NATIONAL QUALITY FORUM

Agenda

Committee In-person Meeting: Addressing Performance Measure Gaps in Home and Community-Based Services to Support Community Living

April 29 – April 30, 2015

NQF Conference Center at 1030 15th Street NW, 9th Floor, Washington, DC

Remote Participation Instructions:

Streaming Slides and Audio Online

- Direct your web browser to: http://nqf.commpartners.com/se/NQFLogin/
- Under "Enter a Meeting" type the meeting number for Day 1: 495303 or for Day 2: 903373
- In the "Display Name" field, type your first and last name and click "Enter Meeting"

Teleconference

- Dial **(888) 802-7237** for committee members and **(877) 303-9138** for public audience

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

Day 1: Wednesday, April 29, 2015

8:30 am **Continental Breakfast**

9:00 am **Welcome, Introductions, and Overview of Meeting Objectives**
Committee Co-Chairs
Marcia Wilson, Senior Vice President, NQF
- Welcoming remarks and brief introductions of committee members
- Review committee's charge and scope of work

9:30 am **Project Definition of Home and Community Based Services**
Juliet Feldman, Project Manager, NQF
Joe Caldwell, Committee Co-Chair
- Discuss results of HCBS definition exercise from February web meeting
- Reach consensus on the draft definition of HCBS
- Discussion and questions

11:00 am **Opportunity for Public Comment and Break**

11:15 am **Beginning the Process of Developing an HCBS Measurement Framework**
Sarah Lash, Senior Director, NQF
Stephen Kaye, Committee Co-Chair
- Past and present efforts related to HCBS quality: HHS and private-sector projects
- Review existing HCBS frameworks
- Committee discussion of intended uses of the HCBS framework and potential components to represent

12:15 pm **Opportunity for Public Comment**

12:30 pm **Lunch**

1:00 pm **Small Group Work: Illustrating the Conceptual Framework**
All Committee Members
- Use drawing techniques to develop visual representation of conceptual framework

2:00 pm **Share Results from Small Group Discussions**
All Committee Members
Sarah Lash
- Share and discuss sketches of the conceptual framework
- Come to agreement about what concepts need to be represented
- Discussion and questions

2:45 pm **Opportunity for Public Comment and Break**

3:00 pm **Defining Measurement Domains for the Framework**
Andrew Anderson, Project Manager, NQF
Stephen Kaye
- Generate and refine domains for measurement
- Discussion and questions

4:15 pm **Opportunity for Public Comment**

4:30 pm **Summary of Day and Adjourn**
Sarah Lash

Day 2: Thursday, April 30, 2015

8:30 am **Breakfast**

9:00 am **Review Results and Themes from Day 1**
Joe Caldwell

9:30 am **Present Methodology for Environmental Scan and Synthesis of Evidence**
Juliet Feldman
Joe Caldwell
- Share and refine planned approach for environmental scan of measures and synthesis of evidence to support measurement
- Discussion and questions

10:30 am **Small Group Work: Defining Measurement Sub-Domains for Chosen Domains**
All Committee Members
- Generate sub-domains for measurement under each of the domains identified during the preceding day

11:30 am **Share Results from Small Group Discussions**
Andrew Anderson
Stephen Kaye
- Share and discuss measurement sub-domains
- Discussion and questions

12:15 **Opportunity for Public Comment**

12:30 **Lunch**

1:00 pm **Committee's Review and Final Refinements to Conceptual Framework**
Sarah Lash
Committee Co-Chairs
- Revisit illustration of conceptual framework
- Revisit domains and sub-domains for measurement
- Discussion and questions

2:15 pm **Round Robin: Identifying Fertile Ground for Measurement**
All Committee Members
- Each committee member responds to discussion prompts

3:15 pm **Opportunity for Public Comment**

3:30 pm **Review Next Steps and Adjourn**
Juliet Feldman

Addressing Performance Measure Gaps in Home and Community-Based Services to Support Community Living

Committee In-person Meeting

April 29-30, 2015

NATIONAL QUALITY FORUM

Welcome, Introductions, and Overview of Meeting Objectives

HCBS Quality Committee

- Joe Caldwell (Co-Chair)
- Stephen Kaye (Co-Chair)
- Robert Applebaum
- Kimberly Austin-Oser
- Suzanne Crisp
- Jonathan Delman
- Camille Dobson
- Sara Galantowicz
- Ari Houser
- Patti Killingsworth
- Charlie Lakin
- Clare Luz
- Sandra Markwood
- Barbara McCann
- Sarita Mohanty
- Gerry Morrissey
- Ari Ne'eman
- Andrey Ostrovsky
- Mike Oxford
- Lorraine Phillips
- Mary Smith
- Anita Yuskauskas

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

Measuring HCBS Quality Project

Provide multistakeholder guidance on the highest priorities for measurement of home and community-based services that support high-quality community living

- Offers an opportunity to address the gaps in HCBS measurement and provide direction for future performance measurement
- Supports the aims of the Affordable Care Act, the National Quality Strategy, and HHS' Community Living Council
- Will maintain a broad and inclusive orientation to community living and maximize opportunities for public input

Project Components

Under contract with the Department of Health and Human Services (HHS), this two-year project will entail:

1. Creating a conceptual framework for measurement, including a definition for HCBS
2. Performing a synthesis of evidence and environmental scan for measures and measure concepts
3. Identifying gaps in HCBS measures based on framework and scan
4. Making recommendations for HCBS measure development

Committee Role

- Contribute content knowledge and expertise over the course of the project
- Ensure input is obtained from relevant stakeholders
- Assist with the identification of existing research, measures, and resources to identify performance measure needs
- Work together as a group to craft consensus on complex issues
- Ultimately, make recommendations for the future state of HCBS quality measurement, including measure development

Ground Rules for Today's Meeting

- Open sharing of, and respect for, differing views
- Terminology is important, but shouldn't be a barrier to building consensus in the group
- Work toward defined meeting objectives
  - Staff will maintain a list of important but out-of-scope "parking lot" issues to be tackled at future meetings
- Always use your microphone for the benefit of remote participants and the transcript
- Members of the public will have the opportunity to provide comments throughout the meeting; verbal remarks should be brief and any details submitted to the staff

Operational Definition of Home and Community Based Services

Purpose and Process of Creating a Definition

- Committee will create a broadly applicable definition of HCBS for purposes of this project
- The definition is the first component of a conceptual measurement framework that will be used throughout the project to help prioritize measurement needs
- Development is iterative with multiple opportunities for Committee and public input
  - Committee and public began offering suggestions at February web meeting
  - Today's session will digest and refine the input received
  - A draft operational definition will be included in the committee's first report due July 15

Principles for Crafting an Operational Definition of HCBS – Established at Web Meeting

- Allow the committee to reach a common understanding of what is meant by the term "HCBS"
- A brief but broadly inclusive statement that emphasizes the goals of HCBS
- Positive in tone, plain-language
- A definition that can be used across public and private payers and accountable entities
- Contribute to an understanding of *high quality* HCBS as part of the conceptual framework
  - Person-centered, enhances quality of life, shared responsibility, accessible, flexible, coordinated, integrated, enables self-determination
- Project-specific: not meant to replace existing guidance or regulations
- To maximize applicability, avoid a laundry list of services, specific consumer populations, or types of settings

Progress To-Date

- NQF staff reviewed approximately 200 published sources for definitions and frameworks related to HCBS
- Following the February 20th web meeting, Committee members, HHS Liaisons, and members of the public submitted their definitions of HCBS to NQF
  - A compilation of all definitions submitted to NQF and identified during the staff review is included in the meeting materials
- NQF staff reviewed all definitions to identify commonalities and developed a "strawman" definition for Committee review and discussion

Aspects Included in the Draft HCBS Definition

1. The What
2. The Who
3. How HCBS are selected
4. The Where
5. HCBS enables…
6. HCBS assures…
7. HCBS optimizes…
8. HCBS System Operations

Please refer to Draft HCBS Definition Worksheet

Draft "Strawman" Definition of HCBS

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 cognitive 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]

Overarching Themes – The "What"

Wide range of services and supports that are:

- Person and family-centered
- Predominantly non-medical
- Selected by the individual
- Easy to access
- Flexible to change with a person's life experience
- Paid and unpaid
- Funded through public and private programs
- Needed for a sustained period of time
- Coordinated to maximize resources
- Provided by culturally/linguistically competent formal and informal providers/caregivers, including family caregivers
- Accountable through measurement and reporting of quality

Overarching Themes – The "Who"

Provided to:

- Individuals, persons, or participants (not recipients)…
  - of all ages across all disabilities
  - with disabilities/limitations/impairments (intellectual, developmental, physical, cognitive, emotional, mental health, behavioral health, substance use disorders, multiple chronic and disabling conditions, etc.)

- People who need support services as a result of functional or age-related limitations, disabilities, multiple chronic conditions, or other challenges participating in community life or accessing needed services

Overarching Themes – The "Where"

Provided in:

- In the homes and communities of their choice using a person-centered planning approach
- Independent living in community-integrated, non-institutional settings (integrated in and support full access to the greater community)
- Includes opportunities to seek employment in competitive integrated settings and engage in the community if desired
- Accessible and affordable to persons requiring them
- Does not segregate individuals by disability, specific disability, or other disability-related characteristics, from the broader community

Overarching Themes – The "Why"

In order to:

- Support the personal, social, health, and employment needs of individuals and their family and paid caregivers
- Assures the individual's basic human rights to privacy, dignity, respect, and freedom from coercion and restraint
- Sustain community living and participate fully in society
- Optimize (but do not regiment)/maintain and improve/promote and protect:
  - Individual choice, control, autonomy, self-determination, initiative, personal living preferences, independence in making life choices
  - Shared responsibility and informed decision-making
  - Inclusion, productivity, social engagement, involvement in meaningful activities
  - Safety and reasonable access to needed services and supports
  - Health (physical and mental) and quality of life

Opportunity for Public Comment and Break

Beginning the Process of Developing an HCBS Measurement Framework

Past and present efforts related to HCBS quality

Environmental Scans:

- AHRQ Environmental Scan of HCBS Measures
- TEFT: Environmental Scan of HCBS Assessments and Instruments and eLTSS Initiative

Performance Measurement:

- National Core Indicators
- AARP: State Scorecard on LTSS for Older Adults, People with Disabilities and Family Caregivers

Policies/Guiding Principles:

- National Quality Strategy
- The Improving Medicare Post-Acute Care Transformation Act of 2014 (IMPACT)

What is a Conceptual Framework?

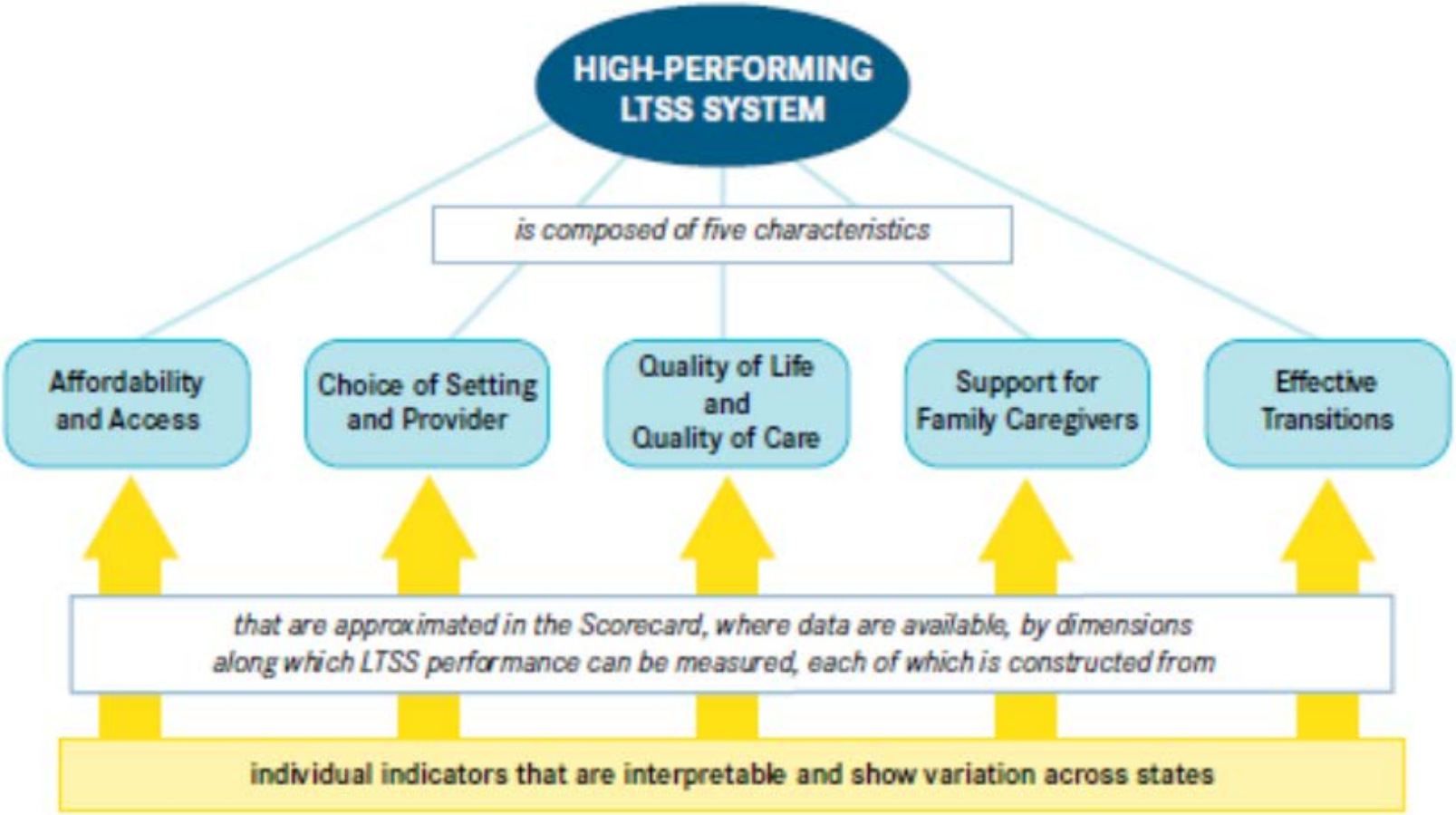
- Conceptual Framework:
  - A network of interlinked concepts that together provide a comprehensive understanding of a phenomenon
  - Not merely a collection of concepts, but a construct in which each concept plays an integral role
  - Lays out the key factors, constructs or variables and presumes the relationships among them

Potential Uses of the HCBS Measurement Framework

- Establish shared understanding of the mechanisms through which high-quality HCBS is achieved
- Guide the environmental scan for HCBS measures and synthesis of evidence
- Assist the committee in prioritizing measurement opportunities
- Provide input to HHS to guide HCBS programmatic initiatives
- Support standardization of HCBS measures by signaling to measure developers gaps in performance measurement
- Inform and stimulate future research

Example Frameworks

Framework for Assessing LTSS System Performance



Reinhard, Susan C. *A State Scorecard on Long-Term Services and Supports for Older Adults,*. Publication. AARP, 2014.

