13:16,17,17 14:11  
 86:3 87:20 112:21  
 126:14 167:21 170:17  
 175:6,13 182:19  
 185:4,8,10 190:8  
 194:16 202:19 204:15  
 205:9 214:1 215:12  
 225:11 226:16,20  
 227:8,11 228:13  
 233:21  
**measurements** 194:12  
 204:5 211:17 213:22  
 222:7  
**measures** 7:11 44:5  
 49:13 82:19 112:19  
 126:11 137:9 172:14  
 173:5,6,7 179:4,13,19  
 181:13 182:10,15  
 183:3 186:2,7,12,22  
 187:2,11,18 191:19  
 194:2 195:8 196:2  
 197:21 198:12 199:18  
 203:21 206:22 207:7  
 207:12,22 208:2  
 209:12 214:4 215:13  
 216:21 217:1,6,17  
 223:8 228:15 229:5  
 230:4 232:11 238:11  
**measuring** 6:4 17:16  
 42:2 154:15 219:3  
 228:18

**mechanism** 106:22  
**mechanisms** 124:1  
 167:2  
**MEd** 2:6  
**mediate** 54:6  
**Medicaid** 130:13 131:4  
 138:18 191:7 206:7  
 229:15  
**Medicaid-funded** 52:1  
**medical** 1:18 13:10  
 27:3 45:20  
**Medicare** 138:18 206:7  
**meet** 9:14 161:8,11  
 209:1 233:12 247:18  
**meeting** 1:3 10:13  
 11:15 12:8 93:18,20  
 97:5,6 115:4 116:12  
 117:14 138:11 154:11  
 154:11 168:10 178:13  
 178:22 180:3 184:12  
 207:10 233:8,19  
 244:12 246:3 247:20  
 248:13  
**megabytes** 227:10  
**meld** 43:6  
**member** 13:5,9 17:9,18  
 18:1,7 20:3,9,14,17  
 20:19 21:5,22 22:11  
 25:8,18,22 26:4,8,12  
 26:19 28:15 29:18,22  
 30:13,15 31:3,19,22  
 33:20 34:22 35:6,10  
 35:14,18 36:3,6,11  
 37:4,13,16,19 38:2,7  
 38:10,17 39:4,21  
 40:18 41:2 42:13,20  
 43:8 44:19 45:14 46:5  
 48:4,5,8 49:15 50:12  
 51:4,7,11,18 52:3,22  
 53:3,9,11,19,21,22  
 54:9,21 55:3,12,19  
 56:10,13 58:10,13  
 59:4,8,16 60:10 61:3  
 61:12,22 62:3,10 63:5  
 63:12,16 64:9,14,19  
 65:10,22 66:15,18,22  
 67:3,19 68:2,8,12,14  
 68:20 69:13 70:2,10  
 70:19 71:4,7 72:7,17  
 73:2,7,10,11 74:3,11  
 74:16,20 75:2,10,13  
 75:16 76:3,16,21 77:1  
 77:2,7,13,17,22 79:3  
 79:6,9,18 81:13,15,19  
 82:2,4,7,15,17,21  
 83:8,15 84:2,8,15,21  
 85:19,22 86:8,11,14  
 86:18,21 88:8,13,17

89:4,11 90:16 91:15  
 92:3 93:10,13 94:4,9  
 94:21 95:5,11 96:1,9  
 96:15,19,22 97:14  
 98:8,12,14,18,22  
 102:3 103:18 106:13  
 107:1,5,8 108:3,7,18  
 109:1,4,14,21 110:16  
 112:3 113:14,21  
 114:2,4,10,14 118:2  
 119:13,17,21 120:5,8  
 120:10,11,13 121:4  
 121:16 122:7 123:12  
 123:13,15 124:3,13  
 124:19 125:5,15  
 126:22 128:5 129:15  
 130:18 131:16 132:5  
 132:17 133:12 134:19  
 135:9,22 136:4  
 140:22 141:22 143:3  
 144:16,19 145:12  
 146:4,19 147:17  
 148:22 149:2,19,22  
 150:18 151:6,8 152:1  
 152:4,17 153:1,5,6,7  
 153:22 155:8,11,19  
 156:3,18 157:5,16  
 158:3,9,17,22 159:15  
 169:18 170:10 171:3  
 172:4,19 173:13  
 174:18 176:2,9,15,19  
 176:21 177:1,4  
 185:20,22 190:5  
 192:12 194:7,11  
 197:17 199:14,17  
 201:2 204:10 206:12  
 210:1 212:14 214:13  
 218:17 220:17 223:6  
 224:2 227:13 232:16  
 234:20 235:17 237:13  
 240:9 244:14 248:1  
 248:11,14,17  
**members** 47:3 72:9  
 80:3 103:16,17  
 106:15 107:2,13,21  
 132:1 141:14 142:1  
 142:12 152:14 155:6  
 163:17 166:8 181:19  
 211:10 216:6 222:15  
**mental** 2:9 57:6,8 62:7  
 144:4 152:15 215:8  
 215:16,18 216:8,13  
 216:18,18,19,21  
 218:5 223:21  
**mention** 22:11 38:18  
 213:21 214:15  
**mentioned** 83:9 117:20  
 159:13 162:2 176:3

183:17 188:2 194:17  
 201:11 202:4 206:17  
 208:11 214:16 221:3  
 226:12 229:12  
**mentioning** 19:20  
**MENTOR** 2:6  
**merging** 82:14 159:14  
**merit** 78:20 110:2  
**message** 6:5  
**messaging** 237:6,11  
**messy** 245:10  
**met** 1:11 115:3 155:14  
 155:15 243:14  
**meta-analysis** 101:9  
**metaphor** 227:4  
**methodological** 198:2  
 208:13  
**methodology** 3:15 12:4  
 24:13  
**metric** 47:8  
**metrics** 40:8  
**MHSP** 216:12  
**Miami** 1:16  
**mic** 66:11 68:18 184:4  
**Michael** 67:18 205:4  
**Michigan** 2:3  
**microphone** 68:17  
 69:15  
**middle** 110:10 220:21  
**Mike** 2:7 31:2,21 33:6  
 34:12 45:13 54:19  
 69:9,12,18 73:11 82:6  
 108:6 116:1 217:13  
 227:6 244:9 246:2  
**million** 101:22  
**mind** 114:17 186:1  
 194:5 196:5 211:18  
 213:21  
**mindful** 65:16 140:2  
**mine** 26:16 123:16  
 227:6  
**minefield** 65:15  
**minimize** 25:14  
**minimum** 46:20 52:2  
 121:9 129:18 130:2,3  
**Minnesota** 101:21  
**minute** 11:8 19:19 84:9  
 185:19  
**minutes** 93:20 114:6  
 117:4 166:11  
**miserably** 97:7  
**misfortune** 128:4  
**missing** 19:12 117:19  
 149:15 168:6  
**Missouri** 2:9  
**misunderstanding**  
 236:12  
**mitigation** 182:17

**mix** 88:14 102:19  
**MLTSS** 187:12  
**mode** 245:22  
**model** 120:9 172:5  
 176:5,6  
**models** 120:12 121:19  
 236:19  
**modes** 6:4  
**modify** 79:14 138:9  
**modulize** 54:3  
**Mohanty** 2:5 20:3,9,14  
 20:17 44:19 54:9,21  
 55:3,12 97:14 98:8,14  
 115:13 152:4 201:2  
**moment** 17:3 42:10  
**money** 188:21 226:4  
**months** 163:3 179:3  
 200:11  
**morning** 4:4 5:9 10:10  
 11:17 44:18 126:3  
**Morrissey** 2:6 39:4 53:3  
 53:19,22 58:20 64:14  
 64:19 65:7 92:3 107:8  
 108:3,18 109:1,4  
 115:18 237:13  
**motion** 84:18  
**move** 14:4 17:1 29:3  
 59:6 60:3 80:22 83:4  
 84:13 117:5 122:5  
 129:7,12 131:8 133:8  
 136:13 146:11 147:16  
 173:18 176:4 195:2  
 209:4 210:15 212:12  
 225:20  
**moved** 79:13,21 235:10  
**moving** 56:6 59:21 60:3  
 83:16 86:1 131:10  
 165:5 176:9 177:1  
 220:6 223:22 236:3  
 242:5  
**MPA** 1:19 2:6  
**MPH** 1:18,20 2:5  
**MPP** 1:21  
**MSW** 1:15  
**multiple** 4:22 9:8 10:4  
 122:1 133:21 165:21  
 244:20 245:21  
**muted** 13:1  
**mutually** 101:10,13  
 154:3

---

**N**


---

**N.W** 1:12  
**Nadine** 2:14 115:21  
 165:1  
**nail** 7:18  
**name** 34:16  
**narrative** 179:21

**narrow** 89:15  
**narrowed** 23:11  
**narrowly** 154:16 198:10  
**national** 1:1,11,17,19  
 2:1,3 186:6 188:13  
 217:1 222:18 223:2  
 238:5  
**nationally** 166:19 230:4  
**natural** 89:13 108:3  
 110:3,8,12  
**nature** 21:9 186:15  
**NCI** 22:19 188:1 208:3  
 221:3 238:8  
**NCIAD** 221:3  
**NCQA** 203:18  
**Ne'eman** 2:6 45:13 46:5  
 55:6,14 62:20 63:10  
 67:14 69:8,10 71:12  
 88:20 90:3,9,19  
 115:14 128:3 130:5  
 130:22 131:22 132:15  
 133:1,10 134:8 135:3  
 135:21 136:2,6,13,18  
 137:19 138:5 139:1  
 141:11 142:9,18  
 145:20 146:14 189:9  
**near** 48:15 188:6  
 207:10 233:3  
**necessarily** 27:14  
 121:14 142:4 148:16  
 154:3,22 169:14  
 203:12 219:16  
**necessary** 95:1 139:22  
**need** 5:19 8:16 12:20  
 13:19 17:6 20:11  
 23:21 25:12 30:17  
 33:1,16 42:1 50:18  
 57:9 60:16 62:18 69:3  
 78:2 79:13 80:18  
 84:22 96:19 97:11  
 104:4 113:9 114:16  
 126:10 131:8 134:5  
 135:19 137:9 138:9  
 144:8,14 148:8  
 150:12 151:4 153:2  
 153:17 159:13 165:3  
 166:12 178:11 181:9  
 184:11 185:19 186:12  
 189:9 193:16 194:2  
 206:19 207:19 209:19  
 211:14 220:14,15  
 222:1,11 225:20  
 226:17 238:4 239:8  
 239:14,15 240:2  
 242:4,12 243:1,2  
 244:5 247:12 248:4  
**needed** 4:21 61:2  
 122:19 241:15



**needing** 236:22  
**needs** 9:14 33:5 41:21  
 48:19 71:17 88:19  
 134:13 136:5 141:8  
 142:7 151:4 152:7,19  
 152:20 155:15 160:18  
 160:19 162:7,14  
 163:11,12,13 166:5  
 170:7 180:20 199:8  
 202:1 219:7 220:8  
 225:11 242:9  
**neglect** 10:21 91:12  
 125:12 153:16  
**negotiate** 54:6  
**neighbor** 80:12 108:3  
**neighbors** 80:4  
**net** 215:3  
**network** 2:6,6 46:7  
 139:8 161:7  
**networks** 41:10  
**never** 196:5 205:22  
 210:15 243:3  
**new** 11:9 38:7,13 93:9  
 185:14 201:4 204:14  
 212:3,4 224:8 229:5  
 236:19  
**newspaper** 96:16  
**nice** 4:13 19:8,11 67:11  
**nicely** 159:16  
**Nielsen** 231:18 232:5,6  
**Nielsens** 231:19  
**night** 4:5 91:4 168:2  
 197:1  
**nine** 48:10  
**nod** 81:14  
**nodding** 37:2,3 68:11  
 85:17 132:3  
**nods** 29:5 33:12 99:2  
**nomination** 248:8  
**non** 88:9  
**non-family** 80:3 89:1  
 109:16  
**nonpaid** 106:14,15,16  
**noon** 113:6  
**Northern** 2:5  
**note** 33:20 125:3 132:3  
 133:6 144:14 146:21  
 152:3 156:14 157:4  
 175:11 194:6  
**notes** 104:6 139:2  
 140:11 146:1  
**notice** 147:20 148:7  
**noticed** 203:4 242:3  
**notion** 53:12 66:3,4  
 148:10 156:9 160:9  
 160:21 161:11,16  
 162:13,19 225:14  
**November** 180:12

