NATIONAL QUALITY FORUM

Meeting Summary

Home and Community Based Services Quality Measurement

April 29-30 Committee In-Person Meeting

The National Quality Forum (NQF) convened an in-person Committee meeting for the Home and Community-Based Services (HCBS) Quality Measurement project on April 29-30, 2015. All members of the Committee were in attendance (see Appendix A). More than 100 individuals attended virtually and in-person, representing a variety of stakeholder groups.

Welcome, Introductions, and Overview of Meeting Objectives

Marcia Wilson, Senior Vice President, NQF, remarked that this project is a collaborative effort across the Department of Health and Human Services (HHS) and will serve as a foundational effort for developing a comprehensive and robust quality measurement guide for home and community based services. The Committee Co-chairs, Steve Kaye and Joe Caldwell, welcomed members and public participants to the in-person meeting and facilitated Committee and staff introductions. Sarah Lash, Senior Director, NQF, reviewed the meeting objectives:

- Discuss and agree upon a working definition of HCBS as the first component of a conceptual framework for measurement
- Collect Committee input on how to best conceptualize the framework visually
- Define potential measurement domains and subdomains for the framework
- Identify the most fertile ground for measurement and direct the ongoing environmental scan and synthesis of evidence accordingly

Ms. Lash reviewed the Committee's charge and scope of work. Ms. Lash noted that this project will provide multi-stakeholder guidance on the highest priorities for measurement of HCBS. Over the course of the project, the Committee will contribute content knowledge and expertise; ensure input is obtained from relevant stakeholders; and assist with the identification of existing research, measures, and resources to identify performance measure needs.

Project Definition of Home and Community Based Services

Juliet Feldman, Project Manager, NQF, began by describing the purpose of the operational definition as the first component of the conceptual framework. Ms. Feldman reminded the Committee of the principles for crafting an operational definition of HCBS from the February 20th Committee web meeting and emphasized that the definition is not meant to replace existing guidance or regulations. To support development of the definition, NQF staff identified 27 definitions of HCBS and long term services and supports (LTSS) from 200+ information sources and solicited definitions from Committee members, HHS liaisons, and members of the public. NQF staff reviewed all definitions to identify commonalities and developed a "strawman" definition (see Appendix B) for the Committee's review.

Joe Caldwell, Committee Co-chair, invited discussion on the "strawman" definition of HCBS. Overall, the Committee recommended that the definition be broad and inclusive, and comprise of two parts: 1) a definition of HCBS and, 2) the characteristics or principles that define high-quality HCBS (i.e., outcomes of interest). Other suggestions related to the definition included:

- Removing "high-quality" as a qualifier in the beginning of the definition since the first part of the definition would be defining HCBS, not high-quality HCBS
- Removing the last sentence since it did not seem relevant to the definition but keeping concepts related to accessibility and affordability
- Keeping language agnostic in terms of payer/payment source for HCBS
- Changing "person-centered" to "person-driven" or "person-directed"
- Reflecting the dual role family caregivers serve as a provider and client of HCBS

In terms of defining HCBS as the first part of the definition, the Committee recommended referencing the definitions submitted by a handful of Committee members who had succinct definitions of HCBS. There was considerable discussion related to the phrase "predominantly non-medical services and supports" in the "strawman" definition, specifically as it relates to best characterizing HCBS. Some Committee members suggested removing the phrase "non-medical" while others emphasized that the definition should reflect coordination and integration of HCBS with medical services. A small group of Committee members will connect after the meeting to further discuss and resolve this issue.

Beginning the Process of Developing an HCBS Measurement Framework

Andrew Anderson, Project Manager, NQF, framed the discussion by presenting past and present efforts related to HCBS quality. This project is not intended to supersede any previous or ongoing work related to HCBS quality. Rather, it is intended to build on these efforts by providing a unified picture of HCBS quality measurement and identify opportunities for measure development. Mr. Anderson clarified that the first approach to this goal is to create a conceptual framework for measurement. He explained the potential uses for the framework, including how it will guide the Committee's work and act as a tool for stakeholders to understand HCBS measurement priorities. Several conceptual frameworks from other related projects were presented to assist the Committee in understanding the abstract thinking involved in conceptual framework development. These example frameworks also served as a starting point for the Committee's discussion.

The Committee shared features of the example frameworks they thought would be useful to apply to the HCBS measurement framework. Committee members agreed the framework had to be large in scope (i.e., a systems level framework). The Committee also agreed the framework should focus on the values and philosophy of HCBS. The framework should illustrate the domains of HCBS and should be comprehensive but not all-inclusive. Lastly, the Committee agreed that the framework should be actionable, useable by major stakeholders and focus on consumer outcomes.

