NATIONAL QUALITY FORUM

Overview of Comments Received on the Interim Report

The National Quality Forum (NQF) was fortunate to receive over 100 comments from federal and state agencies, associations, special interest groups, and individuals during the public comment period. Responses supported the Committee's work, approach and consumer focus, and emphasized the urgency and importance of this work. Many individuals shared personal experiences highlighting critical HCBS concepts. The Committee discussed public comments at the August 28, 2015 web meeting, and will work to reflect these comments and questions in initial components of the conceptual framework.

Operational Definition of HCBS

Overall, there was support for a broad and inclusive definition of HCBS. Comments suggested revising, removing, or adding terms to the operational definition. The Committee discussed comments that the terms *independence* and *integrated* may not apply to all HCBS users and that *needs* may be too broad. The Committee was hesitant to remove *independence* and *integrated*, but agreed *needs* was too broad. In general, the Committee supported suggestions to add *self-determination* and *community inclusion* to the definition, and will further refine the operational definition based on public feedback.

Characteristics of High-Quality HCBS

Comments received on the characteristics were overall positive. Many suggested modifying the language and terminology used, and adding terms that address the social determinants of health, meeting consumer needs, outcome-oriented data, and funding. In light of these comments, the Committee will revise the *person-driven* characteristic to include life preferences and remove examples of goals. The Committee will include *in accordance with individual preferences* to the social connectedness characteristic to reflect individual choices. Comments also highlighted the importance of the HCBS workforce. The Committee agreed that this characteristic should address skills and competencies, and acknowledged that this characteristic description needs more work in order to get to consensus. The Committee agreed with comments calling for engaging designated representatives and consumer advocates in HCBS design, implementation, and evaluation, but stressed that consumer voices should be most prominent.

Measurement Domains and Subdomains

Many comments supported the emphasis on consumer goals and the importance of caregivers. There were numerous suggested additions, and little to no comments that a concept was not important to measure. Based on public comments, the Committee will add *supports for consumers in directing services*, *needs assessment*, and *transportation* as sub-domains. The Committee also supported suggestions to remove *Providers* from the title of the Workforce/Providers domain and to remove *full* from the Full Community Inclusion domain. Given the breadth of comments on housing, the Committee considered a separate housing domain and decided that this issue needs further Committee discussion.

Conceptual Framework Illustration

There were few comments received on the illustration that suggested offering more detail on how quality measurement leads to improved consumer outcomes. Comments also related to the placement of specific domains in the areas of measurement. The Committee discussed illustrating the intermediate step of quality improvement activities between quality measurement and improved consumer outcomes, and emphasized placing *Choice and Control* in the center of the Venn diagram given the Committee's long discussions about choice and control for persons receiving HCBS.

HCBS Quality Project First Interim Report: Comments

Contents

COMMENTS ON DEFINITION AND CHARACTERISTICS

Name	Organization	Comment
Elham Sliman	Texas Health and Human Services Commission	The State of Texas has three concerns specifically related to the draft definition: 1) the definition contains a broad array of services and does not distinguish between, for example, HCBS and State Plan long-term support services. An inclusive definition has implications in terms of measurement; currently, the State's quality measurement standards are different for each of those services and the proposed definition would warrant restructuring of measurement systems; 2) the standardized definition for use by stakeholders in both the private and public sectors may not be applicable since elements/standards may not be applicable to both sectors; and 3) should the definition eventually evolve into a different method of evaluation even if it is not proposed as such now, the domains and sub-domains suggested for performance measurement do not correspond with current CMS expectations.
Nancy Brubaker	DSHS--Home & Community Services Division	We appreciate that the definition parameters do not specify the setting or diagnoses of individuals receiving HCBS (since including these may leave out some individuals receiving HCB services). • We recommend changing "long-term supports" to "long-term services and supports". This more fully describes assistance that individuals receive. • We recommend that the term "integrated" be defined. LTC providers ask for clarity about the extent to which a setting is integrated into the community. • We recommend that the term "non-institutional" be added to the definition since the current federal HCBS definition excludes institutions. The definition could be phrased as "HCBS refers to an array of long-term services and supports that promote the independence...and that are delivered in the home or other integrated, non-situational community setting."

Name	Organization	Comment
Kerri Melda	CQL	CQL|The Council on Quality and Leadership - We reinforce the Committee's Characteristics of High Quality Home and Community Based Services (page 9), and note these characteristics where we feel further clarification would be beneficial: • "a person-driven system that optimizes individual choice and control in the pursuit of self-identified goals". We reiterate that quality be determined/measured based on an individual's self-identified goals or preferred outcomes. As examples, recognizing that one person's preferred employment outcome, or vision of an ideal social network, may look quite different from another's. • "reduc[ing] disparities by offering equitable access to and delivery of services". We reinforce the importance of equity ~ within and across states; with regard to socio-economic status, degree of disability, cultural, racial and language differences, and across service populations.
Kerri Melda	CQL	CQL|Council on Quality and Leadership - With regard to high-quality characteristics tied to "choice and control" and "legal rights", CQL recommends language that incorporates/emphasizes Supportive Decision Making prior to considerations of guardianship.
Jennifer Dexter	Easter Seals, Inc.	The characteristics of home and community-based services (HCBS) included in the report are well thought out, descriptive and positively phrased Easter Seals is particularly appreciative that earlier input to remove the language focused on 'primarily non-medical' that affected access to adult day services was removed.
Clarissa Kripke	University of California, San Francisco	"There was recognition that coordination and integration of HCBS with medical care is important, but "over-medicalizing" HCBS must be avoided. Participants expressed concern that a greater emphasis within HCBS on health services and health outcomes would diminish opportunities for individuals to shape and direct their own services. This would be contrary to the consumer-driven philosophy that the Committee has encouraged. However, creating strict boundaries between health-related and other services is neither practical nor productive from the perspective of fostering holistic wellness and acknowledging the role that both clinical services and HCBS have in the healthcare system." This is a particularly important paragraph and a welcome evolution in thinking about coordination and integration of HCBS and medical care. The list of characteristics on pg. 9 is also comprehensive and well targeted.

Name	Organization	Comment
Urvi Patel	American Health Care Association	The American Health Care Association/National Center for Assisted Living (AHCA/NCAL) is submitting comments on the interim report “Addressing Performance Measure Gaps in Home and Community-Based Services to Support Community Living: Initial Components of the Conceptual Framework.” AHCA/NCAL appreciates the broad definition of HCBS that includes individuals of any age and health needs. AHCA/NCAL is concerned about the term “integrated” as this could be interpreted that assisted living communities which have a secured dementia unit are not integrated. Dementia care is an important part of assisted living communities and should not be excluded from this HCBS definition.
Urvi Patel	American Health Care Association	AHCA/NCAL is pleased that a person-driven system which choice is included as part of high-quality HCBS, since this is a guiding principle of assisted living. Some of the other domains are not appropriate to all populations receiving HCBS and in fact, could pose safety issues for some recipients. It is likely that a significant number of characteristics are appropriate for the entire HCBS population of users but that some characteristics are better suited to certain sub-populations of HCBS users. "Promotes social connectedness by including people who use HCBS in the community to the same degree as people who do not use HCBS" may not be appropriate for all populations served by HCBS. HCBS users should be included in the community to the fullest extent they choose to and without putting their safety at risk. AHCA/NCAL is concerned about the characteristic "ensuring each individual can achieve the balance of personal safety adn dignity of risk that he or she desires" as not all HCBS recipients are able to make appropriate decisions regarding personal safety either due to cognitive impairment, intellectual or developmental disabilities. AHCA/NCAL is in agreement that it is important to holistic wellness to acknowledge the role that medical services and HCBS overlap. Medical services in HCBS are vital services that enable not only older adults to continue to remain in the community-based setting of their choice but also children and younger adults with medical needs.
Megan Burke	The SCAN Foundation	The list of characteristics is comprehensive, touching on key components of a high-quality HCBS system. We recommend the following adjustments for further clarification. Person-Driven System: While providing for a person-driven system is important, there may be instances where an individual cannot personally direct their system of care. Identifying person-driven services as a characteristic could create a risk of developing measures that exclude people from HCBS who are identified as not being able to direct their care. Identifying the characteristic as person-centered and listing person-

Name	Organization	Comment
		directed as one of the descriptors along with honoring their needs, values, and preferences would be more inclusive. We recommend changing this characteristic to read: • Provides for a person-centered system that honors the individual's needs, values, and preferences while optimizing individual choice and control in the pursuit of self-identified goals (e.g. employment, enjoying life). • Integrated Services: Integrating services to promote well-being is important. We recommend adding the promotion of quality of life. A person's definition of quality of life often includes well-being, but that definition can shift as circumstances change. We recommend changing this characteristic to read: Integrates healthcare and supportive services to promote well-being and quality of life. • Coordination and Integration: We recognize the importance of ensuring that resources are coordinated and integrated to maximize affordability and sustainability. Further, we believe the focus should stem from the individual's needs, values, and preferences. Therefore, services should be coordinated and integrated to ensure access to the right services at the right time, in accordance with the individual's needs, desires and preferences. We recommend modifying this characteristic to read: o Coordinates and integrates resources and services to help individuals access the right services at the right time to meet their goals while maximizing affordability and long-term sustainability.
Katie Maslow	Institute of Medicine	The operational definition is clear and includes important concepts but seems to lack the concept that the array of services should be sufficient to meet the needs of the core target groups and subpopulations who will use the services. At present, most communities probably do not include a sufficient array of services to meet the needs of the relevant groups and subpopulations. Thus, if the operational definition is intended to be purely descriptive, it is correct. For quality measurement, however, the sufficiency (or adequacy or comprehensiveness of the services) is important. It is important for people who need various services and their families and government and private sector organizations that are trying to evaluate the quality of array of available services. Perhaps the committee could add wording to include this concept.
Rachel Patterson	Christopher & Dana Reeve Foundation	Overall, we support the definition as written. If any changes to the definition are proposed, we would support changes that promote self-determination, inclusion, and the physical and medical supports necessary to live in the community. We would oppose changes that would define quality services and quality of life prescriptively; quality of life is truly self-determined so we would be concerned with efforts to impose specific domains or accomplishments as a measure of quality of life.

Name	Organization	Comment
Laura Thornhill	Alzheimer's Association	The Alzheimer's Association appreciates the opportunity to comment on NQF's Interim Report on Measure Gaps in Home- and Community-Based Services (HCBS). While we offer more detailed comment below, we note here that the report generally implies that all persons receiving HCBS have normal cognitive function and can clearly articulate their needs and preferences. For example, the committee includes "a person-driven system that optimizes individual choice and control in the pursuit of self-identified goals (e.g., employment, enjoying life)," and "[e]ngages individuals who use HCBS in the design, implementation, and evaluation of the system and its performance" as characteristics of high-quality HCBS. Similarly, the committee provides that "[it should] be a principle of high-quality HCBS that the system maximizes individual autonomy and self-determination. This 'dignity of risk' is fundamental in a person-centered system." While the Association agrees with these characteristics, the committee does not seem to account for the perspective of persons with cognitive impairment or their caregivers. Dementia is a degenerative condition that impairs judgement and eventually robs a person of his ability to make decisions and his capacity to assume risk. Many persons with dementia and their caregivers rely on HCBS, so this framework must accommodate the perspective of this population alongside those individuals who will be able to remain independent in their homes and communities. The committee must recognize this, particularly as it considers the definitions of "integrated" and "full community inclusion." We discuss this in further detail under the "Full Community Inclusion" domain.
Marybeth Mccaffrey	UMass, Center for Health Law and Economics	p. 7 – We support the operational definition as written. We appreciate the term "need" rather than "disabilities" was used to promote the stated approach that is positive in tone, devoid of value statements, plain-language, and concise. The resulting definition may be overly broad, however. Replacing the phrase "that are delivered in the home or other integrated community setting" with the phrase "that qualify for services delivered in the home or other integrated community setting" is a possible alternative.
Jennifer Hitchon	American Occupational Therapy Association	The American Occupational Therapy Association (AOTA) commends this interim report and tremendous work done thus far to improve the quality of home and community-based services. While AOTA agrees with the intent of this broad definition of "home and community-based services (HCBS)", we realize that for some individuals, independence is not always possible, given their prognosis or worsening health status. We propose that the definition includes the goal of "maximizing abilities". For those with progressively deteriorating health, HCBS may be striving to "improve function" and "reduce the rate of decline".

Name	Organization	Comment
Del Conyers	National PACE Association	We have concerns specifically related to the sources referenced to develop the proposed operational definition. While the AARP Public Policy Institute's definition recognizes that people with long term services and supports require "individualized services or supports to live in a variety of settings"; it lacks specificity and is too broad. The Medicaid.gov definition also is too general and does not include the aging population. For purposes of PACE, a slight modification to the CMS State Plan Section 1915(i) Final Rule definition may be suitable with the caveat that the last bullet consider "cognitive ability to choose within a network" albeit a broad and healthy network. The intent of the term "integrated community setting "referenced in the definition of HCBS is unclear. Does this refer to the recent HCBS settings rule issued by the U.S. Department of Health and Human Services? Additionally, we recommend that the term "non-institutional" be added to the current definition as the current federal HCBS definition excludes institutions. We have concerns with any definition that would impede PACE's ability to bring into close proximity to participants' homes (e.g., non-institutional settings) services that would either be co-located in independent housing or located in an adjacent space. Lastly, we question whether the use of "long-term supports" eliminates other temporary but needed services, (e.g., heavy chore service).

Name	Organization	Comment
Jill Barker	SBC Global	Definition of Home and Community-Based Services: The term “home and community-based services” (HCBS) refers to an array of long-term supports that promote the independence, well-being, and choices of an individual of any age who has physical, cognitive, and/or behavioral health needs and that are delivered in the home or other integrated community setting. Of the definitions considered as a basis for HCBS in this report, the one that was decided on by the committee is the least accommodating of the full range of disabilities that must be served. It does not recognize, for instance, that promoting independence is for some people with cognitive or other complex disabilities a fruitless endeavor and that achieving only a small measure of independence or never achieving that goal does not diminish the need for specialized services and care, nor should it diminish the perceived worth of the individual. For contrast, this is the definition from the AARP Public Policy Institute: “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.” This definition at least acknowledges that a variety of settings may be needed by people with a range of disabilities and that these settings, whether or not they are considered “congregate”, are “home” to the people who live in them. This would have been a better choice to serve the full range of people with disabilities.
A. Mcbride	Madison House Autism Foundation	We believe that this subject matter is pivotal in how policy is manifested in the coming decades and the implications will have a great impact on many lives and thus, respectfully, submit the following comments: Autism is a spectrum developmental disability. We have concerns that there may not be anyone on the committee who receives HCBS waiver funding and/or represents individuals who are impacted by high service’s needs, self-injurious and other behaviors that limit their home options for community engagement. We receive calls and emails regarding individuals who have been turned down from home and community opportunities because support providers say they cannot serve someone such high support needs. It is

Name	Organization	Comment
		imperative that there be adequate and meaningful representation of those with intellectual/developmental disabilities who have high support needs and their caregivers. There must be a greater understanding of the range of abilities when discussing quality of supports and the challenges that might pose. Only about 4% of primary research publications on autism and ASD have addressed lifespan issues in recent years. In fact, research focused on adults has consistently been among the smallest categories of autism related research since the 1980s. (Office of Autism Research Coordination (OARC), National Institute of Mental Health and Thomson Reuters, Inc. on behalf of the Interagency Autism Coordinating Committee (IACC). IACC/OARC Autism Spectrum Disorder Research Publications Analysis Report: The Global Landscape of Autism Research. July 2012. Retrieved from the Department of Health and Human Services Interagency Autism Coordinating Committee website: http://iacc.hhs.gov/publications-analysis/july2012/index.shtml) While we acknowledge that "dignity of risk" to individuals is important, it is necessary to mitigate that risk ~ especially in dangerous and life-threatening situations. There are many documented incidents of adults on the spectrum who are criminally apprehended and jailed, or sent to hospitals, at great and unnecessary cost in terms of both anguish and dollars. We are happy that an ASAN representative is on the committee. However, ASAN does not necessarily serve those on the spectrum with high support needs and/or intellectual disability. ASAN's direct service delivery experience primarily consists of acting as an organizer for local advocacy and support groups.
A. Mcbride	Madison House Autism Foundation	We thank the Department of Health and Human Services for contracting with the National Quality Forum (NQF) to convene a multi-stakeholder committee of experts to prioritize performance measurement opportunities and we applaud NQF's work. Established in 2008, MHAF is one of the few organizations in the country to focus solely on adults with autism. MHAF is dedicated to creating awareness of the lifespan challenges autistic adults and their families face; and to finding, developing, and promoting the solutions that allow adults with autism to live as independently as possible and become participating members of our society. First and most important, in order to understand this paper and submit meaningful comments, readers must truly understand the implications of what is being decided and the reasoning behind the chosen methodology. Communicating this vital understanding to all stakeholders, a community of very diverse educational backgrounds, should be the fundamental goal of this report. According to the Flesch-Kincaid readability test, a well-established and standard measure of reading ease, this report is slightly more difficult to read than the Harvard Law Review. Madison House Autism Foundation used three separate online tools to analyze the readability of this report and found the results consistent. This is troubling because stakeholders, particularly those who receive HCBS, must be able to participate in the NQF process and inability to understand reports is a

Name	Organization	Comment
		barrier to meaningful engagement for many.
A. Mcbride	Madison House Autism Foundation	2. Quality should not be discussed in a vacuum. We have great concern that there is no discussion of cost or who will bear those costs, potentially creating unrealistic expectations. Discussing quality without discussing cost or current unmet needs is purely academic; it will not lead to real, quality home and community-based services. In fact, by not acknowledging need and trying to conceptualize performance measures on such a broad base, the committee may inadvertently increase the institutionalization of the most vulnerable populations in nursing homes and prisons. 3. There is little discussion of the urgent, unmet needs of individuals on HCBS waiting lists that may lead to thousands of individuals being institutionalized in nursing homes, incarcerated, or homeless in the next two decades. Nationally, more than a quarter of a million people are on a Home and Community Based Services (HCBS) waiting list. This problem has worsened significantly over the last several years, almost doubling since 2007. Fulfilling the current need nationwide would require a 44% increase in states' HCBS programs, and that need is still growing. (Bragdon, T. (2013). The Case for Inclusion. Retrieved from http://www.ucp.org/the-case-for-inclusion/2013/state_scorecards.html). The number of autistic persons without services is unprecedented and growing. We applaud any policy that would increases innovative housing models, end discrimination against and limits to individual choice, or increases the scarce residential opportunities and limited resources. Madison House Autism Foundation staff has attended and will continue to attend NQF work sessions. Again, we are grateful for all your work for this difficult endeavor.

