



# Public and NQF Member Comments on HCBS Quality Third Interim Report

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## Overview of Comments Received on the 3<sup>rd</sup> Interim Report

The National Quality Forum (NQF) received over 192 comments from advocacy groups, trade organizations, healthcare providers, insurers, state agencies, special interest groups, researchers, and home and community based services (HCBS) consumers and their family members or caregivers. NQF received comments on the operational definition, the global recommendations, the domains specific recommendations, and example promising measures that align with the domains and subdomains of measurement identified by the NQF HCBS Committee. Comments were generally supportive. Many comments requested more specific recommendations and addressed some of most recent efforts to advance quality measurement in HCBS that the Committee should consider before finalizing their recommendations. The Committee discussed these comments at the August 4, 2016 web meeting. During the meeting, NQF requested the Committee's input on potential modifications and additions to be made to various components of the 3<sup>rd</sup> interim report. The Committee did not discuss all of the comments received on the call but they submitted additional feedback based on the public comments to NQF staff following the web meeting. The Committee will continue to review and discuss the comments as they develop the final report.

### Comments on the Operational Definition

Comments on the operational definition suggested rearranging the language, adding words that make the definition more precise, and removing words that may exclude certain populations that use HCBS or services that may be considered HCBS. Based on these comments, the Committee considered moving the portion of the definition that describes where HCBS is delivered closer the beginning. They also considered adding the term "health" to accompany "well-being" and changing the word "individual" to "person". The Committee discussed narrowing the definition to only people who have "limitations in function". However, in an effort to avoid a deficit-based definition the Committee intends to keep the language broad to encompass anyone with a long-term physical, cognitive, and/or behavioral health "need".

### Comments on the Global Recommendations

Comments on the global recommendations focused on increasing their specificity to ensure that there is enough information for stakeholders to take action. Several comments were related to prioritizing certain domains and sub-domains. Many commenters expressed the limited availability of resources which increases the need for prioritization. There is a need to clarify what is meant by a "consistent approach to quality measurement" in one of the seven global recommendations. A number of comments reiterated the importance of outcomes measures. Many comments called for more clarity on purpose, use, and importance of a menu of HCBS quality measures. The Committee will refine and add more specificity to these recommendations for the final report.

### Comments on the Domain Specific Recommendations and Example Promising Measures

Comments on the domain specific recommendations called for modifications to the domain and subdomain descriptions as well the additional recommendations for several domains. The Committee will continue to refine the domain descriptions, but they were resistant to making significant changes that may not provide more clarity. Many commenters suggested actionable short term steps that can be taken in the domains where there were fewer or no short-term recommendations. The Committee

will consider adding these additional recommendations and/or expanded on their existing recommendations. There were also many suggested example promising measures that further illustrate the types of measures that could be found in the domains and subdomains. The Committee will consider including these example measures in the final report.

### **General Comments**

Comments focused on reorganizing and consolidating domains that may have significant overlap. There were also suggestions to clarify important terms like “dignity of risk” and “community” and a call to not lose sight of individuals and families who use HCBS. Many comments requested that the Committee better align their recommendations to important ongoing related work that will impact quality measurement in HCBS in the future. Some comments suggested referencing populations that use HCBS that may not have been explicitly discussed in the 3rd interim report.

## Comments on the Operational Definition and Conceptual Framework

Comments on the Operational Definition and Conceptual Framework		
Comment Submitter Name	Comment Submitter Organization	Comment
Clarissa Kripke	University of California, San Francisco	<p>I would add communication to physical, cognitive and/or behavioral health needs because:</p> <ol style="list-style-type: none"> <li>1. home based services and supports in dispersed settings requires it for safety.</li> <li>2. it has been a persistent, widespread problem</li> <li>3. you can't have self-direction without it</li> <li>4. too few people have access to an effective means of communication</li> </ol>
Gary Montrose	Colorado - Community Living Quality Improvement Advisory Committee (CLQIC)	<p><b><u>Field-based Testing for Survey Reliability:</u></b></p> <p>Ascertaining client's 1) level of cognitive ability to respond to survey questions, especially those with cognitive limitations, 2) communication differences for those who may be hard of hearing or are visually impaired (for example) requires additional conceptual work by consumers and HCBS SMEs, field-based inter-rater reliability testing to assure validity of responses.</p>
Gary Montrose	Colorado - Community Living Quality Improvement Advisory Committee (CLQIC)	<p><b><u>Client Fear of Retribution</u></b></p> <p>Social agencies know from years of field experience that HCBS consumer survey responses are often not reliable as people with severe disabilities are all too often inclined to provide only positive evaluations of their care providers out of fear of retribution; whether justified or not, given how vulnerable they are to neglect and abuse, fear of losing their benefits for being a "difficult consumer," etc.</p> <p>Retribution can include fear of abuse and neglect; such as stealing of personal property in home settings without family members present, medication mismanagement, failure to rotate a person properly, being late to appointments, etc. as so many HCBS clients are totally dependent on the good-will of their care givers and service agencies.</p> <p>The unique circumstances of HCBS populations to provide honest survey responses is an issue that requires substantial and systematic evaluation by clients and SMEs with substantial field-based experience.</p>
Gary Montrose	Colorado - Community Living Quality	<p>It might be useful to place in a 'call-out text box' in the conceptual foundation section a statement (for those with clinical and limited social</p>

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	Improvement Advisory Committee (CLQIC)	<p>service expertise) that:</p> <p>"Approaches to quality measurement that have proven successful in clinical and institutional settings are not sufficient for assessing HCBS quality among clients with limited communication capabilities or those who may fear retribution for providing less than glowing assessments of their care providers."</p>
Gary Montrose	Colorado - Community Living Quality Improvement Advisory Committee (CLQIC)	<p><b><u>Level of Analysis:</u></b></p> <p>The Measurement Framework diagram (p. 9) indicates the important role of "providers" with references to healthcare and social service providers. However, the reporting of HCBS survey results seems to be focused on "performance across agencies and states," "across states." (p14).</p> <p>If HCBS consumer quality surveys are not conducted and evaluated at the individual social agency and healthcare provider level, such survey results will not provide actionable information at the home and community level, where consumers live and services rendered.</p> <p>How, notwithstanding the issue of small survey samples, can HCBS surveys (even if not statistically significant, at the local level) be made useful for informing state and local communities about the quality of social services and health and without being able to identify local 'provider' performance?</p>
Gary Montrose	Colorado - Community Living Quality Improvement Advisory Committee (CLQIC)	<p><b><u>Addressing the Triple Aim for HCBS Consumer Surveys:</u></b></p> <p>Identifying HCBS Quality Metrics (ultimately Endorsed Measures) consistent with the objectives of the Triple Aim (challenging as this might be) would help align any number of national, state and local performance measurement efforts.</p>
linda Thomas		<p>I see you mention the HCBS consumer, but not what level of disability. Many medically fragile individuals are nonverbal and may be severely or profoundly cognitively disabled. They supposedly will be able to access HCBS funding, so they need to be included in the sample, this will need a proxy questionnaire and very unique survey questions. Are you doing this?</p>
Gary Montrose	Colorado - Community Living Quality	<p><b><u>Alternative Survey Methods for HCBS Consumers</u></b></p> <p>There is a lack of guidance on alternative methodologies (best practices) for surveying people with various physical and cognitive limitations, e.g.</p>

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	Improvement Advisory Committee (CLQIC)	<p>I/DD populations; hard of hearing; blind; those with physical disabilities, frail elderly.</p> <p>Different survey methods may be required for different HCBS populations. For example, in some instances, people with disabilities might trust a "peer" surveyor or anonymous on-line survey, but not trust a "professional" surveyor they do not know and may fear could pass negative comments on to their caseworkers. The pros and cons of Peer-to-Peer interviewing (people with similar disabilities to those being interviewed), written, phone, social media survey methods should be identified and eventually evaluated for validity and reliability among various HCBS disability types, age cohorts, children vs. adults vs. seniors; proper use of surrogates.</p>
<b>E. Clarke Ross</b>	Consortium for Citizens with Disabilities	Overall, the framework is well developed and encompasses a broad range of domains and sub-domains that are important. Clarke Ross, American Association on Health and Disability and Lakeshore Foundation
<b>Joe Caldwell</b>	National Council on Aging	We believe “rebalancing” needs to be more explicitly identified in the framework. It currently fits within the sub-domain “Financing and service delivery structures” of the domain “System performance and accountability.” However, the descriptions do not mention “rebalancing.” Rebalancing measures are a priority consumer advocates; and CMS has required rebalancing measures in MLTSS programs. Given its level of importance, we recommend that rebalancing be clearly identified as a separate sub-domain.
<b>Laura Thornhill</b>	Alzheimer's Association	The Alzheimer’s Association deeply appreciates the Committee’s acknowledgement of the necessary balance of personal safety with “dignity of risk” among its identified characteristics of high-quality home- and community-based services (HCBS). As previously noted, 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 we commend the Committee’s efforts to include their perspective in this important framework.
<b>Jennifer Goldberg</b>		Justice in Aging supports the Committee’s efforts to develop high-level measure domains that highlight important areas for quality HCBS. The operational definition and characteristics of high quality HCBS are well developed. To improve this framework, we suggest identifying “rebalancing” as a specific aspect of the framework. Rebalancing

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		currently fits into sub-domain “Financing and service delivery structures” of the domain “System Performance and Accountability.” However, the term “rebalancing” is not specifically used. Rebalancing is a high priority of consumer advocates, and CMS has required rebalancing measures in MLTSS programs. Given its level of importance, we recommend that rebalancing be clearly identified as a separate sub-domain, with its own clearly identified promising measures and measure concepts.
<b>Lindsay Schwartz</b>	American Health Care Association/National Center for Assisted Living	As an association that represents providers who care for frail, elderly and individuals with disabilities, AHCA/NCAL appreciates the broad definition of HCBS that includes individuals of any age and health needs. As mentioned in previous comments, 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. This integration issue has been a topic of discussion regarding the CMS HCBS Final Rule. Dementia care is an important part of assisted living communities and should not be excluded from this HCBS definition. AHCA/NCAL understands the intent on using “integrated” as providers work on integrating residents into the broader community but this can also be subjective and could exclude important HCBS populations.
<b>Peg Graham</b>	QUA INC	It is heartening to see acknowledgement of the importance of support to complete Activities of Daily Living in the Background Section, and to know that the HCBS taxonomy includes collecting data on “equipment, technology and supplies” within Medicaid Statistical Information System (MSIS) for purposes of “national eligibility, enrollment, program utilization and expenditure data.” Yet, there appears to be no further reference to collecting data on how seamless provision of “right equipment, right time” is a measure of interest in LTSS. Published articles from the National Health and Aging Trends Study (NHATS) provide data that should be included in development of HCBS quality measures. Consider Freedman VA, Kasper JD “Behavioral Adaptation and Late-Life Disability: A New Spectrum for Assessing Public Health Impacts” ( <a href="http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3935680/">http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3935680/</a> ) and Wolf JL Spillman BC, “A National Profile of Family and Unpaid Caregivers Who Assist Older Adults With Health Care Activities” ( <a href="http://www.ncbi.nlm.nih.gov/pubmed/26882031">http://www.ncbi.nlm.nih.gov/pubmed/26882031</a> ).
<b>Amy Ingham</b>	Anthem, Inc.	Anthem is supportive of the work of the HCBS Committee to create an operational definition of HCBS and conceptual framework. The HCBS definition is appropriate and reflective of the types of services delivered to individuals in need of supportive services in home- or community-

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		<p>based settings.</p> <p>Anthem appreciates the goals of the conceptual framework but we recommend that the Committee consider revising the graphic on page 9 of the report in order to provide a simpler, clearer illustration of HCBS quality measurement. It appears that many concepts overlap in the diagram which may lead to confusion. One solution could be to present each concept as a separate graphic, illustrated as part of an overarching process or cycle.</p>
<b>Allicyn Wilde</b>	SEIU	<p>SEIU commends the Committee and NQF staff for putting together an excellent operational definition for HCBS. We are particularly pleased that the report identifies characteristics of a high quality system, and highlights workforce among those characteristics. Additionally, the work done to improve and clarify the domains and subdomains within the framework is clearly substantial, and we would like to thank the Committee and staff for their thoughtful revisions from the previous report, which help significantly clarify the framework overall and set realistic expectations as to what should and can be measured. In particular, we would like to thank the committee for the work done in the Workforce domain, and for incorporating many of the suggestions we and others made in the last round of public comment.</p>
<b>Allicyn Wilde</b>	SEIU	<p>The report recognizes the importance of all the domains and the need to treat them equally, and we agree whole heartedly. Quality measures in the HCBS system(s) have been long overdue, and many of the domains and subdomains that the Committee has identified lack meaningful measures and measure concepts – or even basic and consistent data collection. Prioritizing specific domains over others creates a risk that CMS or other entities that may utilize this framework would focus exclusively on areas where there has been some prior development, to the detriment of other areas in desperate need of attention. At the same time, we recognize the functional need for some prioritization in order to give future work a place to start and focus efforts. Therefore, we would urge the Committee to make specific recommendations for prioritization of at least one subdomain within each domain in order to focus the work moving forward while not giving some domains more weight or importance than others. We believe that revisions to the domain specific recommendations could go a long way in achieving a realistic pathway for future quality measure development work – and will discuss further in the Domain Specific Recommendations Section.</p>



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		<p>The report also emphasizes, and we agree, that all the domains should be measured at all three levels (individual, provider, and system levels) whenever possible. To that end, we recommend editing the fifth bullet point on page 13 of the report to reflect all three levels. Ideally, the language would read:</p> <ul style="list-style-type: none"> <li>·Using both systemic, provider or programmatic, and individual level data to develop HCBS quality measures.</li> </ul> <p>Lastly, on page 13, the first sentence under the “Cross-cutting Recommendations” states that “Committee members emphasized that measurement in all domains should be person-centered, with the goal of improving consumer outcomes and promoting community living.” While we certainly agree with the stated goals, it is unclear what the committee means by the reference to all domain measures being person-centered, since some measures would be systemic (e.g. measuring the number of available workers in a state to provide needed services), or programmatic (e.g. whether the number and types of workers dispersed meet specific HCBS program needs), and it is not clear how these different types of measures would be person-centered. We urge the Committee to clarify or revise the statement to better convey its meaning.</p>
John Shaw	Next Wave	<p>Next Wave believes that it is a challenge is to clearly articulate and illustrate the interdependent/cross-cutting nature of most of the domains and subdomains. The HCBS Performance Measurement Illustration in Figure 1 shows that all domains contribute to System, Provider/Service, and Consumer measures and accountability. Perhaps another figure illustrating the connections between the domains along with a narrative description like that provided for Figure 1 could reinforce this reality. In addition, key cross-cutting connections could be represented by bolder lines. A few words highlighting these key connections in several places throughout the text can also reinforce that the domains cannot stand alone.</p> <p>For example, the Workforce and Caregiver Support domains address the front-line workers providing care, but one is paid and the other is not. Both need education, technical support, a voice in care planning, and meaningful involvement in the design, implementation, and evaluation of the HCBS system and policies. Adding the phrase “paid and unpaid” to both the Workforce Domain Name and key Subdomains is a simple change that can highlight this.</p> <p>Another visual example could both illustrate these connections and also</p>

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		<p>reinforce the comprehensive importance of informal caregivers throughout the Domains as described in our input in the General Comments section. Informal Caregivers have their own Domain, but also:</p> <ul style="list-style-type: none"> <li>· Deliver services coordinated with paid caregivers</li> <li>· Provide Person-Centered voice of the patient where they are unable to understand or respond</li> <li>· Negotiate Choice and Control with the family member they care for</li> <li>· Maintain ties to the Community</li> <li>· Represent the vast majority of the front line Workforce</li> <li>· Support the consumer in exercising their human and legal rights</li> <li>· Etc.</li> </ul> <p>Illustrating these connections across Domains with the Informal Caregiver example should be both easy to understand for all Stakeholders and reinforce the recognition of the critical role of the informal caregiver in HCBS.</p>
<b>Maureen Dailey</b>	American Nurses Association	ANA supports the comments submitted by the Alliance for Home Health Quality and Innovation. In addition, ANA review instruments already in use by LTSS providers (e.g., RAI, MDS, OASIS).
<b>Kimberly Austin-Oser</b>		<p>Page 9 – Venn diagram – I think an illustration here is very useful but believe this one does not adequately convey the intended message and, perhaps, is trying to say too much. It might work better to have two illustrations instead of one. Maybe we should consider including the Venn diagram to demonstrate the interrelated nature of our framework – the dimensions that make up the overall HCBS system (admin/funder, provider, consumer) and an additional illustration designed to highlight the domains, how they are intended to be viewed concurrently through these different dimensional lenses, and by putting them all together will help paint a more comprehensive picture of the overall health and quality of the HCBS system.</p>
<b>Teresa Lee</b>	Alliance for Home Health Quality and Innovation	<p>Overall, the Alliance supports the conceptual framework in the home and community-based services (HCBS) interim report as it applies to HCBS overall, as a continuum of services and supports. However, the Alliance does have a few concerns as detailed below.</p> <p>First, the operational definition of HCBS on page 7 of the report is very broad and does not specify sources of funding. As such, it appears even to include the delivery of skilled home health services under the Medicare home health benefit, even though the Medicare benefit is not</p>