Before delving further into how to illustrate the framework, the Committee agreed that they should first define the specific components of a high-quality HCBS system. These components would become a part of the operational definition of HCBS and help to identify some of the domains of HCBS. Using the strawman definition as a starting point, the Committee discussed various aspects of HCBS. From that discussion, the Committee developed the following list of characteristics and then voted on those they deemed most important to measure (each Committee member received ten votes each):

- Workforce: trained, culturally competent, adequate, supported – 23 votes
- Participant engagement in the design, implementation, evaluation of the program – 22 votes
- Choice, person-driven, focused on achieving individual goals, consumer directed, control, dignity of risk – 22 votes
- Privacy, dignity, respect, freedom/independence, legal rights – 21 votes
- Efficient, well-aligned, well-allocated, integrated, data integrity – 20 votes
- Community engagement, Inclusion (to the same degree as people not receiving HCBS), participation; employment and productivity, having fun; social connectedness – 19 votes
- Family Caregivers are supported – 18 votes
- Effectiveness of services/quality of care – 17 votes
- Services are accessible, appropriate, sufficient, dependable, timely – 15 votes
- Equitable system/fairness and distribution of services that eliminate health disparities – 14 votes
- Safety from the perspective of the consumer – 9 votes
- Physical/emotional health and well-being , including sense of safety – 7 votes
- Freedom from abuse or exploitation, neglect – 5 votes

Emerging Themes from Definition and Framework Discussion

Ms. Lash reflected on the current state of HCBS quality measurement and discussed the many ways performance measure information can be used (i.e., quality improvement, informed decision-making, payment). She also summarized the major themes that emerged from the discussions about an HCBS definition and measurement framework including:

- Consumer outcomes are primary – the HCBS system exists to serve them and maximize community inclusion and participation.
- There is a wide variation of quality within the current HCBS system.
- Coordination/integration of HCBS and health services is important, but we should guard against “medicalizing” HCBS.
- Affordability, risk/safety, and other concepts are defined differently by consumers, providers, policymakers, and other stakeholder groups. There is room to measure a topic from more than one angle.
- Some concepts operate at a systems level (e.g., the Triple Aim®) while others relate to more targeted levels of analysis, such as populations or service providers or individuals.

Identifying Measurement Domains for the Framework

The next step in the process of developing a conceptual framework involved identifying possible measurement domains. Mr. Anderson presented NQF's process of identifying domains most frequently cited in the literature. NQF staff reviewed more than 200 sources and 38 were found to contain domains and sub-domains of quality measurement for HCBS. Ten of the 38 sources were selected for a frequency analysis based on relevance, breadth of scope, evidence type, source type, and currency criteria. The domains excerpted from these sources were categorized and presented in a list for the Committee to use as a starting point for their discussion. Domains most frequently and often cited in the literature were cross-walked against the high-quality HCBS system characteristics identified by the Committee on the first day of the meeting (see Appendix C). Most characteristics mapped to one or more of the domains frequently cited in the literature.

The Committee reviewed each characteristic and discussed how to best transform them into measurement domains. From their discussion, the Committee identified the following measurement domains for the framework:

- Workforce/Providers
- Consumer Voice/Ownership
- Choice and Control
- Human and Legal Rights
- System Performance
- Full Community Inclusion
- Caregivers Support
- Effectiveness/Quality of Services
- Services are accessible, appropriate, sufficient, dependable, timely, and coordinated
- Equity and Fairness
- Physical and Emotional Well-being