Name	Organization	Comment
Desiree Kameka	Coalition for Community Choice	The following characteristic suggestions build on the impressive work already done by the committee: "Promotes social connectedness by including people who use HCBS in the community to the same degree as people who do not use HCBS" As written, the text rhetorically values the relationship of non-HCBS consumers as superior to HCBS consumers, as if the social connectedness of neuro-diverse, aging, or other peers with disabilities is not acceptable as high-quality relationships. Many minority populations prefer the relationships to others within their minority, yet access to relationships outside of their minority must not be restricted or limited due to social or physical barriers. This characteristic should be re-evaluated with the goal to identify and reduce barriers to community access. Example: 'Identifies barriers and promotes access to consumers preferred home, workplace, community spaces, and relationships.' "Utilizes and supports a workforce that is trained, adequate, and culturally competent;" Based on discussions of providers within the CCC, quality of supports are correlated to having dependable, long-term staff that knows an individual's daily preferences and support needs: how they like their coffee/tea, their unique communication nuances, their favorite music, their favorite type of events, what triggers pain or anxiety, and who they feel can be trusted during difficult physical or emotional trials. Knowing someone in this intimate way takes time, not just training or physically present bodies. Therefore, expansion of the characteristic to include staff retention would bear another important element of measuring quality. Example: 'Utilizes a workforce development strategy to provide trained, long-term and culturally competent staff "Supplies valid, meaningful, integrated, aligned, and accessible data;" As the Final Rule relies on outcome-oriented characteristics of HCBS, it should be underscored that outcome-oriented data and emphasis on the consumer voice is absolutely essential to measuring quality of HCBS. Example: 'Supplies valid, meaningful, integrated, outcome-oriented, and accessible data that reflects system effectiveness to influence consumers quality of life;' The CCC would also like to suggest an additional characteristic of high-quality HCBS: There are not enough financial resources to provide paid supports for all who could benefit from HCBS, and many communities need more assistance increasing accessible spaces and attitudes. Public-private community partnerships are essential to develop supports for access to more natural, un-paid, relationships and community integration. This should be addressed. Potential text: Maximizes community public-private partnerships to increase access to natural supports and improved community integration.

Name	Organization	Comment
Desiree Kameka	Coalition for Community Choice	First and foremost, the Coalition for Community Choice would like to applaud the National Quality Forum for its work to offer measurement goals of high-quality, long term support services that are truly person-centered and ensure the rights of consumers to have choice and control over their Home and Community Based-Supports (HCBS). The text of an operational definition for HCBS should be inclusive of individual preference and right to choose to live with other aging or neuro-diverse peers. Thus the draft phrase, "... and that are delivered in the home or other integrated community setting," should be changed to underscore personal choice. For example: '... and that are delivered in their preferred home, workplace, and community.', or '... and that are delivered in the settings that meet the goals and preferences of one's person-centered plan.'
Alice Dembner	Community Catalyst	The characteristics of the high quality HCBS laid out in the report are explicit and comprehensive. We suggest a few small improvements in two items. Our changes are reflected in bold type: Engages individuals who use HCBS, their designated representatives, and consumer advocates in the design, implementation, and evaluation of the system and its performance. Reduces disparities by offering equitable access to and delivery of services, plus additional supports that address social and economic determinants of health that have contributed to historic disparities among certain subpopulations.
Abby Marquand	PHI	Given PHI's focus on the direct-care workforce, we are particularly supportive of the committee's recognition of workforce quality and adequacy as an essential characteristic of a high-quality system for the delivery of home and community-based services. They work directly with individuals to ensure independence and community engagement, and assist people with complex medical conditions and functional limitations to continue living in their homes and communities. We agree that a high-quality system of HCBS must "support" the HCBS workforce by providing adequate job quality through proper compensation, training, and career advancement opportunities. A high-quality system must "ensure," not just "utilize," a trained workforce. For the consumer, training supports the safe delivery of high-quality care across a range of personal needs, while abiding by federal and state regulations (where they exist). And for the workforce, a growing body of evidence demonstrates that training increases job satisfaction and reduces turnover, two critical factors for stabilizing and growing the direct-care workforce so that it can meet the surge in demand. Finally, training in this sector has increasingly focused on equipping the eldercare

Name	Organization	Comment
		workforce with the competence to serve more vulnerable populations with unique needs. In spite of the documented benefits of training, in the current system training standards are mostly minimal for the HCBS workforce across the country, and the quality of preparation that worker receive varies considerably from place to place and provider to provider.[i] This raises concerns regarding whether we can begin to address quality of service delivery without first ensuring a more comprehensive training approach for the workforce, given the level of responsibility for outcomes that will be directly tied to the role of the worker. Moreover, “cultural competence” should be expanded to include “linguistic competence”—ensuring that people with limited-English proficiency can access services. The characteristics should include measures that assess whether services target and reach vulnerable and marginalized populations—communities of color, immigrants, and LGBT people, as key examples. Cultural and linguistic competence should also be expanded to cover the workforce; services should be delivered in a manner and environment that acknowledges, respects, and supports a culturally and linguistically diverse workforce. [i]Marquand, A., Chapman S.A. (2014). The National Landscape of Personal Care Aide Training Standards. San Francisco, CA: UCSF Health Workforce Research Center on Long-Term Care. Available at: http://healthworkforce.ucsf.edu/sites/healthworkforce.ucsf.edu/files/Report-The_National_Landscape_of_Personal_Care_Aide_Training_Standards.pdf

Name	Organization	Comment
Dan Berland	NASDDDS	RE: “Addressing Performance Measure Gaps in Home and Community-Based Services To Support Community Living;” July 15 Interim Report for Public Comment The Consortium for Citizens with Disabilities is a coalition of approximately 100 national disability organizations working together to advocate for national public policy that ensures the self-determination, independence, empowerment, integration and inclusion of children and adults with disabilities in all aspects of society. CCD appreciates the opportunity to comment on the HCBS Committee’s Interim Report. These comments are from CCD’s Long Term Supports and Services Task Force and Rights Task Force. Comments on the Operational Definition of the Term “Home and Community-Based Services” and Conceptual Framework CCD Supports the definition as written. We appreciate the Committee’s recognition of the need to “maintain a broad and inclusive orientation as to what might be considered part of HCBS.” CCD also strongly agrees with the specified characteristics of a high-quality HCBS system. We especially wish to laud the committee’s focus, here and throughout the interim report, on person-centeredness and individual choice and control, and the recognition that successful HCBS is driven by and responsive to each individual’s self-identified goals, priorities, and preferences. We also appreciate the committee’s recognition of the “dignity of risk” and the need for HCBS to take a balanced approach to safety.
Ann Page	Assistant Secretary for Planning and Evaluation (ASPE)	Recommend one change to the definition of "home and community-based services;" i.e., changing the word "needs" to "disability or developmental delay". The reason is that EVERYONE has physical needs; e.g., the need for a safe and healthy home, good food and nutrition, physical activity, health care. The group of people for whom we want to provide HCBS is not ALL people with these universal physical needs, but the subset of people with special needs for services that help them compensate for a disability or developmental delay --- as described in the introduction to this report. One can argue that there are universal cognitive and behavioral needs as well. Because of this suggest making the change below: The term "home and community based services" (HCBS) refers to an array of long term services and supports that promote the independence, well-being, and choices of an individual at any age who has physical, cognitive, and/or behavioral health DISABILITY OR DEVELOPMENTAL DELAY and that are delivered in the home or an integrated community setting. Without this change, the definition will define all services delivered to, for example, the homeless, all people

Name	Organization	Comment
		receiving all forms of counseling, victims of domestic abuse, underage single parents and their children, and many others as HCBS services.

COMMENTS ON THE DOMAINS AND SUB-DOMAINS

Name	Organization	Comment
E. Clarke Ross	Consortium for Citizens with Disabilities	American Association on Health and Disability (AAHD): two elements essential to achieving the outcome of community living are in employment and transportation. These are not discussed in the interim report. "Full community inclusion" and "self-determination" are discussed in the report. But they seem to be buried within a comprehensive and detailed discussion of all other elements.
Elham Sliman	Texas Health and Human Services Commission	The State of Texas has some concerns with the proposed domains and subdomains of measurement; 1) the measurability of potential measures due to their subjective nature; 2) the likelihood that these measures are more suited for survey instruments than routine data collection; and 3) the potential implications of using survey instruments on states with limited capacity to develop, implement, and analyze the respective data. We recommend reconsidering or examining the following list of domains or sub-domains based on their subjective nature. Workforce/Providers: Sufficient numbers and appropriately dispersed; dependability; respect for boundaries, privacy, consumer preferences, and values; skilled; demonstrated competencies when appropriate; culturally competent, sensitive, and mindful; adequately compensated, with benefits; safety of the worker; teamwork, good communications, and value-based leadership Consumer Voice: Breadth and depth of consumer participation; level of commitment to consumer involvement; diversity of consumer and workforce engagement; Choice and Control: Achieving individual goals and preferences (i.e., individuality, person centered planning); self-direction; shared accountability

Name	Organization	Comment
		System Performance: Consumer engagement; participatory program design; reliability; publicly available data; appropriate and fair resource allocation based on need; primarily judged by the aggregate of individual outcomes; waiting lists; availability of services; data integrity Full Community Inclusion: Enjoyment or fun; employment, education, or productivity; social connectedness and relationships; social participation; accessibly built environment Caregiver Support: Access to resources (e.g., respite, crisis support); caregiver and/or family assessment and planning; compensation Effectiveness/Quality of Service: Goals and needs realized; preferences met; team performance; rebalancing Service Deliver: Accessibility (e.g., geographic, economic, physical, and public and private awareness or linkage); sufficiency (e.g., scope of services, capacity to meet existing and future demands); dependable (e.g., coverage, timeliness, workforce continuity, knowledge of needs and preferences, and competency); Equity: Safe, accessible, and affordable housing; consistency across jurisdictions;
Ellen Perry	Advocacy in Action	"EXHIBIT 3. DOMAINS OF HCBS QUALITY MEASURMENT - Workforce/Providers & Caregivers Support & Service Delivery" (page 12) Comment: The quality of the workforce would be better and the pool of potential employees would be greater if the pay was better. Currently Direct Support Staff is not paid very much (only $9 per hour for the service of Personal Care), which also affects the level of support for paid staff. This also affects Service Delivery dependability because there aren't very many people who can act as backup staff since the agencies are chronically understaffed. Comment: Also, there is currently a 3 year minimum experience for Direct Support Staff to be able to provide supported employment. This makes it harder to find staff. This rule is being done away with in the new Innovations Medicaid Waiver that will go into effect in January 2015. But this is something that should stay on the radar as a policy that had a negative effect on the ability to find enough staff.
Ellen Perry	Advocacy in Action	"EXHIBIT 3. DOMAINS OF HCBS QUALITY MEASURMENT - Equity" (page 12) Comment: In the state I live in, North Carolina, the service Community Networking is not delivered fairly and equally across the state. This is due to the Managed Care Organizations (MCOs) that oversee the providers in the various regions in which the state is divided. The MCOs need more standardized training so that the definition of Community Networking is better understood and therefore more equitably provided across the state.

Name	Organization	Comment
Ellen Perry	Advocacy in Action	"EXHIBIT 3. DOMAINS OF HCBS QUALITY MEASURMENT – Health and Wellbeing" (page 12) Comment: Since direct support staff that cannot go with me to doctor's visits or go to the brace shop when I need to get my leg braces fixed or go to physical therapy this means the services I receive between HCBS and healthcare are not integrated. This affects my life. I am 57 and live independently and do not have family that can go with me. But I need someone who knows me and cares about me and can help me relay information to the doctor or whoever. Staff could also help me keep up with what the doctor says. Staff can go pretty much any place else with me and assist me. But they can't go with me to medical appointments because of the potential for double billing to Medicaid. This is a problem since I can't drive and I really need help during these times, too. Also, it means I can't make a same day appointment with the doctor because Para-transit requires trips to be booked at least 24 hours in advance.
Ellen Perry	Advocacy in Action	"EXHIBIT 4. DRAFT SUBDOMAINS OF HCBS QUALITY MEASUREMENT – Consumer Voice" (page 13) Comment: In North Carolina, we have had problems getting enough input from consumers about changes to the Innovations Waiver. There are very few stakeholders who are actively involved in the process. I'm not sure all the reasons why this is so, but one reason is because consumers don't understand the content and the state doesn't make an effort to put the information in Simple English for people to understand. Another reason is because consumers often have trouble arranging transportation to go to meetings where public opinions are being asked for and/or they don't have internet access to be able to provide electronic feedback.
Ellen Perry	Advocacy in Action	"EXHIBIT 4. DRAFT SUBDOMAINS OF HCBS QUALITY MEASUREMENT – Workforce/Providers 'Stuffiest numbers and appropriately dispersed' & Choice and Control" (page 13) Comment: I am under the Self-Determination part of the Waiver and awhile back I was not happy with my current provider. I looked for other alternatives (and I live in an urban part of North Carolina) but there weren't any other good options. Thankfully, the provider decided to step things up and do better, but if they hadn't done that I wouldn't have had another option. Comment: There are also not enough Community Guides. I think this is because they don't get paid very much (they get $150 per month per client). If they were paid better, then there would be more options for consumers. I have to have a Community Guide because it's written into the Waiver for people like me who do Self-Direction.
Ellen Perry	Advocacy in Action	"EXHIBIT 4. DRAFT SUBDOMAINS OF HCBS QUALITY MEASUREMENT – Choice and Control" (page 13) Comment: Consumers who are Self-Directed should be trained in the types of services they are getting. This way they would be able to better direct their own services. And have more control over their own lives. They wouldn't be so dependent on the provider agency and their Direct Care Staff to know what to do; they could become much more empowered.

Name	Organization	Comment
Ellen Perry	Advocacy in Action	"EXHIBIT 4. DRAFT SUBDOMAINS OF HCBS QUALITY MEASUREMENT – System Performance & Service Delivery (i.e. 'Timely initiation of services')" (page 13) Comment: In North Carolina we have about 9,000 people waitlisted for the Medicaid Waiver. These are people who deserve to get services – and who need these services in order to live their lives in the communities of their choice. This is a big problem. The fact that things have to go through the Legislature is a big problem. Things get hung up in the system. There has to be a better solution so that everyone who needs services and who has been approved to get them can actually start receiving them.
Ellen Perry	Advocacy in Action	"EXHIBIT 4. DRAFT SUBDOMAINS OF HCBS QUALITY MEASUREMENT – Consumer Voice and Human and Legal Rights" (page 13) Comment: Consumers often don't understand their rights. And we are given so many papers to sign that it is confusing to know what each one is for – especially since the information is not provided in Simple English. It should all be written in Simple English so that people with disabilities are given the chance to understand what their rights are and what they are signing and what recourse they have if their rights are violated.
Ellen Perry	Advocacy in Action	"EXHIBIT 4. DRAFT SUBDOMAINS OF HCBS QUALITY MEASUREMENT – Equity 'Accessible and Affordable Housing'" (page 13) Comment: I have a community that is my home. It is a great place to live – there is even really great public transportation that is free. The problem is that it is very hard to find affordable housing. My boyfriend, who also has a disability, was kicked out of his apartment along with 90 people at the same time because the landlord decided to stop taking Section 8 vouchers. And in North Carolina, a landlord has the right to refuse to take Section 8 vouchers and it isn't fair or equitable. My boyfriend and I live together now and have a shared Section 8 voucher, but we rent an apartment. Every year the apartment complex threatens to increase our rent. We have great credit and work as much as we can. We are good candidates to be low income homebuyers but the process is very long and difficult and very confusing. Only a couple of people have been able to do it and flip their Section 8 voucher from paying for rent into paying for a mortgage. This is an area where there is a lot of room for improvement.
Ellen Perry	Advocacy in Action	"EXHIBIT 4. DRAFT SUBDOMAINS OF HCBS QUALITY MEASUREMENT – Full Community Inclusion" (page 13) Comment: I feel like I am very much a part of my community but I know a whole lot of people who are not. They aren't for a variety of reason, such as: they don't have adequate staff (or no staff at all), they don't have the correct services, they don't know what is available in the community, they don't have enough natural supports and/or their staff is not very helpful. However, when people have good staff and sufficient staffing then they blossom. Comment: I live in an urban area with great public transportation but much of the state of North Carolina is rural. Consumers who live in rural areas have a really hard time with transportation because there just aren't

Name	Organization	Comment
		good options for them. This causes them not to be fully included in their communities as much as they could.
Ellen Perry	Advocacy in Action	"EXHIBIT 4. DRAFT SUBDOMAINS OF HCBS QUALITY MEASUREMENT – Service Delivery" (page 13) Comment: Direct Support Staff have basically no day-to-day oversight by their qualified professional. It can be easy for them to feel like they don't have the support they need from the provider agency. There should be more day-to-day oversight from the provider agency.
Nancy Brubaker	DSHS--Home & Community Services Division	We are pleased that the domains are broad, but this results in overlap (e.g., between domains for system performance, service delivery and health and well-being) For the system performance domain, we recommend excluding the term "ethically" because we are unclear how we would ensure that the system operates ethically. We notice that the other domains do not have a descriptor such as "full", and are questioning why there is a domain with the title "full community inclusion". We suggest the domain be titled "community inclusion". Otherwise, there should be a definition for what constitutes "full" community inclusion. We suggest removing the domain for "effectiveness/quality of services" since the NQF is defining the domains of HCBS quality measurement, and effectiveness and quality of services are part of those other domains. For the health and well-being sub-domain, we would ask that dementia be called out in the same way as behavioral health. As a service that promotes an individual's ability to stay in a home or other integrated community setting, we suggest that "decreasing someone's involvement with the criminal justice system" be added to the domains and sub-domains.