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		<p>considered a type of long-term service or support. Although Medicare-certified home health agencies (that deliver Medicare home health benefits) can, do and should partner with providers of long-term services and supports (LTSS), it is important to understand and note that the Medicare benefit does not cover long-term care. Further, the definition of HCBS is also broad enough to include home care medicine (physician and APRN house calls) and potentially even hospice.</p> <p>While, the Alliance recognizes that the definition of HCBS is likely broad by design, and purposefully neutral as to source of payment, it is important to note that unlike most of the other providers of services that are subsumed in the operational definition of HCBS, Medicare home health agencies are already subject to numerous performance measures, pay-for reporting against those measures, and even public reporting and star ratings on Medicare's Home Health Compare website.</p> <p>Additionally, the domains identified in the interim report are also broad in nature. We support the aspiration of applying the domains in the interim report to the HCBS "system" or "continuum" as a whole, but caution that for individual providers of HCBS, the current state of each provider's role and function should be considered. For individual providers of HCBS (as defined in the interim report), measurement of quality in every domain and sub-domain may not be appropriate. In practice, measures that will be developed to apply to each provider should be tailored and appropriate so that providers are held to what they can reasonably and feasibly be accountable for. Moreover, it is critical that providers be held to a parsimonious set of measures to enable them to focus their performance improvement efforts. As noted in the IOM's "Vital Signs" report measures as actually applied to providers should be thoughtfully chosen and prioritized to enable meaningful performance improvement efforts.</p>
<b>Lisa Price Stevens</b>	Magellan Health, Inc.	We commend the Committee for it's work. The conceptual framework domains provide an opportunity to address quality within a very broad, yet complex category of services.
<b>Elizabeth Cullen</b>	The Jewish Federations of North America	We believe "rebalancing" needs to be more explicitly identified in the framework. It currently fits within the sub-domain "Financing and service delivery structures" of the domain "System performance and accountability." However, the descriptions do

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		not mention “rebalancing.” Rebalancing measures are a priority for consumer advocates, and CMS has required rebalancing measures in MLTSS programs. Given its level of importance, we recommend that rebalancing be clearly identified as a separate sub-domain.
<b>Lauren Aforatus</b>	Family Voices NJ	<p>We strongly agree with the operational definition as “The term ‘home and community-based services’ (HCBS) refers to an array of services and supports that promote the independence, well-being, self-determination, and community inclusion of an individual of any age who has significant, long-term, physical, cognitive, and/or behavioral health needs and that are delivered in the home or other integrated community setting.” Under characteristics of HCBS, we strongly agree that this includes: a person-driven system; social connectedness and inclusion; a flexible range of services; integrated health and social services; promoting privacy, dignity, respect, independence, freedom from abuse; safety and dignity of risk; skilled workforce; caregiver support; stakeholder involvement; reducing disparities; coordination; accessible and affordable care; measuring outcomes; and accountability. We are particularly pleased to see the mention of freedom from restraint as this is inappropriately used and experienced as trauma by individuals experiencing restraints. We would add to this freedom from seclusion and other aversive interventions. We also strongly agree with caregiver support as more people enter institutional care due to caregiver burnout instead their worsening condition. Stakeholder input, including consumers, their families, and organizations serving families, is essential. Reducing disparities is a key issue as individuals with disabilities are seen as an underserved group with worse outcomes (see <a href="http://www.cdc.gov/ncbddd/disabilityandhealth/features/unrecognizedpopulation.html">/www.cdc.gov/ncbddd/disabilityandhealth/features/unrecognizedpopulation.html</a>.) Coordination of resources will follow the effective medical home model (see <a href="https://medicalhomeinfo.aap.org/Pages/default.aspx">https://medicalhomeinfo.aap.org/Pages/default.aspx</a>.)</p>

## Comments on the Cross-Cutting / Global Recommendations

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Clarissa Kripke	University of California, San Francisco	Service need is also an important domain of equity in addition to race, language, gender and age.
Clarissa Kripke	University of California, San Francisco	This should acknowledge the methodological and pragmatic challenges with doing survey research in people with cognitive and intellectual disabilities and the problems with proxy survey reporting. When you ask caregivers and service providers if they are providing good care and achieving great outcomes, the answer is always, "Yes" especially if people worry that they may lose care and custody or have punitive measures if the answer is "no." For this population, methods that involved direct observation in natural settings such as secret shopper research is critically important.
Gary Montrose	Colorado – Community Living Quality Improvement Advisory Committee (CLQIC)	<b><u>Identifying consumers’ level of Effective Communication:</u></b> The interRAI “Assessment System, Home Care Assessment Form and User’s Manual” (v9.1, p. 25) has developed a list of validated questions designed to ascertain consumer’s ability to engage in effective communication; to “Make Self Understood,” “Ability to Understand Others,” “Hearing skills,” “Vision skills” as well as “Mood and Behavior” questions that could be used to assess the communication abilities of different HCBS consumers.
Gary Montrose	Colorado - Community Living Quality Improvement Advisory Committee (CLQIC)	<b><u>Cultural Competent Surveyors</u></b> Given the communication, behavioral, social and cultural diversity of people living within different disability communities (e.g. “deaf communities, “blind communities,” etc.), people conducting personal interviews must be able to demonstrate some level of <b>disability-specific cultural competency</b> , or they will likely not be effective at working with such populations. There are basic cultural competency issues to be addressed, such as being patient, gaining trust, recognizing survey fatigue, when to ask for a family surrogate, etc. Basic cultural competency thresholds should be defined, if not by NQF, then by other groups with such expertise.
Gary Montrose	Colorado - Community Living	<b><u>Peer-to-Peer Interviewing</u></b> Peer-to-Peer (“P2P”) interviewing - engaging people with

## Comments on the Cross-Cutting / Global Recommendations

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	Quality Improvement Advisory Committee (CLQIC)	<p>similar types of disabilities and ideally living in the same community – will likely result more honest, complete and reliable survey results (as “trusted” persons), compared to unknown, able-bodied people who do not speak disability-specific language.</p> <p>The practice of “Participatory Research” has validated the advantages of using “people like me” to gain trust among suspicious, vulnerable populations. We in Colorado are entering our second year of conducting “P2P” interviews, with the National Core Indicator Aging/Disability survey.</p>
<b>E. Clarke Ross</b>	Consortium for Citizens with Disabilities	<p>Equity - page 22 - we suggest inclusion of "access to timely and appropriate care." Holistic health and functioning (page 23) - we suggest inclusion of "integrated primary and specialty care." This is particularly important for individuals with behavioral health needs." Clarke Ross, American Association on Health and Disability and Lakeshore Foundation.</p>
<b>Joe Caldwell</b>	National Council on Aging	<p>We believe additional work is needed to identify priorities for measure development, which is one of the primary tasks of the committee. We feel the draft recommendations do not offer a level of specificity that will assist HHS and advocates in guiding future investments in measure development.</p> <p>While we agree that investments should be made across all domains, this is very unlikely in the short term. Therefore, we believe some additional prioritization is needed to guide CMS on the most important areas for measure development. CMS recently released final regulations on Medicaid Managed Care. Within these regulations CMS required for the first time states to include quality measures on Rebalancing, Community Integration, and Quality of Life. While quality of life is not identified as a specific domain or sub-domain, we believe it crosses several domains and is best assessed via the perspectives and experiences of consumers.</p> <p>While the committee recommends that CMS should improve administrative data. The report contains no specific, actionable recommendations for CMS to undertake. We encourage additional discussion and development of specific recommendations for improvements in administrative data.</p>

## Comments on the Cross-Cutting / Global Recommendations

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		We recommend that the committee make a specific recommendation that performance measures from the HCBS Experience Survey be expedited for NQF endorsement. We are very concerned that the efforts of the NQF Person and Family-Centered Care Measures Committee have not been coordinated with the NQF Committee on HCBS Quality. There appears to be a major disconnect that is not in line with the framework and priority recommendations developed by this committee.
<b>E. Clarke Ross</b>	Consortium for Citizens with Disabilities	The report recommends that CMS improve administrative data but the report contains no specific, actionable recommendations for CMS to undertake. The committee should discuss what specific uses of administrative data will enhance quality and quality measurement for HCBS. Further, the committee should discuss how to incorporate beneficiary experiences (HCBS Experience Survey, CAHPS, National Core Indicators, and Council for Quality Leadership - Personal Outcomes Measures) into administrative data bases. Clarke Ross, American Association on Health and Disability and Lakeshore Foundation.
<b>Laura Thornhill</b>	Alzheimer's Association	The Alzheimer's Association supports the Committee's inclusion of all measures types as the HCBS quality space grows. Due to the progressive and fatal nature of Alzheimer's disease, dementia measures are frequently process- rather than outcome-oriented. It is just as important, however, that the quality of care of these persons and others with degenerative conditions be measured and improved.
<b>Lindsay Schwartz</b>	American Health Care Association/National Center for Assisted Living	AHCA/NCAL strongly agrees with the HCBS Committee, that measurement in all domains should be person-centered. AHCA/NCAL supports the recommendations to support quality measurement work across all domains, utilizing consistent approaches to quality measurement, leveraging technology, and building on existing quality measures. In addition, AHCA/NCAL agrees measurement should include structure, process and outcome measures with a focus on outcome measures.
<b>Carmella</b>	America's Health	We support the cross-cutting recommendations described in

## Comments on the Cross-Cutting / Global Recommendations

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<b>Bocchino</b>	Insurance Plans	the report.
<b>Jennifer Goldberg</b>		<p>We are concerned that the draft cross-cutting recommendations are not specific enough with regard to how to prioritize measure development. The Committee's conclusion that measurement in each domain is equally important leaves CMS and stakeholders without clear direction for immediate action. While we agree that investments should be made across all domains, this is very unlikely in the short term. Therefore, additional prioritization is needed to guide CMS in measure development. CMS recently released final regulations on Medicaid Managed Care, which require states for the first time to include quality measures on Rebalancing, Community Integration, and Quality of Life. While quality of life is not identified as a specific domain or sub-domain, we believe it crosses several domains and is best assessed via the perspectives and experiences of consumers. These rules further require identifying health disparities based on disability status and publicly available External Quality Review reports. This creates greater urgency to invest in measure development and guidance on a menu of measures that could assist states, health plans, and advocates to implement these requirements.</p> <p>We also recommend prioritizing the development of quality measures related to the implementation of the HCBS Settings Rule. Such prioritization would assist states, CMS and all stakeholders who are working toward implementation. Measures of particular importance for this work fall primarily into the domains of Choice and Control and Person-Centered Planning and Coordination.</p> <p>We agree with the overall recommendation to improve administrative data. However, the report is not specific enough in this area. We suggest further development of additional, more specific recommendations to improve administrative data.</p> <p>Justice in Aging supports the recommendation to create a menu of performance measures that apply across populations. As states develop the State Quality Strategy required by the recent federal Medicaid managed care rule, states and stakeholders need standardized, vetted, and endorsed quality</p>



## Comments on the Cross-Cutting / Global Recommendations

Comment Submitter Name	Comment Submitter Organization	Comment
		<p>measures to adopt in their state plan. The proposed menu will be useful for that process.</p> <p>The draft does not indicate a timeline for developing the measure menu. As states will be required to develop their State Quality Strategy in 2017, we urge the Committee to prioritize the menu development and publish a core set of performance measures without any additional delay.</p>
<b>Amy Ingham</b>	Anthem, Inc.	<p><b>Menu of Measures:</b> We strongly support a menu of standardized measures from which a state can select the ones that are most appropriate to their intricate programs, population (including membership variation by health plan since not all plans in a given state, serve members with the same needs), provider base, and administrative structure. These will allow for state to state comparisons and an easier approval process by CMS.</p> <p><b>Data Sources:</b> For states that contract with MCOs and utilize the MCOs to gather evidence on the quality measures, the method of gathering evidence and conducting remediation with providers is subject to contract negotiations and state regulations. While performance measures may be standardized, it would be helpful to retain flexibility for data collection approaches at the state-level in order to allow for the development of innovative data collection and management strategies. Anthem recommends that the Committee encourage HHS to fund the continued exploration of HCBS measurement data collection challenges and solutions with appropriate experts and stakeholder input.</p> <p><b>Investing in psychometric properties of existing instruments:</b> We also support the Committee's recommendation to invest resources to test the psychometric properties of existing instruments, particularly those that are widely used. The instruments may be sources for quality measures that map to the Committee's measurement framework, particularly for domains for which very few quality measures currently exist and where there are considerable measure gaps (e.g., Caregiver Support; Consumer Leadership in System Development).</p>

## Comments on the Cross-Cutting / Global Recommendations

Comment Submitter Name	Comment Submitter Organization	Comment
<b>Allicyn Wilde</b>	SEIU	<p>The report recognizes the importance of all the domains and the need to treat them equally, and we agree whole heartedly. Quality measures in the HCBS system(s) have been long overdue, and many of the domains and subdomains that the Committee has identified lack meaningful measures and measure concepts – or even basic and consistent data collection. Prioritizing specific domains over others creates a risk that CMS or other entities that may utilize this framework would focus exclusively on areas where there has been some prior development, to the detriment of other areas in desperate need of attention. At the same time, we recognize the functional need for some prioritization in order to give future work a place to start and focus efforts. Therefore, we would urge the Committee to make specific recommendations for prioritization of at least one subdomain within each domain in order to focus the work moving forward while not giving some domains more weight or importance than others. We believe that revisions to the domain specific recommendations could go a long way in achieving a realistic pathway for future quality measure development work – and will discuss further in the Domain Specific Recommendations Section.</p> <p>The report also emphasizes, and we agree, that all the domains should be measured at all three levels (individual, provider, and system levels) whenever possible. To that end, we recommend editing the fifth bullet point on page 13 of the report to reflect all three levels. Ideally, the language would read:</p> <p>Using both systemic, provider or programmatic, and individual level data to develop HCBS quality measures.</p> <p>Lastly, on page 13, the first sentence under the “Cross-cutting Recommendations” states that “Committee members emphasized that measurement in all domains should be person-centered, with the goal of improving consumer outcomes and promoting community living.” While we certainly agree with the stated goals, it is unclear what the committee means by the reference to all domain measures being person-centered, since some measures would be systemic (e.g. measuring the number of available workers in a state to provide needed services), or programmatic (e.g.</p>

## Comments on the Cross-Cutting / Global Recommendations

Comment Submitter Name	Comment Submitter Organization	Comment
		whether the number and types of workers dispersed meet specific HCBS program needs), and it is not clear how these different types of measures would be person-centered. We urge the Committee to clarify or revise the statement to better convey its meaning.
<b>Ann Hwang</b>	Community Catalyst	<p>We are encouraged by the Committee’s emphasis that all measurement domains should be person-centered, promote community living, and improve consumer outcomes. We especially appreciate the multi-level approach to measurement wherein HCBS quality measures are developed from individual-, service- and systemic-level data. While we applaud the Committee’s recommendation to prioritize quality measurement work across all domains and subdomains in the conceptual model, we are concerned with the recommended categories and their implications for filling measurement gaps in a timely manner.</p> <p>We recommend that the Committee prioritize the following three domains for measure development: Consumer Leadership in System Development, Community Inclusion, and Equity. These domains are critical to the goal of measurement – ensuring HCBS consumers are able to live with dignity and as much independence and community participation as possible. The second interim report made clear that measures and measure concepts for these domains are less developed, emphasizing the need to focus efforts on these domains. We also believe there is a sense of urgency for these three domains to be prioritized and developed. Recent CMS final regulations on Medicaid Managed Care require states to include quality measures on rebalancing, community integration, and quality of life. Developed measures for consumer leadership, community inclusion, and equity will assist states, health plans and advocates in implementing the new CMS regulations and ensure consumer perspectives and experiences are included. We urge the Committee to elevate these domains as priority areas in the project’s final report.</p>
<b>Shawn Terrell</b>	Administration for Community Living	The report should address the fact that many measures are connected to the same process and therefore need to be coupled or linked in a series. This is particularly important for measures that ask people about choice in some life domain

## Comments on the Cross-Cutting / Global Recommendations

Comment Submitter Name	Comment Submitter Organization	Comment
		(e.g. where to live, employment opportunities, roommates, etc.). In these cases, upstream measures need to ask people about whether they were provided with alternatives that they found meaningful. These measures would address whether adequate information about alternatives was provided, and that the person had adequate opportunity to explore the alternatives. Without such upstream measures the results of choice could be misleading.
<b>Sarah Triano</b>	Centene Corporation	The outlined recommendations in the report are thoughtful, relevant, and set the framework for eventual comparison across states.
<b>Lauren Aforatus</b>	Family Voices NJ	We agree with the recommendations regarding quality measures across domains; consistency in data collection; leveraging technology; building on existing measures; using both systems and individual data; balanced approach to measurement; and developing measures that can be incorporated into existing measure. We agree with the committee's recommendation to "test the psychometric properties of existing instruments," and not to rely on a single data source.
<b>Administration for Community Living</b>	Administration for Community Living	<p>7. Global Recommendations</p> <ul style="list-style-type: none"> <li>a. Measurements of systems, structures, processes and outcomes should flow from a paradigm of person centered thinking, planning and practice and the HCBS definition</li> <li>b. Measures should address all aspects of a given system and relevant subsystems</li> <li>c. The degree to which the values and philosophy of HCBS and person centered thinking, planning, and practice are present in all people working in a given system should be measured.</li> <li>d. Dynamic systems analysis should inform the development of measures.</li> <li>e. Continuous quality improvement should be a measure subdomain for all domains or have its own domain.</li> </ul>
<b>Elizabeth Cullen</b>	The Jewish Federations of North America	We believe additional work is needed to identify priorities for measure development, which is one of the primary tasks of the committee. We feel the draft

## Comments on the Cross-Cutting / Global Recommendations

Comment Submitter Name	Comment Submitter Organization	Comment
		recommendations do not offer a level of specificity that will assist HHS and advocates in guiding future investments in measure development.
<b>Elizabeth Cullen</b>	The Jewish Federations of North America	While we agree that investments should be made across all domains, this is very unlikely in the short term. Therefore, we believe some additional prioritization is needed to guide CMS on the most important areas for measure development. CMS recently released final regulations on Medicaid Managed Care. Within these regulations CMS required for the first time that states include quality measures on Rebalancing, Community Integration, and Quality of Life. The Medicaid managed care rules further required the identification of health disparities based on disability status and publicly available External Quality Review reports. Since these areas are now required of states, we believe there is an urgency to invest in measure development and guidance on a menu of measures that could assist states, health plans, and advocates to implement these requirements. Although quality of life is not identified as a specific domain or sub-domain, we believe it crosses several domains and is best assessed via the perspectives and experiences of consumers.
<b>Elizabeth Cullen</b>	The Jewish Federations of North America	We also believe that development of quality measures related to implementation of the HCBS Settings Rule should be identified as priority areas for measure development. Development of measures could assist advocates and states who are currently working on implementation plans to ensure compliance. These include measures that fall within the domains of Choice and Control and Person-Centered Planning and Coordination.