Defining Measurement Sub-Domains for Chosen Domains

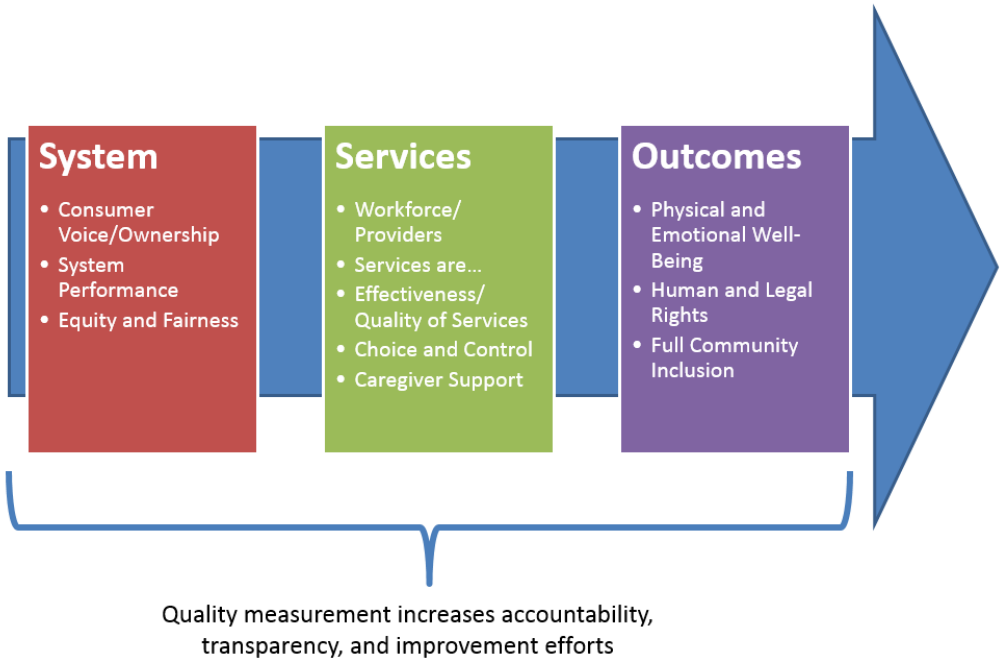
Committee members were pre-assigned to four small groups and given two to three domains to discuss in further detail. Through a brainstorming exercise, they identified sub-domains within the assigned domains they were assigned. Each small group presented their sub-domains to the full Committee. The Committee then worked to refine these sub-domains through discussion. There were several concerns raised about the inclusion of "safety" as a priority measurement domain or a cross- cutting sub-domain (e.g., safety of the caregiver, safety of the provider, and safety of the consumer). The Committee reasoned that the term "safety" may not appropriately describe the many concepts commonly associated with "safety". One Committee member mentioned HCBS should not only be provided safely but it should also keep people safe. The concern over the use of this term also arose in the Committee's discussion about the operational definition and measurement domains. Other issues included how to describe informal care (e.g., family caregiving, unpaid caregiving, etc.) as well as issues around workforce training. From the small group exercise and the larger Committee discussion, the sub-

domains (found in Appendix D) were selected as the first set to be used as a guide for the environment scan and synthesis of evidence.

Committee's Review and Refinements to Draft Conceptual Framework

Ms. Lash began by sharing a synthesis of feedback from earlier discussions related to developing the framework. The Committee expressed that they wanted a nationally relevant framework that is broad, inclusive, and high level. The framework should be fairly simple in style, not overly complex in content, and reflect the primary role of consumer outcomes while demonstrating the role of quality measurement in achieving those outcomes. Based on this feedback, the Committee proposed the conceptual framework featured in Figure 1. The framework illustrates HCBS system-, service- and outcome-level conceptual elements. The domains, identified by the Committee, are placed within these concepts. The draft framework shows a linear relationship from left to right, demonstrating the potential of measurement to increase accountability, transparency, and improvement efforts.

Figure 1. Draft Conceptual Framework



Committee members offered the following suggestions for refining the illustration in Figure 1:

- Display the main objective of the framework, namely that is to serve those receiving HCBS
- Consider how to categorize outputs of HCBS (e.g., satisfaction or experience of services) versus outcomes of HCBS (e.g., improved functional status)
- Consider taking an input and output approach to the framework
- Change the title of "Outcomes" box to "Consumer Outcomes"
- Move the "Outcomes" box so that it is to the right of the arrow

- Transfer the "Effectiveness/Quality of Services" domain to the "Outcomes" box

NQF staff plan to update the framework based on these suggestions and recirculate it to the Committee for further input and revisions.

Environmental Scan and Synthesis of Evidence

Ms. Feldman provided an overview of NQF's progress on the synthesis of evidence and environmental scan of measures and measure concepts. She shared that NQF staff will soon begin the second phase of the synthesis and scan, which will entail tailoring these activities based on the measurement domains and subdomains identified by the Committee. There will be several opportunities for public comment and NQF staff will conduct targeted outreach to learn what HCBS measures may be in development and use. The information gathered during this process will inform the Committee's deliberations and prioritization of measurement gaps.

Round Robin: Identifying Fertile Ground for Measurement

As a final activity, Ms. Lash asked each Committee member to briefly reflect upon and share any promising HCBS quality measurement efforts underway, types of quality measurement that may be most feasible in the short-term, and/or areas for where the evidence base may be strongest. Committee members were invited to share other parting thoughts about key findings from this meeting.

Committee members shared that process, service utilization, and system-level measures are likely to be most feasible in the short-term. They suggested that other data sources in addition to survey data need to be considered, including administrative claims data. Committee members reiterated the importance of consumer-reported data but find it often to be the least feasible data source given that data collection can be expensive and methodologically complex (i.e., use of proxies, response bias). Committee members suggested relying on data sources that already exist and because HCBS is so broad, and looking at measures already in use by various sub-populations, such as the mental health community.