183:18  
**NQF** 2:12 4:8 7:2  
 103:17 169:10 179:2  
 180:14 181:17 182:21  
 183:6,22 207:11,21  
 217:15 218:7 237:17  
 245:14 246:8  
**NQQA** 191:20  
**nuanced** 87:18  
**nuances** 11:6 221:9  
**number** 31:5 43:10  
 46:17 47:2 102:8  
 119:1 128:2 165:10  
 179:13 212:22 213:10  
 222:14,17,19 238:7,8  
**numbers** 139:9 248:7  
**nurse** 45:6  
**nursing** 95:16 223:17  
 236:16  
**nutshell** 167:7

## O

**O-F** 3:1  
**O&C** 138:14  
**object** 19:5 42:18,21  
 47:21 48:7 56:14  
 136:17  
**objection** 49:11 59:14  
 62:17 88:7 132:1,15  
 134:8  
**objections** 99:3  
**objective** 87:11  
**objectives** 182:10  
 247:19,20  
**objects** 244:5  
**obligation** 51:20,22  
 97:22  
**observation** 171:1  
**observations** 185:7  
**observer** 103:18  
**obtain** 116:18  
**obvious** 228:2  
**obviously** 61:9 97:16  
 126:15 144:8 178:20  
 188:1 221:2 222:18  
 223:16 228:1  
**occur** 238:1  
**occurred** 32:19 107:16  
 170:19  
**occurs** 32:5  
**offer** 12:3 87:10 197:18  
 201:20  
**offline** 116:9  
**oftentimes** 27:5  
**oh** 23:7 37:7,20 59:21  
 66:13,17 92:20 93:18  
 108:14 126:20 203:7  
**Ohio** 131:2 230:8

**okay** 12:14 26:15 29:5  
 29:17,18,20 30:14  
 31:20 33:6 34:12,14  
 35:14 36:3 37:5 44:15  
 45:12 46:4 50:21 51:6  
 53:18 56:3 58:18,21  
 64:3,4,20,22 65:2  
 66:21 69:11,14,17  
 70:3 71:20 72:13  
 74:19 76:7,9 77:20  
 79:4 81:14 82:16  
 84:13,21 85:18 86:22  
 91:1 94:6,6,17 95:5,6  
 95:10 98:5 99:8,18  
 100:19,22 101:3  
 105:17 106:6 112:3,3  
 112:9 114:2,10,20  
 116:2 118:6 119:10  
 119:13,19 120:10,13  
 122:5,7 123:14  
 124:11 125:16 126:19  
 128:1 136:3 146:3,11  
 147:15 148:20 149:20  
 153:6,7,20 158:16  
 159:11 164:9,14,20  
 165:12 178:3,10  
 228:14  
**old** 13:14 37:7 38:10  
 97:3 187:14  
**older** 4:21 15:11 140:11  
**oldest** 228:15  
**ombudsman** 124:4,6  
**omitted** 25:1  
**onboard** 33:7  
**ONC** 226:10  
**Once** 196:12  
**one-liner** 34:1  
**one-to-one** 24:20  
**ones** 15:17 16:10 23:1  
 23:2 25:1 189:7  
 215:15  
**onus** 21:15  
**open** 17:1 92:18 99:12  
**operate** 10:2 27:1 43:11  
 87:19  
**operated** 41:11  
**operating** 9:17  
**operational** 180:8  
 181:12  
**operationalize** 185:11  
 186:3  
**operationalizing**  
 174:21  
**operations** 53:2  
**Operator** 165:5,8  
**opinion** 13:7 141:17  
**opportunities** 8:2  
 127:19 148:12 150:17

202:2 212:2 221:17  
**opportunity** 3:5,9 36:13  
 94:13 103:20 114:8  
 116:15 211:6 234:3  
**opposed** 35:22 149:17  
 162:16  
**optimistic** 213:11  
**order** 85:22 151:3 197:6  
 235:22 246:6  
**organization** 13:14  
 52:5 160:11 202:8  
**organizational** 51:14  
 51:16 52:5 64:15,15  
 64:17  
**organizations** 52:6  
 54:13 55:8,9,11  
 196:10 219:1 220:13  
 238:5  
**organized** 100:6 101:19  
 167:8 182:1 183:3  
 245:15  
**original** 148:1 188:17  
 198:16  
**Oser** 115:8  
**Ostrovsky** 2:7 26:19  
 33:20 45:14 55:19  
 66:22 67:3 70:19  
 115:8 129:15 138:8  
 146:19 224:2  
**other's** 234:19  
**ought** 48:19,21 49:4  
**outcome** 80:22 151:20  
 154:12 155:12 171:5  
 171:7,11 172:12,15  
 173:2,7 176:16 178:8  
 187:22 191:19 217:1  
**outcomes** 8:9 10:8  
 18:21 57:1,4 102:20  
 102:21 154:8 159:9  
 167:4,11 171:13,18  
 171:21 172:9,21  
 173:18,21 174:2,14  
 174:22 175:1,7 176:4  
 176:10,12 177:2,6,20  
 177:20,22 193:8,9  
 205:21 206:20 207:2  
 221:22 224:6 242:15  
**outdone** 223:7  
**outputs** 171:13 176:5  
**outreach** 181:7  
**outset** 247:20  
**outside** 176:10 224:8  
 224:11  
**over-medicalizing** 8:17  
**overall** 39:15 57:20  
 125:9 163:5  
**overarching** 179:6  
**overlap** 122:8 123:3

125:6,14 137:20  
138:20 159:14 161:4  
168:22  
**overlapping** 87:17  
**overlaps** 137:17  
**overly** 167:1  
**oversimplify** 45:18  
**overstretched** 219:6  
**owned** 102:4 127:2  
**ownership** 39:6,16 42:6  
52:14 92:10,19 93:10  
94:20,22 95:5,15,18  
97:8,15 98:1,2 99:16  
102:13 126:4 127:7  
127:11  
**Oxford** 2:7 31:22 37:4  
37:13,16 49:15 50:12  
51:4,7 59:16 63:12,16  
64:9 67:19 69:13 71:4  
71:7 73:2,7,10 75:2  
76:21 77:2,7,13,17  
81:13 82:7,15 88:8,13  
93:10,13 94:4 108:7  
109:14 116:1 121:4  
130:18 149:2 170:10  
176:15,21 177:4  
240:9 248:1,11,14,17

# **P**

**P-R-O-C-E-E-D-I-N-G-S**  
4:1  
**p.m** 115:1 248:20  
**PACE** 13:16  
**package** 149:17  
**packet** 22:17  
**page** 23:13 31:14 123:9  
**paid** 46:12,18 80:7  
88:16,17 103:2  
106:14,20 107:2,14  
107:22 108:8,16  
109:16,19 110:2,18  
111:2,3,5,6,19 112:5  
125:20  
**painfully** 192:8  
**paper** 116:11 184:20  
**papers** 189:18  
**paradigm** 41:22  
**paradox** 228:9  
**paradoxes** 228:11  
**parens** 124:22  
**parent** 55:9  
**parentheses** 166:5  
**park** 42:9  
**parking** 105:18  
**parse** 128:8  
**parsed** 160:1  
**part** 20:5,5 33:4 36:14  
41:3,22 48:8 82:18

84:2 87:11 91:11 96:4  
117:9 131:18 140:17  
144:4,19 151:10  
155:13 157:15 158:19  
160:21 173:17 190:22  
192:22 212:17 220:12  
222:5,16 227:15  
236:9 237:16 244:22  
**partaking** 54:15  
**participant** 1:17 16:14  
34:17 36:14 40:10,11  
53:1 92:8 96:2,10  
127:20 198:19  
**participant's** 157:21  
**participants** 58:1  
127:15 189:20,21  
200:10 204:19 230:22  
**participate** 39:9 94:13  
127:6  
**participating** 52:15  
**participation** 8:11  
35:19,21,22 36:1,2,4  
36:7 65:4 67:17,21  
68:1,5,6,6,7,22 69:8  
94:11,12,16,16 97:1  
125:21 126:8 247:14  
**particular** 85:5 95:20  
146:22 154:18 194:4  
205:12 243:5  
**particularly** 24:6 30:2  
46:15 187:11 208:18  
218:3 224:17 230:17  
233:4 240:12  
**parting** 184:9  
**partnering** 204:6  
**partnerships** 238:18  
**parts** 245:8  
**pass** 136:17  
**passed** 150:3  
**path** 6:7 170:9 235:4  
**patient** 28:9 58:1  
**patterns** 24:15  
**Patti** 2:1 36:9 38:15  
40:20 42:13,22 74:4  
115:18 145:11 173:12  
176:3 219:20 230:14  
**Patti's** 51:12  
**pay** 151:2  
**payer** 225:8  
**payers** 100:12 139:4  
225:13  
**paying** 27:6  
**payment** 4:14 6:15 7:21  
110:19  
**payroll** 191:11,13  
**pays** 232:5  
**PCAs** 233:5,16 234:1  
**PCORI** 192:1

**peer** 7:21  
**peer-reviewed** 15:5  
**peg** 50:19  
**Pennsylvania** 2:10  
**people** 4:22 5:1 6:13  
8:10 13:7 24:17 32:22  
33:7 36:20 37:2,2,3  
38:22 42:18 44:12  
46:21 47:3,21 48:6,11  
48:16 50:1 51:3 52:4  
52:15 53:11 54:4 59:8  
62:5 65:3 66:5 69:5  
75:5 80:2,7,9,11  
84:22 85:1 91:13  
93:15,20 101:22  
102:7,22 105:17  
106:7 109:3 112:16  
116:5 120:14,16  
125:19 126:12 134:14  
137:13 141:7 143:4,9  
143:22 144:11 150:12  
155:2 163:19 168:19  
170:15,18,22 171:17  
172:3,8 175:16  
176:17,22 178:11  
181:9 188:14,15  
189:11,12,15 190:17  
190:20 193:9 195:2  
198:21 199:10 200:2  
204:3 205:3 208:16  
208:19 209:7 212:15  
213:4,10 217:18  
223:5,20 225:18  
227:16,16 228:3,10  
232:2,5 235:8,11,11  
235:12 236:11,15,17  
237:2,4,7,9,9,11  
239:1 241:3,7 243:10  
243:20,22,22 244:4  
**people's** 105:17 173:21  
**peoples** 117:17  
**percent** 13:12 80:5  
95:16,17 102:2,3,4,6  
**percentage** 47:14  
**perfect** 110:17 111:1,10  
217:2  
**performance** 1:5 6:9,17  
7:12 8:3 17:10,12,13  
17:13,16 18:4,20,20  
18:21,21 20:20 43:16  
64:10,12,15,19 65:1  
73:3,13,15,17,22 74:1  
74:6,6 115:11 136:21  
154:21 158:10 159:3  
182:19 211:1,21  
215:11 216:20 222:16  
**performed** 80:21 81:3  
**performing** 40:7

**period** 11:16 163:2  
181:6 183:19  
**Permanente** 2:5 201:4  
**permission** 59:22  
**person** 21:10,11 34:22  
35:3 37:1,8 40:20  
43:18 48:22 72:20  
97:5 100:11 121:12  
157:10 160:11 161:22  
162:7 188:8,21 195:6  
196:11,12,13 229:1  
**person's** 43:17 48:12  
145:18  
**person-center** 44:10  
**person-centered** 37:21  
57:21 97:3,6 162:13  
192:2 204:17  
**person-centeredness**  
56:9 204:20  
**person-driven** 36:15  
56:6  
**person-reported** 15:22  
221:22  
**personal** 141:16 161:19  
188:19 197:19 205:21  
**personally** 68:3 168:17  
169:3 240:15  
**personnel** 47:14  
**persons** 223:10  
**perspective** 8:22 14:22  
43:18 48:12 119:11  
124:5 145:17,19  
157:22 161:19 162:3  
190:6 196:3 218:22  
**perspectives** 218:21  
220:19  
**pertains** 148:14  
**PES** 198:16  
**phase** 180:2 181:17,22  
182:5 183:7 196:5  
**PhD** 1:14,15,15,18 2:1,3  
2:8,9,10,13  
**Phillips** 2:8 25:8,18,22  
26:4,8,12 115:19  
158:9 223:6  
**philosophies** 9:12  
**phone** 12:22 119:18  
165:6 248:7  
**phrase** 33:14 56:4 66:8  
74:10  
**phrasing** 82:1  
**physical** 10:20 25:10  
91:13,15,17 101:17  
115:15 152:15 153:8  
160:5 176:16 177:8  
188:14 203:20 221:10  
223:20  
**physical/emotional**