## Comments on the Domain-Specific Recommendations

Comments on the Domain-Specific Recommendations		
Comment Submitter Name	Comment Submitter Organization	Comment
<b>Peter Notarstefano</b>	LeadingAge	<p>APPENDIX E Domain Specific Recommendations</p> <p>Group A. The short term recommendations focus too much on process, and not on the actual outcome, especially concerning service delivery, person centered planning and coordination, choice and control and community inclusion. The System Performance and Accountability domain, holistic and functioning domain and the equity domain relating to housing and homelessness contain useful quantifiable measures that CMS, HUD and ACL could act on. The measures in these domains should be a priority for implementation. In the Equity domain, the subdomain of equitable access and resource allocation, availability and reduction and consistency should also be a priority for measurement. The Request for Information (RFI)—Data Metrics &amp; Medicaid Access to Care RFI (CMS-2328-NC) that incorporates additional approaches CMS and states should consider to improving compliance with Medicaid access requirements would be a good starting point when developing the measures for the Equity domain.</p> <p>Group B. The Intermediate domain addressing workforce should not be focusing on process. It is more important to measure staffing patterns for home and community based services in relation to the individual needs of the older adult or person with a disability being served. Individuals with certain diagnosis may require more staff assistance. The consumer leadership in system development recommendation is too general. It would be difficult to accurately measure level of consumer involvement in HCBS system design and implementation. CMS currently requires proof that the state has given the public opportunities for comment on implementation of a rule or waiver application. Also, The Human and Legal Rights domain are all process measures that are addressed during the survey process.</p> <p>Group C. The caregiver support domain in the Long-term recommendations is also too general. If the caregiver is stressed, and cannot attain their own needs, the older adult or person with disabilities has a greater chance of not being able to remain in the community. The Human and Legal Rights domain are all process measures that are addressed during the survey process.</p>

Gary Montrose	Colorado - Community Living Quality Improvement Advisory Committee (CLQIC)	<p>Some basic Domains seem to be missing or not clearly enough stated:</p> <ol style="list-style-type: none"> <li>1) Satisfaction with Quality of Live</li> <li>2) Individuals definition of Quality of Life and achieving Personal Goals (which may only be practical for longitudinal surveys, at a local level?) - See CQL survey construct</li> <li>3) Functional Status: e.g. as good as can be expected, getting better, getting worse, receiving needed services and supports</li> <li>4) Effective Communications: with Care Provider, Case Management Agency, Service Providing Agency, State Medicaid Agency</li> <li>5) Satisfaction with living arrangement</li> <li>6) Satisfaction with employment training and job opportunities</li> </ol> <p>Many of the above QoL-related topic areas and aforementioned methodological issues have been thoughtfully and comprehensively addressed in various publically available documents in the "interRAI Assessment System," (Home Care, Self-Reported QoL) which does not seem to have been referenced in the NQF HCBS Interim Report(s).</p>
Gary Montrose	Colorado - Community Living Quality Improvement Advisory Committee (CLQIC)	<p><b>HCBS Experience Minimum Data Sets for Benchmarking Purposes:</b></p> <p>In the absence of prioritizing domains and sub-domains at the present time, it might be helpful for the HCBS Committee / ACL to support identification of a "Minimum HCBS Consumer Experience Data Set" that would be usable for state-to-state and community-to-community comparisons; for benchmarking over time and place.</p>
Gary Montrose	Colorado - Community Living Quality Improvement Advisory Committee (CLQIC)	<p><b><u>Common Question Subsets for Comparative Analysis</u></b></p> <p>Local communities could add additional question sets (or refined analysis) to the Minimum Data Set for common benchmarking purposes across agencies; using standardized question sets (endorsed or not endorsed) of interest to local communities; or different questions from one year to another year; alternating by disability type from year to year; experimenting with different methodologies (e.g. paper, phone, Peer-to-Peer, social media, etc.).</p> <p>One way of apportioning questions as sub-question data sets would be to identify standardized demographic cohorts. For example, identifying respondents according to age and disability cohorts: Think of a 4x3 matrix comprising Pediatrics &lt;17, Adults 18-54, Seniors 55+; by disability types, e.g. I/DD, Physical Disability, Frail Seniors, Serious Mental Illness. Such demographic sub-sets would help with identifying</p>

		<p>stratified respondent selection methods and subsequent comparative analysis across states, communities, points in time.</p> <p>Another potentially useful way to bifurcate respondents in a standardized way would be to divide populations according to agency revenue levels: &lt; \$2M, \$2-5M, &gt;\$5M.</p>
<b>Gary Montrose</b>	Colorado - Community Living Quality Improvement Advisory Committee (CLQIC)	<p><b>Core Domains Missing:</b></p> <p>Despite the range of good question domains identified in the HCBS Third Interim Report, we do not see a number of domains that have become central to other mainstream measurement development entities, such as interRAI, NCI, CQL and CMS's Experience of Care, in which the following core measures, among others, have been validated and developed across the country:</p> <ul style="list-style-type: none"> <li>• Effective Communication – ability to express one's self-sufficient to participate in HCBS surveys. See interRAI, Home Care (HC) Assessment Form and User's Manual, 2009</li> <li>• Quality of Life - defined by the consumers' personal life goals, having a sense of purpose and meaning in their live, etc. – See CQL's core question sets.</li> <li>• Functional Status - especially for longitudinal surveys. Functional status is very different from asking about health status, as populations with various physical and cognitive disabilities often are not amenable to being healed by medical providers. See interRai Self-Reported Quality of Life (CQL) Survey and User's Manual, v-3, 2016.</li> </ul>
<b>Joe Caldwell</b>	National Council on Aging	<p>We believe the report relies too much on examples from a few states that were explored in the NQF environmental scan. It does not adequately capture existing measures and measure concepts currently in use in MLTSS programs and duals demonstrations. It also would be helpful to identify individual performance measures by domain and sub-domain that could be derived from consumer surveys that are currently in wide use within states. This is in line with the global recommendation to build on existing quality measurement instruments in use. As the report reinforces, we believe the National Core Indicators, National Core Indicators Aging and Disability, HCBS Experience Survey, Money Follows the Person Survey, and Council on Quality and Leadership (CQL) Personal Outcomes Measures are the most promising surveys. The committee should break these surveys down to identify individual performance measures by domain and sub-domain.</p>
<b>E. Clarke Ross</b>	Consortium for Citizens	<p>In the domain of Community Inclusion, we believe that NQF should prioritize the development of measures that measure social</p>



	with Disabilities	connectedness, relationships, and meaningful activity as defined by the individual rather than specific activities. Rather than ask about activities (e.g., do you eat at restaurants), ask how one feels-enjoys-experiences activities. Both the National Core Indicators and Council for Quality Leadership-Personal Outcomes Measures attempt to ask the individual recipient their perspective and experience with community inclusion elements. Clarke Ross, American Association on Health and Disability and Lakeshore Foundation.
<b>Laura Thornhill</b>	Alzheimer's Association	<p>The Alzheimer's Association appreciates this report's increased emphasis on a person's needs in addition to her preferences and goals throughout the domains. We also applaud the Committee's acknowledgement of populations that may require support in making choices, and the expanded domain of caregiver support. These elements will encourage more complete measurement.</p> <p>Within the "Community Inclusion" domain, the committee notes employment, education, and volunteering as a "meaningful activities." We support these examples and encourage measure developers to consider additional activities for cognitively impaired persons who are not able to work.</p> <p>We fully support inclusion of competencies as a priority area within the "Workforce" domain. Given the unique challenges of dementia, affected persons' needs, and measuring their care, the Alzheimer's Association would be pleased to serve as a resource to the National Quality Forum (NQF), the Centers for Medicare &amp; Services (CMS), and measure developers as the field grows.</p> <p>The Association commends the new domain, "Equity." As the Committee notes, the availability of services means little without equitable access to them. This emphasis on access is all the more significant to persons with impaired decision making skills and judgment and who need additional assistance in obtaining these important services.</p>
<b>Lindsay Schwartz</b>	American Health Care Association/National Center for Assisted Living	<p>Person-Centered Planning and Coordination</p> <p>Although many providers do coordinate services, the waiver system and Medicaid in general is not set up in a way that encourages (through payment) care coordination. Medicaid prohibits duplication of services by providers which can complicate care coordination as there may be minimal overlap. It is important when defining quality measures, that payment practices are aligned to allow for providers to be able to effectively achieve outcomes.</p> <p>Choice &amp; Control</p>

Self-directed services may depend on how the state’s waiver programs are designed. All waiver recipients have the freedom of choice of provider. The concept of self-directed services can be challenging based on a person’s abilities and available supports.

#### Community Inclusion

As mentioned in the report earlier, it is important that providers select measures that are appropriate for the populations they serve. Measuring the percentage of people in competitive employment will be directly linked to the acuity of the people being served so this should be adjusted for acuity and only include individuals who wish to be employed.

#### Holistic Health and Functioning

CDC’s vaccination recommendations should be considered when developing for immunization measures such as percentage of beneficiaries who received the pneumococcal vaccination.

Although, AHCA/NCAL appreciates the thought behind renaming this domain from Health and Well-Being to Holistic Health and Functioning, “health and well-being” is a commonly accepted and utilized term in quality measurement and research. Health and well-being has typically included a view of holistic health not just physical health.

**Jennifer  
Goldberg**

Community Inclusion: We recommend that NQF prioritize the development of measures that measure social connectedness, relationships, and meaningful activity as defined by the individual rather than specific outcomes or activities. For example, many measures of community inclusion ask about whether the individual engages in shopping or eating in restaurants, without recognizing that the individual may not actually enjoy those activities. A measure that asks “are you lonely” is a more effective measure of how that individual feels about his or her access to the community and close personal relationships than one that asks questions about specific activities.

Caregiver Support: The “Family caregiver/natural support involvement” domain falls short in fully evaluating caregiver support. The domain should include an evaluation of the overreliance of natural supports to execute the HCBS consumer’s person-centered care plan. State Medicaid programs and managed care programs justify decreasing hours of Medicaid personal care on the idea that family members are obligated to provide certain levels of personal care. We recommend updating the “Intermediate Recommendation” to ensure the natural support assessments and benchmarks include measuring

for inappropriate reliance on voluntary caregiving.

**Human and Legal Rights:** We appreciate the inclusion of the “informed decision-making” domain and suggest an emphasis on evaluating whether states and MCOs have processes in place for supported decision-making.

**Equity:** We agree with urgency to develop quality measures related to housing and homelessness. We suggest expanding the definition of the current “reduction in health disparities and service disparities” domain to include evaluating protections against nondiscrimination. We also suggest inclusion of “access to timely and appropriate care.”

**System Performance and Accountability:** We strongly support the “short-term” recommendation to expand the use of measures related rebalancing, however, we believe it needs to be more explicitly identified in the framework. The current subdomain descriptions in “system performance and accountability” do not mention “rebalancing.” Rebalancing measures are a priority of consumer advocates; CMS has required rebalancing measures in MLTSS programs, and some states are already utilizing data to evaluate rebalancing progress. Given its level of importance, we recommend that rebalancing be clearly identified as a separate sub-domain.

**Holistic Health and Functioning:** We suggest the inclusion of “integrated primary and specialty care.” This is particularly important from individuals with behavioral health needs.

<b>Carmella Bocchino</b>	America's Health Insurance Plans	<p>In response to the second interim report, a one size fits all approach does not take into account differences in populations being assessed. This appears to be an issue in the third interim report. Rather than assuming all consumers/members want the same thing (i.e. to have their front-line worker involved in care planning or to self-direct), we believe member choice should be the driver of care. For example, for workplace engagement and participation and self-direction we believe including language that emphasizes consumer choice would be preferable. In addition, member choice and self-direction should also take into account state benefit limits as well as costs and budgets.</p> <p>We also support NQF’s decision to include domains and measurements of socioeconomic determinants of health located in the equity and equitable access and resource allocation section. “The extent to which consumers have equitable access and ability to obtain needed services and supports such as housing, transportation, employment services),” however, is a larger systems-change issue that MLTSS plans have some, but not full control over. Alternative language could include: “the extent to which MLTSS plans engage in efforts to address social determinants of health such as housing, transportation, and</p>
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		employment.”
<b>Peg Graham</b>	QUA INC	Choice and Control Domain. From family caregiver point of view, urge inclusion of a measure that captures the degree to which the community care recipient and the family caregiver believe that the mobility aid or other assistive equipment is the best “fit” for their needs. Also suggest that data on the consumer decisions made within programs such as “cash and counseling” be collected so that studies can be done on the trade-offs required by the constraints of that program, i.e., “I needed both x and y but was only able to afford x.”
<b>Peg Graham</b>	QUA INC	Caregiver Support: From family caregiver point of view, urge development of measures that capture family caregiver injury rates. We know that the musculoskeletal injury rate of hospital and nursing home workers is six times the rate of the general workforce ( <a href="https://www.ecri.org/EmailResources/Risk_Management_eSource/2014/HRC_Safe_Patient_Handling.pdf?cm_mid=3146177&amp;cm_crmid=%7B85adb151-4170-e211-8202-005056930045%7D&amp;cm_medium=email">https://www.ecri.org/EmailResources/Risk_Management_eSource/2014/HRC_Safe_Patient_Handling.pdf?cm_mid=3146177&amp;cm_crmid=%7B85adb151-4170-e211-8202-005056930045%7D&amp;cm_medium=email</a> ). The Association of Safe Patient Handling Professionals is creating a common code that will capture activity and equipment use associated with a staff injury. This level of facility-based injury is now being addressed via investments in sophisticated patient handling equipment and training programs. Yet, we lack the data necessary to know if equipment commonly used in homecare will generate a similar injury rate among family caregivers as more adults aging with physical disabilities age at home. In addition to the personal toll experienced by the caregiver and the care recipient, injuries to family caregiver may render them incapable of assisting their loved one, triggering the need for costly institutionalization for their loved one, or drain the resources of an HCBS provider.
<b>Amy Ingham</b>	Anthem, Inc.	<p>Menu of Measures: We strongly support a menu of standardized measures from which a state can select the ones that are most appropriate to their intricate programs, population (including membership variation by health plan since not all plans in a given state serve members with the same needs), provider base, and administrative structure.</p> <p>Data Sources: It would be helpful to retain flexibility for data collection approaches in order to allow innovative data collection and management strategies.</p> <p>Person-centered planning and coordination: Anthem supports finding/developing measures for the “coordination” sub-domain. Health plans’ ability to improve coordination of member services and supports is a key component in state contracting and has great potential to achieve savings and improve services. The Committee should consider cross-cutting measures under this domain.</p>

Community Inclusion: We recommend aligning definitions under this domain with the following HCBS settings rule language: “receive services in the community to the same degree of access as individuals not receiving Medicaid HCBS.” The subdomain “social connectedness and relationships” uses language that could be misconstrued to justify individuals’ relationships within segregated settings.

Workforce: Anthem believes these measures should be coupled with policy, guidance, or technical assistance to foster a strong Workforce Development strategy. The Committee should encourage HHS to consider the relationship between workforce quality measures and an overall strategy to improve the workforce landscape in states.

Caregiver Support: We thank the committee for expanding upon this domain.

Human and Legal Rights: We commend the Committee’s addition of “Informed decision-making” as a subdomain, as well as the recognition that the goal is to ensure individuals are able to understand the information presented and are provided with appropriate supports.

Holistic Health and Functioning: Anthem recommends a more deliberate emphasis on (1) incentives for providers to increase the availability of accessible facilities and equipment, and (2) enhancing health professionals’ skills in appropriately responding to the needs of people with disabilities.

Consumer Leadership in System Development: The new domain title, “Consumer Leadership in System Development,” recognizes that delivery of HCBS is best achieved through the involvement of members, family, and caregivers in the development of programs. To help address the consumer voice measurement gap, we recommend the Committee look beyond health care programs.