Moreover, Committee members offered a range of promising HCBS quality measurement efforts for NQF staff to further investigate. They suggested looking at grey literature and state measurement efforts. Specific efforts that were suggested include the National Core Indicators (NCI) and the new NCI-Aging and Disabilities (NCI-AD) initiative; the Medicaid HCBS Experience of Care Survey and LTSS Continuity Assessment Record and Evaluation (CARE) functional assessment items being developed and tested as part of the Demonstration Grant for Testing Experience and Functional Assessment Tools (TEFT) grant program; measurement efforts stemming from the *Improving Medicare Post-Acute Care Transformation Act of 2014* (the IMPACT Act); measures incorporated in state Medicaid waivers; and the Center for Medicare & Medicaid Innovation (CMMI) grants focused on job and workforce quality. Committee members also suggested that NQF staff speak with health care delivery systems and state health insurance plans.

Other overarching themes from the round-robin exercise included the need to focus on individual outcomes and fully take advantage of technology. Others expressed the need for evidence-based practices for HCBS because no standard service definition and interventions exist. Lastly, Committee members reflected upon the need to consider the utility or hands-on application of measurement and access and transparency of data.

Opportunity for Public Comment

Throughout the in-person meeting, public participants had the opportunity to provide comments and ask questions in-person, over the phone, or via the web chat. Participants' comments were generally focused on: suggestions for how to rephrase or restructure certain aspects of the HCBS definition; considerations related to the characteristics of a high-quality HCBS system, conceptual framework, and measurement domains and sub-domains; and efforts or resources related to HCBS quality for NQF staff to further investigate. Comments are listed in Appendix E. NQF staff will consult all public comments when reviewing and revising the draft operational definition of HCBS and the conceptual framework.

Review Next Steps and Adjourn

Ms. Feldman concluded the meeting by sharing that NQF staff will communicate the major outputs of the meeting, including a draft HCBS definition, conceptual framework, and measurement domains and sub-domains, for the Committee's additional review and feedback. NQF will submit the first draft report detailing the draft operational definition of HCBS and conceptual framework to HHS by July 15, 2015. A 30-day public and member comment on the Draft Report will be from July 16-August 14, 2015. The Committee will reconvene via a web meeting on August 29, 2015 from 12:30-2:00 pm ET.

Appendix A: Committee Members in Attendance

Name	Organization
Joe Caldwell, PhD (Co-chair)	National Council on Aging
H. Stephen Kaye, PhD (Co-chair)	University of California San Francisco
Robert Applebaum, MSW, PhD	Miami University of Ohio
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
Patti Killingsworth	Bureau of TennCare
K. Charlie Lakin, PhD	Retired, Formerly with 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

HHS Liaisons in Attendance

Name	Organization
Coretté Byrd	Centers for Medicare & Medicaid Services
Ellen Blackwell	Centers for Medicare & Medicaid Services
Venesa Day	Centers for Medicare & Medicaid Services
Jamie Kendall	Administration for Community Living
Lisa Patton	Substance Abuse and Mental Health Services Administration
D.E.B. Potter	Office of the Secretary, ASPE
Michael Smith	Centers for Medicare & Medicaid Services
Shawn Terrell	Administration for Community Living

Appendix B: HCBS Draft Definition and Issues for Committee Consideration

The following draft definition and accompanying questions is what was presented to the Committee for the review and discussion.

DRAFT DEFINITION:

High quality home and community-based services (HCBS) refer to an array of predominately non-medical services and supports [1] selected by an individual (or his/her proxy) of any age with disability or functional or cogitive limitation [2] through a person-centered planning process based on an individualized assessment of the person's strengths, needs, and preferences [3]; and safely delivered in a home or integrated community setting of the consumer's choice [4] in a manner that:

- Enables the individual to pursue identified goals and desired outcomes (e.g., health, employment, inclusion, and quality of life); [5]
- Assures the individual's rights of privacy, dignity, respect, and freedom; and [6]
- Optimizes individual initiative and control through informed decision-making, engagement in community, and independence in making life choices [7].

HCBS should be flexible to change with a person's life experience; utilize available technology; and be provided by well-supported, well-prepared, and coordinated providers and caregivers. HCBS should also be accessible, affordable, and accountable through measurement and reporting of quality and outcomes. [8]

ISSUES FOR THE COMMITTEE TO CONSIDER:

[1] – The "What"

- This definition is written to describe high-quality HCBS. Is it realistic to apply this definition to the current state?
- Payment source or type (e.g., publicly and privately funded or contributed without payment) is deliberately omitted.

[2] – The "Who"

- Should the population be more broadly defined as "any individual in need of services and supports to live independently"?
- Should "disability or functional limitation" be further defined with a footnote? (E.g., this includes all physical, functional, cognitive, mental, emotional or behavioral disabilities, limitations or conditions, substance use disorders, and multiple chronic and disabling conditions.)

