PUBLIC AND NQF MEMBER COMMENTS ON MEASUING HCBS QUALITY 2ND INTERIM REPORT

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Overview of Comments Received on the 2nd Interim Report

The National Quality Forum (NQF) was fortunate to receive over 50 comment submissions from advocacy and trade organizations, state agencies, special interest groups, researchers, and home and community based services (HCBS) consumers and their family members or caregivers. NQF received general comments on the second interim report, and specific comments on the compendium of measures, review of selected quality measurement initiatives, and the annotated bibliography. Comments across these topics fell into three broad themes: 1) measurement domains and sub-domains; 2) importance of and challenges facing HCBS quality measurement and 3) balancing the breadth and depth of HCBS measures. Comments were generally supportive of the report and provided several suggestions for next steps. The Committee discussed these public comments at the January 29th, 2016 web meeting. During this discussion, one major point of clarification was raised – the purpose of the compendium. Some comments appeared to interpret the compendium as a set of measures recommended for immediate implementation or representative of the "best" HCBS quality measures. Others suggested that the compendium is a representative sample of the current HCBS measurement landscape and its primary purpose is to be a tool for the Committee to use in identifying and prioritizing measurement gaps. The Committee will use the compendium and incorporate the issues highlighted in the comments during its upcoming prioritization work.

Measurement Domains and Sub-domains

Comments pertaining to the measurement domains and sub-domains focused on the distribution of measures across domains and the need for additional domain and sub-domain refinement. Comments noted the lack of or very small number of measures in the Consumer Voice, Equity, Community Inclusion, Caregiver Support, and Human and Legal Rights domains. Some comments suggested these domains should be prioritized for further measure development. Comments noted a need to delineate differences among domains and sub-domains. The Committee discussed comments pertaining to the place of medically-focused measures within the current set of domains and whether such measures were within the scope of HCBS. The Committee did not reach a final decision on this issue but did acknowledge the issue should be discussed further and supported the need for greater domain and sub-domain refinement.

Importance of and Challenges facing HCBS Quality Measurement

Comments from HCBS consumers or their family members/caregivers strongly supported the importance of and need for assessing and monitoring HCBS quality, but emphasized that quality initiatives and measurements must be person-centered and warned against a one-size-fit all approach. Other comments highlighted the complexities of capturing many of the concepts encompassed by the measurement domains and noted the dearth of valid and reliable measures for many of these complex concepts. The Committee acknowledged there are many challenges to HCBS quality measurement, particularly the difficulty of determining what level of analysis is necessary and appropriate for a given measurement domain or sub-domain. The Committee agreed that any approach to measurement must, at its core, be person-centered.

Balancing the Breadth and Depth of HCBS Measures

Given the large number of measures within the compendium, some comments called for the development of a smaller, harmonized set of measures while other warned against taking a one size fits all approach to quality measurement. The Committee agreed there needs to be a discussion at the in-person meeting around whether to prioritize cross-cutting or population/setting specific measures.

GENERAL COMMENTS ON THE SECOND INTERIM REPORT

Submitter Name	Submitter Organization	Comment
Zim Olson	Zim Mathematics	Hello: I notice you make some effort to determine if the Rubber is actually meeting the Road. As most organizations say they do. But is there any real standard of Indepenced and Truthful evaluation of this. I did not see any. And if I did I would be VERY doubtful that it was any kind of authentic. Every body who evaluates is basically feeding out of the same trough as those they are evaluating. And as most of us know this metaphor can be SUBSTANTIALLY embellished.
Leslie Anderson	Services for Independent Living	Services for Independent Living, a federally-funded Center providing services to the aging and individuals with disabilities since 1980, applauds the Committee for the substantial time and effort to address the issue of service delivery and outcomes related to Home and Community-Based Services. The global shift from institutional care to person-centered care presents challenges beyond the expectation of primarily allocating funds. The following comments are in response to the interim report published in December 2015. 1) The Environmental Context states that $75 billion was spent on HCBS and $71 billion for institutional care. Our questions are: a. Is the $71 billion adjusted by any provider tax? b. For direct comparison of costs, should the costs be derived by only health-care related costs? The report refers to supported employment as being HCBS, yet a person cannot live in an institution and be employed. 2) Under Equity Domain, safe, accessible, and affordable housing is listed as the Subdomain. Unless there are nationally-adopted standards, this outcome will be unachievable. 3) Since HCBS has been further defined as person-centered, should all the measuring instruments

		use person-centered language? 4) Each state, Washington, Oregon, Minnesota, selected for examination has a form of managed care for the majority of Medicaid recipients. Minnesota appears to be the only state that participates in a testing method to capture consumer perspective without involvement of the managed care organization or the administration. We oppose any measurement that marginalizes a consumer's independent evaluation of service delivery, quality of life, and overall customer experience. 5) How will conflicts be measured between an individual having more control over their care compared to the selected outcomes meant to demonstrate value? Thank you for the opportunity to issue comments on the work of the National Quality Forum, and we look forward to your responses in the near future. Respectfully Submitted, Leslie A. Anderson Director of Public Policy & Advocacy
Jeffery Fox	Abilities First, Inc.	I have review the 2nd interim report. From the perspective of a person who has a background in psychometrics and also deals daily with an uncoordinated approach to measurement from state government, it's a pleasure to see the committee approach this in such a methodical fashion. My greatest concern about measuring outcomes for community-based services is the subjectivity involved and the heightened need for valid and reliable measures. I would be very interested in learning more about how NQF can deliver the final results of this project to CMS and states. I am hopeful that NYS would draw on the results of the project to establish meaningful benchmarks as it moves toward a Value Based Payment system, and I would use my interactions with our state officials and our NYS trade associations to bring attention to this work.

David Bulkowski	Disability Advocates of Kent County	Medical-Model vs. Person Centered Approach Having worked in both an AAA and a CIL (both in Michigan since the beginning of HCBS demonstration projects in the late 1990's), I have noticed that quality and success, due to organizational mindset, are measured in far different ways. This is important to realize when measuring HCBS quality, as what is termed a success by one organization (meeting budget and fulfilling contract obligations) may be seen as a failure by another (large percentage of persons requesting services do not receive them due to their 'high need' or 'cost per unit' of service). In working in an AAA, I observed that there is a high value placed on fulfilling contract obligations and serving the largest amount of people with the fewest amount of services. In one light, this can be seen as high quality, as AAAs are serving more people and hence, giving more of the community access to services. Persons with high needs are often deemed by AAAs as 'not appropriate' for HCBS due to their high needs or lack of available housing with contracted providers. Even though the cost in the community would still be lower than the cost of providing services in an institution.However, as a CIL standard, success is not measured in this way. If 10 people ask for home and community based services (instead of receiving services in an "institutional setting") and 8 of them require extensive HCBS to thrive (i.e. 2 person transfers, motorized wheelchairs, many hours of nursing services), is it truly quality if only 20% of the people who have requested services are served? If a person has been institutionalized for many years, and require extensive IL services (pre- and post- transition), is it quality if a transition is done in 6 months or less, or is it quality if barriers are removed at the consumer's pace, so that a person can thrive in their chosen environment – even though the transition will take more one-on-one time and a transition may take even years for the person to transition from an Institution. Since joining a CIL and working side by side with AAA, I have seen numerous cases of a person being "dropped" as non-compliant by AAA so that it is not a transitional failure by the institution or by lack of appropriate/requested services, but rather deemed client choice. These same people have been 'picked up' by a CIL and even if it takes another year, are able to receive the skills and encouragement needed to thrive in a HCBS. I encourage the NQF consider the definition of quality as more than "number transitioned" or "cost per person" and to consider other measures of quality, such as has the transition to HCBS effectively eliminated a person's barriers and whether those requesting HCBS receiving needed services(regardless of higher cost).

David Bulkowski	Disability Advocates of Kent County	Measuring Quality when the tool to determine service provision is flawed The main tool for determining a person's level of services in an institutional setting and in the community (the Level of Care Determination or LOCD) is flawed and subjective. Revision of this tool is not the purpose of this public comment period, but I feel that it should be mentioned and considered when quality measures are put in place. In Michigan alone, there have been several groups convened to address measurement and quality issues with the LOCD. One that I have served on identified over 75 major issues. Two of the top five are: the measurements are subjective and not clearly defined; and different agencies interpret the components of the LOCD differently. This results in cases such as a person not meeting LOC in a NF, but meeting the Criteria for Waiver-based HCBS provision (which, as a criteria for admission into these HCBS programs, one must meet LOCD in a Nursing Facility). Or, a person deemed not meeting the LOCD because of a lack of needing physical assistance, but due to the administer's misunderstanding of mental health, dementia, and behaviors (or differing interpretations of the severity of such), a person is deemed "safe" to receive a lower level of HCBS in the community. Consistently, the person soon fails, resulting in a return to acute care services, lower quality of life, and in some cases, death. In my opinion, until this tool can be made more objective and training is given to those who administer it to assure consistency, measuring the quality of HCBS (which also use a version of LOCD to determine service continuance) is not possible.