91:10  
**physically** 160:10,15  
**physician** 45:5  
**pick** 69:3,7,9 104:4  
 121:12 214:21 215:1  
**picky** 124:15  
**picture** 9:19 173:15  
 247:9  
**pictures** 173:14  
**pie** 237:20  
**piece** 50:3 54:10 59:18  
 60:5 68:3 73:13  
 150:14,15 158:1  
 177:2 180:16 182:8  
 203:13  
**pieces** 15:10 183:16  
 201:6 230:13  
**place** 10:4 41:13 43:13  
 43:13 57:9,22 85:6  
 124:1 194:13 222:12  
 235:1 237:8  
**placed** 138:15  
**places** 10:4 31:8 148:8  
 153:17 174:16 208:21  
 214:11 243:4  
**plain** 71:9  
**plan** 17:15 87:21 138:2  
 163:15,20 164:1  
 201:18,20 202:10  
 203:8  
**planning** 16:14 37:8,21  
 97:4,6 150:13,20  
 201:17 204:17 236:6  
**plans** 12:10 192:1  
 202:6 211:1 221:15  
 222:4,13,18,19,20  
 229:21  
**platform** 165:15  
**play** 27:22 148:12  
**players** 6:2  
**plays** 128:22  
**please** 4:19 17:7 26:17  
 68:17 85:21 112:13  
 112:15 123:14 141:15  
 146:17 165:9  
**pleased** 13:18  
**plucked** 217:6  
**plus** 28:22  
**pockets** 192:18  
**point** 11:21 15:18 16:16  
 27:15 30:7 33:10 39:4  
 45:15 50:17 54:1 64:9  
 72:3 85:22 92:4 97:17  
 107:9,13 108:18  
 132:6,16,18,22 134:2  
 139:2,4 143:10  
 145:21 157:17 158:18  
 169:10 173:18 174:2

174:5 175:13 178:2  
 184:11 185:1 188:5  
 198:2 216:2 218:14  
 219:11 223:19 235:12  
 240:3  
**pointed** 118:3  
**pointing** 176:11  
**points** 21:20 67:12 83:9  
 135:11 224:3 237:15  
**policies** 189:16 191:10  
**policy** 1:21 7:21 59:22  
 216:5  
**political** 130:20 242:15  
**poor** 83:2  
**population** 9:15 135:15  
 218:4 239:22 240:1  
**populations** 129:22  
 133:15,16,21,21  
 134:5,12,21 135:4,6  
 136:8 145:4,5,8 147:8  
 191:22 195:1 214:19  
 215:20 218:10,13  
 223:10 239:22  
**portability** 130:13  
**position** 143:15  
**positive** 186:5 214:4,10  
**possession** 93:2,2  
**possibility** 21:4 235:21  
**possible** 34:11 190:19  
 191:6 206:21 241:12  
**possibly** 118:18 213:9  
**post** 199:21  
**post-acute** 194:22  
**potential** 106:4 161:12  
 211:7  
**potentially** 6:15 107:20  
**Potter** 2:19 195:13  
 197:22 246:1  
**pound** 50:19  
**power** 92:14  
**powerful** 92:9 225:5  
**PowerPoint** 174:8  
**practical** 236:5  
**practice** 208:3  
**practices** 155:21 156:5  
 156:6,8 157:21 197:3  
 237:22 238:3,7  
**precise** 69:1  
**predefined** 181:18  
 182:22  
**predominantly** 224:7  
**prefer** 74:17 234:22  
**preferences** 47:4  
 139:16 142:11 154:12  
 155:14 160:21 162:8  
 162:14 236:13  
**preferred** 165:20  
**premature** 30:8

**premise** 53:4  
**preparation** 168:12  
**preparers** 225:6  
**preparing** 180:3  
**presence** 121:22  
**present** 1:14 2:17,21  
 8:13 117:16 160:10  
 174:12 244:17  
**presentation** 246:19  
**presentations** 213:1  
**presented** 115:4 206:15  
 213:2  
**President** 2:13  
**presiding** 1:13  
**press** 165:9  
**presumably** 107:20  
**pretty** 16:4 18:10 25:4  
 80:1 118:7 139:21  
 145:10,15 169:12  
 170:14 192:16 201:10  
 204:3 216:21 231:10  
 237:20 238:9 246:21  
 246:22  
**prevailed** 237:3  
**preventing** 223:17  
**preventive** 177:11  
**preview** 4:18 178:16  
**previous** 36:12 179:11  
**primarily** 106:10 167:9  
 195:22  
**primary** 8:9 143:21  
 151:19 167:3  
**principle** 236:13  
**prior** 11:15 47:7  
**priorities** 180:17  
 244:20  
**prioritization** 10:11  
 180:16  
**priority** 140:19  
**privacy** 58:22 60:21  
 61:18 62:4,11 139:16  
**privacy/dignity** 61:17  
**privacy/dignity/respect**  
 60:12 63:1  
**private** 160:9  
**privately** 141:1  
**privatization** 242:8  
**privatize** 242:18  
**privatized** 242:13  
**privilege** 232:17  
**probably** 9:11 11:20  
 33:4 39:17 40:3 46:19  
 75:5 77:10 78:14 80:4  
 110:11 111:1 113:17  
 118:8 120:3 122:11  
 126:2,13 132:19  
 134:10 140:22 148:17  
 152:17 156:16 163:7

168:7 187:16 190:5  
 190:21 193:22 195:13  
 203:17 210:4 211:4  
 212:14 214:11 215:9  
 218:5  
**problem** 57:19 85:11  
 93:18 246:12  
**problems** 208:15  
**process** 24:3 30:22  
 33:21 94:12,14 96:4  
 128:17 151:15 163:8  
 166:2 173:2,6 178:17  
 179:20 187:11 192:10  
 204:8 205:6 206:22  
 232:10,15,20 233:6  
 248:9  
**processes** 10:7 57:5  
 138:19 192:7  
**produce** 224:7  
**product** 168:1  
**productivity** 65:4  
**products** 116:12  
 178:18  
**professional** 158:11  
**professionals** 235:19  
**profiling** 200:18  
**program** 7:22 16:15  
 18:20 25:12 35:5,11  
 52:17 59:22 60:15  
 120:11 121:2,8 122:4  
 124:4,6 149:18 163:1  
 189:14 240:21 241:4  
**programming** 34:19  
**programs** 14:21 16:15  
 32:9 49:19 51:22 52:1  
 121:13 122:1,3  
 170:16 199:6 200:21  
 211:2 224:19 243:21  
**progress** 114:19  
 188:10  
**project** 2:14,14,15 5:4  
 5:16 12:5 100:10  
 178:17 179:17 186:6  
 199:13 200:1 206:1  
 244:13  
**promising** 182:14  
 185:9 194:12 204:14  
 205:9  
**promoting** 223:11  
**proposal** 105:16  
**proposals** 118:17  
**propose** 47:17 96:6  
 227:5  
**proposed** 58:12 88:5  
**proprietor** 93:3  
**proprietorship** 93:3  
**prosperous** 239:6  
**protection** 149:9

**proven** 224:16  
**provide** 47:6 51:21  
 111:8 112:6 162:10  
 162:12 183:11,15  
 213:12 222:21 223:1  
 223:3  
**provided** 23:17 161:10  
**provider** 13:11 17:15  
 38:20,21,22 40:20  
 41:9 43:4,16 44:2,6  
 44:21 45:1,5,10 46:6  
 47:10 51:19 52:6 55:8  
 60:16,18,18,19,20  
 61:5,16,18 63:2 139:8  
 145:17 147:10 161:7  
 225:4,9 240:21  
**provider's** 61:19  
**provider-driven** 56:22  
**providers** 9:2,3 41:11  
 41:13,20 42:3,17 43:1  
 43:10,11 44:10 45:7,8  
 45:17,21 46:7 51:1,3  
 51:14,15 80:7 89:2  
 139:9,11,13,15,17  
 140:1,3 166:6 208:5  
 216:5 224:6 225:8,13  
 231:4,14 239:17  
 241:5,10  
**provides** 225:1  
**providing** 39:1 48:22  
 102:7 151:1 181:2  
 241:4 242:12  
**provision** 129:7 177:17  
**proxies** 208:15  
**proximity** 160:3  
**psychology-literatur...**  
 70:20  
**public** 1:21 3:5,9 11:16  
 69:1 99:9,13 106:1  
 160:9 164:17 165:7  
 165:10 166:8 181:3,5  
 181:19 183:14,19  
 221:5  
**publication** 96:16  
**publications** 226:13  
**publish** 189:18  
**published** 15:4 182:7  
 198:10  
**pull** 16:11 161:17 169:5  
 248:9  
**pulled** 15:13 16:7  
 191:21 201:20  
**pulling** 87:5 222:10  
**purchase** 205:14  
**purchased** 205:13  
**purchasing** 205:13  
**pure** 196:1  
**purple** 174:15

**purpose** 151:19 197:13  
 200:18  
**purposes** 135:13  
 225:11  
**pursue** 32:13  
**purview** 148:18  
**push** 67:14 79:21  
 109:11 126:4  
**put** 8:4 14:6 19:2 25:16  
 31:8 47:19 50:8 62:12  
 64:10 73:8 74:9 90:6  
 105:18 106:9 107:9  
 110:18 116:10 118:14  
 120:21,22 124:21  
 141:18 142:20 143:15  
 149:16 168:21 171:19  
 171:20 172:5 175:4  
 177:5 180:2 181:8  
 200:17 216:7 248:10  
**puts** 21:14 172:2  
**putting** 11:1 92:21  
 96:16 107:15 178:6  
 215:11  
**puzzled** 177:3  
**pyramid** 170:22  
**pyramids** 168:2

## Q

**QM** 222:16  
**qualities** 159:19,20  
**quality** 1:1,3,11 2:13  
 4:20,21 5:3,15,20,22  
 6:2,4,8,12,19 7:15,19  
 8:5,13 14:11 15:13  
 16:6,6 19:8 22:9  
 24:17 29:11 32:9 33:9  
 40:8 41:12 43:14 46:6  
 46:15 47:8,10 48:14  
 65:11,17 67:6,10,15  
 70:4,6,13,16 72:15,17  
 72:19,21 73:4,6,8,14  
 73:19 74:12,12 75:6  
 75:10,12,13,19,20,20  
 75:21 76:1,1,18 77:11  
 78:10,17 79:10,14  
 82:19,19 83:2,5,16  
 84:1,3 122:18 123:22  
 130:20 131:20 137:9  
 147:3 149:6,12 154:6  
 154:13,15,16,17  
 156:4 157:12,18  
 158:1 167:5,19  
 169:21 170:6,17  
 175:12 179:12 182:15  
 185:4,8,15 186:9,22  
 187:2,16,22 193:4,5,6  
 193:6,18,18 195:21  
 204:15 207:11,16

209:6 211:10,19  
 213:12,22 216:8,14  
 219:3 222:15 225:11  
 226:1,7,16,19 227:8  
 227:11,18 231:13  
 235:7,13,18 238:11  
 241:12 242:22  
**quality-improvement**  
 8:2  
**Quality/effectiveness**  
 75:15  
**quantity** 67:9  
**question** 21:7 26:20  
 50:22 52:12 67:1 79:1  
 79:19 88:9 113:15  
 120:7 124:13 127:1  
 129:15 131:6,17  
 144:1 158:9 170:10  
 170:13 208:16 214:3  
 234:16  
**questions** 12:12 93:21  
 105:12 113:13 118:9  
 119:22 124:12 129:12  
 140:21 155:6 184:15  
 186:14 190:16 207:5  
 207:6  
**quibble** 61:9  
**quick** 11:16 12:11 18:4  
 23:19 26:20 36:11  
 66:22 121:4 129:15  
 131:16 138:8 146:20  
 164:17  
**quickly** 248:9  
**quite** 6:3 29:14 67:13  
 87:1 150:21 166:21  
 172:10 178:21 188:22  
 195:4 201:8 205:22  
 216:9 223:14 228:2  
 241:18

## R

**race** 165:21  
**rah-rah** 226:4  
**raise** 6:7 17:8 158:18  
 219:11  
**raised** 47:18 50:22 60:9  
 74:4 105:22 208:5  
 220:6  
**raises** 221:17  
**raising** 145:21  
**raison** 4:20  
**ran** 127:14  
**random** 231:1 240:18  
 240:20  
**range** 233:15  
**rapidly** 185:13  
**rarely** 208:22  
**rate** 229:17