<b>Meredith Ponder</b>	Defeat Malnutrition Today	<p>Re: the Holistic Health and Functioning domain:</p> <p>The short-term recommendations under this domain do not currently, but could easily, incorporate nutrition screening. Though there are currently no validated nutrition/malnutrition quality measures, the Older Americans Act already has a mandated (per regulations) DETERMINE Checklist for nutrition screening in community-based settings which could be adapted to use as a quality measure in the short-term. In the intermediate recommendations, nutrition outcome measures should be developed as well as the specified "focus areas." Long-term, it must be made clear that nutrition/malnutrition screening is to be a part of any universal assessment tool developed and disseminated, as nutrition is vital to older adult health.</p>
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<b>Allicyn Wilde</b>	SEIU	<p>As we note above, with some refinement the structure proposed in the report—which entails short-term, intermediate, and long-term goals within each domain – could prove a common-sense approach to help those building on the Committee’s work focus on specific areas in order to develop quality measures for HCBS. However, we are concerned that the lack of short-term recommendations in some domains will have the unintended consequence of suggesting that there is no immediate work to be done in those domains.</p> <p>We are particularly concerned that the workforce domain lacks short term recommendations, even though there are indeed short-term steps that can be taken to adopt meaningful workforce measures, with the longer term goals of linking those workforce measures to other quality outcomes. The measure compendium issued in the second interim report identified seventy-five existing measures and measure concepts, which on further examination and Committee approval, could be recommended for broad adoption. We strongly urge the Committee to continue to refine its work on the Domain Specific Recommendations and create meaningful short-term recommendations within each domain, and especially within the workforce domain. Specific short-term recommendations are included in the “Additional Examples of Measures or Measure Concepts” section of our separately submitted document.</p>
<b>Ann Hwang</b>	Community Catalyst	<p>Consumer Leadership in System Development: We appreciate the Committee’s renaming of the Consumer Leadership domain and its stated underscoring of the importance of active and meaningful participation. Without Consumer Leadership, it is extremely unlikely that HCBS will fully reflect consumer goals, preferences and needs. We realize developing structure and process measures to assess the subdomains will take some time; therefore, we strongly urge prioritization of measure development in this domain. We believe that process measures on the types and amount of support offered to support consumer leadership, such as stipends, travel reimbursement, and training in the subject area, could be implemented immediately while further testing occurs.</p> <p>Equity: We urge the Committee to expand the short-term recommendation beyond just housing and homelessness. The equity domain measures must assess a broad range of services. Administrative data exists that can be tapped immediately to measure the extent of disparities by race, ethnicity, age and primary language in service delivery and in outcomes, where outcome measures already exist. The Department of Health and Human Services released an action plan to reduce health disparities that emphasized the need for a multifaceted health disparities data collection strategy to build effective monitoring and reporting systems. Furthermore, data collection disaggregated by age, race, ethnicity, primary language,</p>

		gender identity, sexual orientation, and disability should be prioritized across all the domains.
<b>Danna Caller</b>	Abbott	<p>Re: the Holistic Health and Functioning domain:</p> <p>We commend the committee on highlighting malnutrition and falls as examples of prevention focus areas that can result in improved population health outcomes.</p> <p>In summary, we recommend the following edits to the Interim Draft report on page 23 and in the Appendix on pages 35-37 to align the recommendations with the prevention priorities.</p> <ul style="list-style-type: none"> <li>· Short-Term: Expand the use of validated quality measures related to falls, medications, immunizations, malnutrition, and other quality measures focused on population health.</li> <li>· Intermediate: Develop outcome measures across all dimensions of holistic health, with particular focus on the dimensions of behavioral, social and nutritional health and functioning.</li> <li>· Long-term recommendations: Develop, test and disseminate a universal assessment tool that includes all dimensions of holistic health and functioning, and to leverage technological innovations to develop systems for monitoring various indicators of population health (e.g., rates of falls, malnutrition and immunizations).</li> </ul> <p>In the short-term malnutrition screening quality measures developed for the acute care setting could potentially be adapted to the home-community-based care setting. In the intermediate recommendations, nutrition outcome measures should be developed as well as the specified "focus areas." Long-term, it is important to call-out that nutrition/malnutrition screening should be a part of any universal assessment tool developed and disseminated, as nutrition is vital to older adult health. For example, the Older Americans Act already has a mandated (per regulations) DETERMINE Checklist for nutrition screening in community-based settings; this could be used or adapted to be used as an assessment for this subdomain.</p>
<b>Kimberly Austin-Oser</b>		<p>Pages 14-25 –While I am fine with the recommendations for each domain being organized and prioritized in terms of short, intermediate, and long-range goals, I believe the content - especially in the short-term category - is too general and, specifically for the less developed domain and sub-domain areas, does not convey the appropriate level of urgency or clarity around meaningful short-term steps. Additionally, even though it is mentioned several times in the text preceding this section of the report that the committee believes all domains should be treated with equal attention, I do think, in</p>

		<p>retrospect, that there are some areas actually needing more attention and resources than others –specifically the less developed domains.</p> <p>I am particularly concerned about the Workforce, Caregiver, Human and Legal Rights and Equity domains where few measures currently exist. I do not believe we want any time wasted when tackling these particular aspects of the work and should convey this in much stronger and clearer terms in the body of the recommendation text.</p> <p>Given the importance of these less developed domains and the critical nature of the workforce and family/natural caregiver domains, in particular, to the overall functionality, health, and quality of the HCBS system, our recommendations should be made stronger and more actionable in the shorter-term.</p> <p>As an example in the workforce category, a short-term recommendation that is more concise and actionable in the near-term could be to bring together a workgroup charged with both developing an intermediate and long-range work plan with timelines around a comprehensive measure development and implementation process as well as creating a strategy around rapid design and collection of baseline workforce data – wages, turnover rates, benefits, access to training and skill-development, geography, dispersion patterns, etc. – on a pilot / testing basis with key national partners who can quickly implement and collect within 6-12 months. Some states already have measures and infrastructure built in this area which could act as a starting point.</p>
<b>John Shaw</b>	Next Wave	<p>System science shows that details and opportunities for system improvement primarily come from the bottom up. This places a premium on incorporating the voices of consumers and front-line workers (both paid and unpaid). The Domains and Subdomains in the Framework acknowledge this, however the implementation falls under Group C: Long Term Recommendations. Next Wave believes that there is value in rapidly incorporating consumer and front-line caregiver voice into assessment, care planning, measure development, and policy. Process measures of this involvement should be rapidly accelerated at least into Group B.</p>
<b>Lisa Price Stevens</b>	Magellan Health, Inc.	<p>Services Delivery and Effectiveness Domain</p> <p>Overall the domain is reasonable and measureable.</p> <p>Sub-domain " Person's needs met", would be interested in how the committee defines needs. Would these be ADLs? The recommendation would be to clearly define and standardize the measureable needs.</p>



How will the measure address dignity of risk and the participants right to refusal of having their identified needs met? Would this those persons be omitted from the denominator?

Example

Measure = Needs Met/ Number of participants measured-(minus) refusals

An alternative recommendation would be to measure" needs met" via a participant experience survey.

Person Centered Planning

Sub-domain - Coordination. Measuring coordination can be challenging. Efforts of coordination do not always result in true collaboration and improved outcomes. An example would be , a measure of exchange of medical records void of true collaboration/coordination of those records.

Recommendation is to consider a participant outcomes type survey (PROMS) for this measure. Example, did your coordination of care between your providers result in better outcomes for your health and well-being?

Choice and Control

Sub-domain choice of services and supports. There are many and broad categories of HCBS services to offer. Recommendation is to gain standardization by identifying key services to measure.

**Sarah Triano** Centene Corporation

1. In general, using language throughout the report which reflects the importance of member choice is preferred to a one size fits all approach that assumes all consumers want the same thing. Under "Workforce Engagement and Participation" on page 20, Centene recommends: "The level to which front-line workers and service providers have meaningful involvement in care planning and execution where appropriate and desired by the consumer." Under "Self-Direction" on page 17, Centene recommends: "The level to which individuals who use HCBS, on their own or with support, have the choice to have decision making authority...."

2. Language should be added throughout the report that takes into account the natural services and supports consumers have to address needs. Under "Personal needs met" (page 15), Centene recommends: "The level to which the HCBS system and natural services and supports are sufficient to address...." Under "Person's identified goals realized," (page 15) Centene recommends: "The level to which the HCBS system

incorporates the HCBS consumer's goal into services and supports, and the individual who uses HCBS is able to achieve those goals through support of the HCBS system and natural supports."

3. Community Inclusion (page 18). Several inclusion measurement challenges are mentioned. Centene recommends adding language acknowledging the unique challenges measuring community inclusion in rural areas with limited or no access to transportation.

4. Under "Demonstrated competencies, when appropriate" (page 20), Centene recommends: "These skills and competencies are fostered in the workforce through the use of competency-based approaches to education, training, and skill development."

5. Under "Equitable access and resource allocation" (page 22), Centene applauds NQF's decision to include domains and measurements of socioeconomic determinants of health. Access to many of these social determinants, however, is a larger systems-change issue that MLTSS plans have some, but not full control over. Centene recommends: "The extent to which MLTSS plans engage in efforts to address social determinants of health such as housing, transportation, and employment."

6. Under "Individual health and functioning" (page 23), Centene commends the Committee for recommending assessment of "aspects of an HCBS consumer's health and functioning, including physical, emotional, mental, behavioral, cognitive and social." Another important aspect of health and functioning for some consumers from diverse communities is spiritual background. To ensure cultural competency, Centene recommends "spiritual" be added to this sentence, and that the Committee suggest assessment measures which capture this.

## Comments on the Examples of Measures, Measure Concepts and Instruments Highlighted in the Domain-Specific Recommendations

Comments on the Examples of Measures, Measure Concepts and Instruments Highlighted in the Domain-Specific Recommendations		
Comment Submitter Name	Comment Submitter Organization	Comment
<b>Clarissa Kripke</b>	University of California, San Francisco	Overall, this is a very strong document. Thanks for the effort.
<b>E. Clarke Ross</b>	Consortium for Citizens with Disabilities	Development of quality measures related to implementation of the CMS HCBS Settings Rule should be identified as priority areas for measure development. These include within the domains of choice & control and person-centered planning and coordination. Clarke Ross, American Association on Health and Disability and Lakeshore Foundation.
<b>Megan Burke</b>	The SCAN Foundation	<p>The SCAN Foundation is an independent public charity devoted to transforming care for older adults in ways that preserve dignity and encourage independence. We envision a future where high-quality, affordable health care and supports for daily living are delivered on each person's own terms, according to that individual's needs, values, and preferences. While many initiatives are in progress within the health care system to better align and integrate medical care with long-term services and supports (LTSS) in order to benefit an individual's health and functioning, the ability to measure quality through structure, process and outcomes of those initiatives lags substantially. We commend the U.S. Department of Health and Human Services (HHS) for partnering with the National Quality Forum and establishing a well-qualified advisory committee to both address the performance measure gaps in home and community-based services (HCBS) and identify priorities for measure development.</p> <p>The Foundation generally agrees with the guidance provided in the recommendations in each domain section. We believe, however, that the Committee's work should culminate in recommendations with much greater specificity. We recommend that the final report include a matrix to inform HHS and other potential measure sponsors of the current status of quality measures related to each priority subdomain. Specifically, we recommend that the Committee identify existing measures and status (i.e., validated, endorsed, extent of use) and gaps where measures need yet to be developed for each priority subdomain. For those subdomains where measures exist, we recommend all be included within the matrix, whether validated or not. We</p>

## Comments on the Examples of Measures, Measure Concepts and Instruments Highlighted in the Domain-Specific Recommendations

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		further recommend that the Committee work to refine its recommendations to address this greater detail. Within this context, a refined set of HCBS Committee recommendations for actions to advance quality measurement for long-term services and supports would be very helpful.
<b>Lindsay Schwartz</b>	American Health Care Association/National Center for Assisted Living	The Holistic Health and Functioning domain is lacking any discussion of quality of life (QoL), which is an important person-centered measure. QoL is not appropriately captured by a tool that assesses ADL and IADL functioning, such as the FASI. There are plenty of general quality of life instruments and health-related or disease-specific instruments (e.g. Quality of life Alzheimer's Disease QOL-AD and Alzheimer's Disease Related Quality of Life ADRQL) that could be utilized for various HCBS populations. Many times, QoL measures are overlooked but are incredibly important, especially when considering holistic health.
<b>Carmella Bocchino</b>	America's Health Insurance Plans	<p>We suggest that NQF include additional detail and links to resources regarding the various measure concepts discussed throughout the report such as Washington State's Medicaid measure instrument that assesses the number and percent of HCBS beneficiaries who had all unmet ADLs and IADLs assigned to a paid provider or the carious LTSS measure concepts discussed on page 24.</p> <p>Specifically, the measures of caregiver support highlighted on page 19 (Zarit Caregiver Burden Questionnaire and Tailored Caregiver Assessment and Referral System) assess the burden placed on caregivers in providing support to patients. We instead recommend including caregiver support measures that assess the resources available to caregivers as opposed to the burdens placed upon them.</p>
<b>Jennifer Goldberg</b>		Justice in Aging strongly recommends NQF prioritize measures that are already in use, and fast-track these measures for release in to the field. The two areas primed for scaling up are the National Core Indicators Survey-Aging and Disability (NCI-AD) and state level rebalancing measures. The NCI-AD includes concepts and questions that align with HCBS domains and should be rapidly expanded. On rebalancing, several states already use a variation of rebalancing measures in their quality evaluation (See Is It Working? Recommendations for Measuring Rebalancing

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		<p>in Dual Eligible Demonstrations and MLTSS Waivers at <a href="http://bit.ly/29CkegB">http://bit.ly/29CkegB</a> and we see no reason to delay rapid endorsement and implementation nation-wide. We urge the Committee to expand these measures so that HHS can implement them swiftly.</p> <p>We are concerned about the overreliance in the draft report on examples from a few states. The NQF environmental scan does not adequately capture all existing measures and measure concepts currently in use in MLTSS and dual eligible demonstration programs. We suggest the Committee look more closely at these measures, as well as the following existing quality measurement instruments in use: HCBS Experience Survey, National Core Indicators Aging and Disability, National Core Indicators, Money Follows the Person Survey, and Council on Quality and Leadership (CQL) Personal Outcome Measures. In particular, the HCBS Experience Survey should be expedited for NQF endorsement.</p>
<b>Peg Graham</b>	QUA INC	<p>Equity: As a family caregiver, I would want to know the degree to which there is equitable access to technologically advanced assistive equipment. The current “Medical Necessity” standard applied by Medicare, Medicaid and commercial insurers for reimbursement of mobility and assistive devices have had the unintended consequence of limiting equipment choice to “cheapest alternative” which might be hard to use for either care recipient or family caregiver, or both, leading to a higher reliance on HCBS resources for support. Data that can detect an effect between ability to achieve functional independence, equipment choice, and intensity of HCBS resources is useful for strategic planning purposes.</p>
<b>Karen Pearl</b>	God's Love We Deliver	<p>Standardize a Risk Assessment Tool for Medically Tailored Nutrition</p> <p>God’s Love We Deliver is a non-sectarian nonprofit provider of medically tailored home-delivered meals for people with severe and/or chronic illness. The mission of God’s Love is to improve the health and wellbeing of men, women and children living with HIV/AIDS, cancer and other serious illnesses by alleviating hunger and malnutrition. We cook and deliver 1.5 million nutritious, high-quality meals annually to people who are unable to provide</p>

## Comments on the Examples of Measures, Measure Concepts and Instruments Highlighted in the Domain-Specific Recommendations

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		<p>or prepare meals for themselves. Our services are also key to improving health outcomes. Research bears this out. When malnourished patients are compared to nourished patients: Health care costs are 3 times higher; Initial hospitalizations are 2 times more likely; Hospital stays are 3 times longer; Discharge to a facility rather than to home is 2 times more likely.</p> <p>There is currently no standardized risk assessment tool in the healthcare system for the services we provide. Measures of food insecurity fall short. Referencing the Holistic Health and Functioning category (p. 23) of the priorities and the Group A, B and C recommendations (p. 35 on) for the same category, we urge the National Quality Forum to include in its recommendations the development of a composite risk assessment tool that uses malnutrition, ADL limitations and diagnosis to come up with a high-risk flag for referral of those who would benefit from medically-tailored food and nutrition. Second, in addition to measuring this risk, a mechanism must be developed to connect vulnerable persons specifically to medically tailored meals and/or Medicare/Medicaid reimbursable nutrition services.</p> <p>Nutrition and food insecurity can influence a number of factors that are crucial to patient health. For example, without proper nutritional instructions, patients may encounter food-drug interactions that can prevent medications from working effectively, impact immune function, and is associated with poorer adherence to medical treatments.</p> <p>By creating a risk assessment tool, patients who are in need of medically tailored home-delivered meals and nutritional services will be referred to agencies who can provide the services they need and eliminate unneeded hospitalizations. Our goal is to keep clients healthy and at home, which lowers healthcare costs and keeps patients happy.</p> <p>God's Love We Deliver has already developed a similar tool for Medicaid MLTC plans to use in conjunction with the NYS DOH Uniform Assessment System. The composite tool uses a variety of responses through the UAS to identify high-risk patients. We would be happy to collaborate or provide guidance on this risk assessment tool for the National Quality Forum. Please feel free</p>

## Comments on the Examples of Measures, Measure Concepts and Instruments Highlighted in the Domain-Specific Recommendations

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		<p>to reach out to us with any questions you may have. Thank you for your consideration.</p> <p>Karen Pearl, President &amp; CEO, God's Love We Deliver</p>
<b>Allicyn Wilde</b>	SEIU	<p>Within the report most of the recommendations in every domain are very vague, and we are concerned that, as currently written, the recommendations will not be useful to HHS, CMS or other measure developers. We strongly recommend that work be done to include Committee-approved specific measure concept examples and measure examples in each domain, as this would be much more helpful to measure developers – particularly in their short-term work. The compendium of measures and measure concepts was a good initial and necessary step to build upon existing work, but the Committee now needs to review and evaluate those measures, and then make specific recommendations based on that analysis in the three categories within each domain. The Committee should specifically develop short term workforce recommendations, which are currently not included in the report.</p>
<b>Ann Hwang</b>	Community Catalyst	<p>Consumer Leadership in System Development: We believe there are helpful existing models and toolkits for meaningful consumer leadership that could be used for measure, measure concept and instrument development. Changes in service patterns resulting from new initiatives developed from consumer input, as well as improved communication and educational materials for consumers based on feedback from consumers can serve as evidence for meaningful consumer involvement. We believe it is possible to immediately begin collecting data on these types of outcomes and develop quality measures for meaningful consumer involvement. We would be pleased to offer our support to NQF to further develop measures for this domain.</p> <p>Community Inclusion: We strongly agree with the Committee's statement that performance measures could be developed from consumer surveys such as CMS's Money Follows the Person Quality of Life Survey and the National Core Indicators – Aging and Disabilities Survey (NCI-AD). We also believe the HCBS Experience Survey is a potential source for measures. These surveys make use of broad measures for social connectedness, relationships and meaningful activity measurement, which are</p>