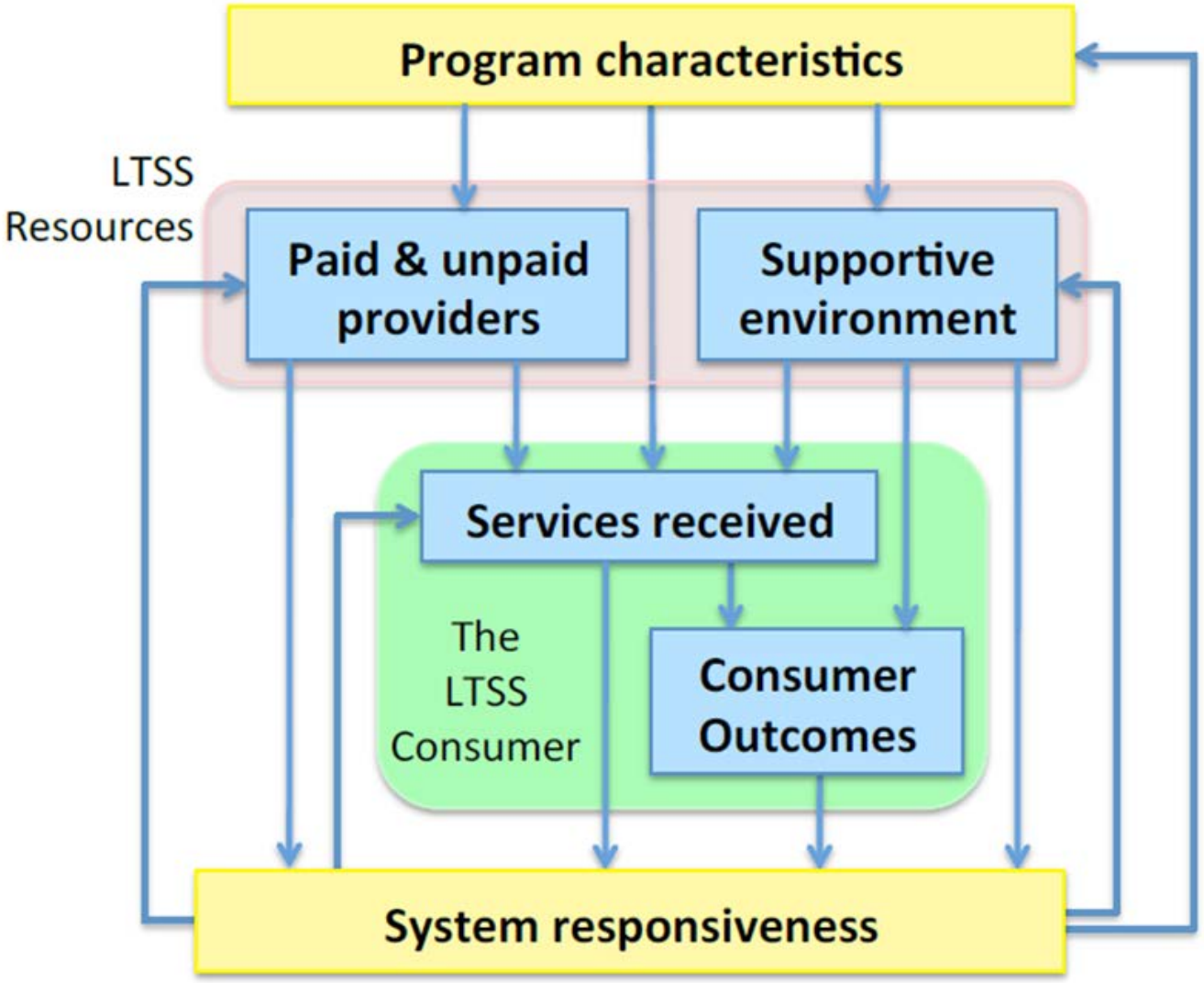
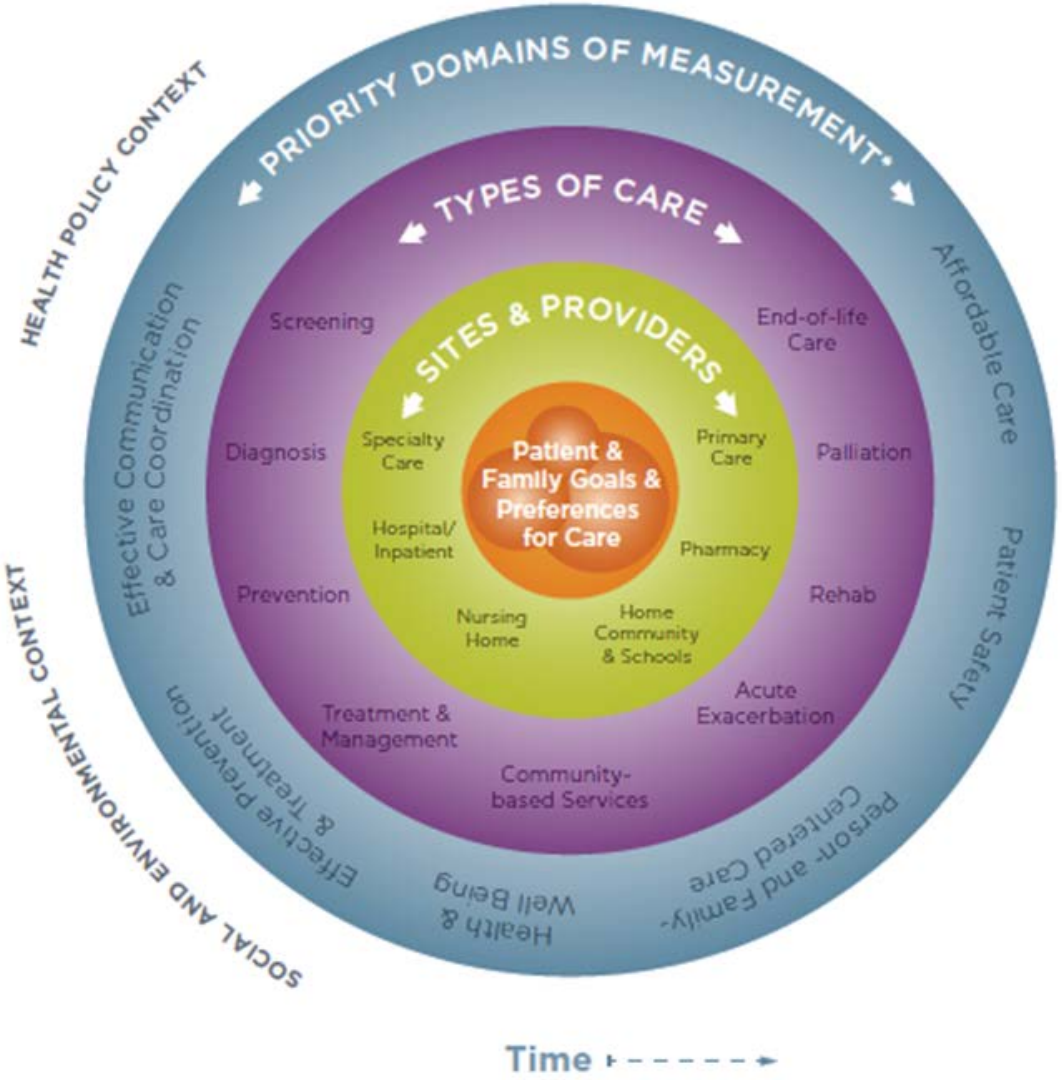


Figure 1. Conceptual Framework for HCBS Quality

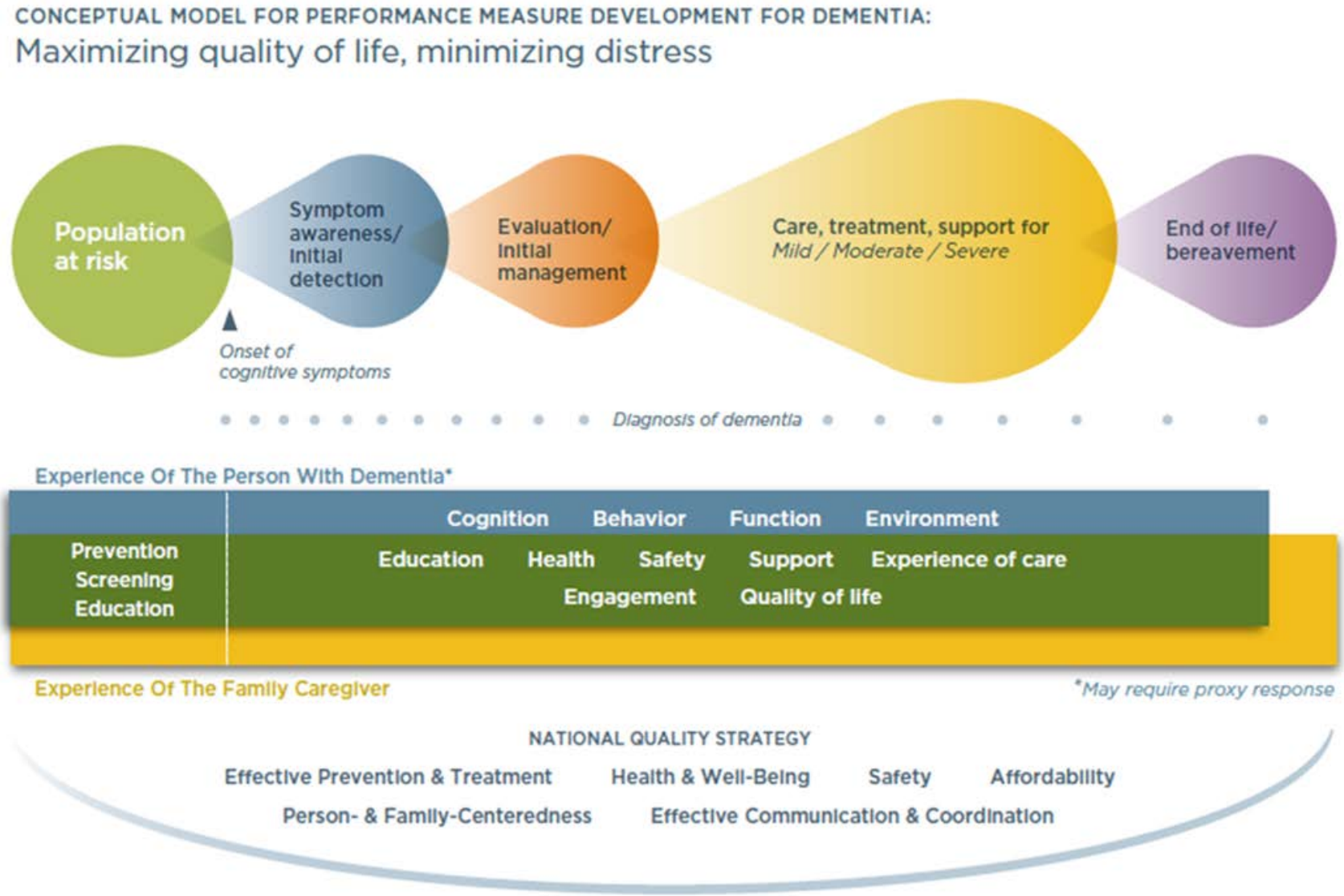
Kaye, Stephen H. "Measuring Quality in Home- and Community -Based Services." *The Gerontologist* (2015). DRAFT MANUSCRIPT

Framework for Measuring the Care of Individuals with Multiple Chronic Conditions (NQF)



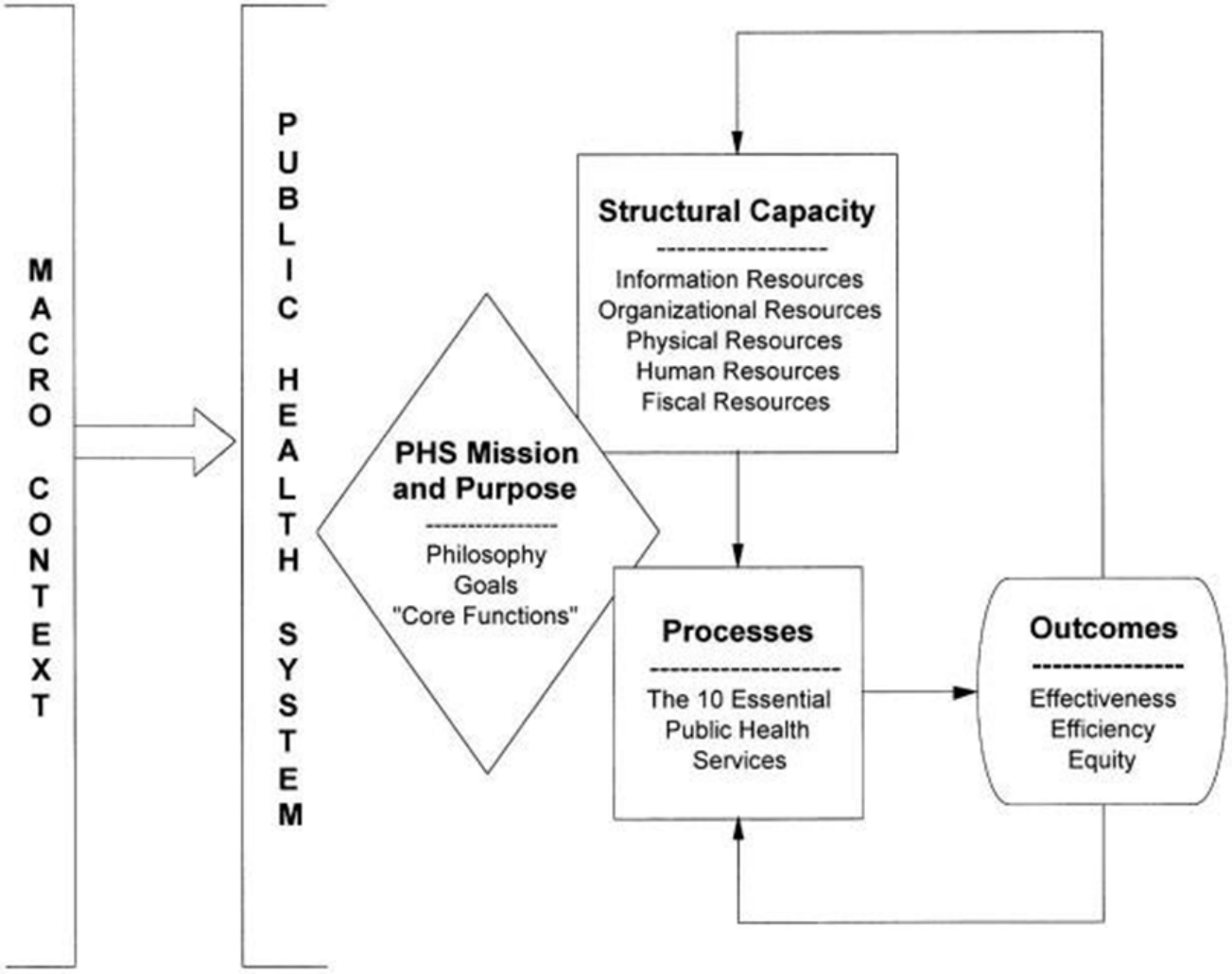
*Each priority domain of measurement may be addressed using several types of measures, including structure, process, outcome, efficiency, cost/resource use, and composite measures.
The use of outcomes measures, when available, and process measures that are most closely linked to outcomes is preferable.