**rates** 46:8 146:5  
**rating** 231:19  
**re-ground** 4:12  
**reach** 88:2 117:10  
 198:7 234:4  
**react** 17:2 96:20  
**reactions** 105:17  
 117:18  
**read** 16:21 96:19 99:15  
 101:4 119:15,19  
 136:18 176:16 228:4  
 228:6 235:13  
**readdress** 111:17  
**ready** 30:1,6 178:11  
**real** 32:18 65:8,9 92:11  
 110:2 121:4 149:14  
 185:5 195:14 200:4  
 207:14 242:20,21  
 243:8,15,22,22  
**real-time** 211:9  
**reality** 25:5 236:2  
**realized** 207:20  
**realizes** 175:1  
**realizing** 154:2  
**really** 4:9,13 5:19,21  
 6:19 7:22 9:18 15:17  
 16:1 17:15 21:7 23:22  
 32:5,6,7,16,17 34:7  
 36:7 38:12 39:8,12  
 40:22 41:13,13,20  
 42:1,1,14 45:2 49:17  
 49:17 50:4,9,17,17  
 68:22 70:22 71:1  
 80:16 84:16 85:3,3,15  
 89:12 95:12 96:14  
 97:8 103:19 116:13  
 117:15 119:4 121:11  
 123:1 124:21 125:22  
 127:5,6,10,20 131:12  
 134:2 136:16 138:12  
 138:13 139:1 140:18  
 146:9 147:2 150:11  
 152:19 154:7 163:22  
 166:20 167:19 169:12  
 170:3 172:12 173:20  
 174:12,21 176:6  
 177:6,13 178:4 180:3  
 180:15 183:21 184:10  
 184:16 187:9,18,19  
 189:2,22 190:3  
 193:13 195:11,12  
 196:14,18 197:2,15  
 198:7,22 199:16,19  
 204:22 206:19 207:5  
 207:6,8 208:10 209:5  
 209:7,14,14,18  
 210:11 215:12 218:21  
 221:9 222:7 223:7

224:20,20 225:5,11 225:14 226:6,11,17 230:14 232:20 233:12 233:14,17,21 234:4 234:21 237:5 238:1,2 238:4 239:1,15 243:1 243:1 245:1,16,17 246:14 247:4,12,13 247:16 <b>realm</b> 205:20 <b>reason</b> 48:9 153:12 208:8 <b>reasonable</b> 81:11 <b>reasonably</b> 128:10 139:18 <b>reasons</b> 10:18 56:19 <b>rebalancing</b> 154:22 <b>recall</b> 143:18,20 <b>recap</b> 10:9 11:11 184:11 <b>recapping</b> 4:12 <b>receive</b> 128:15,16 198:21 211:11 <b>received</b> 73:20 155:16 163:10 <b>receives</b> 102:19 <b>receiving</b> 65:3 190:17 213:4 <b>recipient</b> 151:14,16,18 213:17 <b>recognition</b> 220:9 <b>recognize</b> 15:9 43:17 102:22 125:6 126:12 148:17 230:17 <b>recognizing</b> 107:14 123:3 219:9 <b>recommend</b> 25:8 72:7 <b>recommendation</b> 20:18 <b>recommendations</b> 180:18 235:9 <b>reconvene</b> 103:6 180:13 183:9 <b>record</b> 50:2 103:8 114:22 248:20 <b>recording</b> 232:7 <b>recruitment</b> 146:2 <b>rectangles</b> 174:9 <b>red</b> 143:3 <b>reduced</b> 90:18 <b>reduction</b> 128:12 <b>reemphasizing</b> 210:5 <b>refer</b> 27:2,2 62:20 <b>reference</b> 142:19 <b>referenced</b> 27:18 <b>references</b> 22:2 <b>referrals</b> 149:8,13 <b>referred</b> 35:19 <b>referring</b> 38:3 51:13	181:21 237:4 <b>Refinements</b> 3:11 <b>reflect</b> 139:2 141:16 158:2 167:3 221:9 246:9 <b>reflected</b> 141:19 <b>reflecting</b> 141:12,12 <b>reflection</b> 129:21 <b>reflections</b> 164:22 <b>reflective</b> 143:16 <b>reflects</b> 229:7 <b>regard</b> 121:13 147:12 198:15 220:7 <b>regardless</b> 190:16 192:5 <b>regional</b> 219:16 <b>Rehabilitation</b> 2:2 <b>reimbursed</b> 224:6 <b>reinvent</b> 179:15 <b>reiterate</b> 117:9 219:2 243:5 <b>rejected</b> 109:2 <b>relabeled</b> 172:1 <b>relate</b> 10:22 43:1 117:1 167:9 185:3 <b>related</b> 45:15 70:13 170:7 185:4 <b>relating</b> 137:2,4,6 <b>relation</b> 196:18 <b>relationship</b> 167:17 <b>relationships</b> 89:1,14 238:18 239:2,4 <b>relative</b> 121:21 <b>relatively</b> 11:2 22:4 91:20 92:2,4 119:7 123:8 211:19 <b>relatives</b> 46:22 <b>released</b> 181:5 <b>relevance</b> 14:14 <b>relevant</b> 23:16 166:19 185:2 189:8 225:8 <b>relying</b> 181:7 <b>remain</b> 13:3 158:20 <b>remained</b> 13:6 <b>remaining</b> 102:5 <b>remedied</b> 142:8 <b>remember</b> 112:18 140:8 143:8 232:14 <b>remind</b> 243:18 <b>reminder</b> 243:19 <b>reorder</b> 144:20 <b>replace</b> 172:21 <b>report</b> 15:4 179:21 180:7,11 181:4 183:18 216:9,12,14 235:7 236:1,10 <b>reported</b> 146:16 <b>reporter</b> 17:21 18:2	184:14 <b>reporting</b> 114:5 216:22 217:5 <b>reports</b> 115:4 183:20 <b>represent</b> 54:14 167:19 169:16 178:7 <b>representation</b> 174:6 180:1 240:2 <b>representative</b> 117:1 <b>representing</b> 168:20 218:22 220:20 <b>represents</b> 166:17 <b>require</b> 102:21 103:2 110:19 <b>required</b> 162:10,12 <b>requirement</b> 130:7 <b>requirements</b> 46:21 52:2 63:3 234:1 <b>requiring</b> 124:17 <b>research</b> 2:2 15:5 178:17 179:7 180:1 183:7,12 192:2 199:11 231:9 235:6 <b>researcher</b> 240:19 <b>researchers</b> 242:10 <b>resentment</b> 134:14 <b>reserve</b> 116:7 <b>residential</b> 63:2 187:4 <b>resolve</b> 81:11 <b>resonated</b> 29:10 97:19 <b>resource</b> 1:17 2:7 128:13 134:12 137:7 <b>resources</b> 103:1,4 124:6 127:17 150:10 150:16 172:13 185:2 220:1 <b>respect</b> 30:3 38:19 46:8 58:22 60:20,21 61:7 61:16 62:4,11 122:19 124:22 129:8 137:9 139:15 212:2 233:14 233:15 <b>respectful</b> 122:14,17 124:16,18 <b>respectfully</b> 54:3 <b>respects</b> 61:18 <b>respond</b> 23:19 <b>respondent</b> 208:14 <b>response</b> 12:13 33:11 36:22 42:8 48:1 52:18 59:13 64:21 72:12 84:12 90:22 91:19 99:4,10 208:17 <b>responsibility</b> 61:19 97:21 102:13 118:13 124:7 <b>responsive</b> 123:20 <b>responsiveness</b> 123:12	<b>rest</b> 4:4 16:4 <b>restricting</b> 89:14 122:4 <b>restrictive</b> 155:3 <b>restructuring</b> 166:3 <b>result</b> 24:10 236:21 <b>results</b> 3:2 10:10 114:7 184:20 208:7 <b>resumed</b> 103:8 114:22 <b>resumption</b> 115:3 <b>retention</b> 145:16 146:2 <b>Retired</b> 2:1 <b>return</b> 224:16,21 227:7 227:8,9 <b>revealed</b> 6:22 <b>revenue</b> 13:12 <b>review</b> 3:2,11,15 7:21 11:15 12:4 19:12 24:9 27:16 116:15 182:1 183:4 198:5 207:13 <b>reviewed</b> 14:8 <b>reviews</b> 15:1 <b>revisions</b> 4:17 <b>revisit</b> 71:19 233:9 <b>rewarding</b> 241:22 <b>rich</b> 33:21 211:12 212:12,21 213:2 <b>richest</b> 210:17 <b>richness</b> 198:11 <b>rid</b> 78:19 <b>ridiculous</b> 189:16 <b>right</b> 5:17 13:20 15:11 17:1 19:3 20:7,10,16 21:3 22:14 23:6,7,10 25:20 30:16 31:20 32:12 34:3 35:6 38:9 38:20 39:10 40:17 47:16 48:2,7 49:10 50:11 54:5 58:7 60:1 63:20,22 64:1 69:20 71:18 73:10 74:22 77:6 81:4 82:14 83:3 83:4,5,7,11 84:7 85:6 85:6,6 86:5,16 88:1,2 89:16,19 90:14 91:1 93:2,17 94:4,7,17 96:18 98:11 99:18 100:17 103:10 105:4 108:5 109:7,20,22 112:15,20 126:19 136:12 142:14 152:19 167:18 173:19 176:17 181:8 184:6 200:9 203:19 206:3 211:16 229:13 230:2 233:21 235:4 <b>rightfully</b> 148:9 <b>rights</b> 59:1,18 60:4 62:21 63:6,8,11,13,15
---	---	---	---

63:15,17,18 64:4 93:3  
115:6 123:18 176:21  
177:9  
**righty** 248:17  
**rigorous** 222:15  
**risk** 8:21 9:10 56:8 80:8  
80:11  
**risks** 235:22  
**RN** 2:8  
**Robert** 1:15 115:8  
**robin** 3:19 12:7  
**robust** 218:19  
**rocky** 246:20  
**ROI** 225:8  
**role** 27:22 57:9 107:10  
127:11 128:21 141:9  
167:3,5  
**roles** 101:15,16,16  
**roll** 78:21  
**rolled** 103:22 216:13  
**room** 1:11 9:7 87:19  
99:14 105:8 149:10  
165:5 197:14 228:4  
233:17  
**Rosenbaum** 101:7  
**roughly** 63:1  
**round** 3:19 4:7 12:7  
50:19  
**round-robin** 184:7  
**row** 25:9,19,21 26:5,14  
**rows** 30:18  
**rule** 63:3  
**run** 80:8,10 110:1 117:7  
139:6 240:21  
**running** 241:4  
**rural** 139:11  
**rush** 116:21

## S

**safe** 9:6 128:20 132:22  
133:2  
**safer** 65:18  
**safety** 8:21 9:10 10:19  
91:10 123:3 140:6  
142:18,20 143:2  
153:15 215:22 235:20  
239:3,4  
**salesmanship** 225:21  
**salespeople** 225:16,17  
**sample** 231:1,2  
**SANDRA** 2:3  
**Sandy** 42:19 74:2 84:6  
98:17,21 116:1  
131:14 220:17  
**Sara** 1:20 65:20 115:22  
174:17 201:3 202:14  
208:11 210:6,21  
219:5 221:20

**Sarah** 2:16 3:2,13 105:6  
115:17 117:12 169:13  
244:14 246:16  
**Sarita** 2:5 44:17 54:8  
95:22 97:13 115:12  
152:3 196:17  
**sat** 228:10,19  
**satisfaction** 145:15  
155:9,11 156:19  
171:6,16,16 172:11  
175:9,12,14,15,18  
193:11 230:21  
**satisfied** 155:16 157:1  
**satisfies** 234:5  
**satisfy** 42:18 51:3 81:8  
**saw** 31:1 59:20 130:6  
**saying** 19:18 25:17  
30:12 44:20 51:16  
66:1 85:7,11 93:14  
98:3,21 106:15,17  
107:4,18,19 108:14  
157:1 165:15 192:3  
217:11 232:4  
**says** 28:17 41:8 74:21  
105:21 142:14 209:12  
227:6 228:22 229:1  
**scan** 3:16 12:5 156:15  
180:9,12 181:13  
182:9 183:1 187:13  
198:3 204:4 205:4  
**scanning** 180:4  
**scans** 179:14  
**scars** 192:11  
**scenarios** 152:9  
**scenes** 240:14  
**school** 1:18 228:7  
**scold** 243:18  
**scope** 14:15,17 135:14  
136:1,2,3,9 161:5  
**score** 228:16  
**scorecard** 169:3  
**screaming** 96:13  
**screen** 16:21 119:18  
165:4  
**Scripps** 1:15  
**scroll** 161:13  
**se** 16:12 123:16 149:7  
**search** 22:1 24:11  
138:12 184:21  
**searches** 198:7  
**searching** 138:10  
**seats** 12:18  
**second** 24:8 47:1 52:13  
70:3 79:20 85:20  
180:11 183:17  
**second-hand** 213:13  
**Secondarily** 57:18  
**section** 27:17 63:1