## Comments on the Examples of Measures, Measure Concepts and Instruments Highlighted in the Domain-Specific Recommendations

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		<p>more effective at gathering meaningful consumer responses. Using specific activities, such as whether a person went to the movies or ate in a restaurant to assess community inclusion can limit or misrepresent consumer experiences. Broad measures ensure that personal preferences for different activities are considered and more effectively capture how a person feels about their access to community and relationships. Some of the questions in the NCI-AD survey seem particularly suited for swift adoption as measures:</p> <p>&lt;!--[if !supportLists]--&gt; &lt;!--[endif]--&gt;Are you as independent as you would like to be?</p> <p>&lt;!--[if !supportLists]--&gt; &lt;!--[endif]--&gt;Do you feel in control of your life?</p> <p>&lt;!--[if !supportLists]--&gt; &lt;!--[endif]--&gt;Are you lonely?</p> <p>&lt;!--[if !supportLists]--&gt; &lt;!--[endif]--&gt;Are you doing things inside and outside the home when you want to?</p> <p>&lt;!--[if !supportLists]--&gt; &lt;!--[endif]--&gt;Do you like how you spend time during the day?</p> <p>&lt;!--[if !supportLists]--&gt; &lt;!--[endif]--&gt;Are you able to see friends and family?</p> <p>&lt;!--[if !supportLists]--&gt; &lt;!--[endif]--&gt;Do you need more/different services to live in your choice of setting?</p> <p>Without effective measures for Community Inclusion, HCBS will fall short of the Olmstead ruling of the US Supreme Court and the requirements of new federal Medicaid managed care regulations. We urge the Committee to prioritize translation of these surveys into measures as a short-term recommendation rather than as an intermediate recommendation.</p>
<b>H. Stephen Kaye</b>	University of California San Francisco	State and Federal Medicaid and other agencies, managed care organizations, and measure developers would greatly benefit from the committee's expertise as to what promising measures, measure concepts, and survey items could be used right now either as domain/subdomain-specific interim quality measures in



## Comments on the Examples of Measures, Measure Concepts and Instruments Highlighted in the Domain-Specific Recommendations

Comment Submitter Name	Comment Submitter Organization	Comment
		the field or as starting points for validation or refinement. These promising measures/concepts should be drawn from sources such as state quality strategies and HCBS consumer surveys. Specific measures/measure concepts and their sources should be listed in tabular form, with a few examples of promising measures for each subdomain, to give people concrete ideas as to where they might start.
<b>H. Stephen Kaye</b>	University of California San Francisco	Based on the information contained in the interim report, Federal and state agencies, researchers, and research funders are given very little guidance as to how to begin to attack the long list of domains and subdomains. Given that the committee chose not to prioritize the domains, it is important to explicitly identify which domains and subdomains can be adequately assessed using existing measures and "measure concepts," albeit perhaps with adjustments and further validation. Other domains/subdomains require either further measure development or conceptual development prior to measure development. The domains and subdomains should be distinguished according to whether each is to be prioritized for use in the near future, in the medium term, or in the long-term. The committee did this during the in-person meeting for most of the domains, but NQF has not captured it in the interim report, despite my objections. This is NOT the same information as the short, medium, and long-term recommendations for each domain.
<b>Kimberly Austin-Oser</b>		I believe we should include example measures in an appendix as a way to further express and/or reinforce our intentions as well as provide a resource for those interested in utilizing these recommendations to develop, modify or enhance their current quality related practices. I also believe we cannot do this first part without including sample measures for the less developed areas and, as an individual committee member, will not support the former without the presence of the latter. To say it another way – If the committee agrees that example measures (derived from currently existing measures and which are deemed 'promising') should be included as a way to reinforce the committee's intentions and provide a resource to interested parties, then WE MUST ALSO INCLUDE a selection of sample measures for the less developed domain and sub-domain areas for the same reasons. Failure to do so will easily perpetuate the

## Comments on the Examples of Measures, Measure Concepts and Instruments Highlighted in the Domain-Specific Recommendations

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		imbalance of time and resources given to already developed measures rather than the ones needing the most time and attention.
<b>Jennifer Bogenrief</b>	American Occupational Therapy Association	<p>The American Occupational Therapy Association (AOTA) appreciates the work of the Committee and NQF staff on this important area.</p> <p>Related to community inclusion, AOTA would add that meaningful activity is also important for individuals that may be somewhat isolated.</p> <p>As the efforts related to holistic health and functioning move forward, possibly using measures from the FASI demo, AOTA believes it is important to capture all levels of cognitive impairment, especially mild cognitive impairment. Cognitive impairments have the potential to compromise the safety and long-term well-being of individuals, especially more frail elderly patients. Early identification of performance-related or functional cognitive impairments allows for the timely implementation of an occupational therapy care plan to address ways to mitigate or overcome the limits cognition problems engender.</p>
<b>Sarah Triano</b>	Centene Corporation	The measures of caregiver support highlighted on page 19 (Zarit Caregiver Burden Questionnaire and Tailored Caregiver Assessment and Referral System) are both "burden-based." Centene recommends the inclusion of caregiver support measures that are also "asset-based" and capture the positive aspects of caregiving and effective supports.
<b>Lauren Aforatus</b>	Family Voices NJ	In general, we support all of the domains and most of the revisions. In Appendix C, we actually prefer the initial definition of service delivery as it mentions accessibility in terms of both geographic location and physical access for people with disabilities. We found that once Medicaid managed care was mandatory for people with disabilities in our state, that consumers found many of the doctor's offices, exam tables, and diagnostic equipment was inaccessible to people with disabilities. We would suggest that provider directories note accessibility as well as if they are taking new patients (half of them in our state are not, despite increased numbers of

## Comments on the Examples of Measures, Measure Concepts and Instruments Highlighted in the Domain-Specific Recommendations

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		<p>Medicaid eligible consumers.) We also liked the citation of timely services. We appreciate that in Appendix D the revised “community inclusion” has in bold type “resources and settings to facilitate inclusion.” We would add that resources need to be community based as for too long there has been an institutional bias in Medicaid funding. We actually prefer the mention in the initial domain of caregiver support which specifically mentions respite; this is the #1 requested service from family caregivers, though as stated above we appreciate the mention of financial and emotional support as according to Families USA most bankruptcies are due to medical debt. Also as stated above, caregiver burnout is a factor in unnecessary institutionalization. Indeed, caregivers often receive no support when there is a medical crisis such as resuscitation and are expected to carry on “business as usual.” Perhaps these two (initial/revised) versions can be combined to be more comprehensive. Under “workforce” we strongly agree with demonstrated competencies as there must be disability awareness infused throughout the usual medical knowledge. Here again, cultural and linguistic competency is needed as stated previously. Under “human and legal rights,” we would suggest specific mention of restraints and avoidance of institutional abuse. We support the addition of “accountability” under “system performance” but would suggest specifying consumer engagement as it appeared in the initial version. We also support the revision from “consumer voice” to “consumer leadership” and meaningful involvement.</p>

## Additional Examples of Measures and/or Measure Concepts that Assess the Concepts within the Domains and/or Subdomains of HCBS Quality Measurement

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Comment Submitter Name	Comment Submitter Organization	Comment
<b>Clarissa Kripke</b>	University of California, San Francisco	You can't provide home and community based services to people who don't have stable housing. Housing loss should be a measure. And a key reason for housing loss is change in service need so separating housing from services is also important.
<b>linda Thomas</b>		Yes, two:  The Toronto study and the Quality of Life Experience study would be great to use.
<b>E. Clarke Ross</b>	Consortium for Citizens with Disabilities	National Core Indicators, NCI for aging & disability, HCBS Experience Survey, Money Follows the Person Survey, and Council on Quality & Leadership Personal Outcomes Measures are the most promising surveys and NQF should identify individual performance measures by domain and sub-domain. Also - NIDILRR funded research by Westchester Institute for Human Development to adapt CAPHIS (Consumer Assessment of Healthcare Providers and Systems) for persons with intellectual disabilities. Clarke Ross, American Association on Health and Disability and Lakeshore Foundation
<b>E. Clarke Ross</b>	Consortium for Citizens with Disabilities	CMS recently released final regulations on Medicaid Managed Care. Within these regs, CMS required states to include measures on rebalancing, community integration, and quality of life. CMS MC rules further required identification of health disparities based on disability status and publicly available External Quality Review reports. Urgent investment in these areas is required, given these are now state requirements. While quality of life is not identified as a separate domain or sub-domain, we believe it crosses several domains and is best assessed via the perspectives and experiences of consumers. Clarke Ross, American Association on Health and Disability and Lakeshore Foundation.
<b>E. Clarke Ross</b>	Consortium for Citizens with Disabilities	NQF HCBS committee should make a specific recommendation that performance measures from the HCBS Experience Survey be expedited for NQF endorsement. We are very concerned that the efforts of the NQF person and family-centered care measures committee have "not" been coordinated with the NQF HCBS quality

## Additional Examples of Measures and/or Measure Concepts that Assess the Concepts within the Domains and/or Subdomains of HCBS Quality Measurement

Comment Submitter Name	Comment Submitter Organization	Comment
		committee. There appears to be a major disconnect that is not in line with the framework and priority recommendations developed by the NQF HCBS committee. Clarke Ross, American Association on Health and Disability and Lakeshore Foundation.
<b>E. Clarke Ross</b>	Consortium for Citizens with Disabilities	To avoid silos, we suggest cross-referencing and coordinating the identified gaps with the high priority measure gaps identified by the NQF workgroup on persons dually eligible for Medicare and Medicaid. These are goal-directed, person-centered planning and implementation; shared decision-making; systems to coordinate healthcare with non-medical community resources; beneficiary sense of control/autonomy/self-determination; psychosocial needs; community integration/inclusion/participation; and optimal functioning. All of these are included in the HCBS report, except systems to coordinate healthcare with non-medical community resources. Clarke Ross, American Association on Health and Disability and Lakeshore Foundation.
<b>Megan Burke</b>	The SCAN Foundation	<p>The SCAN Foundation is engaged in identifying and reporting on LTSS quality at various levels including state systems, healthcare entities, and community-based organizations. Four specific bodies of work are in various stages of development:</p> <p>Long-term services and supports (LTSS) case management accreditation: The National Committee for Quality Assurance (NCQA) is due to release an accreditation process for health care entities' case management of LTSS. This expanded accreditation process, to be finalized in 2017, will include modules on: assessments; person-centered planning and monitoring; care transitions; measurement and quality improvement; staffing, training and verification; and rights and responsibilities. NCQA is currently inviting organizations to become Early Adopters with applications due July 22, 2016.</p> <p>Person-centered outcomes: A 2013 report from NCQA outlines a quality framework for integrated care, and could be a resource for identifying potential HCBS quality measures. Additionally, the Foundation, in partnership with the John A. Hartford Foundation, is working with NCQA to develop person-centered quality measures that focus on coordination and delivery of LTSS. This body of work will test two promising methods for documenting person-centered outcomes in a standardized format. These measures will be designed</p>

## Additional Examples of Measures and/or Measure Concepts that Assess the Concepts within the Domains and/or Subdomains of HCBS Quality Measurement

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		<p>for eventual use in NCQA accreditation programs and could form a basis for building person-centered quality metrics.</p> <p>LTSS Scorecard: The State Scorecard on Long-Term Services and Supports (Scorecard), produced by the AARP Public Policy Institute, examines state system performance using five identified dimensions of a high-performing LTSS system: Access and Affordability; Choice of Setting; Quality of Care and Quality of Life; Support for Caregivers; and Transitions of Care. The second LTSS Scorecard released in 2014 measured states' performance across 26 indicators which could be consistently measured across states. A third analysis of state LTSS systems will be released in summer 2017, with some measures adjusted due to changes in collected, available data.</p> <p>Universal Assessment: California statute requires state departments to work with stakeholders to pilot a universal assessment for LTSS as part of the state's dual eligible financial alignment demonstration, the Coordinated Care Initiative. An individualized assessment process with connected uniform data elements that address both health and functional items (often referred to as "universal assessment") can be used to evaluate one's needs in a consistent manner and create a care plan tailored to that person's strengths, needs, and service/support preferences in an equitable manner. This information can be utilized not only for service delivery purposes, but also to support quality measurement by gathering information that can be used to construct LTSS quality measures.</p>
<b>E. Clarke Ross</b>	Consortium for Citizens with Disabilities	<p>Rebalancing - We believe that "rebalancing" needs to be more explicitly identified in the framework. It currently fits within the sub-domain "financing and service delivery structures" of the domain "system performance &amp; accountability." However, the descriptions do not mention "rebalancing." Rebalancing measures are a priority of consumer advocates and CMS has required rebalancing measures in MLTSS programs. Given its level of importance, we recommend that rebalancing be clearly identified as a separate sub-domain. Clarke Ross, American Association on Health and Disability and Lakeshore Foundation.</p>
<b>E. Clarke Ross</b>	Consortium for Citizens with Disabilities	<p>Employment (page 18). We strongly support identifying promising measures in the area of competitive employment. This will allow states to set benchmarks for improvement. We also suggest</p>

## Additional Examples of Measures and/or Measure Concepts that Assess the Concepts within the Domains and/or Subdomains of HCBS Quality Measurement

Comment Submitter Name	Comment Submitter Organization	Comment
		reviewing measures from the National Core Indicators and CQL Personal Outcomes Measures for promising measures to assess employment. In July 2012, the Consortium for Citizens with Disabilities (CCD) Task Force on LTSS identified 6 gaps in existing quality standards as they directly relate to persons with disabilities. One of the 6 was "% in employment or meaningful day." The other 5 were consumer choice & participant-directed services; satisfaction (individual experience with services & supports); % in independent housing (consumer choice, housing appropriateness, stability; integrated primary and specialty care; & access to timely and appropriate care. Clarke Ross, American Association on Health & Disability & Lakeshore Foundation
<b>Lindsay Schwartz</b>	American Health Care Association/National Center for Assisted Living	<p>As mentioned in previous comments, AHCA/NCAL would recommend including overall quality of life measures. It is important to consider disease-specific HRQoL tools, when appropriate as a disease or symptoms from the disease could impact the score on a generic QoL measure.</p> <p>Measuring person-centeredness can be challenging. The Center for Excellence in Assisted Living (CEAL) and University of North Carolina (UNC) collaborated to develop PC-PAL, a tool used to measure person-centered practices in assisted living. This toolkit would be a useful tool to utilize in assisted living and possibly be adapted for other HCBS settings.</p>
<b>Carmella Bocchino</b>	America's Health Insurance Plans	We suggest using existing data from the various assessment tools listed in the document to inform domains such as the Holistic Health and Functioning domain and Service Delivery and Effectiveness domain.
<b>Jennifer Goldberg</b>		<p>Justice in Aging recommends two changes to the Equity and Workforce domain.</p> <p>Equity: We are concerned the current Human and Legal Rights domain does not adequately address nondiscrimination protections. In general, of the 261 measures and 394 measure concepts in the Environmental Scan, there is nothing that can be used to conduct oversight on compliance nondiscrimination protections, detailed in the recent 1557 final regulation (45 CFR Part 92). In the "short-term recommendation," we suggest expanding the assessment of existing</p>

## Additional Examples of Measures and/or Measure Concepts that Assess the Concepts within the Domains and/or Subdomains of HCBS Quality Measurement

Comment Submitter Name	Comment Submitter Organization	Comment
		<p>quality measures to include an expansion of the use of quality measures to examine oversight of: 1) accurate, timely and free access to language services, and 2) oversight of nondiscrimination protections for sex and gender.</p> <p>Workforce: We support the “demonstrated competencies” domain and suggest clarifying that the workforce is able to demonstrate dementia competencies. With Alzheimer’s disease and related dementias on the rise, it is increasingly important that individuals caring for and encountering people with dementia have training in the special needs of individuals with dementia. Most states have few meaningful dementia training requirements for professionals working at home or in the community, particularly compared to institutional and residential staff requirements.</p> <p>Finally, we appreciate the discussion of measurement gaps (pg. 11-12). As this Committee focuses on aligning with other quality measurement efforts, we recommend cross-referencing and coordinating the identified HCBS gaps with the high priority gaps identified by NQF Workgroup on Persons Dually Eligible for Medicare and Medicaid. The Dual Eligible NQF workgroup has identified the following measure gaps:</p> <ul style="list-style-type: none"> <li>Ø Goal-directed, person-centered care planning and implementation</li> <li>Ø Shared decision-making</li> <li>Ø Systems to coordinate healthcare with non-medical community resources and service providers</li> <li>Ø Beneficiary sense of control/autonomy/self-determination</li> <li>Ø Psychosocial needs</li> <li>Ø Community integration/inclusion and participation</li> <li>Ø Optimal functioning (e.g., improving when possible, maintaining, managing decline)</li> </ul> <p>We are encouraged to see that almost all of these were included in the HCBS report, except the gap on measures to evaluate system</p>