"MCC Measurement Framework ." *NQF: MCC Measurement Framework*. Department of Health and Human Services, 1 May 2012.



"Priority Setting for Healthcare Performance Measurement - Alzheimer's Disease ." NQF: Priority Setting for Healthcare Performance Measurement. Department of Health and Human Services, 15 Oct. 2014.

A Conceptual Framework to Measure Performance of the Public Health System



Handler, Arden. "A Conceptual Framework to Measure Performance of the Public Health System." *American Journal of Public Health*. © American Journal of Public Health 2001, 1 Aug.

Themes Among Example Frameworks

- Authors created criteria to uniformly select framework components
- Considered measurement burden
- Used arrows to demonstrate conceptual relationships
- Illustrated highest-level measurement areas
- Built on evidence or guiding principles
- Identified cross-cutting areas that offer the greatest potential for reducing disease burden and/or cost and/or improving health and well-being

Framework Discussion Questions

- Who or what entity is the target audience for using the framework?
- In a well-organized report, the title of a figure explains what it contains. What do you envision as the title for the framework? That is, what should the framework illustrate?
- What level of detail should the framework include?
- Should the framework emphasize system or consumer outcomes? What are the primary outcomes?

Continued Discussion - Framework Components

- What specific components of a high-quality HCBS system should be included in the framework?

Possibilities are endless – can be things or actions

Consumers, Direct Care Workers, Quality Measurement, Quality Improvement, Services and Supports, Family and Friends, Faith-based Entities, Community/Neighborhood, Clinical Care, Institutional Care, Housing/Home, Emergency Arrangements, Recreation/Leisure, Transportation, Employment/Volunteering, Technology, Education, Nutrition/Diet, Person-Centered Planning, Behavioral Health Recovery, Quality of Life, Health Outcomes, Assistive Technologies, Policy and Payment, Public Reporting, etc…

Opportunity for Public Comment

Lunch

Small Group Work: Illustrating the Conceptual Framework

Exercise 1: Illustrating the Conceptual Framework

Task: Illustrate a framework for HCBS measurement in small groups

- Pre-assigned groups of 5-6 members
- Each group will use the same components
  - Groups may add their own components using the materials provided
- Each group will have an NQF staff member and HHS advisor as an observer
- Each small group will present their illustration to the larger group, so designate a representative before you start collaborating

Tips for Building the Conceptual Framework

- There is no “right” representation – be creative!
- Start with a basic, simple structure and add additional variables as needed
- Determine your desired level of specificity, based on the purpose of the framework
- Consider that the relationships depicted are driven by a combination of theory and evidence
- Use different shapes and object sizes; think about placement
- Use lines to denote connectivity
- Use arrows for directionality and to show relationships between components
- If you think of something too detailed, make a note of it. It may be appropriate to include as a domain or sub-domain later…

Group Assignments

Group 1: with Sarah

Joe Caldwell, Kimberly Austin-Oser, Robert Applebaum, Andrey Ostrovsky, Ari Houser

Group 2: with Nadine

Charlie Lakin, Jonathan Delman, Sarita Mohanty, Mary Smith, Anita Yuskauskas, Ari Ne'eman

Group 3: with Drew

Stephen Kaye, Suzanne Crisp, Patti Killingsworth, Gerry Morrissey, Lorraine Phillips

Group 4: with Juliet

Camille Dobson, Sara Galantowicz, Clare Luz, Sandy Markwood, Barbara McCann, Mike Oxford

Share Results from Small Group Discussions

Please describe:

- The specific focus of the framework (e.g., Delivery of HBCS or Population Outcomes)
- The components of the framework, and whether you added any to those pre-defined before lunch
- The major relationships among the components
- How the framework as a whole describes HCBS quality measurement
- Unresolved challenges or questions that you would like the committee to further discuss

Opportunity for Public Comment and Break

Identifying Measurement Domains for the Framework

Step-Wise Approach

1. Review potential domains emerging from conceptual framework work and the literature to determine completeness
   - **Action:** are any high-level concepts missing?
2. Begin to get a sense of measurement priorities
   - **Action:** Committee show of hands for most and least important measurement domains on list
3. Organize and refine measurement domain topics
   - **Action:** review draft list of domains and subdomains, offering suggestions about organization and refinements

Source Selection Criteria

- More than 200 sources were reviewed and 38 were found to contain domains and sub-domains of quality measurement for HCBS.
- 10 of the 38 were selected for a frequency analysis based on the following criteria:
  - Relevance
  - Breadth of Scope
  - Evidence Type
  - Source Type
  - Currency

Domains Frequently Cited in the Literature

Most Cited
Consumer and Caregiver Experience
Access to Supports and Services
Community Integration/Inclusion
Person Centeredness
Service/Care Coordination
Quality of Life
Safety, Security and Order

Often Cited
Functional Status
Performance
Healthcare/ Service Utilization
Provider Capacity and Capabilities
Support for Caregivers
Respect/Dignity
Quality of Care
Meaningful Activity

Exercise Tool: Identifying Sub-Domains
PREVIEW ONLY

Domains	Sub-Domains Across Three Levels of Analysis		
	System (e.g., National, State)	**Intermediate Accountable Entity (e.g., Health Plan, Agency)**	**Individual (e.g., Consumer, Caregiver)**
Access to Supports and Services	*Unmet demand for services* *% of consumers served in community settings of choice*	*Wait time for service exceeding # days*	*Consumer assessment of responsiveness* *Caregiver assessment of responsiveness*
Domain 2	Subdomain A Subdomain B Subdomain C	Subdomain A Subdomain B	Subdomain A Subdomain B Subdomain C
Domain 3	N/A	Subdomain A Subdomain B	Subdomain A Subdomain B
Domain 4	…	…	…

Discussion and Questions

- Based on the domains found in the literature and the themes that emerged from constructing the conceptual framework, which do the Committee want to emphasize?

- Aim for roughly 10 measurement domains. More detailed sub-domains will be defined and organized tomorrow.

Opportunity for Public Comment

Summary of Day

Ahead Tomorrow

- Methodology for Environmental Scan and Synthesis of Evidence
- Small Group Work to Define Sub-Domains
- Review and Refinements to Conceptual Framework, Domains, and Sub-Domains
- Fertile Ground for Measurement

Image Credit: vcpost.com

DAY 2

Review Results and Themes from Day 1

Present Methodology for Environmental Scan and Synthesis of Evidence

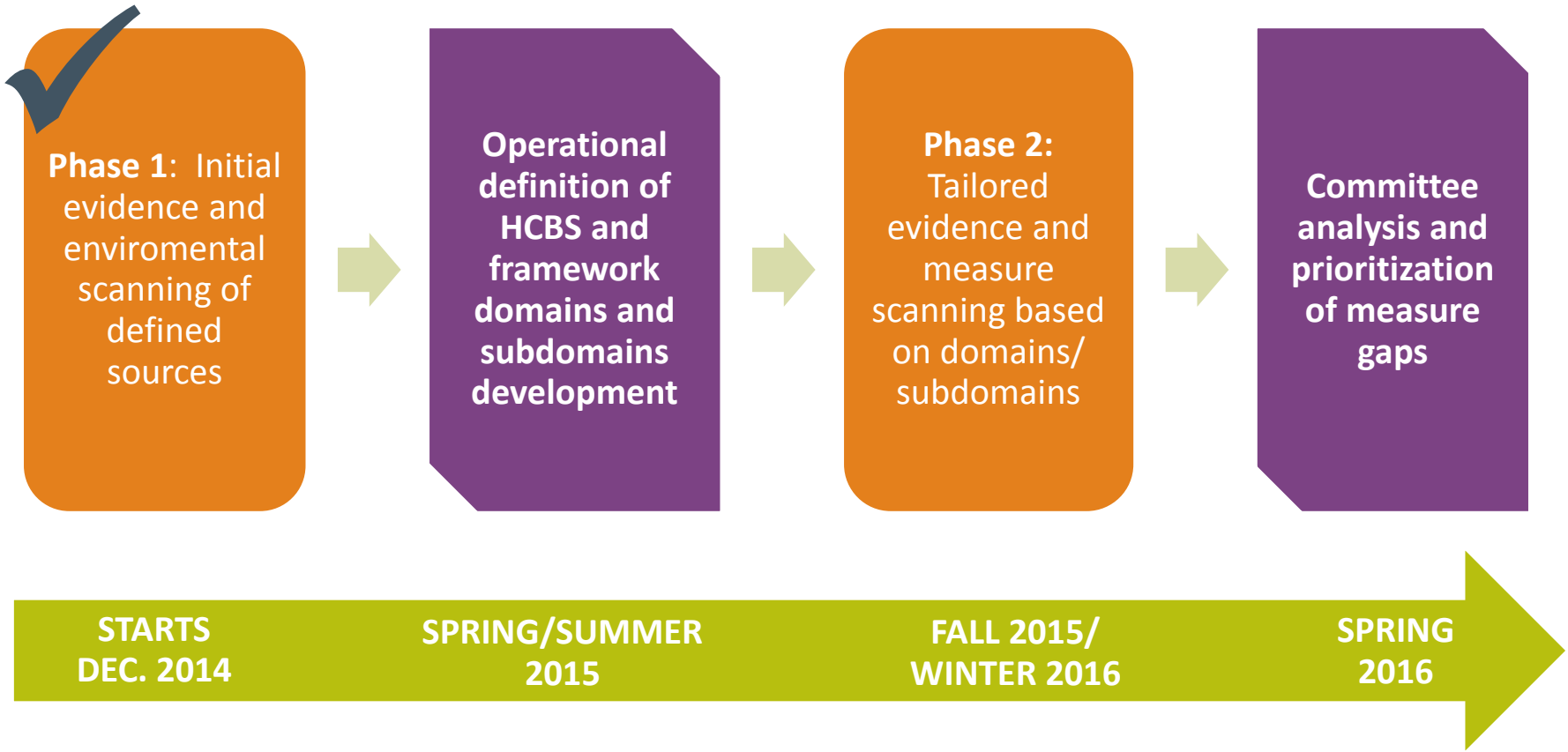
General Methodology

- Environmental scan and synthesis of evidence are distinct but inter-related activities
- Iterative approach with activities related to the synthesis and scan occurring in tandem
- Information gathered will inform committee's deliberations
- Public commenting opportunities to occur throughout as well as outreach to stakeholders to learn what HCBS measures may be in development or use

Considerations

- Research approach will emphasize the factors shared across the facets of HCBS and acknowledge distinctions
- Specific attention will be devoted to understanding previous efforts to measure and improve HCBS quality to position this project for long-term success and impact
- A final list of measures identified during the scan will be produced at the end of the project

General Methodology



Synthesis of Evidence

- Objectives:
  - Directly inform the development of the operational definition of HCBS and a conceptual framework for quality measurement
    - Now partially complete
  - Support the scan for measures by identifying concepts and ideas that should be measured, based on the literature

- The synthesis of evidence will focus on literature describing quality measurement best practices and challenges
- The evidence will support later prioritization of measurement opportunities within the committee's domains and sub-domains

Synthesis of Evidence

- For Phase 1, NQF has consulted a pre-defined list of sources identified by HHS, the Committee, and members of the public to inform the HCBS definition and framework development
- For Phase 2, NQF will conduct an organized literature review guided by the HCBS definition and framework domains and subdomains
- Phase 2 may also include key informant interviews if information sought is unlikely to be published

Environmental Scan of Measures and Measure Concepts

- Objectives:
  - Identify existing measures applicable to HCBS, with an emphasis on those that map to the conceptual framework's domains and subdomains
  - Identify promising examples of HCBS quality measures to guide committee discussion of implementation barriers and mitigation strategies, similar to a case study
  - Identify measure concepts and ideas that should be further developed into future performance measures that would best support community living

Environmental Scan of Measures and Measure Concepts

- Phase 1: similar to synthesis of evidence, NQF has collected and compiled various pre-defined measure sources with input from the Committee.
- Phase 2: NQF to continue scan based on framework domains and subdomains. Measures will be organized for later Committee review.