[3] – How HCBS are selected

[4] – The "Where"

[5] – HCBS enables… [6] – HCBS assures… [7] HCBS optimizes…

- Other suggestions from Committee: freedom from coercion and restraint, personal living preferences, participate fully in society, facilitation of meaningful opportunities for maintaining/developing personal relationships, inclusion, social engagement shared responsibility, daily activities, physical environment, and with whom to interact

[8] HCBS system operations

- Should we be more specific than "providers and caregivers"? For example, should family caregivers be explicitly mentioned?

Appendix C: Crosswalk of High-Quality HCBS System Characteristics and Domains from Literature

Domains most frequently and often cited in the literature were cross-walked against the high-quality HCBS system characteristics identified by the Committee. The Committee developed the domains in brackets high-lighted red.

	Domains Most Frequently Cited in the Literature							Domains Often Cited in the Literature							
A high-quality HCBS system has the following characteristics:	**Consumer and Caregiver Experience**	**Access to Supports and Services**	**Community Integration/Inclusion**	**Person Centeredness**	**Service/Care Coordination**	**Quality of Life**	**Safety, Security and Order**	**Functional Status**	**Performance**	**Healthcare/ Service Utilization**	**Provider Capacity and Capabilities**	**Support for Caregivers**	**Respect/Dignity**	**Quality of Care**	**Meaningful Activity**
Workforce: trained, culturally competent, adequate, supported - [WORKFORCE/PROVIDERS]											X				
Participant engagement in the design, implementation, evaluation of the program- [CONSUMER VOICE/OWNERSHIP]															
Choice, person-driven, focused on achieving individual goals, consumer directed, control, dignity of risk- [CHOICE AND CONTROL]				X											
Privacy, dignity, respect, freedom/independence, Legal rights- [HUMAN AND LEGAL RIGHTS]													X		
Efficient, well-aligned, well-allocated, integrated, data integrity - [SYSTEM PERFORMANCE]									X						
Community engagement, Inclusion (to the same degree as people not receiving HCBS), participation; employment and productivity, having fun; social connectedness - [FULL COMMUNITY INCLUSION]			X												X
Family Caregivers are supported- [CAREGIVERS SUPPORT]												X			
Effectiveness of services/quality of care-[EFFECTIVENESS/QUALITY OF SERVICES]														X	
Services are accessible, appropriate, sufficient, dependable, timely, and coordinated-	X	X			**X**										
Equitable system/fairness and distribution of services that eliminate health disparities- [EQUITY AND FAIRNESS]															
Well-being: physical/emotional health, safety from the part of the consumer, freedom from abuse or exploitation, neglect [PHYSICAL AND EMOTIONAL WELL-BEING]							X	X							

Appendix D: Measurement Domains and Sub-domains

Domains	Sub-domains
Workforce/Providers	Sufficient numbers and appropriately dispersed; dependability; respect for boundaries, privacy, consumer preferences, and values; skilled; demonstrated competencies where appropriate; culturally and linguistically competent/sensitive/mindful; adequately compensated/benefits; safety of the worker; and team work and value-based leadership.
Consumer Voice/Ownership	Meaningful mechanism for input (e.g., design, implementation, evaluation); consumer-owned system (Is this your system?); breadth and depth of consumer participation; level of commitment to consumer involvement; diversity of consumer and workforce engagement; and consumer awareness/PR for engagement (accessibility).
Choice and Control (Self-determination)	Choice of program delivery models, provider, agency, individual worker, and setting; personal freedoms for anybody (high-level) and dignity of risk; achieving individual goals and everyday preferences (i.e., individuality, person-centered planning); self-direction; and shared accountability.
Human and Legal Rights	Respectful for the delivery system/workforce; being treated with dignity and respect; privacy; informed consent; freedom from abuse and neglect; optimizing the preservation of legal and human rights; sense of safety; and system responsiveness.
System Performance	Consumer engagement; participatory program design; reliability; publicly available data; appropriate and fair resource allocation based on need; primarily judged by the aggregate by the aggregate of individual outcomes; waiting lists; backlog; financing and service delivery structures; availability of services; efficiency and evidence based practices; and data integrity
Full Community Inclusion	Enjoyment or fun; employment, education, or productivity; social connectedness or relationships; social participation; resources to facilitate inclusion; choice of setting; and accessible built environment.
Caregivers Support	Training and skill-building; access to Resources (e.g., respite, crisis support); caregiver well-being (e.g., stress reduction, coping); caregiver or family assessment and planning; and compensation.
Effectiveness/Quality of Services	Goals and needs realized; preferences met; health outcomes achieved; technical skills assessed and monitored; technical services delivered; team performance; and rebalancing.
Services are accessible, appropriate, sufficient, dependable, timely, and coordinated	Accessibility (i.e., geographic, economic, physical, and public and private awareness or linkage); appropriate (i.e., services aligned with needs and preferences, and Are goals accessed?); sufficiency (i.e., scope of services, capacity to meet existing and future demands); dependable (i.e., coverage, timeliness, workforce continuity, knowledge of needs and preferences, and competency); timely initiation of services; and coordination (i.e., comprehensive assessment, development of a plan, information exchange between all members of the care team, implementation of the plan, and evaluation of the plan.
Equity and Fairness	Reduction in health and service disparity; transparency of resource allocation; access or waiting list; safe, accessible, and affordable housing; availability; timeliness; and consistency across jurisdictions.
Physical and Emotional Well-being	Physical functioning; cognitive functioning; social or spiritual well-being; safety as defined by the consumer; freedom from abuse, neglect, and exploitation; health status and wellness (e.g., prevention, chronic disease management); and mental health (behavioral health and substance use).