Name	Organization	Comment
Megan Burke	The SCAN Foundation	Quality measures are often developed from a systems perspective rather than the individual's perspective. As such, they do not reflect the totality of the individual's experience in receiving services. Quality measures should address how people experience care delivery, building upon process-oriented measures. We recommend the following adjustments to the subdomains. Workforce/Providers: One subdomain is sufficient numbers of providers, appropriately dispersed. We recommend accessibility of providers be a variable when determining sufficient numbers and dispersal. While a provider may fall within a catchment area and meet basic accessibility standards, s/he may not be accessible if it takes an individual over an hour to travel to the provider using public transportation. Further, building on cultural competencies, experience and training in aging and disability competencies (e.g. providing appropriate accommodations and assistive technology for individuals who are blind and/or deaf) influences quality. We recommend adding the following: 1) sufficient numbers and appropriately dispersed (includes intersection of accessibility with time and distance standards); 2) demonstrate aging and disability competencies. Choice and Control: The listed subdomains demonstrate how choice and control is identified (i.e. self-direction, respect, dignity of risk). However, to make choices, people need to be informed of options, benefits, and risks. We recommend adding the following subdomains: 1) information provided is easily understandable and accessible; 2) information is shared through a dynamic relationship between the individual, the provider, and identified supports. Caregiver Support: The subdomains listed address several aspects of building caregiver capacity. According to AARP's LTSS Scorecard (www.longtermscorecard.org), 58% of family caregivers are employed while 74% were employed at one time while caregiving. The Scorecard elevates policy and legal rights for caregivers as an indicator for a high performing LTSS system. We recommend adding the following subdomain: caregivers are educated about available legal and system supports. Service Delivery: The subdomains address quality at the process level, but not from a person-centered perspective. Individuals should have the opportunity to participate in the care team process to communicate their concerns, values, and goals, and his/her contributions should be documented and guide the care planning process. We recommend adding the following subdomains: 1) solicitation, documentation, and integration of individual's concerns, values, and goals in the care plan process; 2) functional outcomes; 2) tracking outcomes over time as functional needs and personal goals change; and 3) overall improvement in life experience.

Name	Organization	Comment
Kerri Melda	CQL	CQL|Council on Quality and Leadership - CQL makes the following recommendations regarding the use of person-centered vs. system-centered or service-centered language in domain descriptions, emphasizing the outcome for the individual rather than the action of the service or system. For example: Choice and Control - The level to which individuals who use HCBS choose their services and control how those services are delivered. Human and Legal Rights - The level to which individuals who use HCBS experience their human and legal rights. Full Community Inclusion - The level to which individuals who use HCBS are integrated into their communities, and are socially connected. Effectiveness/Quality of Services - The level to which individuals who use HCBS achieve intended outcomes. Choice and Control/Human and Legal Rights - CQL recommends including language that emphasizes utilizing Supportive Decision Making prior to consideration of guardianship.
Urvi Patel	American Health Care Association	Overall, the domains and subdomains cover important areas for HCBS recipients, with the understanding that not all domains and subdomains will be relevant for each individual receiving HCBS. The suggested domains and subdomains appear to have more of an operational focus than outcomes for recipients. AHCA/NCAL realizes this project is still in its early stages but has concerns about how certain subdomains will be operationalized including adequate compensation and benefits, which can be very subjective and vary widely. Choice and Control: Choice of particular workers may not take into account team based approaches to care or be realistic at times due to workforce shortages. Human and Legal Rights: The subdomain of freedom from abuse/neglect/exploitation fits more appropriately in this domain as opposed to the Health and Well-Being domain. Full Community Inclusion: The word "full" should be removed as this may not be possible due to safety issues or preferences of the individual receiving services. Not all subdomains will be appropriate for all individuals, for example retirees may not be interested in employment.

Name	Organization	Comment
		Effectiveness/Quality of Services: It is not clear what rebalancing is being referred to in this domain. Health and Well-Being: The subdomain of freedom from abuse and neglect seems to be more appropriate under the Human and Legal Rights domain.
Katie Maslow	Institute of Medicine	The domains and sub-domains listed in the interim report identify important aspects of high quality HCBS and a high quality HCBS system. However, the domain of assessment or identification of needs seems to be missing. As the report says, many different kinds of individuals require and use HCBS. Assessment and identification of the person's needs and the caregiving-related needs of any family members or others who are helping the person is essential for providing appropriate, high quality of care and obtaining positive outcomes. The emphasis on consumer choice is also important, but many consumers, including both the person and family, need a careful assessment to help them make choices that will work for them. HCBS providers require such assessments to define and provide person- and family-centered HCBS. And government and private sector administrators and payers require assessments to authorize and pay for appropriate services. The committee should add a domain for assessment and identification of needs.
Rachel Patterson	Christopher & Dana Reeve Foundation	Overall, we support the domains. In particular, we want to ensure that caregiver support is adequately measured, including family caregiving. Both immediate family members and families of choice provide crucial support for their loved ones, but may be also in need of additional support in order to maintain their family unit. We support the emphasis on holistic wellness, which should recognize that many people need medical services in their homes as part of HCBS and in order to maintain their independence and wellbeing. We also support that wellness and safety are balanced with dignity of risk as defined by the consumer. We support quality measures that address equity and the reduction of health and service disparities, especially disparities faced by people with disabilities, people of color, LGBTQ people, and people of other underserved groups. Finally, we would support the addition of measures related to employment and transportation. HCBS promotes full participation, which must include working and getting around. Recent actions by the Department of Justice and Department of Labor have affirmed that “Living in the Community Means Working in the Community” (https://blog.dol.gov/2015/06/22/living-in-the-community-means-working-in-the-community/). We encourage NQF to include measures of quality that include the extent to which individuals receiving HCBS can access their community via transportation and seek employment.

Name	Organization	Comment
Laura Thornhill	Alzheimer's Association	The Association offers comments on the following domains and subdomains: “Full Community Inclusion:" The Association cautions the committee as it considers the definition of this term. Some persons with dementia are at risk for wandering and live in facilities with effective methods of deterring wandering while keeping residents engaged, healthy, and safe. Some individuals, however, do not view these facilities as providing the opportunity for “full community inclusion” or “full integration.” We appreciate and support the committee’s acknowledgment of the importance of safety and an individualized approach to safety supports. Safety supports must be available and the quality of those supports must be measured. We also commend the committee’s inclusion of "choice of setting" as a subdomain and remind the committee that settings must meet a person’s preferences and needs. "Service Delivery:" Because the needs of a person with dementia and her caregiver change with the progression of the disease, we applaud the committee’s acknowledgement that services must be sufficient to meet both current and future demands. "Health and Well-Being:" For reasons noted above, we encourage the committee to include "safety and risk as defined by the consumer and caregivers." “Caregiver support:” We applaud the committee’s recognition of the importance of caregivers and the many supports they need. We respectfully suggest that the committee add a caregiver satisfaction subdomain to ensure that they are receiving the right supports at the right time. “Choice and Control:” Similarly, we encourage the committee to include a consumer satisfaction subdomain. We also suggest that the committee include identifying and documenting caregivers as a subdomain and note the caregiver’s role in supporting person-centered decision-making. Persons with dementia will eventually lose their ability to make informed choices and understand consequences. Their wishes, however, can be fulfilled by including caregivers in planning and decision-making. Finally, we suggest that the committee add “Safety” as a domain. Persons using HCBS are frail and vulnerable in many different ways and the safety of settings should be assessed, evaluated, and improved.
Marybeth Mccaffrey	UMass, Center for Health Law and Economics	p. 16 - We support the domains and subdomains of HCBS quality measurement. We are pleased that Equity was included in the domains and subdomains as well as future prioritization of measurement gaps using the IOM 2003 descriptions. We would like the description to be broadened further, as follows: Inclusiveness: equity, as defined by the relevance of an area to a broad range of people with regard to age, gender, socioeconomic status, and ethnicity/race, language, disability, and LGBTQ status; representativeness, as defined by the generalizability of associated quality improvement strategies to many types of populations across the spectrum of HCBS; and reach, as defined by the breadth of change effected

Name	Organization	Comment
		through such strategies across a range of settings and providers.
Maureen Dailey	American Nurses Association	Consumer Choice and Control: Advanced care planning seems to fall under this domain, but is not mentioned specifically. Registered nurses as well as other inter-professional providers are important in team-based, shared accountability for development of advanced care plans, care coordination driving to patient-centered goals, and timely access to advanced illness care such as palliative care. Equity: Equity sounds good on paper, but at least in Missouri, there is an inadequate supply of affordable housing, and some smaller communities offer nothing for HCBS clients. Missouri is largely rural state so older adults are forced into nursing homes since they can't find affordable housing in their small communities. "Money follows the person" only works if the state worker (and therefore the 'person') can locate disabled or ADA senior housing. Health and Well-being: no mention of technology to improve in home safety, but this is the future and we should be measuring benefits of technology use in the home Sub-domain gap areas (can be linked to identified domain areas in parentheses): Are beneficiaries able to do the things they want to do? (Full Community Inclusion) Are there enough options to stay in the home vs. being forced to a nursing home? (Effectiveness/Quality of Services) Do beneficiaries know how to obtain resources and choose options? (Service Delivery) How quickly are beneficiaries able to obtain services? (Service Delivery) With caps on how much the state will pay monthly for each beneficiary, are needs being met to maintain community living? (System Performance) Only older adults can access meals and respite services in MO. What meal and respite needs do younger persons and their caregivers have and to what extent are they unmet? (System Performance, Service Delivery)

Name	Organization	Comment
		What is the extent of caregiver burden versus longevity? (Caregiver Support)
Jennifer Hitchon	American Occupational Therapy Association	AOTA is pleased to see that the HCBS quality measurement domains include Caregiver Support, Choice and Control, Full Community Inclusion, Effectiveness/Quality of Services, and Health and Well-Being. We offer the following comments: · Health and Well-Being: Excellent inclusion of health status and wellness. Can this be expanded to include one's ability to perform everyday functional tasks? In a study of hospitalization among 828 Medicare recipients post hip replacement surgery, Perruccio et al. (2012) reported that when mental well-being and activity limitations were added to logistic regression, these variables were predictive of hospitalization (odds ratios: 1.2, 1.1, respectively). · Choice and Control: Consider adding cultural values after "achieving individual goals and preferences" · Full Community Inclusion: Add transportation as a subdomain · Effectiveness/Quality of Services: Please clarify if technical services include assistive technologies provided to consumers or their homes. · Service Delivery: Please clarify if coordination refers to transitions of care, and extends to health professionals beyond the HCBS team. Consider adding cultural competence. · Reference: Anthony V. Perruccio, Elena Losina, Elizabeth A. Wright, and Jeffrey N. Katz. Aggregate Health Burden and the Risk of Hospitalization in Older Persons Post Hip Replacement SurgeryJ Gerontol A Biol Sci Med Sci (2013) 68 (3): 293-300 first published online August 9, 2012doi:10.1093/gerona/gls151
Del Conyers	National PACE Association	We appreciate the Committee's intent to be inclusive in identifying the measurement domains and sub-domains for HCBS. We would like to offer the following points for the Committee's consideration. As the project moves forward, it will be important for the Committee to specify the level of analysis associated with the measurement (sub) domains (e.g., system-level vs. individual service provider-level). Measurement of some of the (sub) domains may be appropriate at a system level, however, not at a provider level (e.g., housing) Given the variation of the HCBS programs across states, it may be difficult to implement a standardized measure on satisfaction and availability of services. Also, as a high proportion of HCBS involves caregivers and other non-licensed personnel, the validity of satisfaction scores based on dependability and availability of personnel may be questionable. The interim report does not emphasize the need for outcome measures for HCBS (e.g., are individuals healthier or satisfied; live longer than institutionalized individuals). Outcome/effectiveness measures need

Name	Organization	Comment
		to be a part of the policy domain in order for policy makers to assess not only cost but value (i.e., what benefits/outcomes are attained for what cost).We seek clarity regarding the intent of the "System Performance" domain. There is concern that operational efficiency and ethical practices are difficult to measure and the subdomains are not cohesive. With regard to the subdomains, we question the intent of the equity domain. While there is a significant need to address "safe, accessible, and affordable housing" we have concerns regarding how this concept will be measured. Is the expectation that HCBS providers become competent in affordable housing? It is not reasonable to assess the quality of services delivered based on factors for which a provider is not accountable. If the goal of HCBS is to "optimize independence" in the community, then measures related to the achievement of this goal should be a priority. Additionally, given that caregiver support also is cited as a goal, measures related to this goal also should be given priority.
Jill Barker	SBC Global	Domains of HCBS Quality Measurement If the list of Domains of Quality Measurement are in order of priority, this list does not take into account individual priorities in HCBS. For my sons, the most important domains are Human and Legal Rights that assure appropriate care and services in addition to freedom from abuse, neglect, and exploitation, Health and Well-being, Service Delivery, Effectiveness/Quality of Services, and System Performance. Workforce Providers, listed first in Domains, is irrelevant to them – they are unable to perform any task that any reasonable person could call work. The priorities should be set for individuals and not as a standard to measure whether quality HCBS are being provided.
A. Mcbride	Madison House Autism Foundation	We thank the Department of Health and Human Services for contracting with the National Quality Forum (NQF) to convene a multi-stakeholder committee of experts to prioritize performance measurement opportunities and we applaud NQF's work. Established in 2008, MHAF is one of the few organizations in the country to focus solely on adults with autism. MHAF is dedicated to creating awareness of the lifespan challenges autistic adults and their families face; and to finding, developing, and promoting the solutions that allow adults with autism to live as independently as possible and become participating members of our society. First and most important, in order to understand this paper and submit meaningful comments, readers must truly understand the implications of what is being decided and the reasoning behind the chosen methodology. Communicating this vital understanding to all stakeholders, a community of very diverse educational backgrounds, should be the fundamental goal of this report. According to the Flesch-Kincaid readability test, a well-established and standard measure of reading ease, this report is slightly more difficult to read than the Harvard Law Review. Madison House Autism Foundation used three separate online tools to analyze the readability of this report and found the results consistent. This is troubling because stakeholders, particularly those who receive HCBS, must be able to participate in the NQF process and inability to understand reports is a barrier to meaningful engagement for many.

Name	Organization	Comment
A. Mcbride	Madison House Autism Foundation	While we acknowledge that "dignity of risk" to individuals is important, it is necessary to mitigate that risk ~ especially in dangerous and life-threatening situations. There are many documented incidents of adults on the spectrum who are criminally apprehended and jailed, or sent to hospitals, at great and unnecessary cost in terms of both anguish and dollars. We are happy that an ASAN representative is on the committee. However, ASAN does not necessarily serve those on the spectrum with high support needs and/or intellectual disability. ASAN's direct service delivery experience primarily consists of acting as an organizer for local advocacy and support groups. Quality should not be discussed in a vacuum. We have great concern that there is no discussion of cost or who will bear those costs, potentially creating unrealistic expectations. Discussing quality without discussing cost or current unmet needs is purely academic; it will not lead to real, quality home and community-based services. In fact, by not acknowledging need and trying to conceptualize performance measures on such a broad base, the committee may inadvertently increase the institutionalization of the most vulnerable populations in nursing homes and prisons. There is little discussion of the urgent, unmet needs of individuals on HCBS waiting lists that may lead to thousands of individuals being institutionalized in nursing homes, incarcerated, or homeless in the next two decades. Nationally, more than a quarter of a million people are on a Home and Community Based Services (HCBS) waiting list. This problem has worsened significantly over the last several years, almost doubling since 2007. Fulfilling the current need nationwide would require a 44% increase in states' HCBS programs, and that need is still growing. (Bragdon, T. (2013). The Case for Inclusion. Retrieved from http://www.ucp.org/the-case-for-inclusion/2013/state_scorecards.html).
A. Mcbride	Madison House Autism Foundation	The number of autistic persons without services is unprecedented and growing. We applaud any policy that would increases innovative housing models, end discrimination against and limits to individual choice, or increases the scarce residential opportunities and limited resources. Madison House Autism Foundation staff has attended and will continue to attend NQF work sessions. Again, we are grateful for all your work for this difficult endeavor.
A. Mcbride	Madison House Autism Foundation	We believe that this subject matter is pivotal in how policy is manifested in the coming decades and the implications will have a great impact on many lives and thus, respectfully, submit the following comments: Autism is a spectrum developmental disability. We have concerns that there may not be anyone on the committee who receives HCBS waiver funding and/or represents individuals who are impacted by high service's needs, self-injurious and other behaviors that limit their home options for community engagement. We receive calls and emails regarding individuals who have been turned down from home and community opportunities because support providers say they cannot serve someone such high support needs. It is

Name	Organization	Comment
		imperative that there be adequate and meaningful representation of those with intellectual/developmental disabilities who have high support needs and their caregivers. There must be a greater understanding of the range of abilities when discussing quality of supports and the challenges that might pose. Only about 4% of primary research publications on autism and ASD have addressed lifespan issues in recent years. In fact, research focused on adults has consistently been among the smallest categories of autism related research since the 1980s. (Office of Autism Research Coordination (OARC), National Institute of Mental Health and Thomson Reuters, Inc. on behalf of the Interagency Autism Coordinating Committee (IACC). IACC/OARC Autism Spectrum Disorder Research Publications Analysis Report: The Global Landscape of Autism Research. July 2012. Retrieved from the Department of Health and Human Services Interagency Autism Coordinating Committee website: http://iacc.hhs.gov/publications-analysis/july2012/index.shtml)
Caitlin Connolly	National Employment Law Project	We believe the framing of a quality home and community based services should include individual workers and we recommend the committee explore measuring the "level to which the human and legal rights of individuals who work in HCBS are promoted and protected."
Desiree Kameka	Coalition for Community Choice	WORKFORCE / PROVIDERS: The 2012 Disability & Abuse Project survey revealed that 70% of people with disabilities report being abused, 57% on more than 20 occasions, 46% saying it was too frequent for them to count. For those that did report, 52.9% said nothing happened. Thus, consider the addition of measuring accountability of abuse allegations. Measurement of the influencers of long term staff tenure and reasons for staff self-termination. Measurement of the profiles of current workforce for the purpose of understanding what populations may be the future workforce. CONSUMER VOICE: It is important to note that 62.7% did not report the abuse as 58% believed that nothing would happen, 38% had been threatened/afraid, and 33% did not know how to report. The need to measure accessibility of assistance for consumers to identify and report abuse, especially individuals who have difficulty communicating verbally, should be considered. The ability to communicate and be understood by support persons directly influences a HCBS consumer's quality of life. Thus, continual assessment of implemented communication strategies should be measured. CHOICE and CONTROL: Measuring HCBS consumers specific barriers to home and community access is important for identifying necessary systemic change. HUMAN and LEGAL RIGHTS: Continual opportunities for HCBS consumers to learn about their rights and changing policy in accessible formats such as plain language, video, audio recording, etc. should be measured, especially if a continuing goal of the NQF is HCBS consumer participation. SYSTEM PERFORMANCE: Flexibility of consumers ability to access different HCBS supports/waivers based on their changing support and service needs is necessary to be measured. A consumer should never have to voluntarily reject supports of an available waiver slot they could use in the present, in hopes of climbing the waitlist ladder to access supports they know they will need in the future.