Environmental Scan of Measures for Medicaid Title XIX Home and Community-Based Services: Final Report. June 2010. Agency for Healthcare Research and Quality, Rockville, MD. http://www.ahrq.gov/professionals/systems/long-term-care/resources/hcbs/hcbsreport/index.html

Next Steps for Research Efforts

- NQF staff to begin Phase 2 of research efforts based on measurement domains and subdomains identified by the Committee
- August 28, 2015 webinar – NQF to provide the Committee an update on research efforts
- Nov. 15, 2015 – Draft Environmental Scan of Measures and Synthesis of Evidence Report due to HHS
- Nov.-Dec., 2015 – 30-day public comment period on Draft Report

Identifying HCBS Sub-Domains

Day 1: HCBS Domains

Sub-Domains

- Task: Identify sub-domains for HCBS measurement using domains identified on Day 1
  - Pre-assigned groups of 5-6 committee members
  - Each group will have a NQF staff member and HHS advisor as an observer
  - Each group will be given a (different) set of domains and work as a team to identify the sub-domains
    - Groups will be provided with frequently cited sub-domains
  - Each group will designate a person to present back to the Committee

Exercise Tool: Identifying Sub-Domains

Domains	Sub-Domains Across Three Levels of Analysis		
	System (e.g., National, State)	**Intermediate Accountable Entity (e.g., Health Plan, Agency)**	**Individual (e.g., Consumer, Caregiver)**
Access to Supports and Services	*Unmet demand for services* *% of consumers served in community settings of choice*	*Wait time for service exceeding # days*	*Consumer assessment of responsiveness* *Caregiver assessment of responsiveness*
Domain 2	Subdomain A Subdomain B Subdomain C	Subdomain A Subdomain B	Subdomain A Subdomain B Subdomain C
Domain 3	N/A	Subdomain A Subdomain B	Subdomain A Subdomain B
Domain 4	…	…	…

Group Assignments

Group 1: with Juliet

Joe Caldwell, Kimberly Austin-Oser, Robert Applebaum, Andrey Ostrovsky, Ari Houser

Group 2: with Drew

Charlie Lakin, Jonathan Delman, Sarita Mohanty, Mary Smith, Anita Yuskauskas, Ari Ne'eman

Group 3: with Sarah

Stephen Kaye, Suzanne Crisp, Patti Killingsworth, Gerry Morrissey, Lorraine Phillips

Group 4: with Nadine

Camille Dobson, Sara Galantowicz, Clare Luz, Sandy Markwood, Barbara McCann, Mike Oxford

Share Results from Small Group Discussions

Summarize for ~3 minutes, committee will then discuss each set of domains for ~8 minutes

- *Please Describe*:
  - The discussion that contributed to the creation or selection of each sub-domain
    - Were any sub-domains controversial?
    - Where did you have the most agreement?
  - How did you decide which level or levels of analysis your sub-domains fit?
  - Unresolved challenges or questions that you would like the committee to further discuss

Opportunity for Public Comment

Lunch

Committee's Review and Final Refinements to Conceptual Framework

Bringing It All Together

Committee review:

- Presentation of illustration developed on Day 1
- Presentation of measurement domains developed on Day 1
- Presentation of measurement sub-domains developed on Day 2

  - Are any important elements missing?
  - Is the level of detail consistent where needed?
  - Do domains or sub-domains need to be reorganized or more fully defined?

Round Robin: Identifying Fertile Ground for Measurement

Identifying Fertile Ground for Measurement

- Keeping the environmental scan for measures and the synthesis of supporting evidence in mind…
  - Where are promising quality measurement activities taking place now?
  - What type(s) of quality measurement will be most feasible in the short term?
  - Where you do perceive the evidence base to be strongest? Or growing most rapidly?
- Members are invited to share other parting thoughts about the key findings of this meeting.

Opportunity for Public Comment

Next Steps

Adjourn

Thank you for participating!

HCBS Draft Definition and Issues for Committee Consideration

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?

Contributer	Defintion	Notes
Andrey Ostrovsky	Services and supports that assist older adults and people with disabilities (including mental health and substance use disorders) to live with dignity and independence in community settings. HCBS complement medical and other traditional health services, and help people to maintain and improve health and quality of life in their chosen community settings.	ACL's definition for HCBS: http://www.acl.gov/Programs/CDAP/OIP/docs/2402-a-Guidance.pdf
Charlie Lakin	Home and community based services are paid and unpaid services and supports provided to people with disabilities to assist them in living in the homes and communities of their choice with maximum achievable independence, inclusion, productivity, self-determination, health and safety.	
Suzanne Crisp	1) Self-determination has little relevance to disabled and elderly programs. It has total relevance with IDD and Behavioral Health. Recommend we use informed decision-making, shared responsibility, choice and control to convey these thoughts rather than a term that will immediately give the impression that we are omitting entire communities with our terminology. 2. Use individuals, persons or participants not recipients. 3. Use community life not non-institutional. 4. HCBS are offered to persons of all ages across all disabilities in settings selected by the individual using a person-centered planning approach. 5. Include functional but also include cognitive and behavioral limitations. 6. Types of services: Suggest personal assistant and personal care services (ADLs and IADLs are included in the broad definition of the two terms so this is repetitive). Add non-skilled and skilled nursing; support services (skills building and employment), and residential and non-residential services (so long as they meet the HCB setting requirements).	
Mike Oxford	Home and Community-based Services (HCBS) encompass a broad range of services and supports, often associated with various Medicaid Waivers, that are designed to assist people with disabilities of all ages with maintaining or improving independence and integration into home and community life and with promoting and protecting the physical, cognitive, intellectual and health functions of the service recipient. HCBS includes hands-on or verbal assistance from another person, acquisition and use of equipment and technology, assistance with planning, counseling and, oversight of utilization, performance and quality of the services and supports.	
Patti Killingsworth	[High quality] services and supports selected by the individual through a person-centered planning process based on an individualized assessment of the person's strengths, needs and preferences, and delivered in a manner that enables the individual to live [safely] in his or her home and community, access needed health and social services and supports, and pursue individually identified goals and desired outcomes (including employment as applicable) in integrated community settings, and which assures the individual's rights, optimizes the individual's choice, independence, self-determination and engagement in community life, and results in measurable improvement in health and quality of life outcomes.	

Contributer	Defintion	Notes
Clare C. Luz	Health and Community Based Services (HCBS) help all people, regardless of age, disability, or other individual characteristics, who are at risk for institutionalization or functional decline without Long-term Supports and Services (LTSS) that primarily include assistance with ADLs, IADLs, respite, and/or case management, to live in community-integrated settings of their choice and access LTSS that 1] foster basic human rights to dignity, respect, and as much self-determination, independence, and social engagement as desired and possible, 2] lead to positive health outcomes and quality of life, 3] support family and paid caregivers, and are 4] known and user-friendly, 5] coordinated to maximize resources, 6] economically sustainable, and 7] accountable through measurement and reporting of quality.	
Jonathan Delman	Psychosocial Rehabilitation (PSR), Community Psychiatric Support and Treatment (CPST), Habilitation/Residential Support Services, Family Support and Training, Mobile Crisis Intervention, Short-term Crisis Respite, Intensive Crisis Respite, Education Support Services Empowerment Services- Peer Supports, Non-Medical Transportation, Pre-vocational Services, Transitional Employment, Intensive Supported Employment (ISE) and Ongoing Supported Employment	
Sara Galantowicz	Home and community-based services comprise a wide range of services and supports that facilitate people of all ages with physical, cognitive, mental or behavioral health impairments to maximize their independence, personal living preferences and health status in their communities.	
Ari Houser	LTSS are defined as assistance with activities of daily living (ADLs) and instrumental activities of daily living (IADLs) for people who cannot perform these activities on their own due to a condition that is expected to continue for an extended period of time. Assistance may include hands-on and remote personal assistance, as well as the provision and use of assistive technology. The specific services included vary depending on the nature of the condition (e.g. physical, cognitive, behavioral, etc) but do not include health care or social services. It may be difficult at the individual level to define the boundaries between health care and LTSS, and between social services and LTSS. Services provided to family caregivers because of their role providing ADL/IADL assistance for an extended period of time are considered LTSS. HCBS are LTSS delivered in a home- or community-based setting, defined as the person's own home, the personal home of a family member or friend, or another location in the community that the person goes to, from their own home, to receive services.	I think a definition of HCBS would be useful to guide the committee's efforts, however I think any definition should be separate from the goals of HCBS (the goals vary by individual and by population served), normative statements about what HCBS should be, or implicit statements about what quality means in HCBS (e.g. HCBS without choice should still be considered HCBS). I think the key components of HCBS are the following *definition of services (not all services received by people in the community with LTSS needs are HCBS) *expectation of long-term need (to distinguish from rehab or palliative care, which may have significant overlap in the actual care activities) *at the individual level, HCBS may not be distinguishable/separable from health care or social services, but the definition of HCBS should not be so broad so as to include services that are commonly understood to be part of health care or general social services. *definition of community setting *populations served: I think it best not to restrict the definition to specific populations, but it is important to note that the definition of services varies by population (services that would be considered HCBS for one population might not be for another). However, I would call out family caregivers as a population that should be included. *equipment: I think is a big question. I would include technology, both as a service in and of itself (the cane provides mobility assistance) and provision of technology as a service (the program will purchase a cane to assist with mobility).

Contributer	Defintion	Notes
Gerry Morrissey	Home and Community-Based Services and Supports should leverage the skills, wisdom and experiences of people with long-term support needs to enable them to continue to reside in and be full citizens in their community of their choice. The services and supports must be person-centered and choice must reside with the individual. They must also be available in a person's local community as well as accessible and affordable to persons requiring them. Supports and Services should: • Support the person's independence, self-determination, individual initiative, autonomy, and participation in community life as possible • Support people to have a life experience that is as similar to others in the community as possible • Support the person in maintaining (and improving, if desired) their physical and mental health and wellness and quality of life • Be chosen by the person receiving supports, including who provides the services and supports. • Support the person in determining the responsibility of directing their own services and supports • Be flexible to change with the person's life experience. • Be accountable through measurement and reporting of quality and outcomes, including indicators of expenditures, utilization, health status, and consumer quality of life, participation, and engagement with key individuals in their life. Community Services and Supports must be located in a person's community of choice and should have the following qualities: • The setting is integrated in the greater community, including opportunities to seek employment in competitive integrated settings and engage in the community if desired • The setting is selected by the person being supported • The setting ensures individual rights of privacy, dignity, and respect and freedom from coercion and restraint	
Kimberly Autin-Oser	Home and community-based services (HCBS) encompass a rich array of person and family-centered services intended to support the personal, social*, health** and employment needs of individuals of all ages at risk of institutionalization, isolation, and/or functional decline in the setting and community of their choice. HCBS are typically needed for a sustained period of time; delivered in home and integrated community settings (as a preference over the institutional-bias); built upon the principles of self-determination promoting choice, control, autonomy, dignity, respect, and the facilitation of meaningful opportunities for maintaining/developing personal relationships, community engagement, and integrated employment; easy to access; affordable to funders; and, are provided by well-supported, well-prepared formal and informal direct caregivers.	* The term 'social' in this context refers to any and all aspects of the human experience and the interplay of the individual in the context of broader social systems that may impact independence. This can include social determinants impacting health and well-being and putting autonomy at risk including but not limited to housing, food, and economic security as well as other factors. ** The term 'health' in this context is used in broad and holistic terms comprised of all types of services related to health and well-being including but not limited to medical, behavioral, nutritional, spiritual, complementary and alternative medicine (CAM), etc.)
Joe Caldwell	Home and Community Based Services (HCBS) refer to an array of predominately non-medical services and supports that assist individuals with disabilities and older adults who have functional needs for assistance with daily activities to participate fully in society. HCBS are financed and delivered across an array of public and private programs. Types of services include, but are not limited to: personal assistance, respite and family caregiver supports, employment supports, assistive technology, home modifications, and service coordination. High quality HCBS promote choice and self-determination to achieve person-centered outcomes that enhanced well-being, quality of life, and community participation.	

Contributer	Defintion	Notes
Mary Smith	Home-and community-based services (HCBS) are supports and services provided by culturally and linguistically competent providers, with reasonable accommodation, to: (1) older adults; (2) individuals who have an intellectual, developmental, or physical disability; (3) individuals with a disabling chronic physical illness; or (4) individuals with behavioral health illnesses or conditions. HCBS are provided in integrated, non-institutional settings based on a personal care plan developed primarily by the individual with assistance from caregivers and providers that cuts across payers and providers, and are designed to foster independence, autonomy, choice, and self-determination, and ensure freedom from coercion and restraints. Goals are outcome-directed and focused on independent living in community integrated housing, involvement in meaningful activities including competitive employment and being socially connected to individuals and the community through the development of meaningful relationships. HCBS settings are selected by the individual to facilitate reasonable access to necessary services and supports and participation in the individual's community. HCBS enhance the individual's privacy, dignity, and respect. HCBS services may include, but are not limited to, personal assistance, personal care, assistance with activities of daily living (ADLs) and instrumental activities of daily living (IADLs), case management and care coordination, medication therapy management, respite care for caregivers, employment and housing assistance, vocational rehabilitation and assistance with employment placement, facilitating transitions in care and service settings, assistance with socialization and adaptive skills, provision of assistive technology and other adaptive aids, non-emergency transportation, and home modifications.	
Steve Kaye	Home and Community Based Services (HCBS) are an array of predominately non-medical services and supports that are essential to their recipients' ability to live at home or in community settings and participate fully in their communities. Financed and provided by a variety of public and private programs, HCBS are provided to people of all ages with significant physical, cognitive, or emotional disabilities or functional limitations. Services include, but are not limited to, personal assistance, respite services, employment supports, peer supports, assistive technology, home modifications, and service coordination. High quality HCBS promote choice and self-determination and enhance quality of life and community participation.	
Lorraine Phillips	Home and Community Based Services (HCBS) are supports and assistance intended to sustain community living for individuals, who because of physical, cognitive or chronic health conditions, have ongoing disability in performing daily activities. HCBS typically spans the domains of medical and nursing care, personal care and household management, and housing. Eligibility and services are state-specific and long-term care needs may be less severe than required for entry into an institution. Designed to optimize community integration and employment options, HCBS may be delivered across various habitations in accordance with beneficiary choice, excluding those settings classified as institutions.	

Contributer	Defintion	Notes
Anita Yuskauskas	HCBS is a needs-based system of community support services that enables individuals with multiple chronic and disabling conditions to access necessary healthcare, social integration, and other essential resources necessary to optimize health, qualities of life and prevent or manage decline.	I think it is essential that we recognize HCBS is a very broad set of services and supports, not all coming from Medicaid. So while I do think we need a strong definition, it must necessarily be broad and inclusive. WHO: People who need support services as a result of functional limitations, disabilities, age-related limitations, multiple chronic conditions, or other challenges participating in community life or accessing needed services. WHAT: case management, and other support services related to ADLs and IADLs, home modif8ications, delivered meals, caregiver support and respite. WHY: To allow recipients to remain in home and community settings; to foster self-determination, participation in community life, independence, autonomy, personal choice; to access needed healthcare and other needed resources.

Contributer	Defintion
Ellen Blackwell (CMS)	Home and Community-Based Services (HCBS) are services and supports that a person chooses to use to be independent and participate meaningfully in his or her community, in a manner that enables self-determination, health, and well-being; and that enhance the person's relationships and quality of life
Shawn Terrell (ACL)	Home and community based services include myriad, mostly non-medical services and supports that are identified through a person-centered planning process and delivered in home and community based settings that are integrated in and support full access to the greater community, facilitate individual choice, ensures an individual's rights of privacy, dignity and respect, and freedom from coercion and restraint. Services and settings optimize but do not regiment individual initiative, autonomy, and independence in making like choices, including but not limited to, daily activities, physical environment, and with whom to interact.