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		that coordinate healthcare with non-medical community resources and providers.
<b>Amy Ingham</b>	Anthem, Inc.	Human and Legal Rights: The “Informed decision-making” subdomain could include “experiential information” in helping consumers to make decisions. Tennessee operationalized this in their Exploration Service, funding time for new members in the employment program to observe and participate in potential employment opportunities in order to make employment decisions.
<b>Peg Graham</b>	QUA INC	Holistic Health and Functioning: As a family caregiver, “falls measurement” should work with safe patient handling community ( <a href="http://www.asphp.org/">www.asphp.org/</a> ) to capture the data they have been capturing related to equipment, staff training and in-patient hospital falls. This resource is a good reminder of the multi-factorial nature of falls, even more true in the home setting which emphasizes self-care and mobility, as so opposed to hospitals that simply want to minimize patient harm for the duration of a short acute stay and don’t the risk of wrongly accessing a patient’s ability to self-transfer, etc. <a href="http://www.patientsafetyolutions.com/docs/December_22_2009_Falls_on_Toileting_Activities.htm">http://www.patientsafetyolutions.com/docs/December_22_2009_Falls_on_Toileting_Activities.htm</a>
<b>Meredith Ponder</b>	Defeat Malnutrition Today	Re: the Holistic Health and Functioning domain's "Population health and prevention" subdomain:  New quality measures are being submitted to the NQF by the Academy of Nutrition and Dietetics and Avalere Health which will measure malnutrition in hospitals; similar outcome measures can and should be developed to measure malnutrition in home- and community-based settings. Further, the Older Americans Act already has a mandated (per regulations) DETERMINE Checklist for nutrition screening in community-based settings; this could be used or adapted to be used as an assessment for this subdomain.
<b>Allicyn Wilde</b>	SEIU	As noted above, the Final Report should be as specific as possible in terms of developing useful and concrete recommendations in order to best facilitate the continuation of this important work. Below is a table with several examples of more specific and detailed measure concepts for the subdomains within the Workforce Domain that the Committee could explore. Please see the table we have submitted directly to NQF Staff for several examples of more specific

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		<p>and detailed measure concepts for the subdomains within the Workforce Domain that the Committee could explore.</p> <p>(We would have liked to submit it here but the website would not allow for it).</p>
<b>Ann Hwang</b>	Community Catalyst	<p>Community Catalyst would like to commend the Committee members for acknowledging the crucial role of the direct care workforce in the HCBS System, and the need to recognize and support these workers – who deliver the vast majority of direct-touch HCBS care. The six subdomains address what are clearly major steps forward in measuring quality for HCBS services as 80-90 percent of the services are delivered by front line workers. Given the importance of turnover and the evidence of how continuity of care affects quality, we would recommend that you at a minimum move “sufficient numbers, dispersion and availability” into your short term category. NQF could do this by analyzing the average annual turnover rate (percent of direct care workers that left their position as a proportion of total staff employed during the reporting period), broken out by setting and job title, and the percent of workers retained during the reporting period, as well as the average amount of time it takes for consumers to find workers/services.</p>
<b>Danna Caller</b>	Abbott	<p>Re: the Holistic Health and Functioning domain's "Population health and prevention" subdomain:</p> <p>New electronic clinical quality measures have been submitted to the NQF by the Academy of Nutrition and Dietetics to facilitate measurement of malnutrition screening, assessment, diagnosis and intervention in acute care hospital setting; these measures could potentially be adapted to measure malnutrition in home- and community-based settings. For example, the Older Americans Act already has a mandated (per regulations) DETERMINE Checklist for nutrition screening in community-based settings; this could be used or adapted to be used as an assessment for this subdomain.</p>
<b>Sarah Triano</b>	Centene Corporation	<p>Wherever possible, Centene recommends using data from existing sources rather than creating new tools. For example, existing data from the comprehensive assessment tool could be used to inform the Holistic Health/Functioning and Service Delivery/Effectiveness domains.</p>

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<b>Michelle Yip</b>		A measure suggestion is "survival analysis" that is to measure the length of time for a service-recipient staying in a HCBS program before nursing home placement or death.
<b>Lauren Aforatus</b>	Family Voices NJ	We understand that the overarching goals are to create a framework for measurement, synthesize evidence through an environmental scan, identify gaps, and prioritize measures. As stated previously, we highly recommend standardization throughout the states to accomplish this. We strongly agree that "HCBS are essential for many older adults and people with disabilities." However, we caution that care management must be done in the spirit of coordination of services and not limit access to them. We would highly recommend using the Family Centered Care Assessment tools found at <a href="http://www.fv-ncfpp.org/activities/fcca/fcca-families/">http://www.fv-ncfpp.org/activities/fcca/fcca-families/</a> .

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<b>Peter Notarstefano</b>	LeadingAge	<p>Gaps in Measurement</p> <p>On the Medicaid side, the gap in measurement varies from state to state, and sometimes from one population to another population within a state. Persons with disabilities could be served under different waivers than frail older adults, or individuals who are HIV positive. Different state agencies may have jurisdiction to monitor the quality of services provided for different populations. LeadingAge believes that measures must be actionable and relevant for the specific population being served. Developing one set of HCBS for all populations being served under Medicaid will create an additional gap in measurement for populations that may be experiencing poor quality of care for a service that is a priority for them.</p> <p>On the Medicare side, home health is targeted for individuals that have a skilled intermittent need. The needs of this population, as well as their goals are different than the goals and needs for the population receiving long-term services and supports under Medicaid. The IMPACT Act will standardize assessments for critical care issues across the spectrum of post-acute care (PAC) providers and builds a bridge to ensure that patient care is delivered based on what the patient needs, eliminating the silo focused approach to quality measurement and resource utilization.</p> <p>Finally, from a systems and service level, states may have different budget constraints or inefficient infrastructure that will have a negative impact on the results of measuring the effectiveness of HCBS.</p> <p>Prioritization in Measurement</p> <p>We agree with the National Quality Forum Committee’s statement in the Third Interim Report that “measurement in all domains should be person centered, with the goal of improving consumer outcomes and promoting community living.” This goal aligns with the purpose of Medicaid waiver program. These programs provide services to people who would otherwise be in an institution, nursing home, or hospital to receive long-term</p>

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		<p>care in the community. Prior to 1991, the Federal Medicaid program paid for services only if a person lived in an institution.</p> <p>It is critical that NQF and HHS place the Person's identified goals subdomain and the measures based on the person receiving the HCBS as a top priority. The correlation of the person centered plan of care, and the sufficiency of delivery in terms of the scope of services and the capacity to meet existing and future demands must be addressed when prioritizing measures. An older adult may not choose to follow a plan of care recommended by their physician. Their goals may require a different plan of care. Many programs are often state and population-centric and are highly variable in terms of measurement and quality improvement activities.</p>
<b>linda Thomas</b>		<p>In addition to including all-- even the most severely disabled-- I would also suggest that you measure ALL types of settings, even those deemed presumed noncompliant. You will find that quality of life has nothing to do with the four walls or being located in a community, but how individuals are loved and cared for and have opportunities to learn and experience new things during the day.</p>
<b>Alex Shekhdar</b>		<p>The Medicaid Health Plans of America (MHPA) is pleased to submit a response to the National Quality Forum's Home and Community Based Services (HCBS) Third Interim Report. Our comments and suggestions are as follows:</p> <p>MHPA believes that some of the existing domains as contemplated by NQF should be collapsed into one domain (i.e. four large domains/each with 3 subdomains except for the workforce domain.) Under this structure, Domain #1 would relate to "Choice and Control," Domain #2 "Holistic Health and Functioning," Domain #3 "Workforce," and Domain #4 "System Performance and Accountability." Each one of the domains would subsume some of the proposed domains (e.g. choice and control would have person-centered planning and coordination, self-direction, and consumer leadership, etc.)</p> <p>In addition, MHPA agrees with the cross-cutting recommendations presented in the report. These include supporting quality measurements across domains; identifying and implementing of a consistent approach to quality</p>

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		measurement; leveraging technology; etc. Finally, as related to specific measures and measure concepts, MHPA recommends the caregiver support measures include "asset-based" measures, and that existing data from comprehensive assessment tools be used to inform select domains (e.g. Holistic Health and Service Delivery)
<b>Lucille Pivinski</b>	Parent & Advocate	<p>Kindly look back at the comments made on the last draft. It does not appear that any in the following areas noted by many commenters were taken into consideration:</p> <p>The entire concept of Dignity of Risk is dangerous if the individual making their own decisions is not supported sufficiently to understand the potential consequences of their decisions. Beware, Dignity of Risk has become a shorthand for "neglect"; an excuse when things go horribly wrong .... well, they made this choice.....</p> <p>The entire concept of "community" needs clarification in that community is as experienced by the individual.....not as imposed on them, dictated to them, or enforced via financial coercion. Individuals are being steered into living places they would not otherwise choose to live. They are being forced to live in scattered sites in anonymous neighborhoods on with so-called neighbors they would never choose to be friends with and who would not choose to befriend them. Sorry, reality informs. Not everyone wants the same life as everyone else. Yet, recent rules, regs, and intentional misinterpretations of Olmstead are being used to coerce individuals, do as "we" say or lose your life enabling waiver supports. This kind of coercion is a violation of the rights of individuals who have the same rights as everyone else on freedom to associate or NOT and freedom to live where they feel safe and connected to others. Where is the legal protection for these individuals? Not in your proposals!</p> <p>Also, where is the "valued" role of family members, parents, siblings, trusted others once the individual no longer lives in the family home. Seems like they are being read out of the lives of their children, their loved ones. Seems like the goal of supporting the family is limited to prolonging their viability as a cheaper place for the individual to live, in the family home, when so many adults w/ ID/DD do not want to continue living with</p>

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		<p>their aging families and want to live with friends and neighbors of their choosing, with whom they can continue to share their lives. Regardless of where the individual lives, families should be recognized as valued participants in the lives and decisions of their loved ones, particularly their loved ones who have greater needs.</p> <p>NQF, I hope you have not been hypnotized by those who have the agenda of imposing their preferences and life choices on others. For too many, person-centered is just a phrase. Our lives. Our choices. Our perspective. Please tweak this worthy document here, there and everywhere to reflect that.</p> <p>Thanks. Lucille Pivinski mom to one, advocate for many</p>
<b>Gary Montrose</b>	Colorado - Community Living Quality Improvement Advisory Committee (CLQIC)	<p>Different survey methods are likely required for different HCBS populations, but this issue is not acknowledged in the present NQF report. There is a lack of guidance on alternative methodologies, for sampling and surveying people with different disabilities.</p> <p>For example, in some instances, people with disabilities might trust a "peer" surveyor or anonymous on-line survey, but not trust a "professional" surveyor they do not know and may fear could pass negative comments on to case workers, etc. who are in a position to retaliate against vulnerable clients in the privacy of a home setting.</p> <p>Such guidance may be even more important than consensus on domains and sub-domains in order to advance the art and science of surveying people receiving HCBS/LTSS benefits.</p>
<b>E. Clarke Ross</b>	Consortium for Citizens with Disabilities	<p>We believe additional work is needed to identify priorities for measure development, which is one of the primary tasks of the committee. We feel the draft recommendations do not offer a level of specificity that will assist HHS and advocates in guiding future investments in measure development. Suggestions are offered in other comment postings. Clarke Ross, American Association on Health and Disability and Lakeshore Foundation.</p>

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<b>Laura Thornhill</b>	Alzheimer's Association	Because current and future HCBS measures involve different populations--older adults, people with multiple chronic conditions, and people with disabilities--the Alzheimer's Association encourages NQF, CMS, and measure developers to determine which populations use particular services and in what settings to better inform and shape quality measure development. For example, if many HCBS recipients reside in a memory care setting with a secured perimeter, then measures in certain domains should be constructed in a way that reflects safety needs and cognitive impairment of residents.
<b>Lindsay Schwartz</b>	American Health Care Association/National Center for Assisted Living	AHCA/NCAL is pleased with the focus on person-centered quality measures. Difficulty in measuring some of the domains is that every person has different needs and desires, especially when comparing all of the different populations receiving HCBS care. It can be challenging to have statistically valid outcomes if the measures are not adjusted for needs, abilities, and personal situations of the individuals receiving care. Measuring programs without adjusting for the acuity of individuals receiving HCBS wouldn't necessarily indicate the quality of the program or service.
<b>Jennifer Goldberg</b>		Justice in Aging commends NQF for its work. The framework overall includes a broad range of domains and subdomains that capture important aspects of HCBS quality for older adults and persons with disabilities. Moving forward, we recommend increasing the focus on alignment and prioritization. First, we encourage NQF align this work with other Department of Health and Human Services (HHS) and Centers for Medicare and Medicaid Services (CMS) quality evaluation efforts. In the final Medicaid managed care regulation (42 CFR § 438.330(a)(2)), CMS established the authority to specify national performance measures and quality improvement projects. In addition, the Medicare-Medicaid Coordination Office (MMCO) is currently developing a Quality Rating Strategy (QRS) for the dual eligible demonstration programs. This report should align its priorities for measure development with the needs of CMS in those areas. To ensure that HCBS is measured consistently across states and programs, the next NQF draft should clearly detail timelines and priorities for measure release that correspond to these areas. It is important that HHS and stakeholders have an understanding of what measures will be available when as agencies and



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		<p>stakeholders work to create systems for LTSS quality evaluation.</p> <p>Second and most importantly, we recommend that the Committee move swiftly and with urgency to prioritize core measures for development. The work to date has resulted in an impressive compendium of measures and a level of detail that previously did not exist for HCBS. With this foundation in place, NQF is well positioned to begin endorsing measures for use. The field is desperate for specificity, and NQF's foundational work appears to be complete. We strongly recommend the Committee move quickly to prioritize, within the domains and subdomains, specific measures for development. In particular, we suggest prioritizing measures that evaluate: 1) rebalancing, 2) community integration and 3) quality of life. These measures can currently be found within the domains of System Performance and Accountability (for rebalancing), Community inclusion (for community integration). Quality of life measures can cross into a number of domains, including Service Delivery and Effectiveness, Choice and Control, Community Inclusion, Human and Legal Rights, and Equity. The three areas of rebalancing, community integration, and quality of life are ones that states will soon be required to measure under the Medicaid managed care rule and areas where guidance is most pressingly needed.</p>
<b>Carmella Bocchino</b>	America's Health Insurance Plans	<p>In response to the second interim report, AHIP suggested the domains of measurement be more balanced. There continues to be imbalance in the number of domains. Of the eleven domains, six are related to choice/control, two are health-related, and three are workforce/system-related. Having a more balanced number of domains will help ensure greater buy-in and adoption by all.</p> <p>One way to achieve this is to collapse some of existing domains into one logical, larger domain. The result would be four large domains, each with 3 subdomains (except workforce which would have two):</p> <ol style="list-style-type: none"> <li>1. Domain #1: "Choice and Control." This larger domain would have subdomains in the areas of person-centered planning and coordination, consumer leadership in system development, and the existing subdomains under this category related to self-</li> </ol>

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		<p>direction. They are all, arguably, aspects of consumer “Choice and Control” just at different levels - individual and systems.</p> <p>2. Domain #2: “Holistic Health and Functioning.” This larger domain would include subdomains in the areas of community inclusion, service delivery and effectiveness (person’s needs met, goals realized) and the existing subdomains under the holistic health and functioning category. Community inclusion is, arguably, an aspect of holistic health and functioning.</p> <p>3. Domain #3: “Workforce.” This larger domain would have subdomains in the area of caregiver support and the existing subdomains under the workforce category.</p> <p>4. Domain #4: “System Performance and Accountability.” This larger domain would have subdomains in the areas of equity, human and legal rights, and the existing subdomains under the system performance and accountability category.</p> <p>While this does not completely address the current lack of balance, and the large number/overlapping nature of the domains that is acknowledged by the committee, this would help bring greater balance and help encourage adoption.</p>
Aimee Ossman	Children's Hospital Association	<p>Dear Members of the NQF HCBS Committee:</p> <p>On behalf of the nation’s children’s hospitals, we appreciate the opportunity to comment on the interim report entitled, “Addressing Performance Measure Gaps in Home and Community-Based Services to Support Community Living: Priorities for Measure Development.” We understand the time and effort the multi-stakeholder committee has devoted to the quality of home and community services and the importance for many Medicaid beneficiaries, including children. As you work to finalize this report, we hope that you would consider the recommendations and their potential impact on children specifically.</p> <p>Although children’s hospitals are only 5 percent of all hospitals, they provide almost half of all hospital care for children on Medicaid and almost all hospital care for children with complex medical conditions, such as cancers, heart defects or</p>

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		<p>complications arising from prematurity. As we look to provide more care outside of the hospital walls and in the community, better linkages with and supports in the home and community settings are critical. Good quality home and community-based services are important as we build better systems of care that improve care for children with medical complexity on Medicaid and reduce costs. Currently, about 6 percent of children on Medicaid are medically complex and account for 40 percent of the costs for children. The pathway to improving care for these children and reducing the costs includes robust and effective home and community-based services.</p> <p>The report as drafted does not specifically mention children, their need for these services or how your recommendations would uniquely impact them. Much of the language in the report seems to apply to elderly adults and adults with disabilities. We would recommend specifying in the final report in what ways did you consider the unique needs of children and the gaps in performance measurement specific to them. If they were not considered, then it would be good to be clear about that as well. If children were not a focus, then perhaps this could be part of future work of the committee.</p> <p>We appreciate your focus on these services that are a lifeline for many people to remain at home and as connected as possible to their communities. We would respectfully request more clarity on whether children were part of your deliberations/considerations and what you think would be unique gaps that would apply to them.</p> <p>Thank you for all your efforts and we look forward to learning more about your work and the potential impact on children relying on home and community-based services.</p> <p>Sincerely,</p> <p>Aimee Ossman Vice President, Policy Analysis and Implementation, Public Policy Children's Hospital Association</p> <p>Sally E. Turbyville, MA, MS, DrPH Sr. Fellow Quality Policy &amp; Research</p>