117:5 133:9 139:6  
**see** 5:12 12:2 15:14  
18:12 23:1 26:5 29:5  
30:21 37:1,11,15  
40:13 55:7 57:14  
59:10 62:22 65:13  
73:21 74:7,11,12,14  
82:17,19 84:10 92:18  
93:7 104:2,14 106:6  
106:22 108:1 111:15  
116:13 131:18 143:20  
152:12 154:10 155:5  
170:18 177:18 178:10  
185:17 186:19 191:6  
191:20 204:16,22  
216:18 218:13 221:8  
223:9 237:11 241:22  
242:19  
**seeing** 33:12 39:22  
99:2 132:3 143:1  
**seek** 156:21  
**seeking** 5:4 182:7  
240:3  
**seen** 14:9 49:16 235:14  
**sees** 106:1  
**SEIU** 1:16  
**selected** 14:5  
**selection** 14:12 23:17  
**self** 2:6 16:4 55:10  
58:13 118:16 120:16  
121:5,19  
**self-actualization** 71:1  
71:13  
**self-choice** 122:2  
**self-determination**  
58:10,11 118:19  
119:1  
**self-direct** 120:20  
**self-directed** 46:15,18  
49:18,21 50:7,8 60:14  
88:15 127:14 243:9  
**self-direction** 120:15  
120:21 121:2,14  
**self-management**  
224:11  
**sell** 225:20  
**semantics** 175:4  
**seminal** 15:10  
**send** 6:5 232:3  
**sending** 246:8  
**Senior** 2:13,14,16  
**seniors** 238:16  
**sense** 21:17 44:16 98:9  
123:2 134:10,13  
149:19 162:5 169:17  
169:19 178:18 186:3  
193:17  
**sensitive** 123:19 140:2

244:7  
**sensitivity** 243:19  
**separate** 20:11 26:3  
27:14 35:16,16 62:15  
70:12 78:2 122:10  
132:14 133:8 150:10  
155:18 158:21 162:19  
**separately** 62:16 85:12  
132:20 142:13 153:13  
**September** 179:18  
**serious** 125:22 209:21  
**serve** 8:10 139:17  
162:15 189:15 239:2  
**served** 101:22 133:17  
155:2 176:17,22  
**service** 54:7 57:7 61:1  
61:7,10 74:8 75:6,21  
76:4 78:4,17 83:1  
85:6 90:1 100:4  
121:19 125:20 128:12  
129:7 137:10 149:7  
154:18 156:8 157:9  
157:18 159:22 160:1  
160:10,13,18 161:2,7  
166:6 167:11 171:18  
177:14,21 186:20  
187:3 193:11 195:15  
197:6 202:1 203:3  
205:6,12 211:11  
213:18 224:5,8,15  
227:17 228:20 242:13  
**services** 1:3,6,17 8:15  
8:18 13:13 16:1,4  
22:12,13 27:10,22  
28:17,22 29:6,7,12,14  
35:12 43:2 44:4 51:20  
53:5 54:5 56:20 60:16  
60:17 72:15,18 75:21  
76:1,1,2,8,9,13,17,18  
77:9,14 78:7,10 79:12  
80:15,17,18,19,20  
81:2,6,20 82:21 83:5  
84:1 89:21 93:15  
100:11 102:17,19  
115:21,21 124:8  
128:15,16,20,22  
129:1,2,3 130:11,20  
131:7,21 134:1,1,6,17  
135:7 136:10 150:12  
151:15,18 152:11  
154:6,13,16,20 155:9  
155:10 156:4,10,20  
157:1,6 158:6 159:17  
160:7,16 161:15  
162:7,20 163:1  
167:20 170:16 171:6  
171:7,16,20 172:1,11  
173:5,20 177:3,7,10

177:10,15,18,20,21 187:5 190:17 192:5 196:13,15 197:3,10 198:21 200:17 201:21 205:12,14,15 213:5 213:16 216:19,20 221:16 222:5 224:9 226:8,15 230:5 241:4 243:10 245:4 <b>serving</b> 170:15 241:7 <b>set</b> 6:7 113:8 137:1,4,6 137:8 154:10 159:16 183:9 185:14 196:16 214:2 <b>sets</b> 163:11 189:1 <b>setting</b> 5:16 148:7 155:3 <b>settings</b> 63:3 190:10,13 195:9 199:22 236:16 <b>settled</b> 52:8 143:9,19 145:9 <b>seven</b> 15:15 <b>severe</b> 62:6 <b>shapes</b> 167:2 <b>share</b> 8:7 88:20,21 104:8 166:15 169:7 178:15 180:14 183:22 185:7,16 192:11 220:22 <b>shared</b> 18:22 118:10 179:8 <b>SharePoint</b> 248:10 <b>shares</b> 180:22 <b>sharing</b> 114:7,18 119:18 127:9,16,19 230:1 234:18 <b>Shawn</b> 246:2 <b>she'd</b> 244:13 <b>shining</b> 227:3 <b>shooting</b> 66:13 <b>short</b> 101:10 116:4 187:9 205:10 <b>shorter</b> 19:9 56:4 <b>shot</b> 89:18 <b>show</b> 86:15 93:19 104:2 139:14 156:16 158:12 161:22 165:3 166:15 224:21 227:8 231:22 247:2 <b>showing</b> 244:17 <b>shown</b> 243:20 <b>shows</b> 37:21 137:22 <b>Sid</b> 228:15 <b>side</b> 25:1 27:3,4 40:4,5 40:10,11,12 45:4 61:14 78:8,9,10,11,15 93:7 104:17 105:6,7 146:21 174:10 190:8	192:6 193:16 <b>sides</b> 221:19 <b>sight</b> 199:20 <b>significant</b> 46:17 47:1 129:10 134:15 <b>significantly</b> 222:19 <b>silent</b> 13:3,6 <b>similar</b> 66:1 83:7 88:22 137:7 172:20 182:20 190:19 <b>similarity</b> 192:5 <b>simple</b> 166:22 168:16 231:21 <b>simpler</b> 169:6 <b>simplicity</b> 169:19 <b>Simultaneous</b> 16:19 53:13,16 54:18 77:15 77:19 83:20 85:16 94:3 <b>single</b> 84:19 133:16,22 151:15 225:4 <b>site</b> 248:10 <b>sitting</b> 12:17,18 105:5 <b>situation</b> 95:7 <b>six</b> 40:14 103:15 113:2 159:18 <b>size</b> 11:3 <b>sketch</b> 12:1 <b>skill</b> 145:7 150:9 157:12 <b>skilled</b> 47:20 139:18 <b>skills</b> 49:5 154:20 157:7 <b>slap</b> 97:4 <b>slash</b> 38:20 42:17 <b>slide</b> 4:19 6:10 60:12 93:19 104:3 105:11 150:1 161:17 164:9 165:2 180:22 <b>slides</b> 141:19 161:14 164:4 <b>slightly</b> 221:11 <b>slow</b> 246:20 <b>small</b> 3:6 11:18 55:20 87:15 102:8 103:12 113:6 115:3 116:4,11 116:22 136:20 205:4 222:20 <b>smaller</b> 112:5 <b>smart</b> 237:2 <b>Smith</b> 2:9 35:18 65:10 68:2,8 73:11 74:16,20 76:3 77:1 81:15,19 82:2,4 98:12 115:13 132:17 144:16,19 156:18 176:9,19 177:1 214:13 246:2 <b>social</b> 13:10 65:5 68:7 70:14 89:4 108:9 152:15 234:12	<b>somebody</b> 53:17 62:3 89:5 95:7 104:5 119:17 120:22 217:6 <b>somebody's</b> 74:7 <b>someplace</b> 123:4 <b>something's</b> 146:10 <b>somewhat</b> 65:18 139:7 154:16 160:8 <b>sorry</b> 17:21 32:16 84:5 116:20 133:18 <b>sort</b> 4:18 5:7 6:7,10 7:18 10:22 19:22 23:8 23:19 24:14,16 35:21 37:10 45:15 70:21 71:9 73:3 75:4 81:3,7 87:10 105:18 108:9 111:7 113:4 120:19 121:17 130:3 132:8 144:12 146:20 153:12 154:19 155:4 156:9 160:16 161:17 162:9 163:5 166:18 167:5 168:18 171:11 172:5 173:4 178:16 185:14 194:8 206:22 209:1 212:16 228:14 233:8 <b>sorts</b> 33:1 41:18 50:13 83:7 244:1 <b>sought</b> 182:6 <b>sound</b> 34:7 47:20 55:21 154:1 <b>sounded</b> 151:21 <b>sounds</b> 90:7 109:22 <b>source</b> 14:12,15,18 15:2 22:8 23:17 25:3 198:22 203:14 211:12 213:8 <b>sources</b> 14:5,9,10,16 15:7 22:10,15 23:15 23:22 181:18,20 182:22 189:10 212:19 <b>south</b> 124:2 <b>space</b> 189:7 227:1 <b>span</b> 167:14 189:6 <b>sparse</b> 31:16,17 <b>speak</b> 34:13 45:21,22 51:11 128:3 130:4 146:21 181:9 188:8 190:9,12 215:16 <b>speaking</b> 16:19 17:22 53:13,16 54:18 77:15 77:19 83:20 85:16 94:3 99:17 137:1 147:10,18 240:14 <b>speaks</b> 80:16 <b>special</b> 4:7 <b>specific</b> 14:21 37:18 48:19 142:20 175:22	179:10 187:3 191:18 194:6 218:10 219:17 223:8 <b>specifically</b> 20:18 22:9 86:13 137:10 138:12 148:15,19 160:6 226:14,15 <b>specificity</b> 11:19 <b>specified</b> 45:2 <b>spend</b> 114:3 117:4 168:7 189:12 226:5 227:10,21 <b>spending</b> 52:10 <b>spent</b> 128:7 172:13 217:9,18 <b>spilled</b> 92:20 <b>split</b> 159:3 160:17 <b>spoke</b> 34:12 136:22 137:10 140:14 <b>spoken</b> 210:2 <b>spokesperson</b> 118:4 <b>sponsors</b> 244:13 <b>spring/summer</b> 180:6 <b>square</b> 50:19 <b>staff</b> 2:12 4:8 11:14 44:13 86:1 103:17 169:11 179:2,19 180:14 183:22 186:21 221:6 232:19 237:17 240:13 245:21 247:3 248:1 <b>staffing</b> 145:18 191:12 <b>stakeholder</b> 2:15 9:1 53:12,14 54:10,16 55:5,15,18,20,22 58:5 92:12 94:1 245:1,5,13 245:17 <b>stakeholders</b> 57:11,15 137:3 181:7 216:4 <b>standard</b> 129:18 130:3 197:5,5 200:15 207:16 222:16 <b>standardization</b> 191:9 199:19 210:20 <b>standardize</b> 199:22 <b>standards</b> 207:21 <b>standing</b> 207:11 <b>standpoint</b> 15:21 43:5 130:6 136:22 <b>star</b> 165:9 <b>start</b> 25:16 31:16 117:22 128:6 163:1 190:18 196:14 202:18 209:21 246:20 <b>started</b> 31:13 120:16 122:12 133:12,19 139:7 163:3 199:5 216:10 222:13
--	---	---	---

**starting** 31:7 33:10  
103:11 185:18 196:19  
238:13  
**starts** 176:4 199:9  
228:7  
**state** 2:3,10 48:10  
51:21,22 93:18  
100:10 101:22 129:10  
129:10 131:2 135:14  
135:14 149:9 151:2  
186:9 189:13,17  
191:8,8 200:9,16  
209:10 212:21 213:2  
213:5,7 216:21  
219:16 230:5,8 238:1  
238:1,5,5 242:12  
**state-based** 129:9  
**state-collected** 195:20  
**state-driven** 230:18  
**statement** 34:1 96:2  
**states** 1:19 6:1 9:3  
13:15 55:7 128:18  
135:12 187:17,19  
191:18 196:4 198:8  
198:14 208:5 210:7,8  
210:10 211:2 216:17  
217:17 218:11 219:10  
220:20 221:4,15  
222:10,14 229:20  
230:7 238:15  
**stating** 236:11  
**statistics** 18:22  
**status** 25:9,11,19 26:13  
153:10  
**stayed** 127:15  
**stayed-at-home** 235:1  
**staying** 4:8  
**stays** 174:2  
**step** 12:4 41:3 72:2  
206:3 234:2  
**Stephen** 1:12,15 115:17  
**steps** 3:15 178:21  
183:6 186:1  
**Steve** 12:14 22:19  
49:15 99:15 113:1  
118:20 168:12 210:14  
221:2  
**stick** 30:18 50:21  
**straightforward** 118:7  
119:7 123:8  
**stranger** 108:1,17  
**strategies** 182:17  
**Street** 1:12  
**strenuously** 42:19  
**stress** 221:1  
**stressors** 244:2  
**strong** 116:22 140:15  
206:4,9