Name	Organization	Comment
		FULL COMMUNITY INCLUSION: All measures of community integration and inclusion should be based upon an individual's preferred time and extent of participation within the community, not just recorded in terms of hours spent in the community without regard for that individual's life choices. CAREGIVER SUPPORT: Access to information about basic LTSS structure, access to supports, changing policy, and public comment periods must be measured. Measuring what mode of communication delivery is most effective for multiple target populations would also assist in important information dissemination. SERVICE DELIVERY Identifying and measuring roles and structures within the service delivery system in which conflicts of interests are likely to occur is important for transparency and accountability.
Camille Dobson	National Association of States United for Aging and Disabilities	I have concerns about the broad nature of the subdomains in the "Choice and Control' domain – in particular, the words 'choice of program delivery models' in the list provided in Exhibit 4. I ask the Committee, when finalizing the subdomains in this area, to remain cognizant of state flexibility and authority to determine which service models will be offered in their HCBS programs. Not every state offers a self-direction option, and many states require consumers to enroll in managed care plans to receive HCBS services. Focus in this area should more appropriately be on measurement subdomains that address individual autonomy.
Alice Dembner	Community Catalyst	We recommend the following changes in the domains; additions are highlighted in bold: Consumer Voice: The level of involvement and impact of individuals who use HCBS, their authorized representatives and consumer advocates. Full Community Inclusion: The level to which HCBS integrates individuals into their communities and fosters social connectedness and community engagement. Service Delivery: (add) culturally and linguistically competent Equity: The level to which HCBS is delivered in a way that reduces historic and current disparities among subpopulations. Health and Well-Being: (add to end of description) and community engagement We recommend the following additions to the subdomain descriptions, changes in bold: Workforce/Providers: (add) Longevity of persona care workforce; linguistic competency, inclusion of peers, addressing implicit bias.

Name	Organization	Comment
		Consumer Voice: (add) Impact of consumer involvement; level of commitment to and actual supports (stipends, transportation, meals, staffing, etc.) provided to enable consumer involvement. Human and Legal Rights (add): Meets all applicable laws and regulations, including the ADA and Mental Health Parity and Addiction Equity Act. System Performance: (add) Number and type of denials of service; resolution of appeals and grievances. Full Community Inclusion: (add) transportation Service delivery: (add) Culturally and linguistically competent.
Abby Marquand	PHI	We applaud the Committee's recognition of workforce as a primary factor in improving HCBS quality. We recommend that workforce and providers be separated into two domains. The capacity of the workforce is not solely dependent on the quality of the provider; it's shaped structurally by public policies and the economic environment (e.g. sectorial wage ordinances, Medicaid reimbursement rates, training and licensure standards, and more). Some domains could also benefit from additional clarity. For example, we ask: how is a "paid caregiver" different from a member of the "workforce"—and why? The "caregiver support" domain is essential, but this report does not draw linkages between family caregivers and the workforce/providers. And while there are important distinctions between paid family caregivers and other members of the workforce, we also recognize that both groups deserve workplace protections, training and skill-building opportunities, adequate compensation and benefits, the guarantee of safety, and the opportunity to participate in service delivery teams. In turn, an adequate paid workforce, regardless of family status, should be dependable, as well as respectful of boundaries, privacy, consumer preferences, and values. In addition to the subdomains outlined in the interim report, we propose the following additions: TABLE 1: Domain: Suggested Additions Workforce - High-quality, pre-service and ongoing training that addresses person-centered care, independent living, and cultural and linguistic competence – and is recognized by employers and consumers - Proper compensation with a living wage, paid sick leave, and other benefits

Name	Organization	Comment
		- Access to affordable health insurance options - Career advancement opportunities (e.g. advanced roles in care coordination, specialty roles) - Predictable and stable work schedules - Supportive supervision Providers - Turnover and vacancy rates; - Employer-sponsored benefits Human and Legal Rights - Workforce labor protections Health and Well-Being - Workforce access to affordable health insurance and paid sick leave; - Workforce job satisfaction (as an indicator of intent to leave)
Dan Berland	NASDDDS	RE: "Addressing Performance Measure Gaps in Home and Community-Based Services To Support Community Living;" July 15 Interim Report for Public Comment The Consortium for Citizens with Disabilities is a coalition of approximately 100 national disability organizations working together to advocate for national public policy that ensures the self-determination, independence, empowerment, integration and inclusion of children and adults with disabilities in all aspects of society. CCD appreciates the opportunity to comment on the HCBS Committee's Interim Report. These comments are from CCD's Long Term Supports and Services Task Force and Rights Task Force. Comments on the HCBS Quality Measurement Domains and Sub-Domains CCD for the most part supports the domains described in the interim report. We particularly appreciate the recognition of caregiver support as a domain, and the specific inclusion of family caregiving. Both immediate family members and families of choice provide crucial support for their loved ones, but may be also in need of additional support in order to maintain their family unit. CCD recommends the addition of measures specifically related to employment. Although several of the articulated domains, such as Full Community Inclusion, could possibly encompass services related to employment, we believe that employment is so central to full community participation—and such a significant and ongoing challenge for HCBS systems—that it should be called out and highlighted in any HCBS quality measurement system. We encourage NQF to include measures of quality that measure the extent to which individuals receiving HCBS can participate in their community via employment.

Name	Organization	Comment
		The CCD Rights Task Force adds these specific suggestions regarding the domains and subdomains: · Under the Domain of "Workforce/Providers," add "goals" to the subdomain of "respect for boundaries, privacy, consumer preferences, and values" (i.e. ". . . consumer preferences, goals, and values"). · Under the Domain of "Human and Legal Rights," add the following to the subdomain of "optimizing the preservation of legal and human rights": "including the right to live, work and receive services in the most integrated setting appropriate." · Under the Domain of "Effectiveness/Quality of Services" add "individual" in front of the subdomain of "goals and needs realized," to clarify that the referenced goals are the individual's personal goals rather than the general goals of the service.
Maureen Dailey	American Nurses Association	Workforce/Providers: Preparation, scope of practice, and competency of providers should be well-matched to the needs of the consumer to achieve improved outcomes (e.g., prevention of avoidable index hospitalization and readmissions). Additionally, adequate registered nurse access and appropriate skill mix is needed to fully meet the needs of a large percentage of HCBS beneficiaries, including critical priority areas such as safety and care coordination. ANA agrees with the workforce comments, including concerns, submitted by the Eldercare Workforce Alliance (EWA) that "without an investment in the eldercare workforce, which includes the HCBS workforce, even more stress will be placed on often unpaid family caregivers. " EWA included concerns about adequacy of registered nurse access to consumer noting the importance of appropriate staffing and skill mix. There is a gap in NQF portfolio for staffing and skill mix measures for nursing and other disciplines for HCBS and other care settings.

COMMENTS ON THE ILLUSTRATION

Name	Organization	Comment
Kerri Melda	CQL	CQL|Council on Quality and Leadership - In Exhibit 2 and Exhibit 5, CQL recommends that the Venn diagram better reflect the Committee's commitment to a system that is "centered on the achievement of an individual's desired outcome" (page 3), and better articulate the specific "Improved Consumer Outcomes" (pages 10 and 14) to be measured. To do so, we suggest the diagram be more circular in nature, beginning and ending with the person's/people's (individually and collectively) measurement of personal quality-of-life outcomes; and that these areas of inquiry/measurement for consumer outcomes be more clearly defined (more so than what currently exists in the policy/system, services/providers, and individual circles).

Name	Organization	Comment
Katie Maslow	Institute of Medicine	The committee should consider the possibility that the intersection of the three circles should be (or include) the provision of HCBS that best match the needs and preferences of the person and the caregiving-related needs of the person's family and other informal caregivers. Placing this objective at the intersection of the circles would seem to reflect at least an important component of quality in HCBS and therefore, an important target for quality measurement.
Maureen Dailey	American Nurses Association	All six IOM aims of care should be explicit including, including timeliness and access. Patient driven care is beyond "control". The HCBS care team care plan should be consumer driven. Consumer groups have been vocal that patient driven care coordination goes beyond "patient-centered". Safety is also a key concept to be expanded beyond consumer and worker safety to a community perspective. Consumers may want to remain in the HCBS level of care beyond the point that is safe with existing available HCBS, including caregiver support. The integration of home health care was not explicit. Home care has a rich history of coordinating home and community-based services and providing care by registered nursing and other inter-professional team members as appropriate to vulnerable community-based populations to improve prevention, post-acute illness care and advanced illness care. Shared accountability from the team's perspective was not explicit. Patient and caregiver accountability is important but should be expanded across all team members and be measured with shared accountability and attribution.
Jennifer Hitchon	American Occupational Therapy Association	We realize that the availability of measures may be influencing the illustration, but it is unclear why Caregiver Support is located within the levels of: Policy/Systems, Services/Providers, and Individual. Caregiver Support is usually provided within the transaction between the individual and the service provider. The domain, Choice and Control, also does not intuitively fall under Policy/System and Services/Providers. Choice and Control is usually observed in the context of the interaction between the individual and the service provider.
Del Conyers	National PACE Association	Lastly, we suggest placement of the Effectiveness/Quality of Services domain in the center of Exhibit 5. Measurement Domains within the Conceptual Framework Illustration asit relates to Policy/System in terms of value (benefit/cost) as much as it relates to consumers and the providers.
Desiree Kameka	Coalition for Community Choice	Arrows should point in both directions as it is essential that individual HCBS consumers are directly represented in informing and participating in the policy/system, not just via services/providers.
Camille Dobson	National Association of States United for Aging and Disabilities	I believe that the "Choice and Control" domain is better situated in the overlapping circles of Individual and Services/Providers, instead of Policy/System and Services/Providers. Alternatively it could be situated in the overlap of all three circles. It seems incongruous that Choice and Control would not be assessed/measured at the individual level.

Name	Organization	Comment
Thomas Smith	New York State Psychiatric Institute	New York State (NYS) is adding HCBS to its Medicaid benefit package for several populations including long-term care, developmentally disabled, and behavioral health. The NYS Office of Mental Health is committed to making HCBS a key element in a transformed Medicaid program that supports person-centered, recovery oriented care. NYS encourages the NQF to place more emphasis on measuring consumer outcomes. The Initial Components of the Conceptual Framework report comprehensively describes structure and process measures but makes little effort to conceptualize outcomes. This is especially important for behavioral health populations that will use HCBS to pursue individualized recovery. NYS is using the interRAI Community Mental Health assessment with adult service recipients to determine housing status and social outcome indicators in the domains of work, education, criminal justice involvement, and social relations (http://www.interrai.org/community-mental-health.html). The Child and Adolescent Needs and Strengths Assessment (CANS-NY) which will be implemented with children and youth under age 21 to determine social and behavioral needs and strengths for children and their families (https://www.health.ny.gov/health_care/medicaid/program/medicaid_health_homes/docs/cans_6_21.pdf). These assessments are a core part of the NYS implementation of Health Homes in the behavioral health population and the Medicaid Managed Care 1115 Waiver carve in of behavioral health services. We look forward to the committee's work and will be happy to share our experiences.

GENERAL COMMENTS

Name	Organization	Comment
E. Clarke Ross	Consortium for Citizens with Disabilities	American Association on Health and Disability (AAHD): the statement of need for a measurement framework is excellent. Including in the report title that the objective is "to support community living" sends a positive and proactive message that is very important and is fully consistent with the ADA and Olmstead Supreme Court decision. The report provides a good direction for NQF Future staff and committee analysis and discussions. The focus on HCBS "outcomes" is appreciated and very important.

Name	Organization	Comment
Daniel Van Leeuwen	Advocates, Inc.	Advocates, Inc. supports: 1. the HCBS definition: The term “home and community-based services” (HCBS) refers to an array of long-term supports that promote the independence, well-being, and choices of an individual of any age who has physical, cognitive, and/or behavioral health needs and that are delivered in the home or other integrated community setting. 2. the inclusion of supports provided to family members and other unpaid caregivers of individuals with LTSS needs 3. The conceptual framework for measuring HCBS and the related domains We suggest that the challenges of health literacy, data collection and data system interoperability cannot be underestimated. Medical facilities (hospitals and clinics) and funders are already challenged to collect and share accurate data among themselves. People at the center of care (individuals and their caregivers) are not now at the center of design of medical or data systems. The emphasis on a person-centric framework for HCBS implies that people at the center can have a say in the selection of meaningful measures, contribute data about themselves, correct errors in data entered about them by others, and can authorize or not authorize sharing of that data across systems. Community data systems are even less mature than medical systems and have fewer resources available for data management. The results of HSBC measures needs to be worth the work of creation, collection, and analysis. The art of a successful HCBS quality measurement system will be to create a library of meaningful measures with input from people at the center that are actionable. Therefore, meaningfulness to people at the center and actionable should be added to the prioritization matrix for the next phase of the initiative. Thank you for the opportunity to comment.

Name	Organization	Comment
Elham Sliman	Texas Health and Human Services Commission	The State of Texas is seeking additional clarification on the following: 1) What is the potential timeline for implementation of the national measures across the states? 2) What supports will be available to states that do not have the capacity to immediately capture such data? 3) What will the reporting requirements and standards be? 4) If these domains are used to build performance measures for assessing quality in HCBS, will there be additional assurances added or will we continue with the old ones? If the former, how will the new domains correspond to the current assurances? 5) The subdomain for "Human and Legal Rights" contains "abuse and neglect," however, it does not include "exploitation;" could we have further clarification on why this was not included? 6) Will NQF seek out input on identifying and organizing gaps and prioritizing opportunities for measurement from the states?

Name	Organization	Comment
Katherine Berland	American Network of Community Options and Resources	Dear NQF HCBS Quality Committee: The American Network of Community Options and Resources, Inc. (ANCOR) is pleased to offer comments on the interim report, "Addressing Performance Measure Gaps in Home and Community-Based Services to Support Community Living: Initial Components of the Conceptual Framework," issued July 15, 2015. The report begins the challenging work of sorting through the myriad of outcomes possible from which to assess the quality of long term services and supports (LTSS) for people with disabilities. The report presents an operational definition for HCBS and a draft conceptual framework for quality improvement through the measurement of outcomes. This is critical work and especially important in those jurisdictions implementing managed care for the funding of services. Your work is timely and necessary. States embarking on implementing a managed care framework for LTSS have an urgent need for this information. State governments, managed care entities, providers of LTSS, and people with disabilities must all focus accountability on outcomes achieved, and not just on units of attendance as is the current practice in most jurisdictions. Outcomes must be prioritized for the people supported by our systems, and payment should be based in part on whether those outcomes are achieved. ANCOR is eagerly waiting for the next interim report from NQF. Please do not hesitate to contact me should I, or members of our staff, be able to provide information to assist your efforts.

Name	Organization	Comment
Ellen Perry	Advocacy in Action	"One discussion focused on the degree to which traditional health services (e.g., doctors' visits and hospital stays) should be integrated with non-health services that are a part of HCBS. There was recognition that coordination and integration of HCBS with medical care is important, but "over-medicalizing" HCBS must be avoided […] Participants expressed concern that a greater emphasis within HCBS on health services and health outcomes would diminish opportunities for individuals to shape and direct their own services. This would be contrary to the consumer-driven philosophy that the Committee has encouraged. However, creating strict boundaries between health-related and other services is neither practical nor productive from the perspective of fostering holistic wellness and acknowledging the role that both clinical services and HCBS have in the healthcare system. (page 9) Comments: I receive HCBS funded through Medicaid and I have direct support staff that cannot go with me to doctor's visits or go to the brace shop when I need to get my leg braces fixed. I am 57 and live independently and do not have family that can go with me. But I need someone who knows me and cares about me and can help me relay information to the doctor or whoever. Staff could also help me keep up with what the doctor says. Staff can go pretty much any place else with me and assist me. But they can't go with me to medical appointments because of the potential for double billing to Medicaid. This is a problem since I can't drive and I really need help during these times, too. Also, it means I can't make a same day appointment with the doctor because Para-transit requires trips to be booked at least 24 hours in advance.
Nancy Brubaker	DSHS--Home & Community Services Division	The report (p 5) states that the "project considers all types of consumers" and goes on to give some specific examples. We would ask that dementia be called out in this list. It is important that "dementia capability" become an organizing principle in any HCB setting that delivers care for individuals with this disease. Naming dementia as a distinct and important example of consumers that this project represents also links with NQF's "Priority setting for Healthcare Performance Measurement: Addressing Performance Measure Gaps for Dementia, including Alzheimer's Disease". That report states "The economic burden of dementia is high and the emotional and physical burden is immense, not only for people with the condition, but also for their families and caregivers."
Jennifer Dexter	Easter Seals, Inc.	Easter Seals applauds the workgroup for outstanding, comprehensive and in-depth work. We want to call attention to two outside efforts that should inform and be aligned with the NQF initiative. The first is the ONC/CMS eLTSS plan/initiative for home and community-based services (HCBS) beneficiaries. We hope that they are aligned with but not duplicative of NCI/NCI-AD measures and efforts In addition, the National Adult Day Services Association (NADSA) outcomes initiative can also inform the final report. In June, 2015, the National Adult Day Services Association, a key HCBS stakeholder group, convened a group of premier researchers, state associations, providers and others with the goal of identifying the domains of outcomes in ADS and to recommend possible measures of those outcomes.