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<b>Amy Ingham</b>	Anthem, Inc.	<p>Anthem commends the National Quality Forum’s Stakeholder Committee on its third interim report assessing quality measurement of home and community-based services (HCBS). We recognize the Committee great progress improving upon previous iterations of this report and believe the Committee will help advance the goals of stronger HCBS measurement through its leadership of this important project.</p> <p>Anthem’s health plans deliver coordinated long-term services and supports that focus on improving member health outcomes and quality of life, respecting preferences, and maximizing opportunities for members to lead independent lives and achieve their goals. Similarly, Anthem supports access to quality, integrated and culturally competent health care services and social supports delivered in the setting of the member’s choosing, which is most often a home or community-based setting. As the number of individuals in need of HCBS grows, Anthem supports the Committee’s timely work.</p> <p>In the context of managed care, HCBS quality assessment could benefit from the inclusion of targeted, meaningful, and tested measures focused on the processes and outcomes that contribute to good quality of life for consumers with HCBS needs. Others with a broader oversight role in HCBS quality improvement such as state agencies would be better able to measure and improve factors such as family caregiver well-being and consumer leadership/participation in HCBS design. To best facilitate implementation of these measures among health plans and others, Anthem encourages the Committee to prioritize measures that can be derived from information/data that is already routinely collected in order to increase speed of adoption and reduce administrative burden.</p> <p>Please refer to other sections to view Anthem’s domain- and measure-specific comments.</p>
<b>Katherine Berland</b>	American Network of Community Options and Resources	<p>Part 1 of 3</p> <p>The American Network of Community Options and Resources, Inc. (ANCOR) is pleased to comment on the 3rd Interim Report of the National Quality Forum Committee on Home and</p>

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		<p>Community-Based Services (HCBS) Quality. This work is critical for the field as we move forward with the implementation of the HCBS rule.</p> <p>The framework demonstrates thoughtful consideration of areas (domains) potentially intersecting with a person’s day to day life when supported through HCBS waiver funding. This is a huge undertaking, and one requiring a thoughtful approach.</p> <p>ANCOR offers the following thoughts on the report:</p> <p>We commend the committee for the emphasis placed on each of the domains. They bring clarity and broaden the reader’s understanding of a cross disability universe and potentially streamline the work ahead. Some of the domains identified are not currently universally part of systemic protocols used to assess quality across all HCBS waivers.</p> <p>One cannot understate the critical importance of a qualified and adequately compensated workforce. These recommendations should be prioritized for rapid development.</p> <p>We agree with the Disability and Aging Collaborative (DAC) recommendation on employment to prioritize that states set benchmarks for competitive employment.</p> <p>The discussion related to Equity (page 22) broadly addresses issues concerning the allocation of resources but as stated the intent is unclear. Are the recommendations suggesting we shift resources away from long-standing mature systems in favor of building the capacity of other less robust systems? The discussion of resource distribution cannot be understated. There are insufficient resources for all systems and this must be acknowledged as one of the variables. The report should clarify its intent in this section.</p> <p>Holistic Health and Functioning (page 23) should address the benefits of integrating primary and specialty care such as behavioral health and other disciplines.</p>
Katherine	American Network	Part 2 of 3

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<b>Berland</b>	of Community Options and Resources	<p>(ANCOR)</p> <p>Prioritizing measurement development will be important work going forward. The system will attain what is measured, so identifying the actual measures to be used is critical. The development of measures takes time and while we agree that investments should be made across all domains, this is very unlikely in the short term. ANCOR agrees with DAC that some additional prioritization is needed to guide CMS on the most important areas for measure development. CMS recently released final regulations on Medicaid Managed Care. Within these regulations CMS required for the first time states to include quality measures on Rebalancing, Community Integration, and Quality of Life. The Medicaid managed care rules further required the identification of health disparities based on disability status and publicly available External Quality Review reports. Since these areas are now required of states, we believe there is an urgency to invest in measure development and guidance on a menu of measures that could assist states, health plans, and advocates to implement these requirements. While quality of life is not identified as a specific domain or sub-domain, we believe it crosses several domains and is best assessed via the perspectives and experiences of consumers.</p> <p>We also agree with DAC that development of quality measures related to implementation of the HCBS Settings Rule should be identified as priority areas for measure development. Development of measures could assist advocates and states currently working on transition plans. These include measures within the domains of Choice and Control and Person-Centered Planning and Coordination.</p>
<b>Katherine Berland</b>	American Network of Community Options and Resources	<p>Part 3 of 3</p> <p>(ANCOR)</p> <p>We agree with DAC that the report relies too much on examples from a few states that were explored in the NQF environmental scan. It does not adequately capture existing measures and measure concepts currently in use in MLTSS programs and duals demonstrations. It also would be helpful to identify individual performance measures by domain and sub-domain that could be derived from consumer surveys that are currently in wide use within states. This is in line with the global recommendation to</p>

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		<p>build on existing quality measurement instruments in use. As the report reinforces, we believe the National Core Indicators, National Core Indicators Aging and Disability, HCBS Experience Survey, Money Follows the Person Survey, and Council on Quality and Leadership (CQL) Personal Outcomes Measures are the most promising surveys. The committee should break these surveys down to identify individual performance measures by domain and sub-domain.</p> <p>We also agree with DAC that CMS should improve administrative data, and the report contains no specific, actionable recommendations for CMS to undertake. We encourage additional discussion and development of specific recommendations for improvements in administrative data.</p> <p>DAC also recommends that NQF should prioritize the development of measures regarding social connectedness, relationships, and meaningful activity as defined by the individual rather than specific outcomes or activities. For example, many measures of community inclusion ask about whether the individual engages in shopping or eating in restaurants, without recognizing the individual may not actually enjoy those activities. A measure that asks “are you lonely” is a more effective measure of how that individual feels about his or her access to the community and close personal relationships than one that asks questions about specific activities.</p> <p>ANCOR appreciates the opportunity to provide input. Thank you for the important work you and the committee are undertaking.</p> <p>Sincerely, Esme Grant Grewal, Esq., Senior Director of Government Relations</p>
<b>Dennis Heaphy</b>	Disability Policy Consortium	<p>DAAHR endorses recommendations put forward by Community Catalyst, and the American Association Health and Disability. In addition to recommendations put forward by these two entities, DAAHR highlights the following recommendations. In the final ruling on the Medicaid and Children’s Health Insurance Program (CHIP) Programs; Medicaid Managed Care, CHIP Delivered in Managed Care, and Revisions Related to Third Party Liability. In the ruling, CMS failed to put in place objective</p>

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		<p>metrics to measure rebalancing efforts at the state or national level.[1] DAAHR requests that NQF put forward metrics that:</p> <ul style="list-style-type: none"> <li>· Promote rebalancing in spending by:</li> <li>· Clarifying the definition of rebalancing to include requirements for measuring effective transitions to and from medical and rehabilitative settings to community settings as well as reduction in transitions from community settings to institutional settings and increases in transitions from institutional settings to community settings.</li> <li>· Supporting metrics that will support the swiftest opportunities to move people with disabilities and elders from institutional settings to live in the least restrictive setting possible.</li> <li>· Optimize stakeholder engagement by building on the success of existing services including Money Follows the Person Quality of Life Survey and the National Core Indicators – Aging and Disabilities Survey to develop key metrics for measuring consumer engagement.</li> <li>· Establish National Managed Long-Term Services and Supports metrics to ensure that ACOs, MCOs and other managed-care entities are effectively rebalancing spending and addressing disparities based on disability; of particular importance with the rise of MLTSS.[2]</li> <li>· Administrative Data metrics should be developed by CMS to ensure appropriate administration and oversight in the provision of MLTSS. Of particular concern is ensuring that appropriate metrics are in place to measure state capacity to oversee managed care entities delivery of services to people with disabilities and elders as well as containment of administrative costs.</li> </ul> <p>In addition to the above recommendations, DAAHR requests that greater emphasis be placed on quality-of-life metrics, including opportunities for community involvement and employment.</p> <p>[1] <a href="https://s3.amazonaws.com/public-">https://s3.amazonaws.com/public-</a></p>



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		inspection.federalregister.gov/2016-09581.pdf [2] <a href="http://kff.org/report-section/cmss-final-rule-on-medicaid-managed-care-issue-brief">http://kff.org/report-section/cmss-final-rule-on-medicaid-managed-care-issue-brief</a>
<b>Allicyn Wilde</b>	SEIU	Again, SEIU applauds the great work of the Committee and staff that has been done so far in this ambitious and difficult undertaking. HCBS quality measures are long overdue, and we encourage the ongoing work of the committee and final report to be as specific as possible in your recommendations so that they can serve as a useful foundation for continued work on HCBS quality measure development and implementation.
<b>John Shaw</b>	Next Wave	<p>Next Wave applauds the comprehensive framework incorporated into the third interim report, particularly specifying the prioritized subdomains/definitions and the three groups of recommendations. It provides a detailed look at this very complex area so that Stakeholders can visualize that their concerns are “in there” and that there is an action plan to fill gaps.</p> <p>We believe that there is one area that could benefit from some additional consideration for the final report. The report mentions that 85% of the economic investment in HCBS is from family/informal caregivers. This overwhelming majority of investment is not clearly perceived as represented in the report. Members strongly articulated this at the NQF Annual Meeting in the HCBS presentation, in response to the question “Where is the voice of the actual caregivers on the ground? One of the 11 Domains is Caregiver Support and another is Workforce, but other recognition of this issue in the report is less clear. The Committee and Staff understand that much of this is incorporated as cross-cutting links and components inside the other 9 domains. We believe that understanding by other Stakeholder users of the Framework report would be enhanced by additional language and illustrations of the importance of informal caregivers to HCBS in general. See Next Wave’s comments in the Conceptual Framework section for more details.</p>
<b>Roy Afflerbach</b>	National Adult Day Services Association (NADSA)	The National Adult Day Services Association (NADSA) believes the Report correctly identifies that the concept of quality and how to accurately measure it accross a wide spectrum of HCBS providers and funding streams in and of itself carries a different meaning to different people within different programs.

General Comments		
Comment Submitter Name	Comment Submitter Organization	Comment
		<p>We are pleased to note the Report's recognition of the dominant role the Centers for Medicare and Medicaid Services (CMS) plays in both funding and in attempting to measure quality in HCBS. Both the CMS 2014 Medicaid HCBS Rule and the more recently issued MLTSS Rule attempt to establish quality concepts and measures, which are sometimes conflicting, thereby demonstrating the need for balance among such concepts as personal choice and prohibited settings for HCBS funding. We believe, as the Report states:</p> <p>"As a quality measurement framework for HCBS continues to emerge, a number of issues must be considered. These include the relationships between various funding streams, regulators, the extensive and diverse network of providers, service delivery models (e.g., self-direction), and the potential implications for how measurement systems will align across evolving health and LTSS systems."</p> <p>As we reviewed the sections of the Report identifying domains, sub-domains, and recommendations, we recognized concepts and goals which we fully support. For example, we like the revised wording to "holistic" health.</p> <p>We would like to see more effort to distinguish between the unique needs and desires of younger individuals with disabilities and the equally unique, and often distinctly different, needs and desires of elderly individuals and those living with dementia or Alzheimer's disease.</p> <p>CMS failed to consider this distinction in its 2014 HCBS Rule and continues to wrestle with its "one size fits all" mandate that states are finding impossible to meet without eliminating HCBS to vulnerable individuals. We believe that to repeat this error in the construction and application of a uniform quality measurement system would have equally unintended consequences and a de facto denial of HCBS to elderly, vulnerable individuals, thereby forcing them into institutional facilities.</p> <p>Finally, we are particularly pleased that the Report recognizes:</p> <p>"..measuring the quality of HCBS necessitates the added</p>

General Comments		
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		<p>administrative burden of data collection, management, and reporting. Many acknowledge that HCBS are often underfunded, under-staffed, and otherwise under-resourced. Adding further responsibilities to a system with very limited resources does not bode well for efforts to implement quality measurement and quality improvement activities."</p> <p>Many of our country's 5600 adult day services providers operate a single center. Additional unfunded complex mandates, especially for those that serve a predominantly Medicaid population, will place at serious risk their ability to continue to provide HCBS.</p>
Emily Lauer	University of Massachusetts Medical School	<p>While the work on the prioritization of the measurement domains and subdomains is a valuable contribution to the field, this report stops short of making recommendations for prioritization of actual measures within these domains. It seems that this latter piece would be a necessary part of the fourth step of this project to formulate recommendations for prioritization in measurement.</p> <p>Given the identification of promising measures by this committee, this final stage should also prioritize the measures within these domains that are ready (or close to ready) for use particularly because this level of input was provided by committee members. Without this component, the report the utility of this report is diminished due a lack of sufficient information to make it actionable.</p>
Kevin Park		<p>We appreciate the time that the National Quality Forum has taken to create this interim report. We are in support of the general recommendations submitted today by America's Health Insurance Plans (AHIP). In alignment with AHIP, we recommend more focus on key areas, including:</p> <ul style="list-style-type: none"> <li>-development of measurement domains that are more balanced;</li> <li>-emphasis of member choice as the driver of care and service;</li> <li>-formation of domains and measures related to socioeconomic determinants of health; and</li> </ul>

General Comments		
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		- measurement that assess caregivers resources rather than caregiving burden.
<b>Lisa Price Stevens</b>	Magellan Health, Inc.	Great work and effort by the Committee. Thank you for the opportunity to submit comments. Look forward to continued collaboration towards this project.
<b>Sarah Triano</b>	Centene Corporation	While it will be a significant challenge for MLTSS plans to measure some of the proposed domains and sub-domains, Centene commends the NQF multistakeholder Committee on successfully boiling down several large concepts into something tangible, and providing examples of potential tools to be used in developing quantitative and qualitative HCBS measurements.
<b>Barbara McCann</b>		The variety of HCBS populations appears to be lost in the work. Although there are general references to all populations, pediatric and developmentally disabled individuals are not clearly included, nor are the aged. It is not uncommon in works such as this to note the role of the parent, guardian or other individual legally so noted as being included in the referenced “individual” when the individual receiving services is too young or cognitively or developmentally unable to act independently.
<b>Barbara McCann</b>		<p>The writing style of the report makes it very difficult to read easily and grasp the important work done by the NQF staff and the Committee. I speak from the perspective of discussing the report with colleagues from a variety of organizations who are very interested in the contribution of the project. The common response is that they do not understand what the report is saying.</p> <ul style="list-style-type: none"> <li>o Some sentences are so complex and long you cannot identify what the message is. As a Committee member, I have had these read aloud to me by informed and highly educated individuals, including staff at CMS, who ask what did the report mean to say.</li> <li>o The good and brilliant is often lost in the complex writing style. Simplicity is not the enemy of good work, but rather allows it to be understood and utilized by a larger audience.</li> <li>o The use of the term “subdomain” brings nothing to this paper and earlier versions. It makes it more complex. The discussion over what is a subdomain, regardless of your definition, blurs the value of the content. Can we not say that the following elements</li> </ul>

General Comments		
Comment Submitter Name	Comment Submitter Organization	Comment
		<p>are illustrative of each domain topic?</p> <p>o The term “cross cutting” is also a point of confusion in understanding. “Cross setting”, as we know, is a huge term of art that over the past decade is finally being understood and acted upon. To add “cross cutting” as a new term of art in measurement is not helpful and we again loose the sense of the work in not clearly understanding the adjective.</p>
<b>Shawn Terrell</b>	Administration for Community Living	<p>6. Page 5, under “Related Efforts in HCBS and Measurement” Mention the more extensive taxonomy developed and implemented by the Alliance of Information and Referral Systems <a href="https://211taxonomy.org/">https://211taxonomy.org/</a></p>
<b>K. Charlie Lakin</b>		<p>Page 24</p> <p>2nd column, short-term bullets: One thing that was discussed was the need to “Improve the timeliness and thereby the usefulness of public use data on Medicaid HCBS and other Medicaid service use and expenditures to support individual state and cross-state comparative and longitudinal analyses.”</p>
<b>K. Charlie Lakin</b>		<p>Page 22</p> <p>2nd column, 1st bullet: Should this specify some link to HCBS recipients, HCBS-eligible individuals or persons with disabilities?</p> <p>2nd column, 2nd bullet: This seems very vague to me. Will readers know what is being recommended?</p> <p>2nd column, 3rd bullet: I might suggest the following editing: Improve standardization and reporting of waiting list data for HCBS, including demographic and disability characteristics of those waiting, in order to improve accuracy and develop quality measures suitability for assessing equity in access to HCBS.</p>
<b>K. Charlie Lakin</b>		<p>Page 20</p> <p>2nd column, second paragraph: I don’t know how well this was discussed, if at all, but there is huge field of industrial psychology that has been the basis of a number job satisfaction, performance predictors, reason for staying/leaving, intent to leave, etc. research. There are a number of surveys of direct support workers (direct support professionals, PCAs, home</p>