David Bulkowski	Disability Advocates of Kent County	Measuring Quality when Consumers are not receiving appropriate services As mentioned, I have witnessed consumers transitioned from an institutional setting into the community with inadequate services, especially in the mental health arena. People with mental health diagnoses who do not meet door 1 of LOC are being told they do not meet LOC in any of the 7 doors (even though one could argue that they fit in one of the six 'more subjective' doors, but NFs are worried about being audited by someone who wouldn't agree with their observations and then be denied income). This means HCBS (such as intensive counseling or placement in a specialized assisted living or adult foster care home) are not available to the consumer and they must get their services through CMH and/or Home Chore services following discharge. In our area, there is a clear policy written by CMH that a person cannot sign up for CMH services until they have left the institution and consumers are told they must physically go to a CMH location to sign up after they have a permanent address. Due to a lack of funding, there are waiting lists, which often leave gaps in services. This result of a high rate of failure is inevitable. I have witnessed persons who desire to live in the community and receive HCBS be denied due to 'lack of a safe discharge' due to this gap in services, as well as have observed persons entering the community only to be re-institutionalized quickly (or in one case, dying) because proper services could not be set up to assure continuity of service once a person reentered the community. Also there are not adequate services to assist persons interested in HCBS. Those with multiple physical or mental health needs are often passed over and not 'allowed' to enter HCBS due to their high service cost or lack of providers (becasue of low payments and limited funding discouraging more from becoming HCBS providers). I have been told by waiver agents that 'home chore services provided by DHHS' are the only services allowed to be paid for by waiver agents, and if those do not provide adequately, then a person is not a candidate for HCBS. This doesn't make sense to me, when I'm relatively sure that persons in a NF receive more required care than just what a home chore worker would provide. I have also received calls from home chore providers asking if there is anything that can be done if they are only allowed 5 hours of service per week and they feel 10 to 15 are needed. Unfortunately, once service is set up (which cannot be applied for until a person leaves a nursing facility and may take up to 6 weeks to start), there is a long process to be reevaluated, and in the meantime, a person decompensates and returns to an institution when an increase in HCBS would have resulted in a person's ability to stay in the community.

David Bulkowski	Disability Advocates of Kent County	Measuring Quality as 'success' and 'failure' when failure is required to receive appropriate services Of late, our Center for Independent Living has been overrun with requests for help transitioning persons not meeting Level of Care in a nursing facility, but clearly needing extensive mental health services that would best be provided in a structured environment (i.e. specialized group home). However, at least in our service area, it is a requirement that a person "fail" in a general adult foster home before being put on a waiting list to be considered for one of the (far too few in number) specialized home or to be considered for "specialized" (more than once per month) counseling services. If quality is measured in terms of only 'is a person receiving needed services,' or 'quality of care in their environment', then we have already set up many HCBS to fail. They will receive low marks due to turnover or inability to provide needed services, because the correct services are not available when needed. How can quality be measured effectively if the quantity doesn't exist and persons are put into unsafe HCBS environments while waiting to be given appropriate services? In conclusion, I encourage the federal government to look past simple measurements to effectiveness, and also measure and identify the cause of what may be perceived by some as "low quality". Simply, there are too many people and not enough money to help everyone. Can we actually use any of the quality evaluation results to show that HCBS offer alternatives to "all" persons who desire to live in less restrictive communities, if we know that to provide our current measure of "quality" and "success", the system is denying persons the right to HCBS who have complex medical issues and are effectively "too sick." If a program like HCBS exists and is to be considered of quality, it needs to help all people who want to live in community, or quit presenting it as an "option for all."
Linda Costal	Linda Costal Inc	Based on my experience as a person that recieve HCB services I would like to suggest some universal measures that I think will lend themselves to finding out the quality and comparison in different states. number of hours of direct care services in ISP (individual service Plan) the % of hours in ISP that are provided. the number of social outing more than 1 mile from residence % of perticipants that individually decide what they want to eat without having to choose from a set menu

		average number of emergence room visits- this speaks to quality of health sustaining care. how many social trips where transportation is paid by the state vs participant % of participant go to store to choose food. % of participants that go to the store to choose new clothes. These measures would need to be broken down the broad groups like: people 60 - 69 70 -79 80 and older people under the age of sixty people with development disabilities. people who aquire disability over the age of 22 people with physical disabilities people with mental health disabilities people with intellectual disabilities people who use a consumer controlled model of receiving HCB services after these providers get use to these, later you could add by race and ethnisity, sexual orintation, and any other group you would like to test

Kerri Melda	Council on Quality and Leadership	Thank you for including the Council on Quality and Leadership's (CQL's) Personal Outcome Measures (POM) in Table 3: Example of Instruments. To clarify, the POM covers the domains listed (choice and control; effectiveness; and quality of services), and also includes your domains of human and legal rights, community inclusion and service delivery. For the domain descriptions, we recommend person-centered language (vs. system-centered or service-centered), emphasizing the outcome for the individual rather than the action of the service system. Thank you for your hard work.
Frankie Schindler	RAMP	The first suggestion that came to mind is to have person first language used universally, but that is not what we are discussing today. Maybe that is a good way to transition to the comments that I have as an advocate that works at a Center for Independent Living. My primary role at the center is to be a transition coordinator for the Money follows the person program, a program that assists indivudals out of the nursing home to their own home with HCBS's. I as a case manager have limits and barriers when creating a service plan to fit each person. I find it trully difficult to match the needs to the resources that are available, specifically to people with severe mental illness. The door has been closed on this population at this point in the area our Center covers. Many times there are not the "right resources" for when home services are offered, which results in limited choices. Many people are required to fit into a specific "box" if they have a chance of qualifying for services. Being measured by what looks best for most is not the way to measure all. HCBS's are essential for individuals to have a continued choice of their lives and needs to be looked at in such a degree of prevalence and importance of that individual and their needs when considering the forms of measurement for services offered. I don't see how HCBS's can defined as such when they are restricted and measured by a system not by their effectiveness to allow an indivdual to remain in their home.
Lindsay Schwartz	American Health Care Association/National Center for Assisted Living	Again, AHCA/NCAL appreciates the opportunity to comment on this report. As stated in previous comments, AHCA/NCAL suggests NQF keep in mind the populations receiving home and community-based services have a wide range of needs and desires and recommends care be taken to ensure any future quality measurement recommendations do not prioritize the needs and desires of one population over another. If one of the goals of measuring quality is to provide tools to help consumers make informed choices, it seems important to consider, for example, that the aspects of care and life that represent "quality" to individuals with dementia (and their caregivers) may be different than for those without cognitive limitations.

Rick Henley	Seniorlink	On behalf of Caregiver Homes, a division of Seniorlink, I am pleased to submit these comments in response to the National Quality Forum's (NQF) 2nd Interim Report. It is clear from the report that the NQF is taking a very thoughtful approach to ensuring that performance measure gaps are clearly identified and appropriately addressed. Caregiver Homes delivers Structured Family Caregiving (SFC) (more commomly known by the generic taxonomy Shared Living) to more than 3,200 consumers across six states by providing professional supports to consumers who need HCBS and their caregivers. Through this service, a qualified, full-time caregiver (often a family member) lives with and assists a consumer (elder or individual with disabilities) thoughout the day, as the consumers's needs and preferences dictate. The consumer and caregiver are supported by a professional care team, typically a nurse and care manager, who provide care coordination and clinical support. We believe it is the combination of family caregiver and professional supports that enables consumers, who otherwise would need services in more restrictive and expensive settings, to live independently in the community setting or their choosing. From the outset, we have been pleased that the NQF has consistently recognized that support for family caregivers is a primary characterisic of any high-quality HCBS. Accordingly, in following the NQF's work in addressing HCBS performance measure gaps in HCBS, we applaud the inclusion of "Caregiver Support" as a measurement domain. It is noteworthy how few measures and instruments are cited for this important aspect of care in the home and community. Caregiver Homes has long observed, and our outcome data supports, the observation that the caregiver is often the critical ingredient to successful HCBS and accomplishing Triple Aim goals. We routinely measure caregiver satisfaction with services, quality of life, general health status, and the degree to which s/he is acknowledged as part of a person-centered care planning process. For example, our work with dementia caregivers is demonstrating that caregiver engagement is characterized and strengthened by meaning and purpose, acceptance of the dementia condition and caregiving role, connection and "attunement" to the individual with dementia, and the assumption of an active role in the individual's healthcare. We look forward to following your continued efforts. We encourage expansion of the role of the caregiver and inclusion of quality measures addressing their invaluable contributions. If we can assist you in any way in the continued development and expansion of quality measures/concepts regarding any of the Caregiver Support sub-domains, please let us know.