Appendix E: Web Chat Report

Each comment has been carefully reviewed and will be shared with the committee as necessary. NQF staff encourages the public and NQF members to subscribe to project alerts on the NQF HCBS Project webpage. Public and member feedback is essential to our process and we encourage continued participation throughout the life of this project. All materials from the meeting, including the slide deck and transcripts, are available on the project's webpage. The list of information sources consulted for applicable HCBS definitions and frameworks can be found in the February 20, 2015 web meeting materials. The next opportunity for public comment will begin on July 16th for the draft report on the operational definition and conceptual framework.

Messages from Public Participants
The concern re-safety has some well-established outcomes in health care - LTSS. See HCBS - Medicaid report. Suggest this be tabled, and that the committee review what is applicable or relevant to the current purposes. This will hopefully avoid derailing the process into arguments about safety, at least in those areas of personal health and safety outcomes.
Question and a comment: Would establishing "principles of high-quality HCBS" in addition to defining "HCBS" -- might that help address the issues being discussed about quality in the definition itself? This definition does not currently actually define the various aspects of HCBS. This doesn't include the range and type of services, and perhaps, what is not considered HCBS services. Are housing services HCBS services? Employment? Supports for ADL and IADL needs? Currently, this isn't a full definition of HCBS services per se and what they are If these things aren't defined, it feels circular.
3) With regard to location home or integrated community setting what about services received while at a job, while taking part in an activity outside of one home or a medical setting (e.g., religious service, sports game, dining out, shopping, all the places a person spends time in)? I generally don't like definitions that are based on what something is not, but in this case, it might be needed. This suggestion is a bit awkward, but conceptually might be what is needed: HCBS are services provided in a person's home or any community setting outside of medical or institutional settings that Are designed specifically to serve people with disabling conditions.
I would add one more value: HCBS should be provided in a way that recognizes the context of a person's life, integrating with and supporting all of the other resources that a person uses -- family, community, own skills, etc. -- to create the desired outcomes.
Please appoint a parliamentarian to consider the appropriate process on voting and rules of order. This is the stakeholder that is missing from the debate. Please request that the Nominating Committee take up this issue and seek out qualified people to be at the table. Thank You!!!

Messages from Public Participants
1) I suggest leaving high quality fear that without it, we will lose the commitment to person centeredness, which is an essential part of being high quality. 2) Any description of the types of services non-medical, health-related, social, etc. should be as broad as possible. How would one classify personal care, for example? Transportation for social engagement? Employment supports? A service dog? These are all important supports for some people, and should be part of HCBS. The best approach may be that recommended by a Committee member to simply remove the word non-medical, and not try to specify the types of services and supports that are used to achieve the aims of HCBS. 3) With regard to local home or integrated community setting what about services received while at a job, while taking part in an activity outside of one home or a medical setting (e.g., religious service, sports game, dining out, shopping, all the places a person spends time in)? 4) I agree person driven or person directed rather than person centered care for the reasons expressed by others. 5) I disagree with the concept that HCBS should integrate well with medical services, as one Committee member suggested. Not all HCBS recipients have medical needs, beyond typical wellness care that anyone without a disability might have. 6) I'm concerned about the phrase selected by an individual (or his/her proxy) without some consideration to how/when a proxy should be making the decisions. 7) I suggest changing the phrase enables the person to pursue supports the individual in pursuing a fear that enabling is too limited a concept, and may relapse to a medical focus. A person who has adequate health may be enabled to pursue desired goals and outcomes, but still not have the supports to do so. HCBS can support the person in being able to do so (e.g., through provision of employment supports, transportation, etc.). 8) I am concerned by the Ellen Blackwell definition read that made mention of helping a person to be independent. The concept of independence is a tricky one. Is a person who needs receives physical help to do things of his/her choosing, for example, independent? Some would say yes, some would say no. And those who say no might then decide that people who cannot live independently, by their more restrictive concept of what that means, should not receive HCBS as they will never achieve independence.
Concerning the caregiver question, identifying informal supports including family, friends, and neighbors is very important for consideration.
Additional efforts that may be of note and for consideration: -The National Core Indicators (NCI) and National Core Indicators - Aging and Disability (NCI-AD). AoA/ACL's Performance Outcomes Measures (POMP) tools included in their Tool Kit on their Web site. Thank you.
Safety is an important issue, but we need to keep in mind the dignity of risk as well. That is, people have the right to take risks, and to make decisions that others may think are not in their best interest. This issue also can highlight the challenges of balancing personal choice with the choices preferred by family/guardian.
What does a well-supported, well-prepared, and coordinated workforce mean? I fear that could undermine peoples' abilities and rights to hire and train the people they want to support them. Given how much of HCBS may be provided by unpaid people, this concept does not seem to be a reasonable core value.