Name	Organization	Comment
		Measure selection criteria are listed below. Next steps include a national town hall in August 2015 call to gather input on proposed domains and recommended measures from the field followed by presentation at the NADSA national conference in October 2015. Both Easter Seals and NADSA continues to track the great work of this NQF committee and looks forward to collaborating as both NQF and NADSA efforts proceed. NADSA Criteria for Selection of Outcome Domains and Measures: Measures should be appropriate for the setting and people served Measures should be easy to use and to train for use by any level of staff Outcomes assessment should not be time-consuming to administer Measure the right thing—outcomes that are important to potential funders but also reflect what ADS programs can accomplish Measures should be valid and reliable, if at all possible Measures should be in the public domain and available for use without cost Outcome measures should contribute to continuous quality improvement Measures should fit into the usual way ADS programs are conducted Some outcome measures will need to be translated into cost avoidance calculations (e.g., reducing repeat hospitalizations) Easter Seals appreciates the opportunity to provide input to the final report and we look forward to working with you as we move ahead with this important endeavor.

Name	Organization	Comment
Kerri Melda	CQL	CQL|Council on Quality and Leadership - CQL commends the Committee for its hard work to develop definitions and a quality framework in Phase I. In Phase II of the Committee's work, CQL requests that the stakeholder Committee review CQL's Personal Outcome Measures, Basic Assurances, and Person-Centered Excellence tools, as you "scan psychometrically tested and validated surveys, scales, or other instruments directly relevant to HCBS, especially those that assess quality of life and experience with HCBS". A brief description of these CQL tools is provided below. All tools are designed to measure outcomes and performance across human service populations and systems. Personal Outcome Measures - A powerful data set for the valid and reliable measurement of individual quality of life. Instead of looking at the quality of how the services are being delivered, the Personal Outcome Measures approach looks at whether the services and supports are having the desired results or outcomes that matter to the person. Basic Assurances - Look at the provision of safeguards from the person's perspective, and are essential, fundamental and non-negotiable requirements for service and support providers. CQL's Basic Assurances balance concerns for individual health, safety and security ~ and the necessity of social constructs such as respect, natural supports and social networks ~ to ensure sustainable outcomes for people. Each indicator is evaluated on two dimensions (system and practice), and both must be present for the overall indication to be considered present. Person-Centered Excellence - Through our What Really Matters Initiative, CQL developed 8 Key Factors and 34 Success Indicators for Person-Centered Excellence in the delivery of services and operation of systems to support people. These indicators promote personal quality of life, and are effective tools for organizational quality improvement.
Clarissa Kripke	University of California, San Francisco	Overall, this is a very strong document. Particular strengths include: --outcome rather than process oriented. --strong emphasis on real choice, control and community inclusion --addresses disparities/equity --addresses family caregiver needs
Urvi Patel	American Health Care Association	As AHCA/NCAL has stated with previous comments, it is important to acknowledge the heterogeneous populations HCBS supports, which can make it difficult to implement the same quality measures for all HCBS recipients. Quality measures should reflect the primary goals for the population receiving care and be meaningful for both the consumer and provider. As NQF work continues, it may be beneficial to consider stratifying by the subpopulations that HCBS serves.

Name	Organization	Comment
Rachel Patterson	Christopher & Dana Reeve Foundation	The environmental scan of related efforts in HCBS and measurement was very useful. However, we noticed that the National Core Indicators were not included in the list. While the National Core Indicators were originally created to measure quality in the area of developmental disabilities, they are currently being expanded to serve populations that are aging or have physical disabilities. The NCI measures important aspects of wellbeing and system performance, and should at least be included in the environmental scan of current efforts to measure HCBS quality. While Medicaid is the primary and often most important payer of long-term services and supports and HCBS, we appreciate that the project seeks to measure HCBS quality both inside and outside of Medicaid. Toward this end, we encourage the staff and committee to be sure to consider the particular needs of veterans who need HCBS, particularly the Veteran-Directed HCBS program. Veterans with disabilities are a large and growing component of people who use HCBS and may have needs that could be overlooked in a quality measurement system that does not include their input.
Laura Thornhill	Alzheimer's Association	The committee notes that the core users of HCBS are older adults, people with multiple chronic conditions, and people with disabilities. As the project proceeds, we encourage the committee and NQF to look closely at which of these populations use particular services and in what settings to better inform and shape quality measures. For example, measures in certain domains (e.g., Consumer Voice, Choice and Control, Full Community Inclusion) should be constructed to reflect HCBS residents who have cognitive impairment and safety needs.
Maureen Dailey	American Nurses Association	All six IOM aims of care should be explicit including, including timeliness and access. Patient driven care is beyond "control". The HCBS care team care plan should be consumer driven. Consumer groups have been vocal that patient driven care coordination goes beyond "patient-centered". Safety is also a key concept to be expanded beyond consumer and worker safety to a community perspective. Consumers may want to remain in the HCBS level of care beyond the point that is safe with existing available HCBS, including caregiver support. The integration of home health care was not explicit. Home care has a rich history of coordinating home and community-based services and providing care by registered nursing and other inter-professional team members as appropriate to vulnerable community-based populations to improve prevention, post-acute illness care and advanced illness care. Shared accountability from the team's perspective was not explicit. Patient and caregiver accountability is important but should be expanded across all team members and be measured with shared accountability and attribution.
Jennifer Hitchon	American Occupational Therapy Association	We are pleased with the inclusion of the pursuit of self-identified goals as a key characteristic of high-quality HCBS, as occupational therapy practitioners share this patient-centered value. We would appreciate more clarification of the term "dignity of risk". The American Occupational Therapy Association (AOTA) appreciates this opportunity to comment on the National Quality Forum's Interim Report, "Addressing Performance Measure Gaps in Home and Community-Based Services to Support Community Living".
Del Conyers	National PACE Association	The National PACE Association (NPA) represents all 115 operating Programs of All-inclusive Care for the Elderly (PACE), and entities pursuing PACE development and supportive of PACE. NPA appreciates the

Name	Organization	Comment
		National Quality Forum's efforts to develop a conceptual framework and perform an environmental scan to address performance measure gaps in home and community-based services (HCBS) to enhance the quality of community living. 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 community-based supports. With 20 years of experience providing comprehensive community based care, PACE has a unique degree of experience and proven focus on quality. Moreover, PACE serves both Medicare and Medicaid beneficiaries and provides comprehensive medical and social services across an array of care settings including: at home; at a PACE center, where primary care, activities, meals and rehabilitative services are offered; in congregate, assistive residential care settings; in hospitals and in nursing facilities. Through this comprehensive care model, PACE is able to support its participants' ability to live in a community setting rather than be placed in a long-term nursing home stay. NPA is pleased to offer comments on the interim report, Addressing Performance Measure Gaps in Home and Community-Based Services to Support Community Living: Initial Components of the Conceptual Framework. NPA supports the direction of the interim report and its emphasis on individual choice and autonomy. The Committee established that high-quality HCBS should be delivered in a manner that ensures each individual can achieve the balance of personal safety and dignity of risk that he or she desires. How does the full risk assumed by a delivery model such as PACE and the shared risk of other plans/programs, which are becoming increasingly more prevalent, factor into this? Given the diversity and complexity of individuals served by HCBS, we propose that the HBCS Committee consider exploring issues within a care-management model.
Jill Barker	SBC Global	Consumer Preferences: "Consumer preferences and the policy environment also continue to favor community living over more restrictive environments." Preferences vary depending on the needs of the person with a disability and the ability of the family and community to provide for those needs in the least restrictive environment. The determination of least restrictive environment is meaningless without taking into consideration the needs of the individual. Arbitrary standards regarding size and location of a setting do not serve to assure the broadest range of options necessary to serve individuals with DD. The "policy environment": The new CMS rule on HCBS, when it is fully implemented in 2019, could severely limit options in the community that are currently available to many people with the most severe

Name	Organization	Comment
		disabilities. This is not a matter of personal preferences, but instead comes from an ideological perspective that favors the federal government imposing these beliefs on everyone regardless of their needs or preferences. In addition, the unavailability and poor quality of community services is a factor in families deciding that the only way to adequately serve their loved one with DD in a safe environment is to keep them at home. This is not necessarily a “preference”, but an unfortunate reality. "The dignity of risk” For people who are at high risk for abuse, neglect, and physical injury, including those with severe and complex cognitive and behavioral disabilities, there is no “dignity” in ignoring those risks or requiring the person to experience risks that can be reasonably anticipated in order to prove that the risks are real and must be ameliorated. These determinations depend on individual needs. One person’s needs should not prevent another person from being served appropriately in an HCBS system. Suggestions for considering HCBS Quality Measurement One major concern in the collection and analysis of data on HCBS services, is that state and local agencies typically evaluate their own programs based largely on self-reporting by a network of providers. Where is the incentive to report the “bad news” about abuse, neglect, medical errors, and generally poor quality care? There needs to be an independent agency, different from the one charged with administering or providing supports. This independent agency would have incentives to adapt to changing conditions, game playing with the rules by providers, and other sources of erosion of protections. Such an agency would also act to bolster credible reasons for needing protections and health services so that the administrative agencies would not sound so self-serving when asking for adequate resources from legislators.
Marybeth Mccaffrey	UMass, Center for Health Law and Economics	Dear Members of the NQF HCBS Quality Committee: We believe you have articulated the characteristics of high-quality HCBS in a balanced and understandable way. The Interim Report opens cross-boundary communication effectively with an achievable vision for high-quality HCBS and helps make a timely contribution to the compelling need for HCBS quality outcome measures. The scarcity of outcome measures of an individual’s health state resulting from HCBS and rarity of Person Reported Outcome Measures in the existing HCBS measurement tool array makes this effort essential. Outcome measures for HCBS are one of the most essential communication tools for development of models that incent high quality services and provide people who use HCBS with meaningful choices.

Name	Organization	Comment
		Outcome measures can help determine which providers and services consumers value most, are most effective, and most efficient. Integrated health and social service data will stimulate and promote collaboration between social services and healthcare agencies, improve the consumer experience, and bring greater value to the use of public sector resources. You are listening and developing a greater understanding of respective roles that support what is important to a person using HCBS and important for people providing support to the person. Your effort is an inspiring step to building a shared vocabulary between disparate sectors of the health continuum. A shared vocabulary will enable us to measure the impact of services across the full health continuum without "creating strict boundaries between health-related and other services [which] is neither practical nor productive from the perspective of fostering holistic wellness and acknowledging the role that both clinical services and HCBS have in the healthcare system." Interim Report, p. 9. With a shared semantic understanding describing outcomes for people who need support to live independently in the community, systematic measurement becomes possible. We wholeheartedly support your work to address performance measure gaps in HCBS to support community living.
Jill Barker	SBC Global	"Over-medicalizing HCBS" The concern about "over-medicalizing" HCBS would not be a concern if there was a genuine belief that the system of HCBS would be person-centered. One person's need for extensive medical care and supervision might be directly connected to their survival and enjoyment of life. Another person who does not need or desire that care, should not be forced to accept overly regimented medical care as a condition of receiving services that enhance their enjoyment of life. The degree of medical care and supervision needed is a highly individualized determination and should not affect how others who do not need or desire medical interventions are served.

Name	Organization	Comment
Desiree Kameka	Coalition for Community Choice	On pages 4 and 5, the report identifies specific types of consumers that receive HCBS. The CCC would like to request that the 5 million HCBS consumers who have an intellectual / developmental disability (I/DD) be explicitly recognized along with the other subpopulations. 'Individuals with intellectual / developmental disabilities (I/DD)' is widely used terminology and many states have HCBS waivers that specifically target the needs of individuals with I/DD. Page 4 of the report, which offers statistics to illustrate the demand for home and community based services, should include data that explicitly shows the need for growth of HCBS to serve individuals with I/DD who are at high risk of institutionalization. For example: Nearly one million adults with I/DD are living with a family caregiver over the age of 60. These individuals may soon lose their primary caregiver and potentially their home, yet less than 15% of the almost 5 million adults with I/DD have access to HCBS waivers. (2013 State of the States Report) The Coalition for Community Choice applauds the work of the National Quality Forum and looks forward to reading and offering public comment of upcoming reports.
Camille Dobson	National Association of States United for Aging and Disabilities	Page 4 - 5 - Environmental Context I suggest that this sentence "Outlays for HCBS now constitute nearly half of Medicaid's long term care expenditures, and have risen significantly in recent years" be modified and footnoted differently. Instead the sentence should read, "Data from FY 2013 show that HCBS outlays are over half of Medicaid's long term care expenditures, continuing a trend from recent years" and be footnted with CMS' new LTSS expenditure report (available at http://www.medicaid.gov/medicaid-chip-program-information/by-topics/long-term-services-and-supports/downloads/ltss-expenditures-fy2013.pdf) It is important to note that states have had quality measurements in place for their HCBS programs for many years, with increasing levels of sophistication and innovation occurring in recent years. I urged the Committee to look carefully at states' efforts so that the project can be informed by those activities rather than created in a vacuum, and would suggest making a statement to that effect here. I therefore recommend modifying the last sentence in the first column on page 5 after the discussion about the importance of Medicaid in HCBS quality by adding after "states", ", and states' ongoing efforts to measure HCBS quality".

Name	Organization	Comment
Jill Barker	SBC Global	The Policy Environment and Consumer Preferences The “policy environment” has set limitations on options available. Many, if not most, states restrict admissions for people with DD to Intermediate Care Facilities for IID and Skilled Nursing Homes. These settings that provide an institutional level of care could be serving a greater number of people who do very poorly in community settings, but that option has been closed off. In addition, the unavailability and poor quality of community services is a factor in families deciding that the only way to adequately serve their loved one with DD in a safe environment is to keep them at home. This is not necessarily a “preference”, but an unfortunate reality.
Abby Marquand	PHI	PHI congratulates the National Quality Forum Committee on Quality Measurement in home and community-based services (HCBS) on its efforts to produce the first interim report, Addressing Performance Measure Gaps in Home and Community-Based Services to Support Community Living. We support the goals of the Committee, in particular to “develop recommendations for the prioritization of measurement opportunities that would address gaps in HCBS quality measurement.” Though more than half of Medicaid dollars for long-term services and supports are spent on HCBS, significant gaps exist in measuring its quality. The direct-care workforce plays an essential role in the delivery of HCBS and has a profound impact on the quality of supports received by millions of people. Conservative estimates tally the number of direct-care workers at 4 million—the majority of whom are employed in HCBS settings. Moreover, while the demand for this workforce is staggering—home health aides and personal care aides are projected to create more new jobs than any other workforce by 2022—many providers across the country report difficulties in recruiting enough people to perform this work. At the same time, due to gaps in measurement and a serious lack of investment in workforce monitoring and data collection, policy makers have little information with which to evaluate the capacity of the current workforce to ensure access to HCBS for the millions of people who rely on these services. This direct-care workforce is unique in the world of health and human service delivery. Access to high-quality services hinges on a sufficient supply of workers to meet the growing demand, but also on their levels of skill and preparedness, their likelihoods of remaining on the job, and their abilities to make ends meet for their own families. Across much of the country, consumer advocates, provider organizations, and direct-care workers point to the various gaps in policy and practice that create barriers to meeting the growing demand for services. If continued, the instability in the workforce providing HCBS—the net result of from poverty level wages, lack of access to employment benefits or labor protections—will have a detrimental impact on the system of service delivery. PHI agrees with the Committee’s recognition of the central significance of the workforce in HCBS quality, and we recommend ways of strengthening the proposed domains in our enclosed comments.

Name	Organization	Comment
Dan Berland	NASDDDS	RE: "Addressing Performance Measure Gaps in Home and Community-Based Services To Support Community Living;" July 15 Interim Report for Public Comment The Consortium for Citizens with Disabilities is a coalition of approximately 100 national disability organizations working together to advocate for national public policy that ensures the self-determination, independence, empowerment, integration and inclusion of children and adults with disabilities in all aspects of society. CCD appreciates the opportunity to comment on the HCBS Committee's Interim Report. These comments are from CCD's Long Term Supports and Services Task Force and Rights Task Force. General Comments on the Interim Report The environmental scan of related efforts in HCBS and measurement was very useful. However, we noticed that the National Core Indicators were not included in the list. While the National Core Indicators were originally created to measure quality in the area of developmental disabilities, they are currently being expanded to serve populations that are aging or have physical disabilities. The NCI measures important aspects of wellbeing and system performance, and should at least be included in the environmental scan of current efforts to measure HCBS quality.
James Gallant	Marquette County (MI) Suicide Prevention Coalition	[HCBS Definition]: Please consider adding language to clarify that family members and caregivers are also provided HCBS type services. Please consider saying "(HCBS)…that promote the independence, well-being, and choices of an individual (and their family members/caregivers) of any age who has…" I'm also concerned about the fidelity of the approved NQF voting procedures. [Example from page 8]: "Staff compiled a draft definition based on all submissions for the committee's review and refinement at a subsequent in-person meeting. The committee made significant changes to arrive at the consensus definition previously presented." The "draft definition" submitted to the HCBS Standing Committee by the NQF staff 'did not' obtain a consensus (60% vote) of the committee members before they began their deliberations. It appears that any time NQF staff submits a 'draft definition' or 'preliminary analyses' to the Standing Committee it represents the staff's opinion only and the committee must "first" establish a consensus of the members for the staff's opinion to then become the opinion of the committee.

Name	Organization	Comment
		Also, I believe the HCBS Standing Committee used several different voting procedures while approving this 'draft definition' of HCBS (3 votes per member and 10 votes per member). The current rules allow for only one (1) vote per member. Please consider reviewing the NQF Bylaws, the Washington D.C. Non-Profit Corp. Act, and the OMB Circular A-119 to establish a consensus on the legal requirements of NQF's voting procedures and please refer this issue to NQF's Governance Committee for a report and recommendation.