		Sincerely, Richard Henley Government and Community Relations Seniorlink/Caregiver Homes
Ivonne Cameron	Hepatitis Foundation International	January 19, 2016 To Whom It May Concern: On behalf of the Hepatitis Foundation International (HFI), we are pleased to be able to share HFI's comments on the National Quality Forum's (NQF) second interim report. HFI is a 501(c) 3 non- profit organization established in 1994 to eradicate viral hepatitis for 400 million people globally. HFI is also dedicated to increasing and promoting health and wellness, as well as, reducing the incidence of preventable liver-related chronic diseases and lifestyles that negatively impact the liver. Some of these diseases include obesity, diabetes, hepatitis, substance abuse, HIV/AIDS, cardiovascular disease, fatty liver disease and liver cancer. We implement our mission through our touchstones to educate, prevent, serve, support, and reach well over 5 million patients and health care professionals annually. While HFI believes in the general goals stated in this report, we have some concerns regarding implementation. Our first concern is with the variety of data collection within the U.S. The quality measurement initiative data is only collected from 3 states, Minnesota, Oregon, and Washington. It is important to collect data from a number of different states in order to gather a more representative sample. Another consideration that NQF may need to take into account are states who have not expanded Medicaid. Since this interim report only deals with the effectiveness of people on Medicaid, a more diverse representation of other populations is recommended. Finally, other topical issues such as timeliness and sustainability should also be explored in future reports. The Hepatitis Foundation International has a number of additional questions and concerns regarding the interim report found below:

		Could the data collected from this program pose as a framework for a long term services and support programs directed towards people in states that have not expanded Medicaid? Does the NQF plan to expand their framework to measure how other programs related to HCBS personalize health care for individuals who require long term services and supports? Can other programs, especially non-government funded groups, adopt some of these measures to improve outcomes for their target population? We commend the NQF for their progress and substantive work on addressing the gaps in Home and Community Based Services (HCBS) quality measurement. Thank you for the opportunity to comment on this critical issue. Do not hesitate to contact me directly at ifcameron@hepatitisfoundation.orgor by telephone at (301)-565-9410 if we can be of further assistance. Sincerely, Ivonne Fuller Cameron CEO, Hepatitis Foundation International

Kimberly Austin-Oser	SEIU Healthcare	The environmental scan of select international and state HCBS related programs was interesting and helpful in terms of creating a much needed informational tool that will prove especially useful in our future analysis of key measures and gap areas. Here are a few comments for consideration: The sub-domains need sharpening - the content areas tend to bleed into one another creating unnecessary repetition as well as confusing and unrealistic measurement language and expectations. There are some obvious measurement disparities. A few that jump out relate to the inadequacy of the workforce metrics – they lack both breadth and depth as far as system performance and accountability. And, the overall scan sample appears to collect data from programs not necessarily in line with the direction the industry is moving – such as managed, coordinated, and accountable care. Each of these models approach the management and delivery of HCBS in very different ways and, as a result, may impact individual, provider, and system outcomes in very different ways. This is an essential contextual element that must be addressed though we recognize it may fall more appropriately within the dimensions of the conceptual framework than the domains and sub-domains categories. Also, we suggest NQF and/or the committee consider including the GAO's December 2015 report to congress on the Health Care Workforce – Comprehensive Planning by HHS Needed to Meet National Needs, as a part of our research materials informing the discussion and analysis in workforce related areas. While this report is not focused on HCBS or the front-line direct care workforce specifically, it does address the overarching need for comprehensive healthcare workforce planning, coordination, and oversight that is responsive to industry dynamics, which we believe is quite applicable given the context of this project and the system component of the contextual framework.

Alice Dembner	Community Catalyst	NQF's report shows we have a misalignment in the measures across domains: while some domains have more than 100 measures, measure concepts, and instruments, one key domain (consumer voice) has none.We believe that NQF should work toward a small set of measures in each domain that is simple, meaningful and universally adopted. This means winnowing measures in overrepresented domains. It also means NQF should identify ways to spur measure development in three domains where the scan found few or no measures, concepts or instruments.These are: Consumer Voice, Equity and Community Inclusion.They are crucial to the goal of measurement – ensuring HCBS enable consumers to live with dignity, independence and community participation. Consumer Voice is essential because consumers and their family members know first-hand what they need, what is working, and what needs to be changed.For programs to be responsive to their needs, consumers must be at the decision-making tables for design, implementation, oversight and evaluation of HCBS. Measures must assess consumer engagement and the degree to which their input results in change in policy or practices, because input without impact can be meaningless.Also critical is measuring the diversity of consumer voices participating. Community Catalyst has extensive experience in facilitating consumer voice and can meet with NQF to share ideas for measure concepts.The financial alignment demonstrations, which include HCBS, can provide some measure concepts. We recommend prioritizing the Equity domain because of the extent of disparities throughout health care and society, particularly disparities in quality and volume of services based on race, ethnicity, income and disability status. NQF's report on health disparities and cultural competencies provides a starting point for development of HCBS measures of reduction in health/service disparities.The equity measures must include access to a range of services. Underlying any measurement of disparities is the need for data that is disaggregated by age, race, ethnicity, primary language, gender identity, sexual orientation and disability status. This is needed across all domains. For example, examining data from the Choice and Control domain measures by race and ethnicity may help identify equity or inequity. Another important element of equity is the extent to which the workforce is racially and ethnically representative of people receiving HCBS and is culturally and linguistically competent. These measures are currently part of the Workforce domain and should be prioritized. Finally, we urge you to focus on the domain of Community Inclusion, which can spell the difference between an individual surviving and truly thriving. Helping to move measure concepts to actual outcome measures in this arena -- for achieving desired levels of social and civic engagement, employment and education -- is key.

Carmella Bocchino	America's Health Insurance Plans	While we support the need to address performance measure gaps for Home and Community-Based Services (HCBS) and agree that the report aligns with the National Quality strategy, we feel there are several areas NQF should revisit and review prior to finalizing the report. First, the report should be revised to include a clear and defined framework outlining the intent and goals of the identified measures, how these measures will drive an effective HCBS system, and identify specific stakeholder roles. Secondly, we believe that additional organizations, including states who have experience with administering long term services and supports, e.g., Arizona, New York, and Texas, should be included in the conversation prior to the finalization of the report. This will ensure that the experience of these states in providing effective managed long-term support services is reflected in the selection of measures to assess the quality of care for home and community-based services. Thirdly, we recommend NQF consider addressing transitions of care to home and community-based facilities and caregiver support. Addressing transitions of care, especially where a patient transitions from a higher level of care to that of HCBS, is critical in ensuring patients are able to navigate the system, and in matching patients to specific HCBS services needed to promote independence in the community. We also recommend addressing the current gaps that exist regarding caregiver support and patient and caregiver navigation (i.e., family members/caregivers), including education surrounding HCBS resources, awareness of financial options for the patient, and overall patient and caregiver support during transitions from higher levels of care to HCBS which are critical to patient outcomes. Lastly, the measures resulting from this work seem best suited for Medicaid waiver programs, since Long Term Support and Services (LTSS) and Long Term Care (LTC) benefits are already included in those programs. We are concerned that requiring additional responsibilities of LTSS/LTC benefits in commercial health insurance could dramatically increase premiums for consumers and affect sustainability and stability for members' health coverage.

Jennifer Dexter	Easter Seals	On behalf of Easter Seals and other adult day services providers, I wish to commend NQF on this important step forward in beginning to crystallize what methods and measures will best capture quality in adult day services and other HCBS settings. This is an important step in assuring that HCBS are recognized as an equal part of the health care continuum. The compendium, in particular, is an impressive piece of work. The process of identifying and condensing all of the existing work was much needed and will be very useful. As we move forward, I wish to remind the committee of an undertaking by the National Adult Day Services Association that will be helpful as a filter through which to view the information in the compendium. In June, 2015, the National Adult Day Services Association, a key HCBS stakeholder group, convened a group of premier researchers, state associations, providers and others with the goal of identifying the domains of outcomes in ADS and to recommend possible measures of those outcomes. Measure selection criteria are listed below. Next steps include a national town hall in August 2015 call to gather input on proposed domains and recommended measures from the field followed by presentation at the NADSA national conference in October 2015. Both Easter Seals and NADSA continues to track the great work of this NQF committee and looks forward to collaborating as both NQF and NADSA efforts proceed. NADSA Criteria for Selection of Outcome Domains and Measures: i. Measures should be appropriate for the setting and people served ii. Measures should be easy to use and to train for use by any level of staff iii. Outcomes assessment should not be time-consuming to administer iv. Measure the right thing—outcomes that are important to potential funders but also reflect what ADS programs can accomplish v. Measures should be valid and reliable, if at all possible vi. Measures should be in the public domain and available for use without cost vii. Outcome measures should contribute to continuous quality improvement

		viii.Measures should fit into the usual way ADS programs are conducted ix. Some outcome measures will need to be translated into cost avoidance calculations (e.g., reducing repeat hospitalizations) We hope that these principles will prove useful as the process moves forward. Thank you for your consideration.
Jenel Lim	County of San Diego	Aging & Independence Services is the AAA for San Diego County, a core partner in San Diego County's Aging and Disability Resource Connection (ADRC), and is the County's umbrella agency under the Health and Human Services Agency for more than 30 different programs for older adults and persons with disabilities. San Diego County is one of seven counties in California implementing the Coordinated Care Initiative (CCI) which encompasses the integration of Medicare and Medi-Cal (Medicaid) as well as four long term services and supports (LTSS), In-Home Supportive Services, the Multipurpose Senior Services Program (MSSP), Home and Community Based Services (HCBS) and Skilled Nursing care, into Medi-Cal managed care. We commend the HCBS Committee, NQF Project Satff and HHS Advisory Group for the tremendous effort to address systematic measurement of HCBS. Almost 90% of residents receiving care through Medi-Cal in San Diego County are enrolled in a managed care health plan, which under the CCI, includes the provision of HCBS. States that are participating in CMS' dual demonstration projects should be required to have HEDIS and CAHPS measures that thoroughly address, in a person-centered manner, the utilization and quality improvement of home and community cased care services. The utilization of person-centered, coordinated HCBS by healthcare payers and providers have confirmed through other CMS demonstrations like the Community-based Care Transitions Program (CCTP) that HCBS improve quality of care and results in significant reduction of healthcare expenditures.