Messages from Public Participants
Agreed, quality is better measured by outcomes. Things like freedom of choice, supporting independence, etc. I think beginning with mission/vision/principles is a great idea!
Some of the models include services and supports or access to services and support - I think the issue is USE of these services and supports and that point should be made. The services and supports may be there, but its the use that makes a difference. I can give a very interesting example about service coordination in Maryland.
Charlie is correct - outcomes are important
Relative to the Safety issue, it is not just freedom from abuse, exploitation and neglect, but there is the big picture of the emergency situations and viable plans for this population to be in place before hurricanes or other natural or man-made disasters. For example, there was a senior living center right next to the CVS fire in Baltimore on Monday night.
Yes, there are groups who cannot make their own decisions (or even speak) - they need to be included.
Good individual outcomes are often much first dependent on good system outcomes.
RE: the "why" question - capacity to proactively assess for drivers for quality improvement
Don't reinvent the wheel on measurement domains! Work with those accepted by other parts of the system, varying only by exception. HCBS is a huge piece of the answer to transforming the system, but if the domains and measures aren't consistent, the cases for resource reallocation and process changes (demonstration of quality and value) will be MUCH harder to make.
Re FRAMEWORK. Following link is NH Endowment For Health's vision for Elder Friendly Community
It is for a subset of what HCBS supports, but I think it's a very rich and holistic view of what the home and community need to offer for individuals across a variety of population subsets (beyond those who are aging.) Within each piece of the "pie" and the surrounding information/communication ring there is need for structure, process and outcome measures.
I think this "Vision" framework is a good start for the values/principals discussion, as well.
I represent community-based health and wellness organizations, including those supporting aging (thriving) in place. I have HIGH hopes that this framework isn't constrained by current policies and payment models. There is so much home and community based care and support that happens outside of the current models folks in your room are describing. As one example, don't make assumptions, create silos to describe who provides care and services base on payment.

Messages from Public Participants
"INDEPENDENCE" is a dangerous goal. Though commonly promoted, it is unhelpful in many ways. It leads the disabled, seniors, new moms ... feel inadequate if they need help. People endure worsening health conditions, leading to expensive and sometimes impossible "fixes", and it works against individuals reaching out for even simple, neighborly supports which improve health and wellness at little or no cost to the system. CHOICE, CONTROL, or DIGNITY are better principles to design for.
Not sure why we need to qualify what people may receive HCBS services. Not all needs can be defined as being due to disabilities.
Technology, policy, and culture are changing SO quickly, it seems important to have a broad definition of what services are included. I'd vote for "... an array of medical and non-medical ..."
RE: Family caregivers ... include and broaden to include other "outside-the-system" caregivers -- family, other friends and loved ones, community supports. Also include more in "providers" (health, wellness, other services). In #8: "... be provided by ... coordinated service providers, caregivers, community supports and loved ones."
It should be person centered - health may not be the first priority for the person as a measure of quality.
Adult Day Services support people holistically in the community often including medical/health-related needs. In some states, in fact, ADS is referred to as adult day health.
Comment on behalf of the National Adult Day Services Association, please consider removing the term 'predominantly non-medical'
Related to the discussion on medical vs non-medical services and facilitating eventual quality measurement: Would encourage the committee to consider timely and opportune alignment of the HCBS definition with the National Quality Strategy (NQS) followed by development of a more integrated HCBS framework within the context of the triple aim (better care, healthy people, affordable care). The six NQS priorities and a focus on holistic person-centered care (rather than medical/non-medical/social et al.). Reference: Barbara Gage's comments during the Academy Health April 20, 2015 meeting on "Measuring the Quality of Home and Community-Based Services".Would also suggest inclusion of linguistic and cultural competencies in the HCBS framework.Thank you for the opportunity to comment. So delighted that this discussion has begun.
One definition from the internet: Core values are guiding principles that dictate behavior and action...help determine right from wrong...help an organization determine if they are on the right path, fulfilling their goals
Is the 200 published sources list available for the public?
SAFETY!!! Med problems, falls, safe food, freezing in winter.
YES ... Ongoing Improvement as value