LETTERS

Name	Organization	Content
Charlie Lakin	HCBS Committee Member	I found the Addressing Performance Measure Gaps in Home and Community-Based Services to Support Community Living: Initial Components of the Conceptual Framework to be very well-written, faithful to the discussions that took place at the NQF's HCBS Committee telephone and face-to-face meetings, and providing good direction for future staff work and Committee deliberations, I thought it conveyed well the importance of balance between assuring sound psychometric practices in measuring practices and outcomes in HCBS and the need for congruence between what is measured and what is truly important in the lives of people with disabilities who are supported by HCBS. I think the conceptual framework is sound and is reinforced by and reinforcing of other such conceptual frameworks developed to guide efforts to improve performance of HCBS in promoting the independence, physical and mental well-being, productivity, inclusion and self-determination of individuals with disabilities. I do have a few suggestions and comments. Mostly these will simply suggest a little more clarification, emphasis or elaboration. **Page 2.** Let me start with the definition of HCBS. While the Committee came to agreement that the basic definition of HCBS should be a single sentence that conveys the broad purpose of HCBS, I felt that certain key elements of the evolving expectations for HCBS were missing. The initial legislative expectation for state HCBS programs was, of course, quite basic: move people out of institutions or prevent their (re-)admission, and protect their health and well-being. But those expectations have

Name	Organization	Content
		changed over time, as clearly conveyed in the 2014 CMS regulations. I think the proposed definition captures the contemporary understanding of HCBS, except in its omitting of "inclusion" as a expectation of HCBS. The Supreme Court's Olmstead decision rested on the promise in the ADA of non-segregation (i.e., inclusion). I think, too, that we've seen clarification both in the HCBS regulations and in the DOJ actions around segregated day programs and sheltered workshops that productive contribution is also an evolving expectation, although one might argue it is in the name of inclusion. I'd also ask with regard to the definition whether "self-determination" better conveys than "choice" the informed autonomy that is expected for HCBS recipients in high quality HCBS. Is it enough that one has some choices he/she can make (white bread or whole wheat) or is the issue that one directs one's life in matters that are important to him/her as an individual ("self-determination")? Finally, more nit-picking I suppose, some states cover people with major, disabling health impairments (physical disabilities?) under categorical programs such as HIV/AIDS, medically fragile, palliative care. **Pages 4-5**. It seems to me that another important recognition might be made within the general theme of Measurement Landscape and/or Environmental Context. This observation is that, to be effective in guiding the development of measures that hopefully will be widely accepted and adopted, those measures must not only be valid in the minds of the various engaged stakeholders, but must also be consistent and inclusive of the elements of quality established by the primary HCBS funders (esp. CMS), and, of course, the requirements of relevant federal statutes, including interpretations of those statutes by federal courts (most notably the ADA and the related Olmstead decision of SCOTUS). In this regard, it seems important to recognize and accommodate that without such attention measures could be put forward by which a provider could offer HCBS consistent with the NQF endorsed measures, but not be in compliance with CMS standards, or might provide HCBS in compliance with federal Medicaid regulations, but at the same time by in violation of federal legal protections (e.g., the ADA's integration mandate). This latter circumstance was demonstrated most recently when the DOJ found that Rhode Island's system of HCBS with its heavy reliance on Medicaid-certified and Medicaid-financed sheltered workshops and facility-based day programs was in violation of the ADA's integration mandate-a status to which Rhode Island acceded in the Settlement Agreement. DOJ has followed with related actions in other states. My point is that, and perhaps this is assumed, that for the sake of efficiency, effectiveness, comprehensively and ultimately utility, the Committee should recognize the need to be guided not only by thematic and organizational goals of individuals with disabilities and other primary stakeholders, but also by the regulatory requirements for quality in HCBS and other broad protections of HCBS recipients in the ADA and federal laws. I don't believe that the expectations of stakeholders, regulations and federal law will often be inconsistent, just that effort has been made to assure that the measures endorsed by NQF set a standard that has attended to the demands of all three. (Wow! That was long-winded.) **Page 9**. I had a few editorial (content) suggestions for the list of features of high-quality HCBS: • Provides for a person-driven system that optimizes individual choice and control in the pursuit of self-identified goals and personal preferences, including employment; place of residence;

Name	Organization	Content
		housemates, if any; visitors; use of personal space and resources; and individual lifestyle(e.g., employment, enjoying life) ; [I think choice and control is not only about "goals" but also (mostly) freedom to live one's life on one's own terms (what to eat, what to do, who to do things with). Also, I felt use of "e.g.," a sort of cop-out not used elsewhere in this list] • Promotes social connectedness by including people who use HCBS in the community to the same degree as people who do not use HCBS; • Includes a flexible range of services and settings that are accessible, appropriate, effective, sufficient, dependable, and timely to respond to individuals' strengths, needs, and preferences; • Integrates healthcare and social services to promote well-being; • Protects the individual's human and legal rights, including privacy; dignity; freedom from abuse, neglect, and exploitation, coercion and restraint; respect; and independence; choice of service providers; access to personal resources; • Ensures each individual can achieve the balance of personal safety and dignity of risk that he or she desires; • Utilizes and supports a workforce that is trained, adequate, and culturally competent; • Supports family caregivers; • Engages individuals who use HCBS in the design, implementation, and evaluation of the system and its performance; Reduces disparities by offering assuring equitable access to and delivery of services, and monitoring and responding to instances of inequitable access; • Coordinates and integrates resources to maximize affordability and long-term sustainability; • Supplies valid, meaningful, integrated, aligned, and accessible data to all stakeholders; and • Fosters accountability through measurement, and reporting of quality and targeted response to quality-related outcomes. Last paragraph, second sentence: I would replace the word "socialization" with community inclusion (or social inclusion). I think the vast majority of HCBS recipients are not in need of "socialization" (i.e.,

Name	Organization	Content
		training on how to behave socially") and its use might be a bit offensive to some. **Page 10. Exhibit 2**. A couple of things: First, I think the placement of the arrow going from Quality Measurement to Improved Consumer Outcomes is a bit misguided in suggesting an impact for measurement that is not realistic. We can use, indeed sometimes do use, good (enough) measures everyday, year after year, and affect quality very little. Ultimately, I think this project will be viewed as having merit to the extent to which its products are viewed as have a realistic and meaningful role to play in improving quality in HCBS. It seems to me therefore that the diagram's showing the ultimate goal to be Improved Consumer Outcomes for Individuals Using HCBS is just right. But realistically all the measurement in the world will not achieve that goal. To me, the arrow now labeled Quality Measurement needs to be re-conceptualized as something like "Quality Accountability". Then then measurement's role in accountability could be more realistically shown as within a set of sub-components that might include: Effective Quality Measurement, Effective Information Sharing, Data-Based Quality Improvement. Along those same lines, the tile of the Exhibit might become Illustration of Conceptual Framework for Improving HCBS Quality. **Page 12**. First line in second column of HCBS Domains of Measurement: Would it be a bit more clear to say: "be relevant at multiple levels of performance analysis."? **Page 13**. Exhibit 4 table. Minor edits Workforce/Providers, last line: semi-colons after teamwork and communications System Performance, third line: I would suggest a change to "quality judged primarily by individual outcomes" (The aggregate seems to imply a single score for quality which may be the goal of some quality measurement, but certainly not of all.) last line: semi-colon after efficiency; delete "and" Health and Well-Being, first line: semi-colon after "social well-being" **Page 14**, Exhibit 5. See comments on Exhibit 2. **Page 15**, fourth line. Is there a reason to for inserting "community living and" before "high-quality HCBS"? Last sentence of the first paragraph I might suggest a bit more direct wording, something like: These activities will support the goal of winnowing a broad set of potential measures measurement opportunities into a prioritized subset of measures that are congruent with/consistent with/map to (as

Name	Organization	Content
		used below on p. 15) inform and address the conceptual framework set forth by the multi-stakeholder Committee. Under "Continuing Environment Scan" heading, the list of specific objectives for the environmental scan, I wonder if 2. might be more succinctly stated as: Identify "test case" examples of HCBS quality measures to guide Committee discussion of implementation barriers and mitigation strategies , that is, a selection of measures that lend themselves to examination as "test cases" Under "Continuing Synthesis of Evidence" heading, second sentence: It is not clear to me what "38 of the most critical and high-impact sources" means. Could these be better defined (e.g., most widely used)? Minor last editorial observation: The two numbered lists on page 15 are inconsistent in first-word capitalization and end of item punctuation that the numbered list on page 4-5. All in all a really good draft. Thanks!
Patti Cullen	Care Providers of Minnesota	Care Providers of Minnesota is a non-profit membership association with the mission to *Empower Members to Performance Excellence*. Our 800+ members across Minnesota represent non-profit and for-profit organizations providing services along the full spectrum of care, including nursing facilities and skilled nursing facilities. We are the Minnesota state affiliate for the American Health Care Association/National Center for Assisted Living, and with our national partners we provide solutions for quality care. Care Providers of Minnesota Quality Council has reviewed the National Quality Forum (NQF) interim report: "Addressing Performance Measure Gaps in Home and Community-Based Services (HCBS) to Support Community Living-Initial Components of the Conceptual Framework" and want to share the following comments. The majority of our comments focus on the subdomains of HCBS Quality Measurement: In general, our overall impression was there were too many operational measures rather than performance measures—focused on inputs or operational functions rather than outcomes and/or performance. More specifically: 1. Workforce/providers: we are concerned about the subdomain term "adequately compensated" given the range of pay and benefits and job functions across the country. Who will judge the adequacy and using what measure? There also needs to be a consideration for geographic location of services—availability of "sufficient numbers and appropriately dispersed" is more challenging in rural settings.

Name	Organization	Content
		2. Consumer voice: terminology used needs to be reviewed as "workforce engagement" is not common consumer language. In addition, we are unclear about what "diversity of engagement means"—does it mean the experiences need to be diverse OR that there needs to be diversity in the composition of consumer/workforce? 3. Choice and Control: The description does not take into account programs with team-based care; we are concerned about "particular worker" as that is not always possible to accommodate, especially in today's environment where there is a workforce shortage. 4. Human and Legal Rights: Include freedom from abuse/neglect/exploitation under this category and clarify that legal compliance issues are not included under this measure. 5. System Performance: Consumer engagement is already more appropriately covered under the consumer voice section; description includes many subjective measures ("appropriate and fair resource allocation") so we are concerned about how this will be measured; we are unsure if the presence of a waiting list is a positive or negative subdomain and how providers would have control over this system performance measure. 6. Full Community Inclusion: Delete "Full" from this measure as that is subjective; include consumer choice language in this measure—some of the terms should be tied to the extent the consumer chooses to be social, work, etc. 7. Caregiver Support: why is compensation included as a quality measure? 8. Effectiveness/Quality of Services: rebalancing does not fit into this category; we are unsure what is meant by that work and why that word is included. 9. Service Delivery: portions of this subdomain description appear to be designed to highlight what is important for a community but not for individual providers—accessibility, appropriate, sufficient, etc. 10. Equity: we question why this is included as a potential quality measure—there will be significant geographic differences with HCBS delivery. 11. Health and Well-Being: "cognitive functioning" does not fit into the other descriptors; "freedom from abuse, neglect, and exploitation" should be included under the category of human and legal rights.
Sara Karon, PhD	Not listed	Congratulations to the Committee on HCBS for its development of the report on initial components of the conceptual framework. You have accomplished a great deal, and done a nice job of beginning to create a structure for a complex area of work. As you move forward in this work, I would suggest you keep the following issues in mind. 1) The needs, desires, resources, and situations of people who can benefit from HCBS are diverse and complex. While the committee members certainly are aware of that, it does not always come through in the report. In particular, the description of the environmental context (page 4) seems to minimize this diversity in two specific ways. LTSS is described as including services for "people who live in their own home, a residential setting, a nursing facility, or other institutional setting." This statement would seem to exclude people who live with family members, roommates in a shared apartment or home, or other

Name	Organization	Content
		settings that are less formal than what generally is understood as "residential settings." Additionally, HCBS does much more than provide help with ADLS and IADLs. The broader range of services is reflected on page 6 of the report. However, failure to identify the range of services earlier in the report raises concerns that these additional services (e.g., transportation, supported employment, environmental modifications) are viewed not central to HCBS, and may be overlooked. A related concern is identified on page 7, in which HCBS is defined as supports that "are delivered in the home or other integrated community setting." HCBS also may be provided in other community settings, such as sheltered workshops or adult day programs, which are community-based, but not integrated. 2) At several places in the report, the Committee refers to "equitable access" as a means of reducing disparities. I believe it is important to define equitable access in relation to the desired goals. "Equitable access" may be understood – and often seems to be understood – as meaning that everyone with an assessed impairment level of X receives Y hours of service type Z. While that is one way of understanding equitable access, it does not support individual needs and is not person-driven. Given people's very different resources with regard to informal supports, and the very different goals that they may have for themselves with regard to such things as employment, community integration and participation, such a view of equitable access may yet result in disparate outcomes. I would suggest that a better view of high-quality HCBS is that which reduces disparities by supporting individual's achievement of desired outcomes. 3) At different places in the report, HCBS is described as being designed to or to "maximize the ability of people to live independently" or to "improve outcomes for individuals who use HCBS to live independently." People with disabilities who receive HCBS are, by definition, not living independently as that is typically understood. However, HCBS can be designed and delivered in such a manner as to maximize people's abilities to engage in the community, live where they wish, and engage in the activities and relationships that are meaningful to them. Providing these services in a way that is person-driven – beyond "person-centered" – can create the ultimate outcome, of enabling everyone, regardless of disability and need for assistance, to engage in the world to the best of their abilities and of their desires. 4) Overall, I would encourage the Committee to be conscious of the difference between "person-centered" and "person-driven." The former might be accomplished by linking services to some characteristic of the individual (e.g., diagnosis, level of ADL impairment), while the latter is concerned with the individual's preferences and desires. This comes in to play when domains are described in terms of achieving outcomes. The question must be asked: whose outcomes? Again, person-centered outcomes need not be individualized, while person-driven outcomes must be. The concept of "need" also must be carefully defined, to be clear who is determining what is needed; similarly, concepts of community inclusion must be defined by the individual. 5) Many of these comments share an underlying need to make clear the ways in which HCBS is different from other types of service systems. Unlike health care, where quality can be measured by the percent of people who avoid an undesirable event (e.g., hospitalization) or achieve a goal that generally is accepted as preferable for anyone (e.g., HgA1c level within an stated range), HCBS at its best supports

Name	Organization	Content
		people to live the lives they want. By definition, the desired outcomes will be different for each person. This poses challenges for measuring quality, but they are not insurmountable. I look forward to the Committee's work on this challenging, important issue.
Nancy Lundebjerg and Michele Saunders	Eldercare Workforce Alliance	We write to you on behalf of the members of the Eldercare Workforce Alliance (EWA), a group of 31 national organizations – representing consumers, family caregivers, health care professionals, and direct care workers – joined together to address the immediate and future workforce crisis in caring for an aging America. We are writing to comment on the National Quality Forum, Home and Community-Based Services (HCBS) Committee Interim Report titled *Addressing Performance Measure Gaps in Home and Community-Based Service to Support Community Living: Initial Components of the Conceptual Framework*. The Alliance appreciates the opportunity to comment on this interim report and thanks you for including key information on the HCBS workforce. **Characteristics of High-Quality Home and Community Based Services** The Committee requested feedback on whether the characteristics of high-quality HCBS are balanced, understandable, and communicate an achievable vision for high-quality HCBS. Specifically, EWA would like to comment on concepts identified in the report as needing additional consensus-building including how best to support the paid and unpaid workforce and what is meant by culturally competent services. First, EWA would like to share our definition of cultural competency: providing services in a way that is respectful of, and responsive to, older adults of every language, ethnicity, health belief, race, sexual orientation, gender identity, gender expression, disability status, socio-economic status, geographical location, and other cultural identification. More complicated is the discussion of how to appropriately and adequately support the paid and unpaid workforce. Without an investment in the eldercare workforce, which includes the HCBS workforce, even more stress will be placed on often unpaid family caregivers. Due to smaller family sizes, the divorce rate, and geographic relocation – the next generation of older adults may be less able to rely on their families for caregiving. Providing support and training opportunities to family caregivers is essential, especially during a time when nationally: • More than three-quarters of caregivers feel they need more help or information related to caregiving. • Nearly one in five family caregivers who assisted with medication management and one in three who assisted with changing dressings or bandages received no instruction or training in performing these tasks. • 46 percent of family caregivers performed medical/nursing tasks for care recipients with multiple chronic physical and cognitive conditions.

Name	Organization	Content
		Family caregivers must be valued members of care teams, with all providers identifying family caregivers, assessing their needs, and offering training and support. With regard to the paid HCBS workforce there are several key areas of support. High-quality care for older adults, many of whom have multiple complex chronic conditions, requires a health care team with a diverse range of skills for addressing this population's physical, mental, cognitive, and behavioral needs. The lack of standardized geriatric training requirements for both health care professionals and the direct care workforce results, in part, from a lack of recognition that older adults have distinct health care needs. The Eldercare Workforce Alliance (EWA) encourages NQF to focus on recruitment, training, retention, and compensation of the health care teams serving older adults in home and community-based settings, as well as ways to evaluate and support participation in interdisciplinary teams. **Priority Measure Domains and Subdomains** NQF requested feedback on the prioritization of measure domains. On the following pages, please find EWA's efforts to develop two domains focused on family caregivers and the workforce with several subdomains and potential areas of measurements. The interim report did note that workforce training was one of several controversial topics. While the method of training may be controversial, we cannot stress enough that the need for training is critical for the workforce supporting older adults served in home and community-based settings. The Alliance strongly believes that data collection is an important part of measuring and otherwise assessing the workforce ability to care for older adults. To that end, we offer the following recommendations regarding HCBS quality measurement: • Include measures that reveal whether care is person and family-centered as well as coordinated;[1] • Include quality metrics for practitioners and providers that promote quality care and recognize the complexity of caring for older adults with multiple chronic conditions, including those who have cognitive impairment, and support the need to work collaboratively with family caregivers;[2] • Track and assess the geriatrics, gerontological, and eldercare training and education of the workforce; and • Track and assess recruitment and retention practices and workforce data.