Amy Ingham	Anthem	Anthem appreciates this opportunity to provide comments to the National Quality Forum's Stakeholder Committee on its second interim report assessing quality measurement of home and community-based services (HCBS). Anthem's health plans are proud to 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 assessment of the HCBS quality measurement landscape to identify gaps and provide recommendations to the Department of Health and Human Services (HHS). Anthem believes that HCBS quality assessment should include targeted, meaningful, and tested measures focused on the outcomes and quality of life of members, including family and caregivers, which account for the support provided in helping members achieve their goals. To best facilitate implementation of these measures among health plans and others, Anthem encourages the Committee to consider prioritization of measures that can be derived from information/data that is already routinely collected. Overall, the domains and subdomains identified by the Committee for assessing quality in HCBS are consistent with priorities Anthem has identified through serving individuals in need of HCBS across eight states. The following is feedback regarding the environmental scan of measures as they relate to the domains: · Consumer Voice. Through the Committee's research, no existing "consumer voice" measures were identified. Anthem believes that successful delivery of HCBS services is best achieved through the involvement of members, family and caregivers, in the development of programs, services or system redesigns to meet population needs– making consumer voice an important part of meaningful service delivery. In order to address the consumer voice measurement gap, we recommend that the Committee look beyond analyzing measures in health care and service delivery programs. Some options may include analyzing best practices on consumer inclusion in Board Governance of organizations and/or studies on civic engagement and participatory policy making in public administration. · Community Integration. We recommend further analysis to assess the rebalancing of funding

		from institutional settings to home- and community-based settings. The effort to rebalance this funding represents an important movement toward respecting individual preference, independence, community integration, and improving the quality of life of beneficiaries and their families. · Self-Determination. The Human and Legal Rights domain should include assessment measures not only related to addressing abuse and neglect but to supporting members in positive aspects of self-determination, such as their ability to reach their goals and participate in the community. · Supported and Informed Decision-Making. Within the Choice and Control domain, we note that a listed measure seeks to assess whether individuals are offered an “informed choice” of services by a case manager. In order for this measure to accurately assess informed decision-making, it should capture that the individual to receive services is informed in a supported fashion, not just presented with information. · Experience and Satisfaction. Accounting for the experience and satisfaction of members is important to ensuring delivery of quality care. As the Committee knows, survey tools, such as the Consumer Assessment of Healthcare Providers and Systems (CAHPS), may prove inaccurate for those receiving HCBS. Anthem supports development of a tailored HCBS experience and satisfaction tool to fit the characteristics of the population and believes that efforts underway to field test HCBS consumer experience measures are a step toward identifying effective methods. Also, as states pilot National Core Indicators for long-term services and supports (LTSS), the Committee should consider how future measurement development can build on existing measures. · Caregiver Support. In reviewing the Committee’s findings that few caregiver measures currently exist, we recommend that this be recognized as a key gap area for continued analysis. We recommend that future support measures include critical aspects of caregiver assistance, such as: information to caregivers about available services; caregiver counseling; training; respite care to temporarily relieve caregivers from responsibilities; and access to supplemental services. Anthem appreciates the Committee’s efforts and look forward to providing additional input as this work continues. Should you have questions, please contact Amy Ingham at (202) 508-7890 or Amy.Ingham@Anthem.com

Lucille Pivinski	Parent & Advocate	Thank you NQF for your excellent work on this critical matter. In particular, it is promising to see reflected in your draft a respect for the individual's personal preferences and desired outcomes. I pray you will stay the course and keep the focus on what is important to the individual as he or she experiences her own life. Consistent with this focus, I offer the following comments and suggestions for your consideration. With respect to the Operational Definition of HCBS - Just as "quality" of life is as one experiences it, being integrated, being included, being in community with others is a personal sense of belonging and connectedness that is experienced uniquely by each individual. It cannot be defined or imposed on them by others. "Public policy" and the voices of "others" should not be used to steer individuals into lives reflecting someone else's notion of what should be preferred. What others "think" is integration in the greater community, my adult daughter with autism experiences as isolation. She feels lost and confused in the sea of faces and a storm of "noise". Like many people with I/DD, she interacts with the greater community on a regular basis but in small doses and with alot of support. In her much preferred (by her) smaller setting, she experiences life with a much greater degree of freedom and independence and yes, happiness. She shares her life with people she has chosen and who have chosen her based on feelings of trust, acceptance and shared interests and not in accordance with a philosophy that some people are to be valued more highly than others as friends and neighbors. People with I/DD should not have to forego fundamental rights to live their lives in ways they prefer and with people they choose in order to accomplish someone else's agenda. They should not be coerced by threats of forfeiting life-enabling supports based on someone else's ideology. Please resist defining quality, services, supports and settings in any way that is not truly respectful of the individual whose life it is to live. In order to avoid an artificial, arbitrary, non-experiential notion of an integrated community, I recommend simplifying the language at the end of the Operational Definition of HCBS to a more neutral, less judgemental broader concept of community::..........and that are delivered in the home or other community setting of their choosing. Thank you for the opportuniy to comment. Sincerely, Lucille Pivinski, on behalf of my daughter. Her life. Her way. Support that!
Katie Roeper	Virginia Department for Aging and Rehabilitative Serives	The Department applauds the National Quality Forum HCBS Committee, Project Staff and HHS Advisory Group for their work in establishing a conceptual framework for measurement and the environmental scan. One area that Virginia has been working on through No Wrong Door, is the development of a logic model and measures related to community tenure. Ultimately, this would be a comparative measure developed to show progress over time, with sub-measures that correspond to demographics and service provision. Community tenure is a cross-cutting measure that touches a number of domains including service delivery, system performance, effectiveness and health and well-being. As Virginia continues to develop the framework for measuring community tenure through No Wrong Door, it would be valuable to better understand how NQF has considered it as an objective measure. Thank

		you for sharing this interim report and for the opportunity to provide comments. We look forward to learning more as the committee continues its valuable work.
Rochelle Bobroff	AARP	Legal Counsel for the Elderly (LCE) advocates for the rights of D.C. seniors to basic human needs such as income, housing, public benefits including health care and personal assistance, personal autonomy and consumer protection. Within LCE, the DC Long-Term Care Ombudsman Program (DCLTCOP), advocates for approximately 6,000 residents receiving long-term care services in nursing homes, assisted living residences, community residence facilities and in their homes through the Elderly and Persons with Physical Disabilities (EPD) Waiver. Accessibility: In the future, the EPD waiver case manager will be located at a different home care agency than the home health aide providing personal care aide (PCA) services. It will be important for performance measures to assess whether the case managers who provide care coordination are less accessible, when they are no longer working for the same home care agency. Availability of Services: While the EPD waiver in the District has many components, including Environmental Accessibility Adaptations (EAA) to provide home modifications, we learned through a FOIA request that in three years, only one individual obtained EAA (compared to thousands who received PCA services). No individuals were reported to have received homemaker services in that three year period, despite those services being listed as available under the waiver. In addition, it would be desirable to focus on the provision of services to the neediest clients. We recommend that quality measures reflect not only whether a service is provided but also whether it can meet the needs of individuals with severe disabilities who need 24 hour care. Skilled, Demonstrated Competencies: We recommend that dementia-care training include training on basics about psychotropic drugs. We also recommend measurement of staff receiving training on cultural competency, including effective communication with individuals who have limited English proficiency. Freedom from Abuse and Neglect: We suggest looking more broadly at complaints, not limiting the inquiry to those that have been substantiated. We would also suggest that the data compiled by this measure be evaluated periodically to look for trends (e.g., by area, by provider, by employee, by type of alleged abuse/neglect, etc.).