Contributer	Defintion
Diana Autin, Statewide Parent Advocacy Network	"Home and community based services are services that are provided to individuals in their community, in the settings (a) that they choose, (b) that provide individual rights of privacy, dignity and respect, and freedom from coercion, (c) that optimize individual initiative, autonomy, and independence in life choices, (d) that facilitate individual choice regarding services and supports including who provides them, and (e) that do not segregate individuals by disability, specific disability, or other disability-related characteristics, from the broader community."

Source Title and Organization	Defintion
AARP Public Policy Institute/The Hilltop Institute's discussion paper. Characteristics of a high-performing long-term care system.	The ultimate goal of a long-term care (LTC) system is to enhance the well-being and quality of life of individuals who experience functional limitations because of chronic conditions, illness, injury, or other causes of disability.
AARP, The Commonwealth Fund, and The SCAN Foundation's "Raising Expectations: A State Scorecard on Long-Term Services and Supports for Older Adults, People with Disabilities, and Family Caregivers" – 2014	Long-term services and supports (LTSS) may involve, but are distinct from, medical care for older people and adults with disabilities. Definitions of the term vary, but in this report we define LTSS as: > Assistance with activities of daily living (ADLs) and instrumental activities of daily living (IADLs) provided to older people and other adults with disabilities who cannot perform these activities on their own due to a physical, cognitive, or chronic health condition that is expected to continue for an extended period of time, typically 90 days or more. > LTSS include human assistance, supervision, cueing and standby assistance, assistive technologies and devices and environmental modifications, health maintenance tasks (e.g., medication management), information, and care and service coordination for people who live in their own home, a residential setting, or a nursing facility. LTSS also include supports provided to family members and other unpaid caregivers. > Individuals with LTSS needs may also have chronic conditions that require health or medical services. In a high-performing system, LTSS are coordinated with housing, transportation, and health/medical services, especially during periods of transition among acute, post-acute, and other settings. > For the purpose of this project, people whose need for LTSS arises from intellectual disabilities (ID) or chronic mental illness (CMI) are not included in our assessment of state performance. The LTSS needs for these populations are substantively different than the LTSS needs of older people and adults with physical disabilities. Including services specific to the ID and CMI populations would have required substantial additional data collection, which was beyond the scope of this project. Home- and community-based services (HCBS) refer to assistance with daily activities that generally helps older adults and people with disabilities remain in their homes. Many people with LTSS needs require individualized services or supports to live in a variety of settings: their own homes or apartments, assisted living facilities, adult foster homes, congregate care facilities, or other supportive housing

CMS Final 1915(i) regulation	HCBS is defined as having the following qualities: > The setting is integrated in the greater community, including opportunities to seek employment in competitive integrated settings and engage in the community > The setting is selected by the individual > The setting ensures individual rights of privacy, dignity, and respect and freedom from coercion and restraint > The setting optimizes individual initiative, autonomy, and independence in life choices > The setting facilitates individual choice regarding services and supports, including who provides them
Center for Personal Assistance Services at the University of California San Francisco selected quality of life measures for measuring consumers' personal experiences	The proper goal of LTSS programs is not merely to ensure survival, or to reduce institutionalization (for community-based programs) or hospitalization, but also to foster as much independence, self-determination, and participation in community life as possible. To ensure that these goals are not forgotten as the transition to managed LTSS proceeds, oversight must include not only monitoring outcomes specifically related to services received, but also more general measures of consumers' personal experiences, or what might be termed their quality of life (QOL). "
Kaye, H. S. (2014) Toward a Model Long Term Services and Supports System: State Policy Elements. Gerontologist.	A model system of long-term services and supports (LTSS) could be characterized as one that promotes community living over institutionalization, integration over segregation, and full social participation over isolation (Commission on Long-Term Care, 2013; Harkin, 2013). Such a system should be equitable across age groups, disability categories, and other individual characteristics, economically sustainable yet generous enough to reasonably meet demand, and targeted broadly to include all people at risk of institutionalization, isolation, or functional decline in the absence of services (AARP, 2013). It should promote independence and autonomy, offering people the desired level of control over their services, and support in handling that responsibility (AARP, 2013; NCD, 2005). Family caregivers should be supported, and workers providing paid services should be given decent jobs and offered training to provide stable, reliable, respectful, and high-quality services (Commission on Long-Term Care, 2013; NCD, 2005). Finally, the entire LTSS system should be accountable through measurement and reporting of quality and outcomes, including indicators of expenditures, utilization, health status, and consumer quality of life, participation, and satisfaction (AARP, 2013; DREDF & NSCLC, 2013).

Kaye, H.S., Harrington, C. (2015) Long-term services and supports in the community: Towards a research agenda. Disability and Health Journal.	Long-term services and supports (LTSS) comprise the personal assistance, technology, and health care-related services needed by people who are unable to perform routine daily activities without assistance. National surveys indicate that as many as 12 million Americans get help from others in either activities of daily living (ADLs, such as bathing, dressing, and eating) or instrumental activities of daily living (IADLs, such as preparing meals, shopping, and managing money). LTSS can be provided in nursing homes and other institutional settings or in community settings, such as private homes, group homes, and assisted living facilities. The vast majority of those needing LTSS live in the community (about 10 million people), and roughly half are under age 65.LTSS received in the person's home, a day health or activity center, or some other non-institutional setting are often known as home- and community-based services (HCBS), especially when those services are provided through government programs
Long-Term Care: Who Gets It, Who Provides It, Who Pays, And How Much? H. Stephen Kaye, Charlene Harrington, Mitchell P. LaPlante. Health Affairs. January 2010	"Long-term care provided outside of institutions, known as personal assistance services, personal care services, or home and community-based services, also enables many people with disabilities to maintain their independence; avoid institutionalization; and participate in family, community, and economic activities." Article presents three tiers of population estimates based on the level of identified need. > The broadly defined long-term care population needs help with one or more ADLs or IADLs. > The intermediate long-term care population is composed of people needing ADL help > The narrowly defined long-term care population includes people needing help with two or more ADLs (for example, bathing and dressing together, but not bathing alone)
Medicaid.gov – Home & Community Based Services webpage	Home- and community-based services (HCBS) provide opportunities for Medicaid beneficiaries to receive services in their own home or community. These programs serve a variety of targeted population groups, such as people with mental illnesses, intellectual or developmental disabilities, and/or physical disabilities.
Long-Term Care: Status of Quality Assurance and Measurement in Home and Community-Based Services. (1994). United States Government Accountability Office.	"Health, personal care and social services provided over a sustained period to persons who live outside of congregate residential settings and who have lost some capacity for self-care because of a chronic condition or illness. These services include a broad range of supports, from skilled nursing services to assistance with basic activities of daily living (ADIS) (such as bathing, toileting, and dressing) and help with instrumental activities (such as shopping, meal preparation, housekeeping, and laundry). The services may be provided singly, by one or more providers, or in combination, as when a home health aide provides incidental assistance with ADLS."

Long-Term Care: Implications of Supreme Court's Olmstead Decision Are Still Unfolding. United States Government Accountability Office. Allen, K (2001)	“HCBS provided under what is called the 1915(c) waiver program includes a broad range of services such as case management, homemaker, home health aide, personal care, adult day health, respite care, and, for individuals with chronic mental illness, outpatient clinic services.”
The Home and Community-Based Service (HCBS) Experience Survey Part A. CMS (2012)	“Home and community-based services (HCBS), enable chronically ill and disabled Medicaid beneficiaries to receive care at home instead of being institutionalized.” Continuation: "HCBS programs serve beneficiaries with a broad range of severe physical, mental, and developmental conditions, through a wide array of providers. These long-term care services complement acute-care services, to maintain individual health and quality of life and enable this population to live in the community rather than an institution."
Long-Term Care for Older Adults: A Review of Home and Community-Based Services Versus Institutional Care. Minnesota Evidence-based Practice Center, Wysocki, A (2012)	"LTC spans three realms: (1) assistance with essential, routine activities such as eating, bathing, dressing, and tasks required to maintain independence, such as preparing meals, managing medications, shopping for groceries, and using transportation; (2) housing; and (3) medical care. Often, LTC is associated with institutional settings such as nursing homes (NHs). However, LTC is also provided in a variety of non-institutional settings collectively referred to as Home and Community-Based Services (HCBS)." Continued: "Care through HCBS may be provided in a variety of settings, including recipients’ homes; group living arrangements such as congregate housing, adult foster care, residential care (RC) and assisted living (AL) facilities (the last two terms are often used interchangeably although they are not always synonymous—we use the term AL throughout this report); and community settings such as adult daycare and adult day health. Services provided via HCBS may include care coordination or case management, personal care assistant service, personal attendant service, homemaker and personal care agency services, home hospice, home-delivered meals, home reconfiguration or renovation, medication management, skilled nursing, escort service, telephone reassurance service, emergency helplines, equipment rental and exchange, and transportation. HCBS also include educational and supportive group services for consumers or their families. Some services provided through HCBS are construed as respite care meant to relieve family caregivers."

Bipartisan Policy Center – America's LTC Crisis, Challenges in Financing and Delivery (2013). (Definition taken from HCBS settings rule)	HCBS are defined as those services delivered outside of an institutional setting, which could include the beneficiary's home, a caregiver's home, or an assisted living facility.
Home and Community-Based Long-Term Services and Supports for Older People Fact Sheet, AARP Public Policy Institute	The term "home and community-based long-term services and supports" (HCBS) refers to assistance with daily activities that generally helps older adults and people with disabilities to remain in their homes.
Development of Quality Indicators for the Home and Community-Based Services Population: Technical Report. Center for Primary Care and Outcomes Research, Shultz, E (2012)	"HCBS programs allow states to provide long-term supports and services to Medicaid beneficiaries in a home or community setting rather than an institutional setting. For the purposes of this project, HCBS is defined broadly to include the array of long-term care services that could be provided by Medicaid as HCBS. This includes 1915 (c) waiver services and state plan services such as home health care, personal care services, and case management. Such services may be provided by a variety of state administering agencies, not just Medicaid."
Medicaid.gov:1915(c) Home & Community-Based Waivers. CMS	"The 1915(c) waivers are one of many options available to states to allow the provision of long term care services in home and community based settings under the Medicaid Program. States can offer a variety of services under an HCBS Waiver program. Programs can provide a combination of standard medical services and non-medical services. Standard services include but are not limited to: case management (i.e. supports and service coordination), homemaker, home health aide, personal care, adult day health services, habilitation (both day and residential), and respite care. States can also propose "other" types of services that may assist in diverting and/or transitioning individuals from institutional settings into their homes and community."
Guidance to HHS Agencies for Implementing Principles of Section 2402(a) of the Affordable Care Act ,DHHS, Sibelius, K. (2014)	"Home and community-based services (HCBS) are services and supports that assist older adults and people with disabilities (including mental health and substance use disorders) to live with dignity and independence in community settings. "

States' Plans to Pursue New and Revised Options for Home- and Community-Based Services. United States Government Accountability Office, 2012	"Home- and community-based services (HCBS) cover a wide range of services and supports to help individuals remain in their homes or live in a community setting, such as personal care services to provide assistance with ADLs or IADLs, assistive devices, respite care for care givers, and case management services to coordinate services and supports that may be provided from multiple sources."
Environmental Scan of Measures for Medicaid Title XIX Home and Community-Based Services. Thomson Healthcare. Sara Galantowicz (2010)	This source does not contain a definition of HCBS. Peripherally relevant: "used a very broad definition of HCBS services and populations, including populations such as adults with severe and persistent mental illness who are not traditional recipients of Medicaid HCBS". 21 constructs were identified among 3 domains: client functioning, client satisfaction, and program performance.
Assessing the Health and Welfare of the HCBS Population. Agency for Healthcare Research and Quality (AHRQ) (2012).	HCBS may be offered through Medicaid State plans or through a waiver of the established Medicaid requirements. States may offer a number of different HCBS waiver plans, and HCBS waiver plans may fall under different waiver types, which are referred to by the section of the Social Security Act that is being waived: Section 1915(c) waivers allow States to provide long-term care services in home- and community-based settings. Most HCBS-relevant waivers are Section 1915(c) waivers. Section 1115 waivers allow States to test broad and diverse changes to Medicaid requirements, such as limiting choice of provider through mandatory enrollment in managed care. They are less likely to be directly relevant to HCBS, but some States use Section 1115 waivers to cover long-term care under a managed care model. Section 1915(b/c) waivers allow States to enroll beneficiaries in a mandatory managed care program that includes HCBS waiver services. Only a few States have Section 1915(b/c) waivers. (peripherally relevant)
Transitions From Medicare-Only to Medicare-Medicaid Enrollment. Mathematica Policy Research. Borck, R (2014)	This source does not contain a definition of HCBS. Peripherally relevant: defined HCBS users to include individuals enrolled in a Section 1915(c) waiver, which allow states to offer HCBS to targeted groups of Medicaid enrollees with demonstrated need for these services, or with Medicaid claims for HCBS, including services provided through a state plan and services provided under a waiver

An Investigation of Interstate Variation in Medicaid Long-Term Care Use and Expenditures Across 40 States in 2006. Mathematica Policy Research. Wenzlow, A (2013)	This source does not contain a definition of HCBS. Peripherally relevant: defined HCBS to include services covered under Section 1915(c) waivers and personal care, residential care, home health care, adult day care, and private duty nursing services that are mandatory or provided at state option outside of waiver programs. Institutional care includes nursing home care, ICFS/IID care, inpatient psychiatric services for people under age 21, and psychiatric hospital services for those 65 and older.
Medicaid.gov: Quality of Care Home and Community-Based Services (HCBS) Waivers.	This source does not contain a definition of HCBS. Peripherally relevant: Definition of 1915(c) Home & Community-Based Waivers: The 1915(c) waivers are one of many options available to states to allow the provision of long term care services in home and community based settings under the Medicaid Program. States can offer a variety of services under an HCBS Waiver program. Programs can provide a combination of standard medical services and non-medical services. Standard services include but are not limited to: case management (i.e. supports and service coordination), homemaker, home health aide, personal care, adult day health services, habilitation (both day and residential), and respite care. States can also propose "other" types of services that may assist in diverting and/or transitioning individuals from institutional settings into their homes and community.