Messages from Public Participants
Value - address individual/"family" (not just individual), community, and system values and value.
COMMENT: Impact on Triple aim of population is important. (Healthy community/population, improved health care outcomes and experience, improved per capita cost of care.)
Personal Outcome Measures instrument includes 21 outcomes (indicators) grouped in three factors: Factor One: My personal, physical and environmental people are connected to natural support networks. People have intimate relationships. People are safe. People have the best possible health.People exercise rights.People are treated fairly. People are free from abuse and neglect. People experience continuity and security. People decide when to share personal information. Factor Two: My connectedness and life in the community. People choose where and with whom they live. People choose where they work. People use their environment. People live in integrated environments. People interact with other members of the community. People perform different social roles. People choose services.Factor Three: My dream discovery, choice and self-determination. People choose personal goals. People realize personal goals. People participate.
workforce should include dependable
Just a thought: HCBS programs for people with severe mental illness emphasize not only care and coordination, but the concepts of rehabilitation and recovery. The goal of HCBS is not static (care) but dynamic. Perhaps this is indirectly captured in the definition
re NH Endowment for Health Vision ... it has been recently updated to include "EQUITY" as one of the principles (around inner circle ... with person-centered, choice, respect, dignity, independence)
I wanted to make sure that you got the link to the framework I was describing (the comments about the "pie" that were just read). LINK HERE.
IHI Triple Aim, simultaneously improving the health of the population, enhancing the experience and outcomes of the patient, and reducing per capita cost of care for the benefit of communities.
Interested in understanding the domains from the meta-analysis. Are these considered comprehensive and mutually exclusive? Was wondering about broader domain identities to capture comprehensively and in a mutually exclusive way: family roles, community roles, workforce roles, financial independence, physical and emotional health, and vital communities. The 'domains' then cited might fit within those?
Equitable concerns me, unless it is well defined. Are we talking about equitable distribution of services, such that everyone with the same level of disability receives the same mix of services? Or, are we talking about equitable outcomes? Focusing on outcomes requires us to recognize that people come to the table with different resources. Some people will require more paid sources, while others will have greater access to family, friends, and community resources.

Messages from Public Participants
from UMN data, *Of the 1.14 million people with IDD served by state IDD agencies on June 30, 2012, 634,988 (56%) lived in the home of a family member, 10% lived in a home they owned or leased, and 5% lived with a host family or in a family foster home. The remaining 28% lived in a group home or facility. Individuals providing support to people with I/DD is not a small number.
In addition to 'accessible built environment', what about 'access to appropriate assistive and adaptive technology'. Access is important -- but 'appropriateness is critical too'. Just take a look at the rates of equipment abandonment because of poor fit between user's functional needs, and capabilities and the training and equipment they receive.
Adequacy of services
Culturally competent is not an accurate term, as it denotes a level of mastery. However, this is not attainable. Cultural and linguistic humility, as well an understanding of historical trauma is the preferred language as it encompasses multiple issues across race/ethnicity.
Training and education often do not equate equity. Process and restructuring systems is more effective than training alone - the approach should be tailored to the needs and/or goals (systems change, versus service providers, versus users)
Suggestion: Participant governance
RE: Family Caregivers ... consider "ALL" Caregivers.
Re: "Ownership": Consider "Responsibility"
Framework -- Systems, Communities, Consumers at the top level? Programs and services may have impact across all three levels. Need different types of measures (structure, process, and outcomes) at all levels, and for all programs. HCBS should have measurable impact on all three levels.
Are the slides with the domains decided today available somewhere?
Look at work of Village-to-Village national network - UC-Berkeley led evaluation of services in aging in place Villages. PIs: Andrew Scharlach, scharlach@berkeley.edu, Carrie Graham clgraham@berkeley.edu. Non-medical, largely non-professional, huge value adding home and community-based services.
Look at SCALE Initiative of IHI/RWJF -- integrated community-based efforts to improve health and wellness. HCBS are central, and being delivered and supported in non-traditional ways.
Don't leave out structural measures at the community level -- Do they have town/city plan with health priorities? Do they have Parish or Community nurses? Transportation options? Support for low-income residents? (Beyond Fed/State)

Messages from Public Participants
HCBS definitions will (MUST) change -- please don't be constrained by "how different" HCBS is today. Many other health care sectors and community settings (schools, faith organizations, vendors) are taking on responsibilities and services that are effectively HCBS. They should be able to use the consistent measures to prove the value of their work.
Thank you for allowing me to participate from this end of a computer. Very interesting discussion.