		Social Participation: We suggest that the review of social participation measure the appropriateness, quantity and quality of different options offered to individuals obtaining HCBS, breaking out by age and waiver programs. Safe, Accessible and Affordable Housing: Possible measurement standards might include the number of people leaving nursing facilities who have obtained Housing Choice Vouchers and/or housing in federally subsidized buildings, compared with the total number residents who requested subsidized housing. We thank you for receiving our comments. Tina Nelson Managing Attorney Lynne Person DC Long-Term Care Ombudsman
Amy Hewitt	University of Minnesota	The Research and Training Center on Home and Community Based Outcome Measurement (RRTCOM) has developed a comprehensive document providing feedback the to the NQF on its 2nd report regarding HCBS Outcome Measurement. This report provides feedback in the following areas: 1) Problems with the narrowly defined "measure" in the context of HCBS, 2) Lack of person centered focus, 3) Continued medical/health care focus, 3) Need for improvement in measurement in HCBS outcomes not medically focused, 4) Identifying HCBS relevant instruments from which possible measures might be drawn, and 5) Next steps. This report will be sent to NQF staff and ACL staff and is available through the RRTCOM by e-mailing hewit005@umn.edu. The 3,000 limit on characters made it impossible to share in this format.

Mary Lou Breslin	DREDF	Thank you for the opportunity to comment on the NQF HCBS quality measures second draft report. While we appreciate the work of NQF to identify HCBS measures, measure concepts and instruments related to HCBS, we are concerned that the focus of the HCBS quality measures project has drifted significantly from one of its original purposes: to identify measures that emphasize person-centeredness and that promote and support consumer choice, control and community inclusion. Specifically, we are concerned that many measures, measure concepts and instruments that are presently in use or are in development are not identified and included for the domains of Community Inclusion, Equity, Consumer Voice, and even Choice and Control. While measures related to providers, administrators and health-related issues are important and relevant, the draft report's strong focus on domains other than those that are person-centered indicates a departure from a central purpose of the quality measures project and undercut the goal of enhancing consumer direction, choice and control. We urge the NQF staff to review the recently released, "Measuring Quality in Home and Community-Based Services: Selected Inventory of Consumer and Caregiver Survey Questions Related to the National Quality Forum HCBS Domains, by H. Stephen Kaye, PH.D., Community Living Policy Center, University of California San Francisco. Professor Kaye has produced a comprehensive inventory of quality concepts that already have been used to assess the different domains of HCBS quality. While much work remains, this inventory emphasizes person-centered questions that should be reviewed and considered in order to strengthen and redirect the current draft. Thank you for your attention to these comments. Mary Lou Breslin Senior Policy Advisor Disability Rights Education and Defense Fund (DREDF)

Lucille Pivinski	Parent & Advocate	Thank you NQF for an opportunity to comment further. Re Characteristics of High-Quality HCBS. Item 6 is a very complex issue that has recently been used as an excuse for failure to protect very vulnerable individuals who are at high risk for injury to self and others, incarceration, and even death. Please consider expanding this item to at a minimum ensure that the individual is offered reasonable/sufficient/comprehensive? information and input from trusted others to assist him or her in determining the balance of personal safety and dignity of risk that they are comfortable with. Re: items 8 and 9 - Family members/caregivers have extensive knowledge of their loved ones and yet the valuable contribution they can make to all aspects of person-centered planning seems to be minimized, overlooked, missing in this draft. I include here the following suggested revisions with respect to this issue contributed by long-time advocate Lila Klausman, President of Parents Planning Programs (PPP) for the Developmentally Disabled of Florida, Inc. Suggested revisions include: item 8 Supports family caregivers and invites their expertise and input.. Item 9 Engages individuals who use HCBS and their families and designated representatives in the design, implementation, on-going evaluation and delivery of services in all aspects of HCBS provided to the individual consumer. Respectfully submitted, Lucille Pivinski
Marybeth Mccaffrey	UMass, Center for Health Law and Economics	Dear Members of the NQF HCBS Quality Committee, Thank you for your continued effort to build a shared vocabulary for quality outcome measurement between disaparate sectors of the health continuum. The Measure Compendium, Annotated Bibliography and Second Interim Report offer a rich and needed synthesis of information to advance quality measurement. I am concerned that the Compendium excludes interRAI measures which can be constructed from the Minimum Data Set for Home Care (MDS-HC) tool. The MDS-HC is used across care settings by Arkansas, Connecticut, Georgia, Iowa, Indiana, Louisiana, Maryland, Massachusetts, Michigan, Mississippi, Missouri, New York, Oregon and Vermont. (www.balancingincentivesprogram.org/sites/default/files/CSA_State_Summary_2015_v3.pdf) This assessment data offers a readily available source to construct outcome measures related to the effectiveness of services, individual health and well-being, as well as community inclusion. The interRAI measures would enable some states to leverage data already being collected by aggregating results of individual assessments, creating benchmarks for participant outcomes and determining whether specific programs, providers, or regions have best practices that lead to better participant outcomes and quality of life. The measures have been published in peer-reviewed articles

		(Hirdes, John P., et al. Home Care Quality Indicators (HCQIs) Based on the MDS-HC. Gerontologist. Vol. 44, No. 5, 2004; Morris, John N. et. al. InterRAI Home Care Quality Indicators. BMC Geriatrics Vol. 13, No. 127, 2013). The measures have been used to compare quality outcomes in European countries (Dalby, Dawn M., et al. Variations of Quality of Home Care Between Sites Across Europe as Measured by Home Care Quality Indicators. Aging Clinical and Experimental Research. Vol 19, No. 4, 2007) and Canadian provinces (Mofina, Amanda, et al. A Comparison of Home Care Quality Indicator Rates in Two Canadian Provinces. BMC Health Services Research. Vol. 14, No. 37, 2014). Perhaps the interRAI outcome measures are included in one of the 75 Instruments noted in Table 1 on page 11 of the Second Interim Report? Is it a source for some of the Canadian measures listed in Table 5 of page 19 of the Second Interim Report? Thank you, in advance, for clarifying whether these measures are already in the Compendium and whether the Committee supports states leveraging this ready-made repository of assessment data to measure HCBS outcomes. Respectfully submitted, Marybeth McCaffrey
Ellen O'brien	Ellen O'Brien Consulting	I appreciate the opportunity to comment on “Addressing Performance Measure Gaps in Home and Community-Based Services to Support Community Living: Synthesis of Evidence and Environmental Scan,” Interim Report, December 18, 2015. The report is a useful start, but the report reflects just how far we have to go to arrive at a meaningful set of quality measures for home- and community-based services (HCBS). Interested readers, including the committee members, will need to carefully review the compendium of measures and the 1915(c) measures in order to arrive at an assessment of whether the measures and concepts are “directly relevant to HCBS quality.” (p. 11) Unfortunately, much of what is included here misses the target. Many of the measures and concepts included in the compendium are clinical quality measures. These medically oriented measures can be included in a comprehensive evaluation of an HCBS program, but including these measures in an HCBS compendium risks diverting attention from the committee’s focus. For example, NQF reports, in Table 1 on page 11, that they found 111 measures of the quality and effectiveness of HCBS. Many of the reported measures come from the Home Health Quality Reporting System. Few of these measures seem to align with quality and effectiveness of HCBS as defined by the committee. Other measures (e.g., those associated with the Money Follows the Person evaluation) are more relevant, but are measures of

		utilization rather than quality. Measures of HCBS quality need to focus on the intended outcomes of those services which relate to attainment of life goals and reducing burdens on family caregivers, for example. As the committee continues to identify gaps and set priorities, they will need to provide a more nuanced assessment than the current draft report provides of "what's out there" in terms of HCBS quality measures.
David Ivers	Arkansas Association of Area Agencies on Aging	Thank you for the opportunity to comment. Based on oure experience the following are appropriate measures based on at least some ability of HCBS providers to affect outcomes: 1. Time between care plan and initiation of service delivery (adherence) 2. Provision of hours of approved services provided (adherence) 3. Rate of institutionalization 4. Substantiated allegations of abuse, neglect, maltreatment 5. Client quality of life (with adjustment for client circumstances) 6. Client satisfaction with provider and services Arkansas Association of Area Agencies on Aging
Lucille Pivinski	Parent & Advocate	Further brief suggestions re: wording in this 2nd interim draft: Characteristics of High Quality - item 11 recommend adding the words "and preferences" after the word needs. Domains - Choice and Control - recommend adding the words "and where" after the word how. Community Inclusion - recommend adding the words "with persons of their choosing" after the word connectedness. Thank you. We look further to continued refinements.