**Strongest** 205:20  
**strongly** 47:12 79:21  
136:16 198:18  
**structural** 173:5  
**structure** 173:1 245:5  
245:16  
**structures** 10:7 137:11  
**struggle** 16:21 86:22  
112:4 145:2 150:8  
158:1 217:22  
**struggled** 157:17  
**struggling** 45:9 87:9  
214:17  
**stuck** 243:11  
**study** 195:14 230:8  
**stuff** 24:21 32:10,12  
35:21 50:2,5,13  
100:20 137:14,17  
168:18 169:1 190:2  
192:13 208:9,12  
216:11 223:5 227:17  
240:15 247:10  
**sub** 3:6 14:10 49:12  
50:15 67:11 87:6  
112:10 117:1 159:20  
207:8  
**sub-bullets** 159:2,2  
**sub-domain** 27:18  
36:16 58:16 68:12,13  
73:9 77:4,18 92:13  
101:15 108:19 112:21  
155:18  
**sub-domains** 11:20  
15:13 18:19 23:14  
24:10 34:2,5,7,11  
40:14 69:3 86:10 87:3  
87:16,19 103:12  
104:9,13 111:15,16  
112:1 113:2 114:16  
116:5,9 117:11  
119:22 159:16,21  
164:10,15 182:3,13  
183:2,8 184:18 186:4  
186:11 238:22 247:8  
**subdivisions** 130:21  
**subgroup** 24:2 144:11  
**subject** 47:5 245:2  
**subjective** 15:21  
**submitted** 165:14  
207:13  
**substance** 215:17  
217:4  
**substantially** 55:8  
**substitute** 132:9 151:2  
**subsumed** 25:10  
214:19  
**successful** 194:2  
**suddenly** 129:6

**suffice** 67:4  
**sufficiency** 83:4,6,22  
83:22 84:4 161:3,5,9  
**sufficient** 28:18 29:8  
43:3,10 76:10 78:8  
80:16 82:10,18 94:10  
139:9 161:11 163:21  
**sufficiently** 9:5 163:15  
**suggest** 28:17,19 46:9  
172:19 223:19  
**suggested** 24:1 37:20  
52:13  
**suggesting** 58:2 81:15  
83:15 113:1  
**suggestion** 52:15 176:3  
176:7 198:14  
**suggestions** 5:6 168:4  
**suggests** 101:18  
**sum** 245:8  
**summarizing** 4:12  
**Super** 248:11  
**support** 1:6 4:21 33:1  
43:20,21 44:12 46:11  
47:7 49:5 72:8,10  
75:6 80:1 88:6,9 89:1  
89:8 102:7,9 103:2  
105:21 106:22 109:9  
110:4 111:7 115:16  
150:7 151:3,17,19  
154:18 173:21 181:13  
195:15 246:6  
**supported** 47:3 69:21  
72:5 107:15 109:6  
151:8 240:6  
**supporting** 90:8 111:3  
**supports** 16:1 22:13  
33:3 39:1 43:13 48:22  
75:22 76:13 89:13  
108:4 110:8,12  
150:12 177:16 196:15  
197:4,10 201:22  
212:8  
**supposed** 71:10 159:10  
**sure** 14:18 30:16,18  
32:22 40:21 42:2,2,20  
44:3 54:20 56:12  
65:22 67:2 78:16,22  
84:15 87:1,14 95:1  
102:16 106:16 109:22  
111:19 118:11,14  
119:3 123:21 128:10  
133:6 135:9 136:2  
141:2,20 147:8 148:3  
150:3,13,19 152:6  
153:3,10 158:13  
159:4,15 164:4  
171:19 185:20 191:8  
195:4 211:20 212:6

221:14 223:5,7,16  
233:7  
**surface** 192:21  
**surfaced** 184:18  
**surprising** 24:19  
**surrounding** 180:19  
**survey** 156:22,22 186:7  
188:4,11,18,19,22  
194:17 198:17 199:9  
218:2,3,4 221:6 231:1  
**surveys** 175:10 188:12  
188:22 189:6,11  
198:15 208:21 218:11  
221:2  
**suspect** 91:9  
**sustainability** 18:22  
147:6 225:10  
**Suzanne** 1:17 37:17  
42:4 52:21 58:12  
72:16 94:8 95:21  
115:17 212:1  
**switched** 198:17  
**synergy** 5:13  
**synonym** 97:9  
**synonyms** 69:2 92:18  
93:1 128:10  
**synthesis** 3:16 12:6  
24:9 180:9 181:10  
182:20 205:18  
**system** 4:21 8:10,14  
10:12 17:13 18:6,20  
19:7 20:1,7,22 21:8  
21:15 29:15 36:1,1,4  
37:13 39:5,9,15 40:4  
40:6,7,10 43:4 44:4,8  
44:9 54:7 57:8,20  
61:10 64:12,18,19,22  
73:16,21,22 74:6 78:1  
78:5,8,10,14,16,18  
86:4,15 87:7,8,20  
92:7,9 93:16 94:5  
97:10 98:6,10 100:4,5  
104:18 115:10 120:9  
122:14,18,21 123:12  
123:19,19,22 124:5,9  
124:10 125:8,20  
127:1,2,6,7,12,18,21  
130:7 131:3,3 135:12  
138:2 146:8 148:18  
149:7,10 155:1,2,4,4  
161:7 166:5 167:10  
172:1,13 173:4,20  
174:22 175:19 190:1  
195:7 201:3,16,19  
203:11 206:16 214:5  
219:7 222:6 230:6,18  
239:16  
**system-level** 14:22



**system/fairness** 89:20  
**systematic** 15:1 24:12  
 243:8  
**systems** 9:17 27:2  
 36:17 39:8 41:12  
 43:12,15 46:15,18  
 53:4 74:13 82:11  
 100:9,10,14 129:5,8,9  
 136:21 138:19 162:21  
 164:9 166:3 186:9  
 187:10 191:7,13  
 202:15 203:1,4 206:6  
 206:18 211:17 225:6  
 229:22 230:1 238:2

# T

**T-A-B-L-E** 3:1  
**T-MSIS** 213:11  
**T.V** 232:7  
**table** 92:22 102:22  
 147:14  
**tackle** 11:22  
**tailored** 166:4  
**take** 11:16 17:3 22:5  
 25:6 46:21 92:12  
 99:14 101:3 103:13  
 105:1 112:7 113:11  
 127:6 131:8 144:13  
 146:7 149:11 191:3  
 196:9 202:8 207:17  
 225:12 226:3 246:5  
**takeaway** 138:10  
**taken** 167:7 185:9  
 202:17  
**Tale** 228:5  
**talk** 17:4 24:12 41:20  
 44:21 49:22 59:9 86:5  
 86:7,13 97:19 100:9  
 118:16 142:12 144:14  
 164:13 175:11 206:7  
 206:8 208:6 222:13  
 233:19 239:21  
**talked** 9:16 32:19 41:21  
 48:16 94:11 118:8  
 126:12 127:8 148:3  
 151:11 155:20 156:4  
 192:4 197:9,12,13,14  
 213:10 215:14 217:3  
 217:13 223:9 228:12  
**talking** 24:21 39:8  
 42:22 43:4 45:16 49:2  
 51:16 72:1 102:20  
 108:14 120:16 127:17  
 136:7 144:8 177:6  
 191:14 196:17 198:20  
 198:21 200:20 202:14  
 205:22 206:18 217:10  
 217:16 229:9 230:3

234:7  
**tangents** 127:9  
**tap** 195:17  
**task** 246:6  
**taxes** 50:1  
**tea** 92:20  
**teacher** 228:9  
**teaches** 228:9  
**team** 24:4 154:21  
 158:10,12 159:2,4,7,8  
 159:8,9 163:17  
**teams** 7:21  
**tease** 10:5 175:14  
**technical** 94:15 154:17  
 154:17,20,20 155:10  
 156:16 157:6,7,9,12  
 209:6  
**technically** 156:9,10  
 157:8  
**technology** 211:6,8  
 225:1,3,15,21,22  
 226:6,21,22 237:5  
 239:10,11  
**TEFT** 194:15  
**teleconference** 2:21  
**television** 231:20  
**tell** 48:14 209:18 217:7  
 221:13 228:17,19  
 229:12  
**tells** 47:6 164:11  
**temperature** 146:7  
**ten** 117:4 218:6  
**tends** 173:4,5,7  
**TennCare** 2:1  
**Tennessee** 48:11  
 187:17  
**tenure** 223:11  
**term** 32:4 63:7 65:6,15  
 67:11,15 70:15 75:3  
 102:11,12,14 135:5  
 135:12 165:16 175:21  
 187:9 205:10 230:5  
 240:6  
**terms** 14:14 22:1,21  
 24:11 31:18 32:8  
 36:18 40:6 44:11  
 96:22 113:5 123:8  
 126:7 142:7 145:3  
 150:11 157:6 161:21  
 171:8,9 172:6 180:4  
 180:19 183:5,6  
 184:21 186:1 187:15  
 217:20 233:6 237:21  
 238:7 239:18 241:16  
 242:21  
**Terrell** 246:2  
**terrible** 56:20  
**territories** 216:17

**terse** 247:4  
**tested** 209:1  
**testing** 194:22  
**text** 237:6,11  
**thank** 4:5 12:17 13:5,9  
 13:20 14:1 18:2 26:19  
 42:13 58:6 103:5  
 114:14 165:12 166:7  
 185:21 187:6 204:9  
 206:11 218:18 224:2  
 232:15,16 237:17  
 240:7,11,13 244:9,9  
 244:14,16 245:13,14  
 245:19 246:3 247:22  
 248:14,18  
**thanks** 33:6 69:17  
 99:11 146:19 157:4  
 166:8 184:5 194:7  
 206:12 218:15,15  
 246:17  
**the-ground** 241:3  
**themes** 3:2 201:10  
 203:7  
**thereof** 155:21  
**thermometer** 7:3,5  
**they'd** 82:9  
**thing** 5:9 10:9 18:15  
 19:22 20:8,11 21:5  
 22:15,16 25:4 31:12  
 35:9 37:18 38:18  
 40:18 42:5 50:14 56:5  
 57:13 58:8 59:16 67:8  
 67:9 69:5 70:18 72:1  
 75:18 81:10 95:14  
 100:4,4 121:17  
 122:11,22 125:11  
 130:2 133:8 137:22  
 143:16 152:8 169:14  
 169:17 170:15,19  
 186:1 193:5 197:8  
 202:21 203:17,18  
 205:2,21 213:20  
 215:13 226:10 227:6  
 244:6  
**things** 6:14 7:20 8:7,12  
 9:20 11:5,11 15:1,3  
 17:4 19:14,17 28:22  
 31:14 33:2 36:19  
 41:18 47:17 49:1 58:9  
 60:6 61:8,15 64:2  
 65:10,13 69:5 70:13  
 71:22 73:4,5 75:5  
 78:19 84:11,11 92:8  
 107:19 121:1 122:20  
 123:18 127:17 130:14  
 130:16 134:4 135:17  
 142:5 146:8 148:13  
 149:8,15,16 152:10

157:2 159:4 164:3  
 167:2 168:20,21  
 171:6,8,13,13,19,20  
 172:11 175:17 176:11  
 186:14 187:18 189:5  
 190:7 192:17 193:2  
 193:14,19,21 194:13  
 198:19 199:4 201:10  
 201:11 202:3,6  
 206:16 210:5,14,19  
 212:16 214:14,15  
 216:2,15 217:12  
 218:15 219:21 220:22  
 229:7 233:1 237:8,20  
 237:22 239:1,8  
 241:20 242:2 244:2  
 244:15  
**think** 4:11 5:13,18 7:10  
 8:1 10:1 13:2 15:16  
 15:18 16:4,10 19:5,14  
 19:21 20:3,14 21:16  
 21:19 22:15,20 24:18  
 25:5,22 26:6 27:9,11  
 27:13,15,19 28:1,4,11  
 29:11,14 31:4,9,14,15  
 34:8 35:18 36:18,20  
 38:1 39:2,6,11,18  
 40:5,9 41:2,5,7,18,21  
 41:22 43:8,15,22 44:1  
 44:5,6 45:1,4,5,6,7,14  
 45:16,19 46:1,16,19  
 49:3,7,8,10,11,15,21  
 51:13,18,21 54:10,11  
 55:4,6,16 57:6,16  
 59:18 60:10,11,13  
 61:13,19 62:14,17,18  
 63:20,22 64:18 65:10  
 65:13 67:5,13 68:2,4  
 68:6,8,14,20 69:2  
 70:4 71:15 73:4,12,12  
 73:13 74:16,18,20  
 75:3 76:4,21 77:2,4  
 77:12 79:3,6 80:1,7,8  
 80:9,11,14 81:2,19  
 82:8,9 86:19 88:2,8  
 89:11,14,17 92:6,9,13  
 94:5,9 95:6,14,18,19  
 96:3,22 97:2,2,8,10  
 97:22 98:1,10 100:9  
 105:22 106:2 107:9  
 107:18 108:6,15  
 109:18 110:1,5,10,21  
 111:10,11,13 112:3  
 112:14,16 116:18  
 117:8,21 119:6,7,12  
 120:2,4 123:7,15  
 124:5 125:2,19 126:2  
 126:5,9,15 127:4