[1] The Eldercare Workforce Alliance. EWA Toolkit for Advocates of Older Adults Who are Dually Eligible for Medicare and Medicaid: Part II: Key Workforce Interventions. October 2014. http://www.eldercareworkforce.org/files/DUALS/Part_II_from_EWA_Duals_Tookit.pdf

Name	Organization	Content
		On behalf of the members of the Eldercare Workforce Alliance, we thank you for this opportunity to submit comments on the *Addressing Performance Measure Gaps in Home and Community-Based Service to Support Community Living: Initial Components of the Conceptual Framework* and for your commitment to improving the lives of older Americans.

Name	Organization	Content					
			Domain	**Sub-Domains Across There Levels of Analysis**			
				System (e.g., National, State)	**Intermediate Accountable Entity (e.g., Health Plan, Agency)**	**Individual (e.g., Consumer, Caregiver)**	
			Workforce	• Workforce Adequacy workforce retention by discipline area, geographic region, organization, industry, and employment vs. unemployment [1] Amount of variation in state and local "ideal forecasts" of HCBS workers needed for given areas. This may include forecasts for a Health Professional Shortage Area (HPSA), Medically Underserved Area (MUA), Primary Care Shortage Area (PCSA), or county, etc. [1] the ratio of discipline-specific workers to the baseline needs of specific populations, using census data [1]	• Workforce Adequacy quarterly staffing reports identifying entity staff (including contract staff). Reports should include staff category of work, turnover, tenure and consumer (resident/patient) census. Also include employees' start dates and end dates care continuity and adequacy – number of individual direct service entity staff (including contract staff) that have served each person in a calendar year yearly cost of recruitment and training for direct service entity and contract staff, with the latter quantified by paid time spent by staff in training	• Workforce Adequacy	

Name	Organization	Content					
				access to appropriate HCBS provider, as measured by percentage of instances in which individuals received desired appointments or met with desired professional [1]	(both trainer and trainee) vacancy rate – wait time for services exceeding a specific number of days?		
				• Interdisciplinary Care and Training number of hours of training that educational programs or institutions devote to team-based practice, person- and family-centered care, and to providing care in new care delivery models [1] inclusion of core competencies for the care of frail older adults and persons with disabilities, within educational programs or institutions [1]	• Interdisciplinary Care and Training assessment of community engagement and team-based practice in entities and systems that provide preventive care and care coordination in the HCBS system. Such assessment should use and build upon nationally endorsed measure sets (e.g., the ACO measure set), associated with team mix [1] availability of programs within HCBS systems or	• Interdisciplinary Care and Training person and family overall experience of care delivered by inter-professional teams person and family perceptions of the adequacy and efficiency of team-based care [1]	

Name	Organization	Content					
				availability of instructors or faculty in educational programs or institutions who can teach new competencies needed for new models of care (hours and re-teachability are assessed) [1]	long term care systems/facilities to train/retrain workers in team-based practice, person- and family-centered care, and providing care in new care delivery models [1]		
				• Scope of Practice and Licensure Adherence by each discipline to accepted standards of practice, as outlined by licensure boards and professional associations	• Scope of Practice and Licensure ratio of providers practicing under the supervision of respective licensed professionals (e.g., number of direct care staff under supervision of a single licensed nurse or number of social service staff under supervision of a single licensed professional social worker)	• Scope of Practice and Licensure person and family overall experience of care delivered through delegation	

Name	Organization	Content					
				• Cultural Competency Representation of people of color, as represented in census data, in the HCBS workforce for any given community [1]	• Cultural Competency provider/facility level for cultural competency captured on existing standardized tools for experience of care for persons and families [1]	• Cultural Competency cultural competency scores on existing standardized tools for person and family experience [1]	

Name	Organization	Content					
			Family Caregivers	• Accessibility of Supports Accessibility and availability of caregiver supportive services in a geographic region. Supportive services as defined by the five areas of services in the National Family Caregiver Program: information to caregivers about available services, assistance to caregivers in gaining access to the services, individual counseling, organization of support groups, and caregiver training, respite care, and supplemental services, on a limited basis	• Accessibility of Supports percentage of family caregivers to whom support services are offered [3] percentage of family caregivers who utilize proffered services [3]	• Accessibility of Supports percentage of family caregivers who report they usually or always receive needed support	

Name	Organization	Content				
				• Assessment	• Assessment performance of family caregiver assessments using a uniform assessment tool [2] percentage of family caregivers who are given an assessment of some nature [2]	• Assessment
				• Training	• Training availability of training/retraining programs within health systems or long term care systems/facilities for caregivers in team-based practice, person-centered care, and to providing care in new care delivery models [1]	• Training

SOURCES:

[1] National Quality Forum. Priority Setting for Healthcare Performance Measurement: Addressing Performance Measure Gaps for the Health Workforce. August 2014.

[2] Eldercare Workforce Alliance. EWA Toolkit for Advocates of Older Adults Who are Dually Eligible for Medicare and Medicaid. October 2014.

[3] Disability Rights Education & Defense Fund, National Senior Citizens Law Center. Identifying and Selecting Long-Term Services and Supports Outcome Measures. January 2013.

Name	Organization	Content
		[4] Centers for Medicare and Medicaid Services. Proposed fiscal year 2016 payment and policy changes for Medicare Skilled Nursing Facilities: Staffing Data Collection. April 2015.
Alex Shulman and Kimberly Austin-Oser	SEIU and HCBS Committee member	**Environmental Context** Consumer Need and Workforce Supply: The report does a very good job of framing consumer needs for HCBS, the growing demographics that will drive and grow demand for HCBS services, the increasingly complex care needed due to an increase in older adults with multiple chronic conditions, and the financial difficulties the HCBS system faces that are expected to be compounded as the demand for LTSS and HCBS continues to grow. The argument for the growth of demand is made clearly, but the system is also facing a supply issue – we have, and will continue to have a home care workforce shortage – that the report does not acknowledge in this section, yet is essential to framing the workforce issues that are included later in the report. The demand for home care worker jobs is expected to grow at an unprecedented rate – by 49% for personal care aides and 48% for home health aides during the next decade. i Current estimates of the "care gap" show there are only two million paid caregivers in the labor market, combined with 19 million seniors living at home or in other community settings in need of home care services. ii The vast majority of states have already reported "serious" or "very serious" shortages in the home care workforce. iii Furthermore, an estimated 200,000 new workers will be required each year to meet the future needs of our growing senior population**. iv** The current treatment of the home care workforce—poverty wages, a lack of benefits, and few investments in training—is associated with lower quality service delivery and higher turnover and vacancy rates.v As the Commission on Long Term Care noted in its report to Congress, low wages and a lack of training lead to disruptions in the continuity of care that adversely affect the quality of services.vi These conditions also make it difficult to attract potential care workers to fill the positions needed. SEIU would like to see this type of workforce framing included in the environmental context in future iterations of the report. Privately Funded HCBS: Additionally, while the Committee has agreed to undertake the task of including private pay HCBS, there are very few mentions of it in the report. It is essential to recognize that there is very little data from or regulation of this increasingly growing market, and the Committee needs to be very thoughtful and deliberate in its attempts to create a framework that could actually be applied to the private industry and eventually result in data collection, where almost no publicly available data currently exists. Managed LTSS/HCBS: In this section and throughout the report, there is very little mention of the growing presence of managed care in HCBS. In 2004, only six states had any form of managed LTSS programs, and that number has shot up to 26 states implementing or submitting plans to implement managed LTSS, often with multiple managed LTSS programs operating within single states. vii There is also almost no discussion of how managed care or coordinated care entities would fit into the quality

Name	Organization	Content
		framework or what the role of these types of entities would be. We would urge the committee to take these types of entities specifically into consideration as the report develops, and to define their responsibilities to ensuring or tracking quality in the overall system. **Characteristics of a High-Quality HCBS System** Scope of Characteristics: SEIU believes that the explanation of the characteristics should be slightly broadened in its scope. On page 9 of the report, the end of the first paragraph the last sentence should read: *"Through extensive discussion, the Committee established that high-quality HCBS should be designed, administered, and delivered in a manner that: ..."* We believe this language addition better reflects the tenor of the committee's perspective in the characteristics component – placing equal importance and focus on the design and administration aspects in addition to delivery. Also, it acknowledges the reality most in the industry understand regarding the direct and profound impact the design, administration, and perhaps even more so, the funding, has on the delivery of services. Funding HCBS: The Committee seems reticent to take on the issue of funding in the HCBS system. While we understand that it is a difficult issue to tackle, it is also an essential determinate in the access to and quality of HCBS services, both in the private and public realms. Additionally the cost-effectiveness of the funding should be taken into consideration, ensuring the right amount of money is being spent in the right manner to ensure the highest quality system possible. High-quality services cannot be delivered to those who need them if they are not adequately funded in the public system, or are unaffordable to those paying out of pocket in the private market. SEIU would like the committee to consider adding an additional characteristic of a high-quality system, and would suggest adding the following bullet to the list: • *Is adequately and appropriately funded and resourced in order to deliver high-quality services, and that those services are accessible and affordable to those who need them*. Workforce: SEIU commends the inclusion of workforce among the characteristics, and largely agrees with the substance in that bullet, which currently reads: *"utilizes and supports a workforce that is trained, adequate, and culturally competent."* We believe this bullet would read better if changed to the following: • *Supplies and supports a workforce ample enough to meet the demand for services and needs of recipients including sufficient training, preparedness, compensation, and advancement opportunities for the workforce*. SEIU certainly agrees with the concept of cultural competencies. We feel that would be one among many outcomes of worker training, and is better emphasized and clarified in the section of the report that deals with subdomains. **Conceptual Framework**

Name	Organization	Content
		Policy/System: In the illustration of the conceptual framework, the report lays out three levels at which the HCBS system can be measured – "Policy/System," "Services/Providers" and "Individual." In general these are the right levels to consider, but we recommend changing the titles for clarity. The topmost level should not include the word "system" because all three dimensions conceivably make up the HCBS "system" with each playing unique roles and responsibilities. As such, we suggest changing "policy/system" to "policy/administration" or something similar to more accurately reflect the role and responsibilities of that dimension. Individual: In the "individual" sphere, it seems unclear as to which individuals specifically are covered. In the written section describing the initial diagram (Exhibit 2), it seems to be broadly defined as those individuals "who use or are involved in HCBS" which could include consumers, family members, or individual workers, among others. However, in the second framework illustration including domains (Exhibit 5) there is only one domain that pertains to any individual that is not a consumer. We urge the committee to clarify who is intended to be included in the "individual" level, and to rework the domains and their placement to reflect that it does indeed mean all individuals involved in the HCBS process. **HCBS Domains of Measurement** **Workforce and Providers:** SEIU feels strongly that the workforce and providers should be addressed in different domains. While some aspects do overlap, many do not, and that providers (as employers, businesses, payers, or employer-like entities) should either have a separate dedicated domain, or be included in the "Service Delivery" domain as it better reflects their responsibility and level of control within the HCBS system. During the committee discussion, workforce was the main focus of that domain, and providers were added at the end of the domain conversation as a bit of an afterthought. With that change in mind, the description of the workforce domain should change to read: "*The adequacy and availability of an appropriately prepared and compensated HCBS workforce*." Additionally, we recommend the "**Service Delivery**" domain to change to "*Providers and Service Delivery*" with the following description: "*The adequacy and appropriateness of the provider network to deliver services that enable a positive consumer experience (e.g., accessibility, respect, dependability, well-coordinated)*." This combines the provider description from its previous domain with the service delivery domain. **Human and Legal Rights:** This domain currently covers the crucial protections that need to be preserved for consumers. However, the description should be broadened to cover the human and legal rights of other individuals in the system such as workers and family members, and this would be consistent with the way individual is defined in the framework section. Home care workers' rights, including labor and employment rights, protections from discrimination and harassment, and the right to unionize and bargain collectively are all recognized legal and human rights to which the system should be held accountable. We recommend that the current language change to read: "*The level to which the human and legal rights of individuals who use or are involved in HCBS are promoted and protected."* **Funding and Resources:** Consistent with our comments in the "Characteristics of a High Quality HCBS System" section, there should be a domain that looks at the funding and resources available for the HCBS

Name	Organization	Content
		systems. Funding largely dictates how public programs are developed and administered, and directly relate to the quality and availability of the services that can be provided. In the private sector, the services an individual receives are the direct result of what they can afford. The under-funding and unaffordability of HCBS services is what keeps the wages of home care workers despicably low. Despite their important role in supporting families and providing care to vulnerable individuals, home care workers are among the lowest paid workers in our economy. Currently home care workers earn a median wage of about $13,000 per year, or $9.61 per hour.viii Additionally, the underfunding of HCBS is a factor in the current over-reliance and under-support of family caregivers, and keeps thousands of qualified consumers on waiting lists for HCBS services across the country. We urge the Committee to take the following domain and description under consideration: "*Funding and Access: The level at which resources are adequately and efficiently allotted to deliver high-quality HCBS services and achieve the goals of the HCBS system*." **HCBS Subdomains of Measurement**: Workforce and Providers: As stated above, SEIU would like to take this opportunity to reiterate that the "Workforce/Provider" domain should be separated out, and that many applicable provider subdomain measures are already in the "Service Delivery" domain. The Committee should take some time to consider additional subdomain measures specific to the wide array providers, including businesses, assisted living environments, agencies and employers, managed and coordinated care entities, and in some cases the states/programs themselves, and not lump them together with the workforce. In the workforce domain, SEIU urges the Committee to clearly define the subdomains it proposes and focus on subdomains that would be the most useful in the eventual development of specific quality measures. For instance, the draft subdomains of "sensitive and mindful" and "value-based leadership" do not currently have any definitions (and are not intrinsically clear), and it is especially unclear how these might be measured. We recommend that the Committee consider the following to be included in the list of workforce subdomains: Overall skill level of the workforce and its ability to meet consumer need; training – its availability, effectiveness, and impact in both voluntary and mandatory training systems; available advancement opportunities; worker safety and working conditions; ability for employers and consumers to find, attract and retain workers; wages and other compensation (like benefits and time off); worker productivity; and workforce supports. Training: We note the lack of any reference to training in the workforce subdomain, despite the specific inclusion of a well-trained workforce in the definition and characteristics section. In the "Caregiver Support" domain there is a specific sub-domain for training and skills building, but it is confusing as to whether "caregiver" means a paid or family caregiver, and largely seems to refer to the latter. Later in the report, it is noted that training was among the more controversial elements discussed. However, it seemed that there was general consensus that workforce training was important to measure as part of quality. There was some vocal concern around the inclusion of training in the workforce subdomain by a few committee members, and specifically that including training in the subdomains may result in mandated

Name	Organization	Content
		training. Such a drastic policy change is certainly beyond the scope of NQF in general and this Committee in particular. Rather, it is important and in the purview of this Committee to encourage the measurement of worker training where it exists and to examine its impact on quality. This will eventually assist policy makers in determining when and where worker training is most impactful and helpful to both the workers who are overwhelmingly asking for it, and those consumers and families who would prefer that a worker coming into their home and delivering intimate care have some level of meaningful training – as most home care workers, for instance, currently have no access to any real training. We encourage thoughtful, and even contentious, discourse as crucial to the decision making process, but would like to note that "consensus approach" is not synonymous with a unanimous one. The overall concept of training measurement did not seem controversial; rather there was some disagreement on the framing or aspects of training that should be included, and this is exactly the type of conversation that should be taking place within the Committee. We would urge the Committee not to shy away from difficult conversations and hope that if the majority of the Committee members feel workforce training is important to measure, that it will be explicitly included in the framework.
Josephine Kalipeni	Caring Across Generations	I write to you on behalf of Caring Across Generations (CAG). CAG is a national movement of families, caregivers, people with disabilities, and aging Americans working to transform the way we care in this country. By harnessing the power of online action, grassroots organizing, and innovative culture change work, we are shifting how our nation values caregiving and calling for policy solutions that enable all of us to live and age with dignity and independence. Please find below our comments on the National Quality Forum, Home and Community---Based Services (HCBS) Committee Interim Report entitled *Addressing Performance Measure Gaps in Home and Community--- Based Service to Support Community Living: Initial Components of the Conceptual Framework*. We appreciate the opportunity to comment on this interim report. Like the National Quality Forum, we agree that demand for community---based services is rising and that we need solutions that allow people to live well outside of institutional settings. CAG also believes that we need solutions to allow people to live well with dignity. In addition to quality, affordable services, a well---equipped and supported careforce — the community of paid and unpaid people, including family caregivers and home care workers, providing varying degrees of care to an individual — is vital to make living outside of institutional settings possible. **1. Definition of Home and Community---Based Services** While the definition of home and community based services is indeed positive and in plain language as the committee had intended, we advise the intentionally including the word "dignity" as part of the list of what is promoted in the actual definition. While it is implied, we believe that

Name	Organization	Content
		explicitly naming dignity in this list is crucial in setting forth a framework for HCBS. CAG believes that care should include honor and respect of all stakeholders involved. Explicitly including "dignity" in the framework for HCBS speaks to the culture of aging and care we want to create as a nation. Additionally, we recommend including the careforce in this definition to clearly set forth the understanding that investment in the careforce is vital in making care outside of institutional settings possible. Per our recommendation, the definition would read: "Home and community---based services refers to an array of long---term supports and the careforce that provides them that promote the dignity, independence, well---being, and choices…" **2. Characteristics of High---Quality Home and Community---Based Services** We commend the committee's attempts to communicate what HCBS *should* be. We advise that the committee should include: "Invests deliberately in quality care jobs that include basic job protections and a living wage; Is affordable for all consumers without compromising the quality of care jobs; Recognizes and formally records identified members of the careforce;" While the careforce is mentioned and we understand there is more consensus---building necessary, CAG believes that more inclusion of the careforce voice and their needs must be better balanced in the Committee's reports and recommendations. According to a new report released by the National Alliance For Caregiving, the typical family caregiver is a 49---year old woman who is caught and pressed between two sets of caregiving responsibilities--- assisting her parent or in---law and working at a paid job outside the home, often while simultaneously caring for her own children — a population we refer to as the sandwich generation. Including the voices and needs of all caregivers, with a particular focus on the sandwich generation, in these quality measures is very important. We know that women already make less than their male counterparts. Caregiving affects earnings and professional mobility, and often, women leave the workforce to care for a family member, further impacting their economic and retirement security. Addressing the needs of the sandwich generation is a moral imperative that will improve the lives of women and will also have a positive economic impact on them and their families. Recognizing, identifying, tracking, and assessing members of an individual's careforce, including family caregivers, in care coordination is a simple start in developing much---needed data about this (often invisible) support system. As the committee continues consensus---building around the definition of cultural competence, CAG supports Eldercare Workforce Alliance's working definition of cultural competence that defines