Alixe Bonardi	Human Services Research Institute	Below are a few comments for consideration as you move the content of this report forward. The domains represent a thoughtful review by the Committee and NQF staff, although we agree that the subdomains could still be refined, as they overlap in several areas. In the section, where the report provides 'examples', it is unclear how the NQF Committee will move forward from these examples to gain a sense of where there are true gaps in HCBS measures. Are these examples a starting place for the Committee? How will they synthesize the variable extent to which each of these measures and measure concepts may address the domain? This current assessment of measures is high level, and may not provide the committee enough information to determine where there are true gaps. For example, the 'Population of interest' Evaluation Criteria for instruments examine whether the tool has been designed or tested for more than one HCBS population, but does not examine the extent to which it captures or describes a representative portion of any of the populations . The National Core Indicators survey, for example, is administered to a sample of people receiving supports and services from their DD state agency. In most participating states, the sample frame includes every HCBS waiver for adults with DD, and a representative sample is drawn. This allows for state-level reporting, and comparison across the NCI averages with 33 states participating in NCI data collection in 2015-2016 (some states alternate years). NCI-AD has a similar sample strategy, with 14 states participating this year. Will the committee be developing a follow up compendium with synthesized findings? One example of a compendium that he committee may want to consider as a potential format is at. https://umassmed.edu/uploadedFiles/cdder/Health_Surveillance_for_Adults_with_Intellectual_Disabilities/Compendium%20of%20Health%20Data%20Sources%20for%20Adults%20with%20Intellectual%20Disabilities%20FINAL%20tagged.pdf There may be potential bias in the evaluation criteria as designed. For example, the 'Feasibility' criteria prioritize administrative data collection over responses from a single survey respondent. While we recognize that administrative data provides a highly efficient means to collect information relative to

		survey responses, some information are unlikely to be available in administrative records such as reflections on consumer choice and the extent to which consumers voice is included in the design and administration of any given HCBS service. We encourage the committee to continue to focus on the domains that have been agreed upon and, as they develop their recommendations, consider the utility (or not) of existing tools, their current and anticipated reach, and the relationship between the related efforts in HCBS measurement.
Lucille Pivinski	Parent & Advocate	Suggestions on Subdomains Consumer Voice - after level of commitment for consumer involvement - add- level of commitment for involvement of family members/caregivers/trusted others of the individual's choosing. Caregiver Support - add - Family members &/or caregivers given the opportunity to share their person-specific knowledge and contribute to the design and delivery of supports for the individual consumer.
Suzanne Chevallier	Advocacy Center	The Advocacy Center is the protection and advocacy agency in Louisiana. We appreciate that NQF is making a strong effort to measure quality of home and community-based services (HCBS); however, it is true that many of the measures will always be skewed unless a completely neutral party collects the data. One of the programs within the Advocacy Center’s scope is an Ombudsman program for people with developmental disabilities receiving HCBS. We find many people are very afraid to offer even the mildest complaint to their service providers or the state agencies that oversee the program. People are typically afraid of losing the services if they offer criticism in any form. We strongly suggest that NQF not only offer the measurements and metrics to CMS, but also make a strong suggestion as to how the data is collected. We note that in general key words that long-term supports and services was used, but not long-term care. Although, we recognize that this term is not current, we wonder if there would be more tools and metrics available if this term were considered? In addition, although we recognize that it is not the fault of NQF that there are few or no metrics in the areas of Consumer Voice, Equity, Community Inclusion, Caregiver Support, and Human and Legal Rights, it is our experience that these areas are of great importance to people receiving HCBS. We hope a recommendation can be made to CMS to fund a design and study of tools that can measure quality in these areas. As the report points out, participants of HCBS are susceptible to being victim of substantial abuse, neglect or exploitation. In our work we see many participants of HCBS who become victims of these types of abuses by their caregivers (paid staff/family members).

Joan Carr	concerned citizen	Alaska has 47,000 lives for each SNF or NH bed, logistics are a nightmare. Would suggest some folks actually travel to Alaska and experience their processes. Reading about them doesn't do the efforts Alaskans justice because your reading material leaves out the roving wild animals, distances, snow, seasonal sunshine, and let's not forget the honey-pots!
Michael Feore		Please refer to my comments in the measuement section.
Marilee Fosbre	Home and Community Services Division Aging and Long Term Support Administration	a. Page 15, 2nd Paragraph under Examples of HCBS Quality Measurement Activities: Washington is in the early stages of implementing two measure sets within the state—one for use in contracts with agencies providing HCBS services and the other for public and private health providers. Recommend: Adding the word “in” between is and the b. Page 15, 1st Paragraph under Washington: Approximately 84 percent of Washington State Medicaid enrollees receive long-term services and supports in a home or community setting.10 Comment: Endnote #10 is not current or is inactive c. Page 15, 2nd Paragraph under Washington: Washington state agencies are working to select a subset of performance measures for initial adoption and inclusion in their 2016 contracts with providers. Recommend: Adding the subset of measures in a table TYPE MEASURE SOURCE Annual-experience measures Adults’ Access to Preventative/Ambulatory Care NCQA HEDIS Annual-experience measures Alcohol/Drug Treatment Penetration Rate State defined Annual-experience measures Mental Health Treatment Penetration Rate State defined Index-event measures Plan All-Cause Readmission Rate NCQA HEDIS Utilization measures Emergency Department (ED) Visits CHIPRA Utilization measures Home and Community-Based Service (HCBS) State defined d. Page 31, #7: Supplies and supports an appropriately skilled workforce that is stable and adequate to meet demand. Comment: Does the service supply the workforce in a person-driven system? This seems somewhat contradictory.

		e. Page 31, Workforce: The adequacy and appropriateness of the provider network and HCBS workforce. Comment: Appropriate is unclear here. How would "appropriate" be measured? What does that mean in this context? f. Page 33, Workforce: a. "Sufficient numbers and appropriately dispersed" Comment: It seems clearer to say sufficient numbers in all areas, rather than "appropriately dispersed". b. "Adequately compensated, with benefits" Comment: This may be a goal in itself for the workforce but is it a quality measure for HCB services? Are there studies which link workforce compensation and benefits with quality of care? c. "Value Based leadership" Comment: What is the quality measure with "value-based leadership"? g. Page 33, Care Giver Support: Training and skill-building; access to resources (e.g., respite, crisis support); caregiver well-being (e.g., stress reduction, coping); caregiver and/or family assessment and planning; compensation. Comment: This may be a goal in itself for the workforce but is it a quality measure for HCB services? Are there studies which link workforce compensation and benefits with quality of care?
Amy Hewitt and Brian Abery Co-Directors, RRTCOM	University of Minnesota, Research and Training Center on Community Living	As the Co-Directors and Co-Investigators of the recently funded Rehabilitation Research and Training Center (RRTC) on Home and Community Based Services Outcome Measurement (HCBSOM), we would like to take the opportunity to offer comments with respect to the recently released NQF report entitled *Performance Measure Gaps in Home and Community-Based Services to Support Community Living: Synthesis of Evidence and Environmental Scan.* ***Problem with a Narrowly Defined "Measure" in the Context of HCBS Outcomes*** The report starts (p. 3) by defining a measure, measure concept, and instrument. A measure is defined as "a metric that has a specific numerator and denominator and has undergone scientific testing." Although it is helpful to operationally define these constructs, the conceptualization of a measure limited only to metrics that possess a numerator and denominator is both narrow and likely to lead to an over simplification of many of the

		outcomes that persons who receive HCBS deem to be most critical (e.g., community inclusion, self-determination, etc.). This approach limits the ability to fully understand the experiences and outcomes of persons who receive HCBS to things that can be counted, in spite of the fact that many of the most important social psychological outcomes associated with HCBS cannot be fully understood by simple frequency counts or proportions. The operational definitions of measurement constructs provided in the report may be well suited for medical and health-related outcomes measurement. However, they do not capture the complexity of measures needed to assess HCBS outcomes in their full breadth and depth for people with different types of disabilities. It is imperative for the field to remember what sociologist William Bruce Cameron (1963) declared over 50-years ago when he stated that: *"It would be nice if all of the data which sociologists require could be enumerated because then we could run them through "computers" and draw charts as the economists do. However, not everything that can be counted counts, and not everything that counts can be counted."* On p. 9 of the 2nd draft NQF report, the authors state that they removed 2,461 measures from their review because they did not specify a numerator or a denominator. This suggests that a medical or healthcare measurement orientation has been adopted by the NQF to study outcomes that are not medical in nature. We believe that this approach has little potential to lead to an understanding of complex psychosocial variables of importance to HCBS recipients and payers. A basic difference between the healthcare and human services fields that does not appear to have been taken into account by the authors of the report is that in medicine and the rehabilitation sciences, specific guidelines can be generated for expected processes or outcomes for patients (e.g. healthy range of blood pressure, red blood cell count, range of motion). For many HCBS outcomes, however, especially those associated with domains that the authors appear to conclude are not or are minimally covered by existing HCBS outcome measurement instruments (e.g., consumer voice, equity, community inclusion and caregiver support) there are no specific guidelines through which to establish numerator values.