129:16 130:5,22  
 131:3 132:12,17  
 133:5 134:19 135:18  
 135:18 136:6,8 137:1  
 137:12,13,14,19  
 138:11,19 139:4,5  
 140:7,17 141:7 142:2  
 142:3,6,19 143:4,5,9  
 143:11,12,14,15,18  
 144:2,7,22 145:20  
 147:10,22 148:6,22  
 149:5,15,22 150:5  
 153:1,8 154:2,16  
 156:3,13 157:16  
 159:1,18 160:5 161:4  
 161:14,16 162:2  
 163:8 164:7,9,11  
 166:16 168:14,21  
 169:18 170:4,11,20  
 171:12,15 172:21  
 173:3,9,13 174:1,19  
 174:20 175:6,10  
 176:5 177:4 178:3,4,6  
 178:9 184:3,9 185:10  
 185:22 186:7 187:10  
 187:14,18,22 188:1,3  
 189:2,3,15 190:2,4  
 191:1 192:15,20  
 193:13,20 194:16  
 195:7,16,17,18 196:8  
 196:14,20,22 197:7  
 197:15 198:9,12,14  
 198:19,22 199:1,3,7,8  
 199:19 200:19 201:9  
 201:10 202:4,13,14  
 202:17,19 203:13,14  
 203:16,18 204:2,8  
 205:16 206:4 207:1  
 207:15,17 208:4,9,13  
 209:17,20 210:8,10  
 210:13,14,16,18  
 211:4,7,14,15 212:1,7  
 212:9,17 214:1,16,21  
 215:21 216:15 217:8  
 217:13,15,21 218:14  
 218:22 219:20,21  
 220:8,11,21 221:18  
 222:7,11,17,21 223:3  
 223:6 224:16 225:3  
 225:10,14,20 226:3,8  
 226:17 227:1,16,20  
 227:22 229:3,7  
 230:11,16 231:15,16  
 232:13,17 234:12  
 235:2 237:3,6,12  
 238:2,4,5,8,13,16,19  
 238:22 239:12,14,15  
 239:18,20 240:1,22

241:2,11,14 242:20  
 244:7 245:8 246:5,11  
 247:1,11,18 248:2,7  
**thinker** 168:17  
**thinkers** 235:3  
**thinking** 5:14 9:19 20:4  
 34:6 47:17 67:10  
 86:17 93:11 95:2  
 100:13 112:8 122:13  
 131:1 155:1 166:17  
 169:7 171:4 172:18  
 177:5 186:2 195:21  
 198:2 204:18 214:12  
 228:3 240:2 242:14  
**thinks** 28:10 79:4  
**third** 29:6 125:15  
 161:15 188:7 235:11  
 238:21  
**thought** 10:14 11:1  
 16:13 23:19,20,22  
 24:15 25:15 36:12  
 39:16 53:3 85:3,15  
 107:12,15,17 118:19  
 120:16,22 124:20  
 133:18 148:5 150:8  
 170:13 173:15 174:21  
 199:7 215:2 228:14  
 242:19 246:20  
**thoughtful** 239:5 245:4  
 245:12 246:18 247:13  
**thoughts** 145:13  
 166:16 184:9,9  
 233:15 240:7,18,20  
**threat** 235:19  
**three** 10:15 91:5 104:16  
 105:4,10 112:22  
 121:12 122:3 153:12  
 159:3 161:14 167:14  
 172:22 173:1 225:16  
 225:17  
**three-word** 74:10  
**thrive** 245:17  
**throughput** 171:11  
**throw** 67:20 75:3,5  
 99:22 192:6 193:21  
**throwing** 168:11  
**THURSDAY** 1:8  
**tie** 128:5 147:18  
**tied** 128:16 186:12  
**time** 7:5 8:16 9:13 12:8  
 17:19,20 50:7,20 51:8  
 52:11 69:19 85:6  
 109:3 115:2 116:18  
 116:20 119:20 120:1  
 120:3 125:20 128:8  
 136:12 139:14 156:2  
 161:22 163:2 165:7,8  
 165:11 172:13 183:10

183:12 184:8 189:12  
 189:21 197:1 206:14  
 212:10 217:18 222:21  
 231:11,22 242:1  
 248:16  
**timeliness** 46:8 129:1  
 162:18 222:5  
**timely** 28:19 29:8 76:11  
 80:16 81:20 82:11,18  
 161:21 162:17,20  
 163:4,4  
**times** 54:12 152:14  
 207:1 214:16 228:8,8  
 228:19  
**timing** 113:5  
**tip** 196:19  
**tired** 168:1 169:8  
**title** 51:2 62:18 87:4,5  
 93:3 99:20 108:21  
 119:3  
**titles** 19:9 30:20  
**today** 8:8 24:11 109:8  
 117:10,15 167:8  
 178:18 207:16 215:14  
 232:11 239:14,18  
 247:3  
**today's** 4:13,17 11:9,15  
 239:19 248:13  
**tool** 32:7  
**tools** 188:20 210:20  
 241:13  
**top** 22:15 31:15 48:15  
 48:16 52:11 65:12  
 147:20 150:2 170:22  
**top-line** 213:6  
**Topeka** 2:7  
**topic** 9:8 168:8 178:14  
**topics** 10:3 155:19  
 167:14 185:3  
**tossed** 242:15  
**totally** 47:9  
**touch** 181:8 196:19  
**touched** 149:4  
**touching** 234:14  
**touchpoints** 184:2  
**tough** 125:16 204:10  
**town** 242:16  
**track** 71:11 158:15  
 245:15  
**tracks** 218:6  
**traction** 96:8  
**trademark** 194:19  
**tradeoff** 235:20  
**traditional** 51:19 57:13  
 224:9  
**traditionally** 138:17  
**train** 44:13 47:4 48:18  
**trained** 47:14,19,22

48:19 49:8 231:6,7  
**training** 7:20 13:10 33:3  
 43:12 46:9,10,11,13  
 46:14,21 47:12,22  
 48:14 51:21 52:2  
 139:19 141:4,9 142:6  
 142:16 143:13,20  
 144:2 145:6 150:9  
 166:1,4 193:10  
 208:22 233:16,22  
 234:9 243:9  
**Transfer** 32:10  
**transit** 132:8  
**transitions** 27:18,20  
 28:2 219:15 224:10  
**translate** 19:6 163:14  
**translates** 147:6,7  
**transparency** 19:1  
 128:13 167:22 242:7  
**transparent** 128:17  
**transportation** 33:2  
 131:19 132:2,6,10,13  
 132:16,19 133:2,7  
 224:14 243:6  
**trauma** 165:20  
**travel** 12:9  
**treated** 171:10,17  
**tremendous** 57:22  
 124:7 231:12  
**trends** 189:20  
**trial** 188:12  
**tricky** 129:3 154:14  
 171:12  
**tried** 85:7 90:5 147:22  
 154:15 161:17 163:8  
 168:16,21 169:1  
**triple** 9:18 193:7 234:10  
**trouble** 59:2  
**troubled** 141:3  
**true** 79:8 197:2 212:8  
**truly** 163:10 195:6  
 196:11,13  
**try** 11:10 30:6,9 33:22  
 50:8,20 81:10 89:12  
 104:5,11,12 112:15  
 112:16 113:1,3 117:4  
 126:6,10 169:5 172:7  
 192:20 202:8 224:21  
 232:22 247:3  
**trying** 4:9 5:21 12:8  
 19:6 20:6 38:6 39:11  
 43:6 50:19 53:1 71:2  
 92:5 107:18 121:15  
 126:3 127:18 128:8  
 131:12 135:17 143:21  
 145:3 148:9 172:5,14  
 178:7 185:6 187:18  
 200:9,16 202:7,9,10

219:22 239:13 243:14  
**turn** 69:14 90:17 246:15  
**turnover** 146:5 162:3  
**Turns** 12:21  
**tweaked** 140:7 142:19  
**two** 10:18 12:19 15:19  
 27:13 33:16 47:17  
 48:6 50:18 58:9 59:12  
 71:16,22 76:20 81:9  
 82:14 90:5 93:20  
 104:16 105:3,10  
 148:8 149:1 153:15  
 162:6 174:18 182:4  
 193:19 194:15 213:5  
 217:8 218:20 228:6  
 230:12 232:6 238:8  
 244:18 247:16  
**two-word** 74:10  
**twofold** 19:5  
**tying** 173:8  
**type** 14:15,15 15:1,2  
 186:7  
**typed** 117:3  
**types** 5:1 9:3 10:7  
 45:20 138:18 160:2  
 163:11 190:17  
**typical** 60:5 235:1  
**typically** 57:13 213:19

## U

**U.S** 216:17  
**ultimate** 242:21  
**ultimately** 242:12  
**umbrella** 25:13 27:6  
 65:6,11 67:11  
**un** 72:1  
**under-staffed** 213:7  
**undergoing** 179:2  
**underneath** 40:14  
 85:13 209:9  
**understand** 4:10 38:3  
 40:19,21 44:19 61:12  
 78:18 80:2 86:1 87:2  
 97:16 132:18 141:6  
 170:1,3 200:3  
**understanding** 19:4  
 27:1 36:15 87:13  
 90:16 101:8 133:14  
 133:19 165:19 179:11  
 209:8  
**understood** 107:13  
**unfair** 143:15  
**unifying** 230:4  
**unique** 190:18 245:6  
**United** 1:19 135:12  
**universally** 194:9  
**University** 1:16,18 2:3  
 2:8,11 101:21

**unpaid** 106:3,5,10,19  
 107:14,21,21 108:15  
 109:16 110:3,8 112:6  
**unresponsiveness**  
 124:9  
**unsafe** 9:6  
**unsure** 37:3  
**update** 183:11  
**updated** 216:14  
**updates** 181:2 183:16  
**updating** 138:21  
**uphold** 60:21  
**uproar** 241:19  
**urge** 112:16 136:17  
**use** 7:2 30:20 33:18  
 54:2 65:17,19 66:9  
 67:15 68:16 93:15  
 113:10 160:7 179:4  
 179:14 186:17 189:18  
 200:9,12 202:22  
 203:1 208:1 209:12  
 212:19 215:19 218:12  
 220:11 221:1 222:3  
 224:10 229:11 231:13  
 237:10 239:3 247:5  
**useful** 202:18 212:19  
 220:19 223:2 241:13  
**user** 200:13  
**users** 57:19 166:6  
 200:19  
**usually** 35:18 65:11  
 150:21 245:11  
**utility** 241:2  
**utilization** 205:12  
**utilized** 203:12  
**utilizing** 47:13 187:3

## V

**vacancy** 146:5  
**vagaries** 186:13  
**vague** 160:8  
**validated** 226:1 231:8  
**valuable** 185:2 224:15  
 245:3,6  
**value** 41:3,19 186:8  
 218:21 225:12  
**values** 139:16 140:17  
**values-based** 140:16  
**variable** 132:21 209:12  
**varied** 241:6  
**varies** 135:14,14,15  
**variety** 72:8 89:7  
 136:22 191:15,22  
**various** 9:3 127:9 181:7  
 182:21  
**vary** 191:7  
**vast** 198:3  
**vein** 46:1

**vendor** 225:16,21,21  
 226:9  
**vendors** 202:22 203:1,6  
 203:6,11  
**venue** 142:5  
**verbs** 247:7  
**version** 140:11 143:5  
 145:22 188:13,17  
 216:14 218:7 236:1  
**versus** 8:21 9:10 45:10  
 74:13 78:4,18 81:12  
 129:18 166:6,6  
**veterans** 240:1,5  
**Vice** 2:13  
**view** 175:13 198:3  
 235:17,19 237:3  
 239:19 240:3  
**views** 9:4 141:12  
 237:19  
**violations** 123:18  
**visits** 48:10  
**visual** 168:17 179:22  
**visualization** 170:5  
**visualize** 167:15  
**visually** 168:20 169:16  
 170:11  
**vital** 101:17  
**voice** 53:6,8,10 92:11  
 96:2,7,10 98:13,15  
 100:5 184:10  
**voice/ownership** 98:19  
 98:21 99:2,6,20 115:5  
**voices** 13:21  
**volume** 184:19  
**volunteer** 88:17  
**volunteering** 88:16  
**vote** 62:16  
**votes** 91:5