Source Selection Criteria

The objective of this activity was to identify all existing domains related to HCBS/ LTSS quality measurement within the sources identified for this project. NQF rated each source based on the following criteria:

Relevance:

A relevant source must contain domains/sub-domains specifically related to HCBS/LTSS quality measurement. Thirty-eight of the two hundred sources were found to meet this criterion.

Breadth of Scope:

The scope of this project is broad and inclusive. The best sources had to have a system level approach and be comprehensive, including domains that incorporate all settings, populations, services and major stakeholders.

Evidence Type:

The selected sources had to be systematic in their approach to identifying domains and subdomains. The best sources have strong methods to substantiate findings/conclusions/recommendations.

Source Type:

Some sources carry a higher perceived credibility than others. For example, peer-reviewed journal publications were rated higher than an opinion piece.

Currency:

The body of evidence surrounding HCBS/LTSS quality measurement is rapidly expanding and the older the source the less likely it will contain analysis based on new evidence.

The following top ten sources we selected based on these criteria.

- Agency for Healthcare Quality and Research: Environmental Scan of Measures for Medicaid Title XIX Home and Community-Based Services
- Agency for Healthcare Quality and Research: Long-Term Care for Older Adults: A Review of Home and Community-Based Services Versus Institutional Care (2012)
- Disabilities Rights Education & Defense Fund: Identifying and Selecting Long-Term Services and Supports Outcome Measures (2013)
- AARP: A State Scorecard of Long-Term Services and Supports for Adults, People with Disabilities, and Family Caregivers (2014)
- H. Stephen Kaye: Selected Inventory of Quality of Life Measures for Long-Term Services and Supports Participant Experience Surveys (2012)

- Long-Term Quality Alliance: Measurement Opportunities & Gaps, Transitional Care Processes and Outcomes Among Adults Recipients of Long-Term Services and Supports (2011)
- National Core Indicators: Using National Core Indicators (NCI) Data for Quality Improvement Initiatives. National Association of State Directors of Developmental Disabilities Services and Human Services Research Institute. Retrieved from the National Core Indicators Website: http://www.nationalcoreindicators.org/ (2012)
- New York State Department of Health: 2012 Managed Long-Term Care Report
- Centered for Medicare & Medicaid Services Disabled and Elderly Health Programs Group: Environmental Scan of HCBS Assessment Items/ Instruments and Quality Measures (2014)
- H. Stephen Kaye: Measuring Quality Home-and Community-Based Services

HCBS Domain Frequency Chart

Domains that were found in more than five or more of the selected sources are colored in purple and domains found in more than three are colored in green.

Domain Category	Sub-Domains	AHRQ Environmental Scan of Measures for Medicaid HCBS	AHRQ Long-Term Care for Older Adults: A Review of HCBS vs. Institutional Care	DREDF: Identifying and Selecting LTSS Outcome Measures	AARP: A State Scorecard on LTSS for Older Adults, People with Disabilities and Family Caregivers	Kaye: Selected Inventory of QOL measures for LTSS Participant Surveys	LTQA: Measurement Opportunities & Gaps in Translational care Processes and Outcomes	National Core Indicators	NYSDH: 2012 Managed Long-Term Care Report	TEFT: Environmental Scan of HCBS Assessment Items and Instruments	Kaye: Measuring Quality in HCBS
Consumer and Caregiver Experience	• Client Experience • Participant Satisfaction • Overall satisfaction • Member satisfaction • Participant outcomes	x		x					x	x	x
Access to Supports and Services	• Participant Access • Access to Personal care • Affordability • Availability of Assistance with Everyday Activities When needed • Costs	x		x	x			x		x	x
Community Integration/Inclusion	• Relationships • Friendships • Maintenance of Family Relationships • Living Arrangement	x		x		x		x	x	x	
Person Centeredness	• Choice of provider	x		x	x	x	x	x		x	

	• Choice of Setting • Choice and Control • Autonomy/Choice • Self-Determination • Participant Centered Service Planning and Delivery • Individuality • Shared Accountability										
Service/ Care Coordination	• Transitional care processes	x		x			x	x		x	x
Quality of Life	• Well-being • Goal Attainment			x	x	x			x	x	x
Safety, Security &Order	• Participant Safeguards • Environment • Harms • Serious Reportable Events			x		x		x		x	x
Functional Status	• Client Functioning • Change in Daily Activity Function • Incontinence	x		x					x	x	
Performance	• Program Performance • System Performance • Performance Outcomes • Sustainability • Descriptive Statistics	x		x			x			x	

	• Shared accountability • Transparency										
Healthcare/ Service Utilization	• Acute Care Utilization Avoidable Hospitalization		x					x	x		
Provider Capacity and Capabilities	• Provider competency • Staff Stability • Structural Measures			x				x		x	x
Support for Caregivers	• Friends and Family • Un-paid Caregiver Focused Outcomes • Family Indicators			x	x			x		x	
Respect/Dignity	• Comfort • Privacy			x		x		x		x	
Quality of Care				x	x					x	
Meaningful Activity	• Work • Employment • School Attendance • Enjoyment • Education					x		x		x	x
Physical Health	• Changes in physical health • Physical Function • Health, functional and healthcare related outcomes • Health Status • Management of Acute Conditions • Management of		x	x						x	

	Chronic Conditions • Mortality • Medication • Ulcer • Pain										
Cognitive Function	• Changes in Cognitive Function		x							x	
Mental Health	• Neurological/Emotional/ Behavioral Status		x						x		

NATIONAL QUALITY FORUM

Final Committee Roster

Home and Community-Based Services Quality

COMMITTEE MEMBERS

Joe Caldwell, PhD (Co-chair)
Director of Long-Term Services and Supports Policy, National Council on Aging
Washington, DC

H. Stephen Kaye, PhD (Co-chair)
Professor, University of California San Francisco
San Francisco, California

Robert Applebaum, MSW, PhD
Professor, Scripps Gerontology Center, Miami University
Oxford, Ohio

Kimberly Austin-Oser, MS
National LTSS Policy Director, SEIU Healthcare
Washington, DC

Suzanne Crisp
Director of Program Design and Implementation, National Resource Center for Participant Directed Services
Chestnut Hill, Massachusetts

Jonathan Delman, PhD, JD, MPH
Assistant Research Professor, University of Massachusetts Medical School
Stoneham, Massachusetts

Camille Dobson, MPA, CPHQ
Deputy Executive Director, National Association of States United for Aging and Disabilities
Washington, DC

Sara Galantowicz, MPH
Senior Associate, Abt Associates Inc.
Cambridge, Massachusetts

Ari Houser, MA
Senior Methods Advisor, AARP Public Policy Institute
Washington, DC

Patti Killingsworth
Assistant Commissioner, Chief of Long-Term Services and Supports, Bureau of TennCare
Nashville, Tennessee

K. Charlie Lakin, PhD
Retired, Former Director of National Institute on Disability and Rehabilitation Research
Minneapolis, Minnesota

Clare Luz, PhD
Assistant Professor and Lead Evaluator, Michigan State University
East Lansing, Michigan

Sandra Markwood, MA
Chief Executive Officer, National Association of Area Agencies on Aging
Washington, DC

Barbara McCann, MA
Chief Industry Officer, Interim Health Care
Alexandria, Virginia

Sarita Mohanty, MD, MPH, MBA
Executive Director, Community-Clinical Care Integration, Kaiser Permanente Northern California
Oakland, California

Gerry Morrissey, MEd, MPA
Chief Quality Officer, The MENTOR Network
Boston, Massachusetts

Ari Ne'eman
President, Autistic Self Advocacy Network
Silver Spring, Maryland

Andrey Ostrovsky, MD
CEO, Care at Hand
Brookline, Massachusetts

Mike Oxford
Executive Director for Policy, Topeka Independent Living Resource Center
Topeka, Kansas

Lorraine Phillips, PhD, RN
Associate Professor, University of Missouri
Columbia, Missouri

Mary Smith, PhD
Associate Director, Decision Support, Research, and Evaluation, Illinois Division of Mental Health
Chicago, Illinois

Anita Yuskauskas, PhD
Coordinator, Health Care Policy & Administration, Pennsylvania State University
Center Valley, Pennsylvania

Robert Applebaum, MSW, PhD

Robert Applebaum is Professor of Gerontology and Director of the Ohio Long-Term Care Project at the Scripps Gerontology Center, Miami University. He has been involved in the development and evaluation of long-term care programs across the United States for more than thirty years. He has worked with a number of states on innovations in long-term care service delivery, and completed a series of state and national studies on long-term care quality. Dr. Applebaum has been a frequent speaker at national and state conferences on long-term care. He has authored more than 85 articles and monographs, and four books on long-term care.

Kimberly Austin-Oser, MS

Kimberly Austin-Oser serves as the Long-Term Care Policy Director with SEIU Healthcare. One of her primary responsibilities is leading the organization's innovative workforce development program and policy initiatives built upon the premise that front-line workforce practices and job quality are key drivers for both individual and service system quality improvements. Kimberly has spent the majority of her 25-year human services career dedicated to all aspects of the development and administration of HCBS for older adults and individuals living with developmental and other disabilities. Prior to joining SEIU Healthcare, she served as the Elderly and Disability Services Division Director and the Developmental Disabilities Deputy Division Director for the state of New Mexico. She also served as the Medicaid Disability Policy Coordinator and Consultant for Special Populations for the state of Ohio.

Joe Caldwell, PhD

Joe Caldwell is Director of LTSS Policy at the National Council on Aging. He has over 20 years of experience in the field of HCBS as a researcher, policy expert, provider and parent of a son with disabilities. He leads Disability and Aging Collaborative, a coalition of 37 national aging and disability organizations working together to advance HCBS policy. Joe is also an Adjunct Research Professor at the University of Illinois at Chicago, where he earned his doctorate in Disability Studies. He has a strong research background in outcomes of family support and HCBS programs for consumers and family caregivers.

Suzanne Crisp

Suzanne Crisp is Director of Program Design and Implementation for the National Resource Center for Participant Directed Services. She is a national expert on participant direction and in-home services on both the state and federal levels. She is the Center's expert in managed care. She was the Arkansas Assistant Director of Aging Services and Director of Integrated Services at the Centers for Medicare & Medicaid Services. She has over 25 years of experience developing, managing, and evaluating state and national programs. She implemented the first Cash & Counseling Demonstration and Evaluation program in the nation and participated in all aspects of its empirical evaluation. In her position with CMS, she assessed and approved all state Medicaid waiver and demonstration programs that offered participant-direction and later provided national technical assistance to develop quality management strategies and in-home services for CMS. Suzanne was an active member of the National Quality Enterprise which was a CMS sponsored group developed to provide states with guidance on quality assurance and improvement strategies. Area of concentration was performance indicators directly tied to participant direction.

Jonathan Delman, PhD, JD, MPH

Jonathan Delman is currently an Assistant Research Professor, University of Massachusetts Medical School, Department of Psychiatry and is the director of the Program for Recovery Research. From January 1999 to June 2011, Dr. Delman served as the founding executive director,

Consumer Quality Initiatives, Inc. where he developed a nationally recognized model for consumer-driven results-oriented evaluation and developed a nationally recognized model for conducting community-based participatory action mental health research. He received his PhD from the Boston University School of Public Health and holds a JD from the University of Pennsylvania School of Law.

Camille Dobson, MPA, CPHQ

Camille Dobson is a certified professional in healthcare quality. She holds an MPA from GWU and has spent the past 18 years working in Medicaid policy and development, with a particular emphasis on Medicaid managed care. She directed the team which crafted CMS' principles for state MLTSS programs (released in May, 2013) and was the Medicaid project lead for an intra-agency group working to address HCBS measure gaps at CMS. She has a deep understanding of program development and management at both the state and Federal level, and clearly understands the nexus between quality measurement and program improvement.

Sara Galantowicz, MPH

Sara Galantowicz has two decades of health policy and disability research and evaluation experience, with an emphasis on publicly-funded long-term services and supports. Her areas of expertise include quality metrics and quality improvement, home and community-based services, Medicare post-acute care, and Medicaid claims analysis. In addition, she has more than ten years' practice in experience-of-care survey development and testing, including cognitive and field testing, with a focus on self-reports from people with disabilities. Ms. Galantowicz has significant project and client management experience, and has given multiple conference presentations and trainings. She is currently a Senior Associate with Abt Associates; previously she was a Research Manager for Truven Health Analytics and a Senior Evaluator at the U.S. Government Accountability Office. Ms. Galantowicz holds an economics degree from Princeton University and a Masters in Public Health from the University of Michigan.

Ari Houser, MA

Ari Houser is a Senior Methods Advisor in the AARP Public Policy Institute, where his work includes demographics, disability, quality and patterns of use of long term services and supports, family caregiving, and methodological advising on many topics. Prior to joining the AARP Public Policy Institute, Mr. Houser worked at the RAND Corporation on a variety of topics including occupational health and safety management. He has a bachelor's degree from Swarthmore College and is a Ph.D. candidate (ABD) in measurement, statistics, and evaluation at the University of Maryland.

H. Stephen Kaye, PhD

H. Stephen Kaye is a professor at the Institute for Health & Aging and the Department of Social and Behavioral Sciences at the University of California San Francisco. He serves as director and principal investigator of the Community Living Policy Center, a Rehabilitation Research and Training Center funded by the National Institute on Disability and Rehabilitation Research and the Administration for Community Living, U.S. Department of Health and Human Services. He received a Ph.D. from Stanford University in 1983. His primary research interests focus on community-based long-term services and supports needed by people with disabilities of all ages, employment issues among people with disabilities, use of information and assistive technology, and disability measurement and data collection.

Patti Killingsworth

Patti Killingsworth is an Assistant Commissioner and Chief of Long Term Services & Supports for the Bureau of TennCare. She has led the implementation of an integrated MLTSS system for

seniors and adults with physical disabilities, expanding access to HCBS and rapidly moving toward a rebalanced long term care system in Tennessee. Her commitment is to changing systems to better meet the needs of consumers and families, promoting the development and expansion of HCBS, and ensuring that that the voice and perspective of consumers, family members, and other key stakeholders is brought to bear in policy and program decision-making processes.

K. Charlie Lakin, PhD

K. Charlie Lakin has more than 40 years' experience in disability services. Between 2011 and 2014 he served as Director of the National Institute on Disability and Rehabilitation Research. Prior to coming to NIDRR, Mr. Lakin spent 35 years at the University of Minnesota, including 23 years as director of the Research and Training Center on Community Living. At Minnesota Mr. Lakin directed dozens of research projects and (co-)authored more than 300 publications based on that work. He frequently consulted with state, federal and international agencies on policy, research and evaluation. Among recognitions deriving from Mr. Lakin's work are presidential appointments by Presidents Clinton and Obama as well as service, research, leadership and humanitarian awards from the American Association on Intellectual and Developmental Disabilities, the American Network of Community Options and Resources, The Arc of the US, the Association of University Centers on Disability, the National Association of County Behavioral Health and Developmental Disabilities Directors, and the National Association of State Directors of Developmental Disabilities Services. He is also a recipient of the University of Minnesota's Outstanding Community Service Award.