General Comments		
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		health workers, etc.). Unfortunately, the research on the workforce is rarely, if ever, integrated into evaluation topics of the other domains. But there is a foundation on which to build that goes beyond simple, albeit important, studies of turnover, absenteeism, wages, ...I think the CMS National Clearinghouse on the Workforce (Lewin et al.) can provide some guidance on these.
K. Charlie Lakin		<p>Page 18</p> <p>2nd column, first paragraph; The last sentence notes that Relevant performance measures could be developed from survey instruments such as ...the National Core Indicators...The way this is written it will not be clear to the reader that the data gathered by the National Core Indicators are managed by the Human Services Research Institute and that they are submitted by the states to aggregated and analyzed so that they can be presented back to states in just the formats suggested (e.g., percentages, averages, etc.) to allow states to compare their results with those of other states.</p>
K. Charlie Lakin		<p>Page 17</p> <p>2nd column, Recommendations: There are two bullets suggesting the development and expanded use of process and structure measures related to or for assessing programs practices that promote/achieve choice and control. I think as written there would be many people concerned about the broad stroke of this recommendation and who would feel it important to note that ultimately such process and structure measures must only be identified through their established association with choice and control as actually experienced by individuals. As written there is no suggestion of how the validity of the recommended structure and process measures will be established.</p>
K. Charlie Lakin		<p>Page 16</p> <p>1st column, 1st sentence: Would this be better stated as “This measurement domain is defined as the process by extent to which a person directs the development of a plan, based on his or her goals”. It seems to me to better convey the ultimate focus on outcomes in people’s lives.</p>

General Comments		
Comment Submitter Name	Comment Submitter Organization	Comment
		<p>2nd column, 1st paragraph: The NCI/DD has a service coordination sub-scale (“composite”) of several items that are used to assess the quality of service coordination. It has good internal consistency.</p> <p>Same paragraph: The CQL Personal Outcome Measures are powerful, but are probably best described as “a process to discover whether an individual achieves outcomes that are important”..., rather than as an instrument that assesses.</p>
K. Charlie Lakin		<p>Page 15</p> <p>1st column 1st bullet: the clause “the ongoing assessment of the correlation of delivery and the plan of care” seems simply to repeat the previous one.</p>
K. Charlie Lakin		<p>Somewhere on page 13 or 14:</p> <p>It seems important to mention the need to assure rich individual and service setting descriptive information as a means to identify those individual and program factors related to variation in outcomes in order to allow targeted service improvement efforts, identify notably effective services and settings, appreciate variations in outcomes in providers serving markedly different populations, to permit “risk-adjustments” as appropriate in comparing providers, etc.</p>
K. Charlie Lakin		<p>Page 13</p> <p>1st column, bulleted Cross-Cutting Recommendations: I think it is important to note the importance of “attending to appropriateness in data collection methodologies as well as the simple measures”. There is huge variation in sampling approaches (size of sample, completeness of sample frame), selection and training of data collectors, nature of data collection (phone/face-to-face, individual/proxy, etc.).</p>
K. Charlie Lakin		<p>Page 10</p> <p>2nd column, 1st paragraph: I felt here that the distinctions between measures, measure concepts and instruments broke down a bit with the term measure sometimes being used generically to refer to measures, measure concepts and instruments. This seems exemplified in the last sentence of the</p>

General Comments		
Comment Submitter Name	Comment Submitter Organization	Comment
		paragraph. Also I am not sure of the basis for saying what is written in that last sentence of the paragraph.
K. Charlie Lakin		<p>Page 10</p> <p>1st column, 3rd bullet: I wonder if what an instrument is might be clarified by saying: “An instrument is a survey, scale or other measurement tool that is made up of a range of items that are or could be individually established a measures or measure concepts.”</p>
K. Charlie Lakin		<p>Page 8</p> <p>2nd column, 1st paragraph: delete “though they do not have a 1:1 relationship”. That seems clearly implied by saying they “closely correspond”.</p>
K. Charlie Lakin		<p>Page 7</p> <p>1st column, 2nd paragraph: I would delete the first sentence. I don’t remember a discussion of HCBS “boundaries” being porous or subjective, but more importantly the meaning is not easily apparent and there is no need for observation. In the next sentence I think I might add “variety of HCBS services”</p>
K. Charlie Lakin		<p><u>Page 6</u></p> <p>1st column, last sentence: “The project intends...”. Is there more to come?</p>
K. Charlie Lakin		<p>Page 4</p> <p>1st column, 1st paragraph: I am not sure the relatively novice reader from this what HCBS entails. I think a somewhat more extensive description of HCBS as used in this report would be helpful. Perhaps you could bring forward some of the examples of services from the CMS taxonomy referred to on page 5.</p> <p>1st column, 2nd paragraph: It was unclear to me whether the 13.6 million persons with mental illness were included in the 37 million total with disability. Also I wondered if some brief textual reference (according to...) would be warranted given that often the estimate is +/-56 million.</p>



General Comments		
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K. Charlie Lakin		<p>Page 5</p> <p>2nd column, 2nd paragraph: What about the NCI/DD which is more broadly used (i.e., in more states) than the NCI/AD? Also with referred to the NIDILRR project I would say something like it “aims to develop and/or evaluate existing quality measures”.</p> <p>2nd column, 3rd paragraph: I think it should be noted also that: Even the more widely used measures and instruments lack consistency in their implementation (methods of sampling, selection and training of interviewers, etc.). At the end of that paragraph if you are again note the decentralization of the system, I would again urge to note the reluctance of CMS to establish expectation for quality assessment.</p>
		<p>Page 2</p> <p>2nd column, 1st bullet: Regarding “the lack of standardized measures across the country...” There are some good, widely used measures, albeit imbedded in instruments and work is going on within CMS and the NCI consortiums to establish good psychometrics on them. I think the opportunity to validate, test and promote them is critical to moving forward with some haste to a data-driven approach to quality in HCBS and should be a highlighted imperative.</p> <p>In that same list I would emphasize it is not just the flexibility offered to states that has impeded the development of quality assessment nationally, it is also to low expectation on the part of CMS that states and providers do so. CMS expects other Medicaid LTSS providers, notably nursing facilities to invest extensive efforts in data collection, just not the alternatives to nursing facilities.</p>
K. Charlie Lakin		<p>Page 3</p> <p>1st column, 1st bullet: Again, seriously, this is a \$150 billion industry that has extremely poor evaluation expectations and performance. There needs to be some priority placed on what is being bought and whether it fulfills the intent of the programs provided.</p>

General Comments		
Comment Submitter Name	Comment Submitter Organization	Comment
		In the list of cross-cutting recommendations, I think again that the limited expectations of CMS need to be highlighted.
<b>Lauren Aforatus</b>	Family Voices NJ	Thank you for the opportunity to provide input on “Addressing Performance Measure Gaps in Home and Community-Based Services to Support Community Living: Priorities for Measure Development.” The Statewide Parent Advocacy Network (SPAN) is NJ’s federally designated Parent Training and Information Center. Family Voices (FV) is a national network that works to “keep families at the center of children’s healthcare.” The NJ State Affiliate Organization for FV is housed at SPAN, which is also the home of the Family-to-Family Health Information Center and chapter of the Federation of Families for Children’s Mental Health. The Family Voices Coordinator also serves as volunteer for the National Alliance on Mental Illness as well as NJ representative for the Caregiver Action Network, addressing caregiver issues across the lifespan. Thank you again for the opportunity to provide input.
<b>Elizabeth Cullen</b>	The Jewish Federations of North America	<p>finally, we appreciate the discussion of measurement gaps (pages 11-12). To avoid silos, we suggest cross-referencing and coordinating the identified gaps with the high priority gaps identified by the NQF Workgroup on Persons Dually Eligible for Medicare and Medicaid:</p> <ul style="list-style-type: none"> <li>- Goal-directed, person-centered care planning and implementation</li> </ul> <p>All of these are included in the HCBS report, except systems to coordinate healthcare with non-medical community-resources and service providers.</p> <ul style="list-style-type: none"> <li>- Shared decision-making</li> <li>- Systems to coordinate healthcare with non-medical community resources and service providers</li> <li>- Beneficiary sense of control/autonomy/self-determination</li> <li>- Psychosocial needs</li> <li>- Community integration/inclusion and participation</li> <li>- Optimal functioning (e.g., improving when possible, maintaining, managing decline)</li> </ul>

## Letters and Attachments



July 15, 2016

DELIVERED ELECTRONICALLY

Joe Caldwell, PhD  
H. Stephen Kaye, PhD  
Co-Chairs  
National Quality Forum  
Committee on Home and Community Based Services

Dr. Caldwell, Dr. Kaye, other Committee Members, and NQF Staff,

Please find the public comments submitted by the Service Employees International Union (SEIU) on the Committee's third interim report, *Addressing Performance Measure Gaps in Home and Community Based Services to Support Community Living –Priorities for Measure Development*, attached below.

SEIU would like to commend the work of National Quality Forum (NQF) and the Committee thus far in developing a Home and Community Based Services (HCBS) framework, definition, domains and subdomains that are of excellent quality. SEIU would also like to commend the Committee members for acknowledging the crucial role of the direct care workforce in the HCBS system, and the need to recognize and support these workers.

SEIU represents over 500,000 home care workers across the country who provide hands-on HCBS services to individuals with Long-Term Services and Supports (LTSS) needs in 22 states across the country. The inclusion of workforce in the development of an HCBS quality framework is essential, and in addition to considering the crucial elements of wages and training. As the work of the Committee continues, SEIU urges the Committee to consider additional factors, like recruitment and retention, turnover and vacancy rates, career advancement opportunities, and the overall funding and resourcing of the HCBS system generally and of the workforce in particular when considering and recommending measures and measure concepts.

SEIU thanks the Committee for the opportunity to submit comments on the interim report, and very much look forward to our continued participation in this very challenging, but critical work. If you have any questions about these comments, please do not hesitate to contact Allicyn Wilde, Policy Coordinator, at [allicyn.wilde@seiu.org](mailto:allicyn.wilde@seiu.org), or (617) 316-0440.

Sincerely,

/s/  
Arun Ivatury,  
Policy Director  
Service Employees International Union

MARY KAY HENRY  
International President

GERRY HUDSON  
International Secretary-Treasurer

NEAL BISNO  
Executive Vice President

LUISA BLUE  
Executive Vice President

HEATHER CONROY  
Executive Vice President

SCOTT COURTNEY  
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## Operational Definition and Conceptual Framework

SEIU commends the Committee and NQF staff for putting together an excellent operational definition for HCBS. We are particularly pleased that the report identifies characteristics of a high quality system, and highlights workforce among those characteristics. Additionally, the work done to improve and clarify the domains and subdomains within the framework is clearly substantial, and we would like to thank the Committee and staff for their thoughtful revisions from the previous report, which help significantly clarify the framework overall and set realistic expectations as to what should and can be measured. In particular, we would like to thank the committee for the work done in the Workforce domain, and for incorporating many of the suggestions we and others made in the last round of public comment.

## Draft Cross-Cutting Recommendations

The report recognizes the importance of all the domains and the need to treat them equally, and we agree whole heartedly. Quality measures in the HCBS system(s) have been long overdue, and many of the domains and subdomains that the Committee has identified lack meaningful measures and measure concepts – or even basic and consistent data collection. Prioritizing specific domains over others creates a risk that CMS or other entities that may utilize this framework would focus exclusively on areas where there has been some prior development, to the detriment of other areas in desperate need of attention. At the same time, we recognize the functional need for some prioritization in order to give future work a place to start and focus efforts. Therefore, we would urge the Committee to make specific recommendations for prioritization of at least one subdomain within each domain in order to focus the work moving forward while not giving some domains more weight or importance than others. We believe that revisions to the domain specific recommendations could go a long way in achieving a realistic pathway for future quality measure development work – and will discuss further in the Domain Specific Recommendations Section.

The report also emphasizes, and we agree, that all the domains should be measured at all three levels (individual, provider, and system levels) whenever possible. To that end, we recommend editing the fifth bullet point on page 13 of the report to reflect all three levels. Ideally, the language would read:

- *Using systemic, provider or programmatic, and individual level data to develop HCBS quality measures.*

Lastly, on page 13, the first sentence under the “Cross-cutting Recommendations” states that “Committee members emphasized that measurement in all domains should be person-centered, with the goal of improving consumer outcomes and promoting community living.” While we certainly agree with the stated goals, it is unclear what the committee means by the reference to all domain measures being person-centered, since some measures would be systemic (e.g. measuring the number of available workers in a state to

provide needed services), or programmatic (e.g. whether the number and types of workers dispersed meet specific HCBS program needs), and it is not clear how these different types of measures would be person-centered. We urge the Committee to clarify or revise the statement to better convey its meaning.

### **Draft Domain Specific Recommendations**

As we note above, with some refinement the structure proposed in the report—which entails short-term, intermediate, and long-term goals within each domain – could prove a common-sense approach to help those building on the Committee’s work focus on specific areas in order to develop quality measures for HCBS. However, we are concerned that the lack of short-term recommendations in some domains will have the unintended consequence of suggesting that there is no immediate work to be done in those domains.

We are particularly concerned that the workforce domain lacks short term recommendations, even though there are indeed short-term steps that can be taken to adopt meaningful workforce measures, with the longer term goals of linking those workforce measures to other quality outcomes. The measure compendium issued in the second interim report identified seventy-five existing measures and measure concepts, which on further examination and Committee approval, could be recommended for broad adoption. We strongly urge the Committee to continue to refine its work on the Domain Specific Recommendations and create meaningful short-term recommendations within each domain, and especially within the workforce domain. Specific short-term recommendations are included in the “Additional Examples of Measures or Measure Concepts” section of our comments.

### **Highlighted examples of Measures or Measure Concepts and Instruments within Domain Recommendations**

Within the report most of the recommendations in every domain are very vague, and we are concerned that, as currently written, the recommendations will not be useful to HHS, CMS or other measure developers. We strongly recommend that work be done to include Committee-approved specific measure concept examples and measure examples in each domain, as this would be much more helpful to measure developers – particularly in their short-term work. The compendium of measures and measure concepts was a good initial and necessary step to build upon existing work, but the Committee now needs to review and evaluate those measures, and then make specific recommendations based on that analysis in the three categories within each domain. The Committee should specifically develop short term workforce recommendations, which are currently not included in the report.

### **Additional Examples of Measures or Measure Concepts that Assess the Domains and/or Subdomains of HCBS Quality Measures**

As noted above, the Final Report should be as specific as possible in terms of developing useful and concrete recommendations in order to best facilitate the continuation of this

important work. Below is a table with several examples of more specific and detailed measure concepts for the subdomains within the Workforce Domain that the Committee could explore.

### Workforce Domain Detailed Measure Concepts

Subdomain	Short-term	Intermediate	Long-Term
Person-centered Approach to Services	Collect data on whether person-centered approaches are encouraged or prioritized in service delivery, and to what level	Percent of workers who have access to training on person-centered approaches  Percentage of workers who completed person-centered approaches training	Percent of direct care workers able to successfully apply person-centered approach in daily work (use data from worker and consumer experience survey, and compare to key outcomes measures)
Demonstrated Competencies, Where Appropriate	Collect data on whether competency requirements are in place, and whether training to achieve competency within HCBS programs is available	Number and type of competencies required percentage of workers demonstrating competencies in daily work	Workforce and consumer experience/satisfaction regarding demonstrated competencies
Safety and Respect for the Worker	Number and percentage of workers reporting safety issues, injuries or adverse treatment  Number of service disruptions caused by worker injury (e.g. days of work missed due to safety issues or injury)	Number and type of responses (e.g. simple reporting, process for resolution) to reports of safety issues, injuries, or adverse treatment	Number and percentage of safety issues or reports of adverse treatment that were resolved successfully
Sufficient Numbers, Dispersion and Availability	Average annual turnover rate by setting and job title (percentage of direct care workers that left their position as a proportion of total staff employed during reporting period)  Percentage of workers retained during the	Proportion of available direct care workers compared to individuals seeking services, or providers seeking employees), stratified by geography and other socio-demographic indicators; average vacancy rate by setting and job title	Existence of workforce recruitment and retention strategy and impact on turnover and availability

	<p>reporting period</p> <p>Average amount of time it takes for consumers to find workers/services</p>		
Adequate Compensation & Benefits	<p>Average hourly wage by setting and job title</p> <p>Average hours worked weekly by program type and job title</p> <p>Proportion of average hourly wage to local living wage standards;</p> <p>Percentage of workers earning a living wage by setting and job title</p>	<p>Compare data looking at wages rates against turnover data.</p> <p>Percentage of direct care workers with no health insurance coverage from any source, by setting and job title</p> <p>Percentage of direct care workers with affordable employer-provided health insurance coverage provided by, by setting and job title</p> <p>Percentage of direct care workers with paid sick or vacation leave, by setting and job title</p>	<p>Compare turnover rates to consumer satisfaction and key quality outcome measures</p> <p>Compare availability of affordable health insurance, paid leave, and full-time employment to worker satisfaction and key quality outcome measures</p>
Culturally Competent	<p>Workforce demographics in comparison to consumer demographics</p> <p>(need to examine whether the NQF endorsed (#1919) Cultural Competence Implementation measure is appropriate for HCBS settings)</p>	<p>Percentage of direct care workers who have access to cultural competency training</p> <p>Percentage of workers who have completed cultural competency training</p> <p>Percentage of HCBS providers who utilized Cultural Competence Implementation Measures</p>	<p>Workforce and consumer experience/satisfaction outcomes regarding cultural competency</p>



Workforce Engagement	<p>Collect data on existence of workforce representation and ability to provide input within the system and at program/provider level</p> <p>Number of opportunities for stakeholder input where direct care workers are invited to participate in past year; Number of instances when direct care workers provided input</p>	<p>Number and percentage of coordinated care teams in which direct care worker is able to participate</p> <p>Number and percent of coordinated care teams which a direct care worker does participate</p>	<p>Performance of care coordination teams in reduction of avoidable outcomes when a direct care worker is included v. when a direct care worker is not included</p>
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### General Comments

Again, SEIU applauds the great work of the Committee and staff that has been done so far in this ambitious and difficult undertaking. HCBS quality measures are long overdue, and we encourage the ongoing work of the committee and final report to be as specific as possible in your recommendations so that they can serve as a useful foundation for continued work on HCBS quality measure development and implementation.