## W

**wages** 122:20  
**wait** 19:19 29:3 84:9  
 133:10 163:2  
**waiting** 128:19  
**waiver** 240:4  
**waivers** 195:22 242:7  
**walk** 48:20  
**walks** 231:12  
**want** 6:5,5 7:10,14 8:4  
 10:14,17 14:2 16:11  
 25:6,20 26:2,13,19  
 28:21 30:9,19 34:13  
 38:19 40:19 42:11  
 46:9,20 47:16 48:17  
 49:7 51:11,13 54:2  
 57:4,13 58:3 59:6,11  
 60:2 72:15 74:15  
 78:21 79:21 80:13

81:10 84:6,10,11 86:1  
 88:1,4 89:22 91:6  
 92:13 95:19 101:14  
 108:13 110:13 116:7  
 119:8 121:7 122:16  
 123:4,10 126:18  
 133:1 134:3,3 137:22  
 141:1,4,5 149:2 155:6  
 161:9 179:15,15  
 185:7 187:7 189:5,22  
 190:2 192:17 193:20  
 193:22 194:5 210:15  
 212:9,16 214:6,7  
 215:16 220:15 225:9  
 233:6 235:12 236:22  
 240:10,12 242:18  
 243:3,5,12,17 244:10  
 245:19 246:10,14  
 248:6  
**wanted** 8:7 10:9 12:16  
 19:2 25:16,17 38:18  
 42:21 52:22 53:4  
 56:14 92:1 101:4  
 105:16 106:6 113:5  
 119:3 120:8,17 125:7  
 126:20 131:15 138:6  
 140:18 150:18 152:4  
 153:3,9 167:3 173:17  
 175:8 190:21 197:17  
 202:21 210:3 219:11  
 230:21 231:3 232:9  
**wants** 52:21 54:19  
 76:22 146:15  
**Washington** 1:12  
**wasn't** 14:20 141:11  
 143:16,16 145:9  
 241:17  
**waste** 7:5  
**watch** 196:21 224:17  
**watching** 232:7  
**way** 7:15 9:9 11:10  
 19:16 21:1 22:4 24:16  
 28:20 29:1 32:16 37:6  
 39:22 45:18 82:1 85:7  
 94:14 101:13 106:4  
 109:11 111:3 112:19  
 116:17 117:21 122:4  
 124:20 127:21 131:1  
 132:2 150:2 153:18  
 157:13 169:1,5  
 174:20 190:18 191:15  
 212:7 214:12 225:6,7  
 229:20,22 231:16  
 232:13 233:7,10  
 238:12 239:5,6  
 243:16 245:11 248:3  
**ways** 70:11 120:14  
 125:17 126:1 135:16

144:3,9 154:4 195:8  
208:10 212:4 222:2  
224:13  
**we'll** 4:11,17 5:9 10:5  
11:7,16,20 12:6 24:12  
33:15 52:8,20 65:18  
81:9 84:13 94:17  
103:6 104:4 110:14  
114:15 116:22 117:22  
121:8 125:3 126:9,20  
128:2,6 133:6,7  
141:20 144:13 149:20  
150:6 152:2 153:17  
179:10 182:7 183:12  
183:13,15 185:17  
186:13 196:3 211:12  
232:12 248:9  
**we're** 5:21 7:16 11:10  
12:7 14:3 16:22 17:1  
19:6,19 30:1,6 34:4,6  
34:8 38:12,13,21 42:2  
45:15 50:18 52:10,11  
57:16 62:22 69:4,18  
71:1,8,9 72:1 78:1  
80:9,14 84:16 85:9,14  
86:1,2,4,6,12,16 87:4  
88:2 90:8 93:5,8,14  
94:6 96:16 99:12,13  
102:16 103:14 104:10  
105:1 106:13,15,17  
107:18 108:14 109:8  
109:12 110:5 114:3  
119:18 123:21 131:12  
135:3 136:7 138:21  
143:15 145:3 149:6  
149:22 154:2,22  
157:3 164:13,15  
166:8 168:10 169:20  
173:19 174:3 178:12  
178:15 185:5 186:18  
187:6 195:7,22 199:7  
201:16 202:7 204:6  
204:16 205:5 206:18  
207:7,15 209:6,20,22  
210:18 211:20 212:6  
212:10 217:16 219:22  
220:4,9 221:8 224:18  
227:18 229:14 234:14  
237:14 238:12,17  
239:12,12 242:6  
243:2,13  
**we've** 4:13 33:22 35:16  
38:11 71:16 104:20  
110:1 124:7 126:16  
153:20 154:11 156:3  
167:7 181:20 182:3  
183:8 185:3 186:11  
195:17 197:12,12

198:20 205:21 207:9  
211:18 212:5,9 215:8  
215:10,15,21 218:19  
222:8 229:12 246:21  
247:21  
**wearing** 128:5  
**web** 101:4 165:13 198:6  
**webinar** 165:15 183:10  
**wedded** 154:22  
**week** 88:18 248:16  
**weeks** 116:16 232:6  
**weigh** 113:22 144:13  
155:13 187:8  
**weighed** 144:10  
**weight** 222:6  
**weird** 176:13  
**welcome** 4:3 14:2  
142:12 220:1  
**well-aligned** 18:5 64:5  
73:17 78:12  
**well-allocated** 78:13  
**well-being** 10:16,20  
25:13 26:14 91:8,12  
91:13,16,18 153:9  
176:17 190:14 215:22  
**well-served** 132:8  
**well-trained** 41:16  
**wellness** 153:11  
**went** 71:22 103:8  
114:22 127:8 228:3  
231:5 248:20  
**weren't** 111:3 118:11  
118:14 125:22 233:9  
**whatnot** 206:9  
**wheel** 179:15  
**Wheels** 224:19  
**wide** 136:22  
**widely** 193:22  
**widespread** 208:1  
236:14  
**WILSON** 2:13  
**window** 7:3  
**wins** 99:6  
**wish** 134:13 185:16  
**wonder** 75:6 175:20  
**wondered** 69:7 73:2  
**wonderful** 191:2  
**wondering** 47:18 63:5  
85:2 101:11 130:18  
155:22 169:20 218:8  
**word** 33:14 39:6,11,16  
39:17 47:22 52:4,5  
54:2 55:20 64:11 82:4  
92:10 97:8 98:2 106:2  
107:15 110:15 147:21  
155:1 192:7 225:18  
239:3  
**wording** 124:15 144:21

**words** 75:9 92:14,15,16  
94:15 96:13 107:22  
109:5 118:20 123:8  
125:17 126:1,4  
**wordsmith** 56:3 92:5  
**work** 3:6 4:5 5:14 6:6  
7:11 13:10 14:4 15:10  
41:4 44:13 45:11 47:8  
49:7 50:9 51:1 52:6,8  
67:21 91:22 100:12  
101:16 103:12 104:12  
107:11 110:19 111:7  
113:6 117:3 121:8  
126:10,16 135:8  
138:15 143:22 147:1  
148:11 152:21 153:18  
165:4 173:10,22  
178:9 179:1,16 184:1  
191:2,17 193:3,4,6,15  
193:19 199:5 210:8  
214:20 219:7 224:4  
233:4 234:8,12 237:5  
239:17 241:1 244:21  
247:21  
**worked** 13:15,16 154:5  
174:19 175:9 197:22  
198:16,16 240:13  
245:15  
**worker** 13:10 46:14  
89:4 107:22 122:19  
140:7 142:18 161:22  
162:18  
**worker/provider** 42:5  
**workers** 43:14 46:12,12  
47:4  
**workforce** 34:15,16  
38:19,20,22 41:16,16  
41:17,21 42:17  
106:12 109:20 110:4  
110:9 111:21 122:15  
124:16,17,22 125:7  
139:6 145:14 146:8  
**Workforce/Providers**  
115:10  
**workgroup** 117:16,22  
144:20  
**working** 94:15 113:9  
114:18 140:11 146:10  
146:10 181:6 194:14  
199:18 200:8 202:15  
204:4,6 205:3,5 215:8  
216:17 224:18,20  
230:7,20 238:19  
240:11  
**workplace** 143:22  
**works** 9:18 32:17  
**world** 36:6 50:7 58:14  
88:15 95:15 126:14

144:4 187:12 243:10  
**worried** 57:11 135:5  
227:18,22 242:2  
**worries** 100:8  
**worry** 49:17 87:4  
**worse** 229:20  
**worst** 228:8  
**worth** 147:13  
**wouldn't** 7:10 60:5 75:6  
118:2  
**Wow** 210:1 232:12  
**write** 136:20 189:18  
247:6  
**writing** 94:10  
**written** 124:21 159:17  
168:9 237:2  
**wrong** 142:21  
**wrote** 139:19

---

**X**


---

**X** 25:9,17,18 26:13  
**X'ed** 76:12  
**Xs** 31:8,14,18

---

**Y**


---

**Yea** 58:20  
**year** 13:14 217:10  
221:5  
**years** 13:14 15:9 49:16  
89:12 92:7 185:12  
187:14 192:9 197:22  
205:22 215:9 218:6  
231:18 232:12 238:10  
238:14 239:14,17  
**yelling** 96:13  
**yesterday** 5:8 6:11,18  
8:6 11:14 12:18,21,22  
14:8 16:7 18:17 19:7  
24:22 47:18 68:5  
71:21 78:3 86:20  
92:21 101:6 107:12  
107:16 109:7 118:8  
133:13 166:18  
**yesterday's** 4:10 5:12  
10:13  
**young** 237:6,9,14  
**Yuskauskas** 2:10 17:9  
17:18 18:1,1,7 89:11  
96:22 115:13 126:22  
135:9,22 136:4  
155:19 169:18 176:2  
194:11

---

**Z**


---

**zeal** 239:9  
**zero** 233:22

---

**0**


---

<b>1</b>	<b>30</b> 1:9 23:12 215:10 <b>30-day</b> 181:5 183:19 <b>38</b> 14:10,16 22:10,15,15 23:11,14	
1 3:2 115:5 150:2 <b>1.14</b> 101:21 <b>1:05</b> 115:1 <b>1:45</b> 116:3 <b>10</b> 15:8 23:5,10,16 79:19 92:7 102:3 239:13,17 <b>10-word</b> 56:5 <b>10:43</b> 103:8 <b>100</b> 22:2 <b>1030</b> 1:11 <b>11</b> 247:5 <b>11:00</b> 103:6 <b>11:03</b> 103:9 <b>11:15</b> 114:22 <b>1115</b> 242:6 <b>115</b> 3:7 <b>12:00</b> 113:10 <b>12:30</b> 113:11 <b>13</b> 169:2,4 221:4 <b>14</b> 3:4 <b>15</b> 239:13,17 <b>152</b> 238:22 <b>15th</b> 1:11 <b>165</b> 3:9 <b>166</b> 3:13 <b>179</b> 3:17 <b>18</b> 48:10 235:11 238:10 238:14 <b>187</b> 3:20 <b>1915</b> 195:22 <b>1963</b> 228:16 <b>1982</b> 227:13,22 228:5 <b>1st</b> 221:4	<b>4</b> 4 3:2 115:20 153:21 <b>45</b> 114:6 <b>45,000</b> 213:4	
	<b>5</b> 5 92:7 102:4 <b>5,000</b> 230:22 <b>50</b> 13:12,14 <b>500</b> 93:19 <b>56</b> 102:2	
	<b>6</b> 60 95:16 <b>600,000</b> 102:1	
	<b>7</b> 73 7:4,6 75 95:16	
	<b>8</b>	
	<b>9</b>	
<b>2</b>		
2 115:10 128:2 182:5 183:7 <b>2:30</b> 168:8 <b>20</b> 215:9 221:14 <b>200</b> 14:8 22:2 23:22 <b>200-plus</b> 198:12 <b>200-some</b> 181:20 <b>2001</b> 235:7 <b>2012</b> 102:1 <b>2015</b> 1:9 180:6,11 183:18 <b>2016</b> 179:18 180:14 <b>22-year</b> 230:8 <b>25</b> 237:18 <b>28</b> 102:6 <b>28th</b> 183:10		
<b>3</b>		
3 115:15 147:16,18 <b>3:30</b> 12:9 <b>3:34</b> 248:20		

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This is to certify that the foregoing transcript

In the matter of: Home and Community-Based Services  
Quality Committee in-Person Meeting

Before: NQF

Date: 04-30-15

Place: Washington, DC

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