Clare Luz, PhD

Clare Luz is the Assistant Professor in Family Medicine at Michigan State University. She has over 30 years of HCBS experience, as a provider in long-term care settings then as a gerontologist/ health services researcher. Her research focuses on functional health of older adults and programs and policies that improve quality of care, health outcomes, and life. Most recently, Dr. Luz served as Michigan's principal investigator for a national demonstration/community-based project to develop and test a training program for personal care aides who provide home care to older adults. She teaches research methods and serves on the Governor's Long Term Care Supports and serves on the Governor's Long Term Care Supports and Services Commission.

Sandra Markwood, MA

Sandra Markwood is the CEO of the National Association of Area Agencies on Aging (n4a), which represents the nation's Area Agencies on Aging that provide critical home and community-based services throughout the United States. Prior to joining n4a, Markwood worked for the National Association of Counties, National League of Cities and as Assistant to the County Executive in Albemarle County, VA.

Barbara McCann, MA

Barbara McCann is a 25 year national leader and facilitator of consensus around standards of care, quality measurement and actionable improvement in the delivery of home and community based care with experience as: a social work professional delivering care in the home; national staff support to current Medicaid/Medicare providers in 36 states and dual demonstrations in 6 states; staff of a national payer (Blue Cross and Blue Shield) and a national accreditation body, JCAHO: and a Board member of the Community Health Accreditation Program. Over the past two years she have also added the experience of working with Interim Health's sister companies in Ireland, the UK, and Australia in operationalizing new regulation, including the use of standardized assessments to develop packages of community services delivered to the disabled and elderly, and directed by those individuals at their choice. She brings a breadth of national and international experience, as well as daily involvement with those delivering this care in a variety

of urban and rural communities.

Sarita Mohanty, MD, MPH, MBA

Sarita Mohanty is the Executive Director, Community-Clinical Care Integration for Kaiser Permanente, Northern California, with a focus on operations, strategy, and delivery of the social care services. Dr. Mohanty has over 15 years of experience in health care delivery, quality improvement, and health services research. From 2011-2014, Dr. Mohanty was the Senior Medical Director for LA Care Health Plan, where she was instrumental in the implementation of Long Term Services and Supports. Dr. Mohanty earned her BA from UC Berkeley, her MD from Boston University, and her MPH from Harvard University. In 2012, she obtained her MBA from UCLA's Anderson School.

Gerry Morrissey, M.Ed, MPA

Gerry Morrissey is Chief Quality Officer for The MENTOR Network, he has designed a quality improvement program that established a clear set of standards and expectations, increased capacity to monitor and report on key quality indicators, and directs quality improvement initiatives across all Network operations. As the Commissioner of the Massachusetts Department of Developmental Services, he led the design and implementation of a new client information system to enhance the capacity to use data for driving decisions and improving outcomes. As past president of the NASDDDS, he was engaged in the development of the National Core Indicators for IDD services.

Ari Ne'eman

Ari Ne'eman is the President and co-founder of the Autistic Self Advocacy Network. In 2009, President Obama nominated Ari to the National Council on Disability, a federal agency charged with advising the executive branch. He currently chairs the Council's Entitlements Committee. From 2010 to 2012, he served as a public member to the Interagency Autism Coordinating Committee, a Federal advisory committee that coordinates all efforts within HHS concerning autism. Ari also served as an adviser to the DSM-5 Neurodevelopmental Disorders Workgroup convened by the American Psychiatric Association.

Andrey Ostrovsky, MD

Andrey Ostrovsky is a practicing physician and social entrepreneur who leads Care at Hand's executive management and strategic vision. Dr. Ostrovsky has led teams at the World Health Organization, United States Senate, and San Francisco Health Department toward health system strengthening through technology. He has contributed to legislation at the city and national level to advance care delivery for vulnerable populations. He is a published researcher in public health informatics, quality improvement, healthcare innovation, social entrepreneurship, and care coordination.

Mike Oxford

Mike Oxford has been Executive Director of Topeka Independent Living Resource Center over 20 years. His experience with long term services & supports (LTS&S) ranges from direct support worker, to developing and providing innovative services, to using services. Programs Mike operates are known for innovation and quality and he has been very involved with policy and research over the past two decades. Recipient of a HCFA Director's Citation of Merit in for innovation and quality in LTS&S in 1997, Mike has presented on LTS&S and has served on many public and private research panels, forums and academic research projects.

Lorraine Phillips, PhD, RN

Lorraine Phillips' studies focus on the health and functioning of elders in long-term care settings, in particular, the role of late-life physical activity on disability progression. As a gerontological nursing educator, researcher, and clinician, she has expertise in care delivery in both home-based and institutional settings. Her work on the Aging-in Place (AIP) research team at the University of Missouri has involved longitudinal measurement of functional outcomes of TigerPlace senior housing residents as well as comparison of AIP costs to nursing home costs (1, 2, 3). She is also the principal investigator on a NIH-funded longitudinal study, Physical Activity and Disability in Residential Care/Assisted Living (RC/AL) Residents. Dr. Phillips prior research includes analysis of the Minimum Data Set to identify predictors of new depression and psychometric analysis of depression measures specific to persons with dementia. As a registered nurse from 1978 to 1993, she has worked in acute and tertiary care settings, including hospitals, offices, home care, and long-term care that includes assisted living. She practiced as a Family Nurse Practitioner from 1996 to 2010 within family, internal medicine, women's health, cardiology, and long-term care practices. Dr. Phillips has expertise in evidence synthesis, quantitative methods, and geriatric functional assessment.

Mary Smith, PhD

Mary Smith is the Associate Director of Decision Support, Illinois DHS Division of Mental Health with responsibility for developing/implementing policy regarding MIS design, performance measurement, and coordination of research/evaluation activities including MIS design/data analysis for the Williams vs. Quinn Olmstead Consent Decree. She is the principal investigator for a series of SAMHSA data infrastructure contracts, and a past chair of the MHSIP Policy Group, co-authoring the Mental Health Quality Report. She has provided consultation in the use of data for planning, performance measurement, and MIS implementation. Dr. Smith holds a Ph.D. in organizational/social psychology.

Anita Yuskauskas, PhD

Anita Yuskauskas presently works for Pennsylvania State University (PSU), Lehigh Valley Commonwealth Campus, as the Coordinator for the Health Policy and Administration Program. From 2003 to 2014, she worked with the Centers for Medicare and Medicaid Services, where she served as the Technical Director for Quality in Medicaid Home and Community-based Services (HCBS). While there she was the Agency lead for quality in HCBS and participated on numerous cross-federal quality measurement teams. Yuskauskas also did policy development work relative to person centered and managed care service delivery models and served as a liaison for HCBS policy issues related to American Indian-Alaska native tribes. Preceding her federal tenure, Yuskauskas served as Division Chief in Hawaii's Department of Health, overseeing the developmental disabilities, Hansen's Disease, and brain injury programs. She also served as Chief Policy Analyst for the Center for Outcome Analysis in Rosemont, Pennsylvania. In addition to her work at PSU, Yuskauskas' prior academic experience includes teaching at the University of Delaware, University of New Hampshire, Syracuse University, and the New Hampshire Technical and Community College at Manchester.

Home and Community-Based Services Quality

HHS ADVISOR BIOGRAPHIES

Ellen Blackwell, MSW

Ms. Ellen Blackwell is a geriatric social worker with a background in disability services. At CMS, she works on programs that impact quality, efficiency, accessibility, and beneficiary satisfaction that support better care, smart spending, and healthier people. She joined the Federal service in 2001 as a Presidential Management Fellow. Prior to joining CMS, Ms. Blackwell worked at The Horizon Foundation, a philanthropic organization that promotes local health and wellness. She interned as a graduate student at The Hilltop Institute, a health research center at the University of Maryland, Baltimore County, and at the Howard County Maryland Office on Aging. Ms. Blackwell founded the Howard County chapter of the Autism Society in 1992. She also self-directs the home and community-based services of an adult family member. Ms. Blackwell graduated from the University of Maryland - Baltimore, and the University of Wisconsin.

Jennifer Burnett, BA

Jennifer Burnett is the Director of the Division of Community Systems Transformation in the Disabled and Elderly Health Programs Group at the Centers for Medicare & Medicaid Services. Prior to her appointment at CMS in 2011, she served as the Deputy Secretary for Long-Term Living in Pennsylvania's Departments of Aging and Public Welfare, where she was responsible for overseeing long-term living programs for seniors and persons with disabilities. Earlier, she served as Chief of Staff in the Office of Long-Term Living and for 4 years in the Governor's Office of Health Care Reform, as the Strategic Operations Administrator for the Long-term Living project. Jen has been involved in systems change at the state and federal levels for more than three decades. Before her work in government, she built a successful consulting business, specializing in grant management, public relations and disability rights. Her clients included the Commonwealth of Pennsylvania, Statewide Independent Living Councils in Maryland and Pennsylvania, Speaking for Ourselves, the National Council on Independent Living, and the American Association of People with Disabilities. As Project Director of PA Transition to Home, a nursing home transition demonstration funded by Center for Medicare & Medicaid Services, she built and administered a program for Pennsylvania. The project has been rolled out statewide to become a program serving thousands of people. In 2012, Ms. Burnett (with others) was awarded the CMS Administrators Special Citation Award for her work on defining a set of principles for home and community-based services, and in 2013, she received the Key Executive Leadership in Government Certificate from American University.

Corette Byrd, MS

Ms. Corette Byrd is a nursing professional with over a decade of experience in leading and directing projects and programs, quality management, ensuring regulatory compliance, and developing national and local policies and procedures. In 2012, Ms. Byrd joined CMS to lead the "National Consensus Development and Strategic Planning for Healthcare Quality Measurement" portfolio of work. This work involves endorsing standardized health care performance measures, making recommendations on an integrated national quality strategy and priorities for healthcare

performance measurement, and convening multi-stakeholder groups for input on national priorities and the Secretary's selection of quality and efficiency measures. Prior to joining CMS, Ms. Byrd was a Senior Associate with the American College of Physicians (ACP) where she led various programs, developed policies related to the Patient-Centered Medical Home model of care, and represented senior leadership in a variety of forums. Prior to ACP, Ms. Byrd oversaw the quality, risk management, and corporate compliance areas at a large federally-qualified health center, Unity Health Care. Ms. Byrd has nursing experience in critical care, public health, and urgent care; and she continues practicing today. Additionally, Ms. Byrd holds national certifications in Healthcare Compliance and Healthcare Quality. Ms. Byrd holds degrees from The University of Alabama – Birmingham, Georgetown University, and George Mason University.

Venesa Johnson Day, MPA

Ms. Venesa Johnson Day is currently Technical Director with the CMS Office of Federally Coordinated Health Care (the Medicare-Medicaid Coordination Office or MMCO, leading the Office's quality efforts around improving care for Medicare-Medicaid Enrollees. In addition, she leads the Office's Managed Fee-For-Service Financial Alignment Demonstrations team. The Managed Fee-For-Service team is responsible for developing the policy and quality frameworks for demonstrations designed to provide better, more coordinated, more cost effective care for Medicare-Medicaid fee-for service beneficiaries. She has worked at CMS for 15 years in various areas including Medicaid financial management. In her previous role, Venesa served as the payment lead for Medicaid provider-preventable conditions policy working across Agency components on payment driven quality initiatives. Prior to coming to CMS Venesa worked for the Department of Labor, Bureau of Labor Statistics as a budget analyst. Venesa earned a BA in Political Science (International Relations and Policy) from Morgan State University, and an MPA from The American University.

Jamie Kendall, MPP

Jamie Kendall is currently the Acting Director, Independent Living at the Administration for Community Living, U.S Department of Health and Human Services. She also serves as the Director of the Office of Policy Analysis and Development, at the Center for Policy and Evaluation at the Administration for Community Living (ACL). Jamie began her federal career working at the Administration for Children and Families at HHS and has also worked at the Social Security Administration, developing policies for low income families and individuals with disabilities. She holds a Masters in Public Policy (MPP) from Georgetown University. She previously served as the Deputy Commissioner at the Administration on Intellectual and Developmental Disabilities (AIDD) between December 2010 – March 2013 where she provided leadership to the programs authorized under the Developmental Disabilities Assistance and Bill of Rights Act of 2000 and the Help America Vote Act.

Lisa Patton, PhD

Dr. Lisa Patton is a clinical psychologist and Chief of the Quality, Evaluation, and Performance Branch within the Center for Behavioral Health Statistics and Quality, SAMHSA. Dr. Patton serves as the quality and evaluation lead for the Center. Prior to joining SAMHSA, she worked in the Division of Aging, Long-term Care, and Policy within the office of the Assistant Secretary for Planning and Evaluation. Dr. Patton conducted mental health services research in the private sector for over a decade. She also worked in community mental health, working primarily with adult survivors of trauma and persons with serious mental illness. Throughout her career, her work has focused on ensuring that vulnerable populations receive services.

D.E.B. Potter, MS

Ms. D.E.B. Potter has worked for the U.S. Department of Health and Human Services (HHS) for

over 25 years. Her work focuses on improving the measurement of vulnerable populations including the disabled, frail elders, persons needing long-term services and supports (LTSS), and behavioral health (BH) care. Efforts include quality measures development; data collection and instrument design; measuring health care use and quality; and estimation issues involving persons that use institutional and home and community-based services (HCBS). For over 20 years with the Agency for Healthcare Research and Quality (AHRQ), she is now a Program Analysts with the HHS's Office of the Secretary, Assistant Secretary for Planning and Evaluation (ASPE). She currently leads an ASPE, AHRQ and Centers for Medicare & Medicaid Services (CMS) joint project to develop risk adjustment methods for quality measures for HCBS populations. Other responsibilities include managing the development of BH quality measures and advancing quality measurement for the population with dementia. While at AHRQ she oversaw AHRQ's work in response to the Deficit Reduction Act to develop quality measures for the HCBS population and AHRQ's Assisted Living Initiative. Ms. Potter currently serves on numerous Technical Expert Panels (TEP) and across Agency workgroups including the HHS Liaison Group that oversees the current National Quality Forum HCBS measures project, the Measure Applications Partnership (MAP) Duals Eligible Workgroup, the HHS Committee for the Consensus-Based Entity, CMS's HCBS Experience with Care Survey, and on the National Advisory Panels for AARP's State Scorecard for LTSS, and the National Long Term Quality Alliance (LTQA). In 2002, she (with others) received HHS Secretary's Award "for developing and implementing a strategy to provide information the Department needs to improve long-term care."