Name	Organization	Content
		it as: "providing services in a way that is respectful of, and responsive to, older adults of every language, ethnicity, health belief, race, sexual orientation, gender identity, gender expression, disability status, socio---economic status, geographical location, and other cultural identification." Caring Across Generations adds that, in addressing the care needs of our changing demographics, cultural competence needs to be considered from the perspective and needs of the careforce, and not just the consumer, to ensure a truly culturally competent system. Another area that CAG would like to offer recommendations is regarding the best displays and measures of adequately supporting the careforce, paid and unpaid caregivers alike. Intentional financial investment in the careforce is necessary to improve current jobs, retain workers, and develop the quality jobs needed to meet the rising demands. Supporting, assessing, and training family caregivers will be a critical component of meeting the need as over 85% of current care is provided by family caregivers. Smaller family sizes, increasing populations of childless adults, and families living further and further apart are changing individuals' access to family supports. As these economic factors impact family dynamics, the next generation may be less likely to rely on family members for care. Because of this, there must be a focus on the paid careforce. We encourage NQF to focus on recruiting, retaining, training, and protecting home care workers and other members of the paid careforce. Offering a living wage and benefits to the paid members of the careforce providing care, with a focus on home care workers, is vital in recruitment and retention. NQF should also consider conducting surveys of the paid careforce in order to gather much---needed data to inform the Committee about the self---identified needs of the careforce. **3. Priority Measure Domains and Subdomains** The report noted that workforce training was a controversial topic. While details about method, standardization, certification, and amount of required training may be controversial, the need for affordable, interdisciplinary training is not. A Rutgers report highlights Pennsylvania as an example of a state with a training model that pairs a consumer with their caregiver and achieves successful outcomes for both the caregiver and the consumer. CAG recommends that NQF consider separating providers and workforce as separate domains in order to clearly articulate the distinct roles and responsibilities of what systems, employers, and providers must do. CAG also recommends, as subdomains of the careforce domain, a focus on supports, assessments, data collection, training, and retention of family caregivers, paid workforce, and youth caregivers. Within this domain, we hope NQF considers the development of quality job standards as a subdomain. Additionally, there are incredible gaps in data around the workforce and NQF presents a very real opportunity to better track the careforce. This is just one of many

Name	Organization	Content
		examples of how these quality measures can be used to influence the standards of quality care administered through the private market. The measures should be designed with the intent to influence the heavily unregulated private pay industry. CAG encourages NQF to include the careforce perspective in already proposed domains. While it may be implied, some domains sound explicitly consumer---based, void of the worker voice. We suggest intentionally including the careforce lens in the subdomains of the following domains: • Human and Legal Rights • System Performance • Effectiveness/Quality of Services • Service Delivery • Equity • Health and Well---Being Lastly, CAG is concerned about overall affordability of care for consumers, which includes the careforce. A domain to address affordability and gather data would be fruitful for many other proposed domains and will be critical in drawing connections between care and quality. Data is particularly sparse for the populations who are private---pay consumers who desire or are receiving in---home care but are ineligible for public programs. As an additional note for the committee, when advocates raise the changing demographics in our nation, the focus is often on aging Americans and care. CAG includes undocumented immigrants as an important population when discussing the country's changing demographics. One---quarter of today's home care workers were born outside the United States. The three million people currently in the direct care workforce cannot meet the current need, let alone the growing demand for care. We include undocumented immigrants in our work through 2 critical lenses: 1. Undocumented immigrants are vital members of the careforce. 2. Undocumented immigrants are a growing population of the aging population in America who will also need care. Immigration policy is inseparable from the issue of care and quality of life as we age. Addressing the needs of the undocumented immigration population--- valuable members of our society who are living, working, and aging in our communities--- is a critical lens that we hope the committee carries and considers in its work moving forward. The consumer and careforce relationship is vital in making home and community---based services

Name	Organization	Content
		possible for consumers to live well and with dignity in their homes and other non--- institutional settings. On behalf of Caring Across Generations, I thank you for this opportunity to submit comments on the *Addressing Performance Measure Gaps in Home and Community--- Based Service to Support Community Living: Initial Components of the Conceptual Framework*, and for your commitment to improving the lives of older Americans.
Josh Fraum	Florida Blue	Thank you for the opportunity to comment on the Interim Report, *Addressing Performance Measure Gaps in Home and Community-Based Services to Support Community Living: Initial Components of the Conceptual Framework*. We appreciate the Committee's hard work and time spent developing a conceptual framework for Home and Community-Based Services (HCBS) Quality. Specifically, we commend the Committee for the operational definition of HCBS Quality presented in the Interim Report. We understand that it is early in the project; however, we want to emphasize the importance of not only improving quality and health outcomes, but also reducing costs and increasing access. We believe it is important, as part of this project, to understand the roles and responsibilities of government health care programs and private health plans regarding HCBS Quality, especially the role of the Medicaid program. Importantly, Long Term Support and Services (LTSS) and Long Term Care (LTC) benefits are already included in the Medicaid program. We are concerned that injecting additional responsibilities of LTSS/LTC benefits into commercial health insurance will dramatically increase premiums for consumers. Likewise, adding LTSS/LTC benefits to the Medicare program will dramatically increase premiums for Medicare beneficiaries. We appreciate the need to align and coordinate these efforts amongst all stakeholders. All health plans have the responsibility to work with community partners towards better health outcomes for their members. This includes a leadership role in the care coordination and care management of vulnerable populations. The Interim Report contains many domains with a potential to include many new measures. It is critical that any new measures be aligned and harmonized with existing measures to avoid duplication. New efficiencies and greater effectiveness can be best achieved with a minimal number of essential measures. In addressing domains specific to the Interim Report, we recommend reducing the number of domains to four. For example, merging "Consumer Voice" and "Choice and Control"; "Health And Well-Being" and "Effectiveness/Quality of Services"; and "Workforce/Providers," "Service Delivery," and "System Performance" into three distinct domains. Therefore, we recommend these four domains: "Access and Availability," "Quality," "Care Management," and "Member Voice/Rights";

Name	Organization	Content
		listing the current domains as subdomains under these four domains. Since the current subdomains appear to be descriptions of the current domains, these would fit well as definitions for the new subdomains. We would also like clarification on how the Committee is defining these subdomains, similar to what is listed on page 13 of the Interim Report.

Ohio
Department of Medicaid
John R. Kasich, Governor
John B. McCarthy, Director

August 14, 2015

National Quality Forum
1030 15th Street NW, Suite 800
Washington, DC 20005

Re: State of Ohio Comments Re Interim Report, "Addressing Performance Measure Gaps in Home and Community-Based Services to Support Community Living"

To Whom It May Concern:

The Ohio Departments of Medicaid, Aging, Developmental Disabilities and Mental Health and Addiction Services have reviewed the above-referenced Interim Report prepared by the National Quality Forum (NQF) and respectfully submit the following comments for the NQF's consideration as it proceeds with its work to address performance measure gaps in home and community-based services (HCBS).

First, Ohio agrees a framework for performance measurement is essential to the effective and efficient administration of a high quality HCBS delivery system. Ohio believes this framework should be comprehensive in that it is comprised of both quality indicators and compliance indicators, and it should be flexible enough for the State to develop its own measures.

In the section entitled, *Characteristics of High-Quality Home and Community-Based Services*, there is a discussion about not "over-medicalizing" HCBS. However, Ohio urges caution and a more balanced approach so that the more medical components of HCBS (e.g., nursing, therapies) are adequately addressed. This may be especially important when thinking about how individuals might use HCBS on a short-term basis.

Ohio requests clarification regarding whether the proposed domains and subdomains are, as a whole, intended to serve as new measures to gauge program operations, or as program requirements that would be implemented as part of the design process.

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If the domains and subdomains are intended to be quality measures,

- The State would benefit from further definition of them, as well as from information regarding where such data might originate. How will these subdomains be operationalized to generate useful data elements or data indicators?

- It would be beneficial for states if CMS would develop a crosswalk comparing the proposed subdomains to existing waiver assurances. This would help provide some context to determine how the domains and subdomains fit into the current quality framework. If a new framework is designed as a result of this initiative, additional detail is needed regarding how that will impact existing waiver programs.

- How will remediation be structured? Several subdomains described in the Interim Report appear to focus on an individual's experience in their waiver program. How will they influence CMS' emphasis on remediation? Will CMS again require individual remediation or will its focus on systems level remediation continue?

If the domains and subdomains are to be incorporated into the design criteria of HCBS, will there be updates to the 1915(c) waiver application and corresponding guidance materials? Technical guidance should specify expectations while providing states flexibility to design programs that meet the needs of target populations.

Ohio is concerned that many of the measures that would be associated with the proposed domains and subdomains could be difficult to quantify. For example, they embody the core philosophy of personal independence in service delivery and decision making. However, without additional information about program expectations, designing performance measures for the subdomains could be challenging and may not yield useful data to identify system improvement opportunities.

Also with regard to the proposed domains and subdomains, Ohio suggests adding the availability of accessible housing to either *System Performance* or *Full Community Inclusion*. Additionally, we note that case management/care coordination is not identified as either a domain or subdomain. Perhaps the NQE viewed it as inherent in all of the proposed domains and/or subdomains, however its absence is notable given the emphasis the Centers for Medicare and Medicaid Services (CMS) places on care coordination and conflict-free case management in HCBS. Finally, how will issues such as HCBS for children v. adults, assisted living and behavior health be addressed in HCBS quality measurement?

States should be given latitude to design a quality strategy that meets the basic requirements of the proposed domains and subdomains. This includes developing tools to gauge compliance that occurs outside of the traditional waiver quality strategy ((1915 (c) Appendix H) and waiver sub-assurances, including such things as individual satisfaction surveys or participation in the NCI/AD survey.

Finally, Ohio recommends that thought be given to how this work by the NQE can be aligned with quality measurement for institutional long term care. As the role of nursing homes change to more short term stays, and individuals move between institutional and community-based settings as their needs change, it seems that there is value in consistency where it makes sense.

The State of Ohio thanks both the NQE and CMS for the opportunity to review and comment on the Interim Report. We look forward to reviewing the remaining installments that are forthcoming.

Sincerely,

John B. McCarthy, Director

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U.S. Department of Justice
Civil Rights Division

Special Litigation Section - PHB
950 Pennsylvania Ave, NW
Washington, DC 20530

September 1, 2015

Via Electronic Mail

Drs. H. Stephen Kaye and Joe Caldwell
HCBS Quality Committee Co-chairs
National Quality Forum
1030 15th Street NW, Suite 800
Washington DC, 20005

Re: Department of Justice's Comments on the July 15, 2015 Interim Report "Addressing Performance Measure Gaps in Home and Community-Based Services to Support Community Living"

Dear Dr. Kaye and Dr. Caldwell:

Thank you for the opportunity to comment on the first report regarding the ongoing development of quality measures for home and community-based services ("HCBS"). We apologize that we were unable to transmit these to you before now. The Department of Justice enforces the Americans with Disabilities Act ("ADA"), including the integration mandate in Title II of the ADA as interpreted in the Supreme Court's decision in *Olmstead v. L.C.*, 527 U.S. 581 (1999). Ensuring that people receive high quality home and community-based services is important to furthering the goals of *Olmstead* and the ADA.[1] Not only does the quality of community-based services determine to a large extent whether individuals with disabilities have opportunities to live their lives like individuals without disabilities, but equally important, the quality of these services – and the ability of consumers and stakeholders to access information about the quality – plays a critical role in the decisions people make about where they want to receive services.

We are encouraged by the HCBS Quality Committee's inclusive approach to developing HCBS quality measures. We appreciate the HCBS Quality Committee's recognition that a wide variety of people with varying disabilities receive HCBS, that a wide variety of services are provided, that a variety of entities pay for these services (even though Medicaid is the primary pay source), and that service decisions are made in varying ways. We also appreciate the Forum's attention to the fact that measuring the quality of HCBS is about more than measuring the quality of health care services. We support the HCBS characteristics proposed by the Forum and encourage the Forum to continue prioritizing the need for HCBS quality measures to capture

[1] See, for example, Statement of the Department of Justice on Enforcement of the Integration Mandate of Title II of the Americans with Disabilities Act and *Olmstead v. L.C.*, available at http://www.ada.gov/olmstead/q&a_olmstead.htm.

how services integrate people with disabilities into the broader community and reflect person-centered goals that maximize independence.

As the HCBS Quality Committee requested in its initial report, we write to provide some additional subdomains for your consideration in devising quality measures. While we support many of the proposed subdomains, we hope these additions – influenced by our work across the country enforcing *Olmstead* – will be helpful. Based on engagement with numerous state agencies involved with our work, we also believe these subdomains could lead to appropriate measures that could be accurately reported on. Our proposed additions are included in Appendix A.

Finally, we remain interested in the HCBS Quality Committee's work and would be interested in providing additional comments as the development of quality measures progresses. If you have any questions, please feel free to contact me at (202) 514-8103 or benjmain.tayloe@usdoj.gov.

Sincerely,

Benjamin O. Tayloe, Jr.
Deputy Chief
Civil Rights Division
Special Litigation Section

Attachment

cc: Jodie Anthony
Senior Policy Analyst
Centers for Medicare and Medicaid Services

Appendix A: DOJ Suggested Additions to Proposed Subdomains

Domains for Measurement	Current Proposed Subdomains	Suggested Additions
Workforce/Providers	Sufficient numbers and appropriately dispersed; dependability; respect for boundaries, privacy, consumer preferences, and values; skilled; demonstrated competencies when appropriate; culturally competent, sensitive, and mindful; adequately compensated, with benefits; safety of the worker; teamwork, good communications, and value-based leadership	Provider licensing violations; staffing retention and turnover; staffing caseloads; access to training and information; adequate supervision
Consumer Voice	Meaningful mechanism for input (e.g., design, implementation, evaluation); consumer-driven system; breadth and depth of consumer participation; level of commitment to consumer involvement; diversity of consumer and workforce engagement; and outreach to promote accessible consumer engagement	Access to quality reporting; consumer involvement in system performance evaluations
Choice and Control	Choice of program delivery models and provider(s) including self-direction, agency, particular worker(s), and setting(s); personal freedoms and dignity of risk; achieving individual goals and preferences (i.e., individuality, person- centered planning); self-direction; shared accountability	Service plans developed through person-centered process; individualized goals in service plans
Human and Legal Rights	Delivery system promotes dignity and respect; privacy; informed consent; freedom from abuse and neglect; optimizing the preservation of legal and human rights; sense of safety; system responsiveness	Access to information about legal rights; access to legal advocacy and counseling services
System Performance	Consumer engagement; participatory program design; reliability; publicly available data; appropriate and fair resource allocation based on need; primarily judged by the aggregate of individual outcomes; waiting lists; backlog; financing and service delivery structures; availability of services; efficiency and evidence based practices; data integrity	Trend analysis; effectiveness of corrective action plans; identification of service gaps and delays; identification of barriers to services

Domains for Measurement	Current Proposed Subdomains	Suggested Additions
Full Community Inclusion	Enjoyment or fun; employment, education, or productivity; social connectedness and relationships; social participation; resources to facilitate inclusion; choice of setting; accessibly built environment	Integrated employment, education, and community activities; relationships with non-paid individuals; maintenance of chosen living arrangement; maintenance of chosen employment or day setting; transportation access. We would also encourage the Forum to reconsider the order of its proposed subdomains. Although access to enjoyable community recreation is an important component of community inclusion, its position as the first subdomain overemphasizes its role compared to integrated, competitive employment and other productive, inclusive day activities.
Caregiver Support	Training and skill-building; access to resources (e.g., respite, crisis support); caregiver well-being (e.g., stress reduction, coping); caregiver and/or family assessment and planning; compensation	Outreach efforts to caregivers; access to technology; caregiver well-being (e.g., stress reduction, isolation, coping)
Effectiveness/Quality of Services	Goals and needs realized; preferences met; health outcomes achieved; technical skills assessed and monitored; technical services delivered; team performance; rebalancing	
Service Delivery	Accessibility (e.g., geographic, economic, physical, and public and private awareness or linkage); appropriate (e.g., services aligned with needs and preferences, whether goals are assessed); sufficiency (e.g., scope of services, capacity to meet existing and future demands); dependable (e.g., coverage, timeliness, workforce continuity, knowledge of needs and preferences, and competency); timely initiation of services; coordination (e.g., comprehensive assessment,	Responsiveness to changes in status, e.g., timely modification of services.

Domains for Measurement	Current Proposed Subdomains	Suggested Additions
	development of a plan, information exchange between all members of the care team, implementation of the plan, and evaluation of the plan)	
Equity	Reduction in health and service disparities; transparency of resource allocation; access or waiting list; safe, accessible, and affordable housing; availability; timeliness; consistency across jurisdictions	Consistency across disability populations; access to language services
Health and Well-Being	Physical, emotional, and cognitive functioning; social well-being, spirituality; safety and risk as defined by the consumer; freedom from abuse, neglect, and exploitation; health status and wellness (e.g., prevention, management of multiple chronic conditions); behavioral health	Injuries; use of seclusion/restraint; deaths; avoidance of negative outcomes, including admissions to emergency departments, admissions to institutions, homelessness, and law enforcement contact