		The self-determination construct provides a good example of the difficulties encountered in assessing HCBS outcomes in the manner suggested in the report. Although it is clear that self-determination is an outcome highly valued by persons with disabilities, the degree of control over life, including choices and decisions, that people desire varies considerably from individual to individual based on age, cultural group membership, and a host of other personal and environmental characteristics. As a result, we lack the capacity to specify, for a broad group of individuals of varied ages, cultural group membership, and disabilities the degree of choice and control over those aspects of life that people deem most important that should be considered to be within an optimal or satisfactory range Unlike the medical field, the degree of personal control that a person desires to exercise and over what aspects of life, will vary so significantly by person that attempting to establish “numerators” would be a futile effort. It must also be understood that medical patients of different age groups with different health care conditions do not necessarily equate with people with different types of disabilities (e.g., autism spectrum disorder (ASD), intellectual disability (ID), traumatic brain injury (TBI), physical disability (PD) or mental health challenges (MH). One individual person with ASD may have a much in common with a person with a MH condition, while another may have much more in common with someone with ID when compared on a different set of outcomes. Due to the set of operational definitions of measures adopted by the authors, for which no real scientific, philosophical, or other justification is provided, thousands of potential HCBS outcome measures have been excluded from the NQF 2nd report based on the exclusionary criteria adopted, that desperately needs to be examined for people across different types of disabilities (see Table 1, pp. 11). The report’s conclusion that 0 measures, measure concepts, or instruments are available that assess *consumer voice* and almost as few that assess *equity*, *community inclusion* and *caregiver support* has the potential to provide readers with the mistaken impression that little work has been undertaken at the federal, state, and local level to assess these constructs which are critical for an understanding of HCBS outcomes. In fact, significant work has been undertaken in developing measures within each of these areas which are widely used. This is not to suggest that these measures are sufficient;

		many are in dire need of further study to establish their psychometric qualities. However, is it misleading to imply that only those measures that possess both a numerator and denominator are either needed or sufficient to understand the outcomes of persons who receive HCBS. ***Lack of a Person-Centered Focus*** In 2014, Centers for Medicare and Medicaid Services (CMS) issued a new rule on HCBS that emphasizes the importance of *person-centered services*. The rule also highlighted the need for the measurement of *person-centered outcomes* including choice, privacy, and community inclusion in the most integrated settings. In order to assess these outcomes in the most valid way, CMS advises the use of measurement approaches that are based on an individual's experience and choices rather than those focused primarily, if not solely, on location, geography and/or physical characteristics. Person-centered outcomes, first and foremost, need to address what individuals who are the recipients of HCBS services experience (i.e., the quality of life that they live). In spite of the recent CMS recommendations, and the draft NQF framework, the measurement focus in the most recent NQF report (including the majority of examples and illustrations the authors use) focus on program or what might be referred to as systems performance/outcomes. It is important to acknowledge that the performance of those organizations that provide HCBS is a critical aspect of measurement systems. It is also apparent that these types of outcomes easily lend themselves to frequency counts (e.g., percentage of home care patients who receive their first nursing visit within 5 days of authorization; whether a person had access to a person-centered planning facilitator; how many times a person was taken in to the community in the past month). However, systems performance also needs to be considered an intermediate outcome with the most critical variable of interest needing to be the extent to which program recipients experience the types and quality of life they desire. Although system performance is included in the draft NQF framework for HCBS Outcome measurement, many of the more person oriented domains and subdomains are hardly discussed in spite of the fact that many of these (e.g. Consumer Voice; Community Inclusion) are by the author's own admission measures that are few and far between.

		It is disappointing that the concept of person-centered outcomes and outcome measurement are barely touched on in the report in spite of the fact that at least some attempts have been made to go beyond the measurement of what people experience to measuring whether the recipients of services experience *the types of outcomes they desire* (i.e., person-centered outcomes). For example, within the PEONIES program, efforts were made to include items that attended to individual personal preference and to develop a process for assessing whether goals for the person based on these preferences were met or not. The absence of measures that provide information as to whether the recipients of HCBS are receiving services and supports based upon their preferences and the outcomes toward which they desire to work and achieve is a critical gap in current measurement systems. However, the lack of measures in the area of person-centeredness is perhaps largely due to a lack of measure development and not necessarily because this type of measure cannot be developed. It would appear the many of the “measures” identified and/or highlighted in the report do not focus on the actual outcomes that *individual* receiving HCBS experience, but rather, even in areas such as choice and control, “system level outcomes.” In many areas, the measures do not reflect an attempt to integrate in to measurement systems data with respect to what people desire to experience, but rather, appear based on the perception that more is necessarily “better” (i.e. more friends, more community outings). ***Continued Medical/Health Care Focus*** On p. 7, the report states that “Throughout this project, NQF will continue to be guided by related efforts (e.g., the CMS planning grants (i.e., TEFT) and build on previously completed work such as the Prioritizing Measure Gaps projects on Alzheimer’s Disease and Related Dementias, Care Coordination, and Person-Centered Care… .” In addition, the large majority of examples provided in the report suggest that the majority of past measurement efforts that NQF will be using as their guide are based upon a healthcare perspective and the application of a medical model (e.g. Patient Health Questionnaire-9 (PHQ- 9); Consumer Assessment of Healthcare Providers and Systems (CAHPS®) Survey measures). Unfortunately, this approach does not suit measurement of many of the outcome domains and subdomains that the draft

		NQF framework identifies as important indices of quality. ***Need for Improvement in Measurement of HCBS Outcomes Not Medically Focused*** We agree with report that, despite the existence of several established frameworks and/or lists of quality measurement domains for Long Term Services and Supports (LTSS) and HCBS, the availability and uptake of performance measures remains limited and lack uniformity across states and other levels of analysis (e.g., provider, managed care organization) exists. In light of the increasing use of HCBS nationally and the associated costs, this is a deficit in quality measurement. The question is, however, what methods are going to be used to fill in the gap? Analysis of the 2nd NQF report on HCBS clearly highlights the need to move away from the medical and health models and reinvent measure evaluation of HCBS outcomes that truly reflect those aspects of quality of life that matter most to HCBS recipients (who are individuals with disabilities) in their daily lives. In doing so, there is a need to avoid oversimplification of concepts and constructs, such as those that have not been successfully reviewed in this report (e.g., Consumer Voice and Self-Determination). A thorough investigation needs to be conducted not only to validate the NQF domains and subdomains with HCBS recipients across different populations, but also to arrive at scientifically-based conclusion as to which concepts and constructs it makes sense and is possible to specify a numerator and denominator as well as how to best measure outcomes in their true complexities. Meeting the “measure” criteria set forth in the NQF 2nd draft report may be possible for some of the outcomes that previous research in the disability field clearly indicates significantly contribute to the quality of life experienced by individuals. One example of how this might be undertaken relates to the construct of self-determination (which is in itself a far more complex concept than choice and control). Based on previous research (Stancliffe & Abery, 2003; Abery & Stancliffe, 1997; 2003) it is likely that such a measure could be defined with a numerator. The formula for the numerator may not, however, be a simple frequency count or proportion, but rather, far more complex formula taking into account not only the extent to which individuals make choices and decisions but how much control they desire over various aspects of life, and how

		important each aspect of life assessed is to them. On the other hand, asking people whether, they have as much control over their life as they want is a potential simple self-determination measure, which has a denominator (number of people surveyed) and a numerator (number saying yes). ***Identifying HCBS relevant instruments from which possible measure might be drawn*** Many of the instruments identified in the NQF 2nd draft report appear to have nothing to do with HCBS. It would be more clear had relevant HCBS instruments been identified and the questions aligned as “measure concepts” within the HCBS framework domains. Had this been the approach taken, more person-centered, non-medical measures would have been seen under domains. It is clear that NQF does not endorse instruments; however, the identification of instruments in the environmental scan confuses the issue. A companion document to this feedback is a recent report written by Steve Kaye (Kaye, 2016) who is an investigator in the RRTCOM. This document breaks down the relevant instruments by domain and provides a useful picture of potential measures that are relevant to the NQF HCBS framework. We urge the NQF to focus their work on certain HCBS survey instruments (those included in the report authored by Steve Kaye and those that have been identified by the RRTCOM) and organize these within the measure framework. One important note is that the “Consumer Voice” domain (which appears to be a systems level domain) had no identified potential measures under it in the NQF environmental scan nor in the Kaye document. It may be important to consider re-evaluating it as a separate domain or as something that likely falls into multiple domains. ***Next Steps*** On p. 22, the report plans next milestones for its work. We think it is important to recognize that the NQF report was intended to be an environmental scan of what is, not what can be or should be. As an environmental scan it is not particularly helpful in prioritizing recommendations for measure development. The NQF committee and staff are encouraged to collaborate with the RRTCOM researchers and staff to come to a common and more relevant

		focus and understanding of outcomes measure for people with different types of disabilities as they live their daily lives. It is important that the people who receive HCBS are able to provide input into how their outcomes are measured before it is concluded that measuring systems outcomes is a sufficient indicator of their life quality and the quality of and outcomes of the HCBS they receive. A more valid approach to finding results that can actually help people with disabilities and their family members plan for and experience more fulfilling and productive lives is needed. Moreover, people who are recipients of HCBS services should be included and involved in all of the processes that are underway (now and in the future) that involve decisions about what and how best to measure the outcomes of their services. If services are going to reflect consumer choice and be person centered, then individuals with disabilities should be at the table when determining what measurements are most appropriate. HCBS outcomes are many and they are complex. The process to develop outcome measures must take into account this complexity and the voices and opinions of HCBS recipients. If sufficient time is taken, we are confident that person-centered outcome measures can be developed across important HCBS domains. **Reference:** Kaye, S. (2016). Measuring Quality in Home and Community Based Services: Selected inventory of consumer and caregiver survey questions related to the National Quality Forum HCBS domains. Community Living Policy Center, University of California San Francisco