NATIONAL QUALITY FORUM

Meeting Summary

Home and Community Based Services Quality Measurement Committee Web Meeting

The National Quality Forum (NQF) convened a committee web meeting for the Home and Community-Based Services (HCBS) Quality Measurement project on Friday, February 20, 2015. More than 500 individuals attended the web meeting, representing a variety of stakeholder groups. All members of the committee were in attendance (see Appendix A). An online archive of the web meeting is available for playback.

Welcome and Review of Webinar Objectives

Jamie Kendall, Director, Office of Policy Analysis and Development, Administration for Community Living began by welcoming participants to the webinar. Ms. Kendall 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 set for home and community-based services (HCBS). Wendy Prins, Vice President, NQF, also provided opening remarks, welcomed members and the public audience to the in-person meeting, and introduced Helen Burstin, Chief Scientific Officer, NQF, who conducted introductions and disclosures of interest for all committee members. Finally, Ms. Prins reviewed the meeting objectives:

- Build a shared understanding of the project objectives, activities, and the committee's role
- Introduce foundational information about quality measurement
- Begin to gather committee input in the development of an operational HCBS definition and conceptual measurement framework
- Request relevant sources for ongoing evidence synthesis and environmental scan of measures

Project Overview

Andrew Anderson, Project Manager, NQF, discussed the importance of HCBS quality measurement, the project objectives, deliverables, and the role of the committee. Mr. Anderson shared key points as to why it is essential to measure HCBS quality. As states continue to shift resources from institutional care to HCBS, there is an increased need to understand the quality of care that is being provided. A high-quality HCBS system is needed to support older adults and people with disabilities of all ages in order to optimize independence, good health, and quality of life. He added that there are existing frameworks and quality domains for evaluating long-term supports and services (LTSS) and HCBS, but the field lacks a unified picture of quality.

Mr. Anderson noted that this project will provide multi-stakeholder guidance on the highest priorities for measurement of HCBS. It will offer an opportunity to identify priority areas and address gaps in HCBS quality measurement through specific activities, including developing an operational definition of HCBS

and conceptual measurement framework, conducting a synthesis of evidence and environmental scan of measures and measure concepts, identifying the measurement gaps, and making recommendations for HCBS measure development. The creation of the operational definition will guide the development of a conceptual framework that incorporates the domains and sub domains of HCBS. This foundational work will then inform the identification of gaps in HCBS measures and priority areas for measure development. The final product will be a report with recommendations from the committee to HHS.

Mr. Anderson concluded by stating that this project will not emphasize a clinical point of view. The committee will be focusing on how to measure the quality of supports and services that enable community living. The committee will not be reviewing specific measures for endorsement; NQF endorsement is a separate formal process. The committee will examine existing quality measures and measure concepts, many of which are not endorsed by NQF, and identify a range of actions to increase the use of measures of HCBS.

"Crash Course" in Quality Measurement

Juliet Feldman, Project Manager, NQF, provided an overview of NQF and its role in the broader performance measurement enterprise. All NQF committees, including the HCBS committee, are purposefully balanced with stakeholders representing a wide variety of perspectives. NQF conducts its work in a transparent way to maximize stakeholder input. Ms. Feldman described how the HCBS project fits in the larger enterprise of performance measurement; it is upstream guidance.

Ms. Feldman presented foundational information about performance measurement to build a common understanding of terminology and basic measurement science.

- **Why Measure?** Measures can drive improvement, inform consumers and other stakeholders, and influence payment. It is important to remember that measurement is just a tool to help create change – it is not an end in itself. Careful deliberations are needed to determine what we should measure and how that information should be used; especially in the HCBS field where performance measurement is not yet systematic.
- **What is a Measure?** Measures allow for comparison against a standard or reference point. Essentially, measures offer a defined methodology for understanding quality in a fair and systematic way. A performance measure holds an entity accountable for a specific structure, process, or outcome. One form of outcome measurement is derived from information reported directly by consumers (person-reported outcomes or PROs). PROs can be the data source for performance measures (PRO-PMs) that assign accountability for achieving results.
- **Who can be measured?** Measures operate at various levels, including individual provider, facility, health plan, state, region, or nation.
- **How do measures drive change?** Accountability programs (e.g., public reporting and performance-based payment) tie rewards to performance on quality measures. When incentives such as payment, reputation, and market competition are on the line, measurement programs have more impact and also come under more scrutiny.

Developing HCBS Definition and Conceptual Framework

Sarah Lash, Senior Director, NQF, began by describing the purpose of the operational definition and conceptual framework. To support development of the definition, staff reviewed 200+ sources and identified 27 definitions for HCBS and LTSS. Ms. Lash explained that while these definitions contained many useful phrases, they do not meet the needs and scope of this project. Ms. Lash then suggested an approach the committee could take when developing the definition. For example, the definition should be person centered; use positive language; and contain the components of goal, recipients, services. She reminded the committee that this definition is not meant to replace existing guidance or regulations. Ms. Lash invited discussion on the approach to developing a definition of HCBS and the committee members offered the following suggestions:

- Focus on the three W's of HCBS (i.e., what is HCBS, who are these services for, and what is the goal)
- Be inclusive of everyone that benefits from HCBS, including children, people with behavioral health needs, family members, and caregivers
- Look at various initiatives such as work on eLTSS that are also working to define HCBS
- Goals of HCBS should be positive (e.g., "allow people to thrive in their communities" rather than "help keep people out of institutions")
- Emphasize person-centeredness
- HCBS link people to myriad other services and supports, including medical care
- Describe a "spectrum of available HCBS services" rather than listing each one

Each committee member was asked to submit a draft definition of HCBS by February 27, 2015. The definitions will be compiled and synthesized into a single draft definition for further refinement at the April meeting.

Opportunity for Public Comment

Throughout the web meeting, public participants had the opportunity to provide comments and ask questions. Participants' comments were generally focused on issues of project scope, related policy, and suggestions for developing the definition of HCBS. Comments from the chat are listed with responses from NQF in Appendix B.

Call to Action and Next Steps

Ms. Lash noted that NQF welcomes the committee's submission of the following items to the project team at HCBS@qualityforum.org:

- Submit draft definition by February 27th
- Sources to consult for HCBS operational definitions, conceptual measurement frameworks, the synthesis of evidence, and/or the environmental scan of measures

In closing, Ms. Lash thanked the committee members and the public for participating in the meeting. NQF will convene the next committee meeting on April 29-30, in Washington, DC.

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

Appendix B: Webinar Chat Report with NQF Responses

Message from Participant	Response from NQF
Will these performance standards affect Older American funded programs under Title III?	The committee has been tasked with identifying high quality HCBS measures and gaps in HCBS measurement. The committee will also provide recommendations to HHS for measure development. The recommendations will be general and it is not foreseeable that they will have an immediate impact on Title III or any programs.
Although I think this was alluded to in suggesting it might be a % or ratio, the distinction between measures and instruments is not always clear (e.g., NCI, PES have been mentioned, but are instruments, not measures per se--perhaps to some extent collections of measures, but not really as focused as "composites"). Some instruments are very widely used and there may be important consideration of measures that are imbedded in these instruments so as not to disrupt or dissuade use of broader scale effort. Also it seems important to consider the units of analysis (providers vs. systems). These have implications related to methods and demands of sample size or population surveys. It may also suggest that there are benefits to looking for measures within instruments so as not to disrupt broad scale use and associated benefit of the quality-related instruments.	The committee will take care to note the distinction between an instrument and a measure when conducting their review. The committee may also review instruments that contain questions that might be converted into stand-alone measures to ensure a complete picture of existing quality measures.
Is there any plan to address the issue of the increased costs that will be experienced by HCBS when they're asked to implement new and/or additional measurement tools and analyses?	This is an important question and the committee will consider costs and feasibility when evaluating measurement opportunities. However, projecting the cost of implementing measurement in HCBS is outside the scope of this project.
A participant raised the question of provider, individual, proxy provided information. That's really important. Beyond that, there are questions of response bias-especially among persons with cognitive limitations. Another issue is the discriminative vale of some measures. Many of widely used instruments items (or "measures") are 85%-90% positive. They are important items, but don't show much variation for discriminating	This is an important point. During the prioritization process, the committee will consider the strength of potential measures based on these and other considerations.

Message from Participant	Response from NQF
quality.	
In terms of transparency would there be some utility in identifying which members are consumers - it seemed like if a member was a consumer they had a position in an organization versus a "community member"	The committee was carefully selected to include representation from many stakeholders. Several committee members are consumers or have family members that use HCBS. However, this will not be designated on the roster.
What about including measures related to social determinants of health?	The committee will determine if measures related to social determinants of health are a priority, if any suitable measures currently exist, and if so how they might be implemented.
Can you confirm what programs will be used in collecting this information? This would be helpful for someone like me who is not in a public program.	The committee has been tasked with identifying high quality HCBS measures and gaps in HCBS measurement. The committee will also provide recommendations to HHS for measure development. The recommendations will be general and it is not foreseeable at this time what data collection strategies may be necessary.
How will independent organizations be using measurements/processes NQF endorses? How will we be notified of endorsements? Will these endorsements be given to funding sources to require NPs to complete, or are these voluntary suggestions?	The recommendations of the committee will be general and it is not foreseeable at this time how measurement will be implemented at the provider level. This project is well upstream of the policy and processes you describe. For reference, all NQF-endorsed measures can be found in the Quality Positioning System (QPS) on the NQF website. However, this project will not endorse individual measures.
How are we proposing to overcome limitations posed by state databases in terms of data entry and reporting capabilities?	Data infrastructure is an important factor to consider when determining the feasibility of adopting measures for HCBS. The committee may make recommendations about how to strengthen current capacity.
I would propose that we need to understand the elements of the HCBS before we can discuss scope or outcomes.	The first task of the committee is to develop an operational definition of HCBS to frame the committee's discussions.

Message from Participant	Response from NQF
States vary in terms of budgets, which can affect quality of care. Example: New Hampshire told me a max of 40 hours/week of home care services is available to an elder on the HCBW. Another state is more liberal in terms of available services. This would impact quality of care/satisfaction.	HCBS recipients differ in many ways; risk-adjustment and stratification of measures likely need to be used to enable fair comparisons. This is an important point that the committee will weigh when making its recommendations.
With person centered planning focus, Is it correct for the State to dictate to a client to state in their plan of care what days they are able to travel to destinations? (i.e. Doctor's appointments, grocery store, shopping for a 6 month timeline)	A person-centered approach increases the ability of an individual to choose when, where and how they receive their services. Policies that hinder ability to choose would be considered less than person- centered, but must be weighed against other practicalities. This level of detail is beyond the scope of the committee's deliberations.
One slide mentioned measures influence payment. To the extent states have autonomous ability to identify their own measure criteria, this goal seems incompatible unless a methodology is developed that takes this into consideration.	This committee's work is intended to provide the framework and guiding principles that would support more standardization of measurement across states.
How will the committee respond to the variability in impact, for purposes of this point, after traumatic brain injury in terms of injury severity and consequences, since no 2 injuries result in the same challenges?	HCBS recipients differ in many ways. Prioritization of measurement opportunities is likely to favor the measures that are cross-cutting and relevant to the most consumers.
There is already a list of things that must be present in order to qualify for a setting that qualifies for federal funding of waivers of HCBS	The committee will be using the settings rule, and other sources, while crafting the operational definition for this project. The definition will not conflict with the rule, but the rule is intended for a different use.
One of challenges in avoiding the "laundry list" of services is that many service recipients are served by multiple providers and those multiple providers offer specific services. Also many would argue that high quality in services would differ in content for persons with different types of impairments.	The committee is creating a high level definition of HCBS for the purposes of this project. It is intended to provide broad guidance on what high-quality HCBS is.
I feel many HCBS actually DO provide Health Care; the problem is one of nomenclature; services provided by physicians is MEDICAL CARE; HCBS services that provide nutrition, exercise, etc. keep people healthy, and therefore really do deserve the health care label, even though they are not traditionally thought of as such.	For purposes of this project, we regard HCBS as including both clinical and non-clinical services. The committee will be cognizant of differences in nomenclature surrounding HCBS when making its recommendations.

Message from Participant	Response from NQF
I think that HCBS includes supports that are not services like new technologies that obviate the need for a caregiver's help and that should be included here - also virtual monitoring or therapeutic meeting kinds of supports. (I would add to the third column heading in slide 38)	Thank you for the suggestion. The committee may discuss this when refining its definition of HCBS and creating domains and subdomains for measurement.
There is a really great broad definition that was just created here: http://wiki.siframework.org/eLTSS+Glossary	This source is now included in the project references.
I think it's great to build on existing efforts as much as possible to avoid duplication of efforts	Taking advantage of existing efforts is in line with our effort to create a complete and unified picture of HCBS quality measurement
The committee might need to distinguish between the push to respond to or modify the environment, universal design vs the need for comprehensive services including quality	The built environment may be considered in the committee's prioritization of measurement opportunities.
Increasingly, HCBS service options for frail older adults will be offered through integrated care options, such as PACE and managed care, which also incorporate primary and acute care services alongside with community based supports. How will this project address the quality of services in fully integrated care models, such as PACE.	The committee will be reviewing a variety of existing measures and measurement opportunities through the environmental scan. If a gap is identified in the measurement of HCBS through integrated care models, the committee may consider recommendation for development in this area.
I want to let the Committee know that CMS through the TEFT program, is maintaining the ties between eLTSS and the work of this committee	Thank you for the comment. This project is tracking a variety of related efforts and will coordinate to the extent possible.
When I hear comments like: "Availability of services should be mentioned as well as consumer choice," I worry that "choices" might be limited to what is available rather that when is actually needed. The success of the HCBS hinges on the independence and integrity of the person centered plan.	Thank you for the comment. This issue may be addressed during the committee's discussions of priority domains and sub-domains for potential measurement.
Also wanted to mention that it would be helpful to include administrative data as a source of important and valuable information	The committee will consider all credible and reliable sources of data when considering the feasibility of HCBS quality measures.
Please next time emphasize the connection to the e-LTSS which has been discussed several times	We have included the e-LTSS glossary in our list of research sources. The committee will reference it when developing the operational definition and conceptual framework.