Amber Smock	Access Living	On behalf of Access Living, we appreciate this opportunity to comment on the National Quality Forum's Second Interim Report on Performance Measure Gaps in Home- and Community-Based Services (HCBS), issued December 18, 2015. Established in 1980, Access Living is the Center for Independent Living for the Chicago metropolitan area. We are committed to our mission of fostering an inclusive society that enables Chicagoans with disabilities to live independent , fully-engaged, and self-directed lives in their homes and communities. With the advent of mandated state compliance with the new federal regulation on requirements for settings that qualify for federal HCBS funding, we recognize the critical importance of quality measures that will assure that consumers are truly experiencing inclusion in an integrated community setting, satisfaction in their quality of life, and person-centered direction of their services and supports. Oregon's 49-item Individual Experience Assessment (Interim Report, at 16) is a good example of the kind of experiential data that should be captured in order to measure compliance with the new federal regulation on settings. We are very concerned that the Forum found no acceptable measures, measure concepts, or instruments in the domains of consumer voice and community inclusion (Interim Report, at 3, 11), both of which are essential factors in determining the effectiveness of HCBS. Our own research has disclosed some tested, validated, and reputable instruments in these and other areas - including accessibility, transitional care, and functional status -that the Interim Report does not address. We want to assure that the Forum's elimination of 2,461 performance measures that did not specify a numerator or denominator (Interim Report, at 9) will not foreclose the use of valuable measure concepts that could be adapted to meet the Forum 's rigorous quantitative standards. We urge the Forum to take a closer look at the following areas.

		1. Access to Care We did not see mentioned in the Interim Report accessibility to services, referring to the availability of accommodation s to people with disabilities. Health care, for example, is not available to people with disabilities when it is inaccessible. When people with disabilities cannot get in the door, when they cannot get on an examination table, when they cannot be weighed, when they cannot communicate with their providers, they definitionally will not receive even minimally adequate care. We strongly urge the Forum to include measures of accessibility of health care - examination and diagnostic equipment, sign language interpreters -that have been proposed by the highly respected Disability Rights and Education Defense Fund DREDF) 1 and that are mandated by the Affordable Care Act and U.S. Access Board. These essential measures can be adapted and expressed as percentages and subjected to field testing. • Availability of wheelchair-accessible weight scale • Availability of height-adjustable examination table with a minimum height capacity of 17 to 19 inches from floor to top of cushion • Availability of mammography equipment for which the imaging receptor lowers to a minimum height of 24 inches from the floor to the top side of the imaging receptor platform; and with sufficient clear knee space from the stand to the front edge of the imaging receptor to enable wheelchair users to go into position for mammography without running into protruding imaging platforms or tube heads connected to the central stand • Availability of patient print education and instruction materials in alternative formats, e.g., audio recording, large print, digital, Braille • Availability of Sign Language interpreters and assistive listening devices We recommend three additional questions on accessibility that pertain to all HCBS services: • The percentage of consumers reporting that they are able to consult with necessary specialty providers;

		• The percentage of consumers reporting that staff members meet their linguistic and communication preferences and needs; and • The percentage of consumers who report that ADA accommodations are made when requested or needed.2 DREDF also recommends adoption of the "Assessment of Health Plans and Providers by People with Activity Limitations (AHPPPAL),"a field-tested survey of primary care that has adjusted the Consumer Assessment of Healthcare Providers and Systems (CAHPS survey) in ways that measure more accurately the experiences of people with disabilities.3 Care Transitions Another aspect of HCBS that seems to be missing from the Interim Report is not only the number of people moving from institutional care to HCBS but the quality of care transitions, including coordination and continuity of health care and other services as people move from and to different levels of care. Such measures are essential in determining the effectiveness of transitional services in assuring success in the community. We recommend use of the well-tested and accepted Care Transition Measure (CTM), developed at the University of Colorado Health Sciences Center. The CTM has been tested and endorsed by HHS-CMS and by scholars alike.4 Indeed, one source found a significant correlation between CTM scores and readmission after discharge,5 and inclusion of these measures therefore can be of assistance in preventive steps to avoid costly readmissions. The three CTM questions or statements testing consumer understanding of hospital transition factors are: During this hospital stay, staff took my preferences and those of my family or caregiver into account in deciding what my healthcare needs would be when I left. When I left the hospital, I had a good understanding of the things I was responsible for in managing my health. When I left the hospital, I clearly understood the purpose for taking each of my medications. Each of

		these questions can be adapted to state a percentage in accordance with the Forum's standards. We recommend two additional questions on the transitional process, both of which would also require adapting to a percentages measure. Length of time to transfer to a community setting after being determined eligible Availability of peer support and peer recovery specialists to assist with the process of transition. Care Coordination A central feature of Medicaid managed care is care coordination and its projected impact in avoiding inefficiency, redundancy, and waste in a fragmented care system. Care coordination will be of utmost importance in assuring that community resources can be marshaled in an efficacious and cost-effective manner. While the Interim Report does mention care coordination, it seems to address only the single measure of whether consumers were "able to contact" their care coordinators. (Interim Report, at 12) We commend inclusion of this measure but urge that it be broadened to encompass other factors, such as length of time required to make contact, the frequency of contacts, whether the contacts helped consumers get services they needed, and -of great significance in determining the success of person-centered planning now mandated by the new federal rule on HCBS settings -the degree to which consumers participate in service-related planning with care coordinators and direct service-related choices and decisions. The National Core Indicators, which the Interim Report recognizes as a valuable resource, include several measures on care coordination that address these areas,6 and we urge that they be recognized and adopted by the Forum. They are: • The percentage of people reporting that care coordinators ask them what they want; • The percentage of people reporting that their care coordinators help them get what they need; • The percentage of people who have met their care coordinators; • The percentage of people who report that care coordinators call them back right • away;

		• The percentage of people who were involved in creating their care plan. Because Access Living's consumers in the Illinois Medicaid managed care program have reported to us extended delays in being assigned care coordinators and receiving services, we also recommend the additional three questions (after adaptation to meet Forum percentages standards): • The length of time from enrollment to assignment of a care coordinator; • The length of time from assignment of a care coordinator to the commencement of coordinated services. • Number of face-to-face meetings with a care coordinator in the last three months. Quality of Life To a large extent, the success of HCBS services may be measured by how consumers perceive their quality of life. We commend the Forum's inclusion of Wisconsin's PEONIES survey (Interim Report, at 14), which measures quality of life from the consumer's perspective. Functional Status and Quality of Life To assure that HCBS services are adequately meeting needs, it is essential to assess consumers' functional status with a focus on optimizing or maintaining functional status or, at a minimum, preventing deterioration. We recommend the tested and well-respected Medicare Health Outcomes Survey (HOS),7 which examines functional status from the consumer's perspective and includes physical activity level and emotional state. The HOS instrument and program is described as "a valuable tool that provides a rich set of data that is useful for quality monitoring and improvement efforts."8 One advantage of using the HOS functional status data is its usefulness in identifying consumers who are at risk of declining physical and mental functioning,9 thus providing opportunities for preventive intervention and avoidance

		of costly institutional care. Community Integration Drawing from extensive work done by researchers and from measures put into practice in several health care organizations, the authors of a 2005 article have proposed measures specifically geared to integration of people with disabilities into the community.[10] Some of those measures gather valuable information, expressed in percentages, reflecting independent living goals and provide useful measures in addition to those in the PEONIES survey. We recommend inclusion of the following: • Percentage of consumers reporting involvement in planning, designing, delivering, and evaluating their home and community services; • Percentage of consumers reporting full-time, part-time, or temporary employment; • Percentage of consumers able to transition off SSI because they have attained stable employment; • Percentage of consumers who report improvement in their housing situation. We also recommend inclusion of one additional measure relating to community integration: Percentage of consumers who report they are informed about available community services. Conclusion With respect to both consumer satisfaction and successful outcomes in community integration, input from consumers themselves -who do, after all, know best what does and does not work for them -is essential. We believe that the best measures of success in HCBS provision are those that place primacy on the consumer voice, and we thank the Forum for this opportunity to comment on those gaps in the performance measures selected in the Interim Report.

		Very truly yours, Amber Smock Director of Advocacy, Access Living asmock@accessliving.org 1Breslin, M.L., Disability Rights and Education Defense Fund (DREDF}, Letter to AHRQ, Health Quality Measures for Medicaid Eligible Adults (March 2011), pp. 2-3, htto://www.thearc.org/document.doc?id=3260 2 Breslin, M.L., Disability Rights and Education Defense Fund (DREDF), Letter to AHRQ, Health Quality Measures for Medicaid Eligible Adults (March 2011), p. 4, htto://www.thearc.org/document.doc?id=3260 3 Breslin, M.L., DREDF, Letter to AHRQ, Health Quality Measures for Medicaid Eligible Adults (March 2011), p. 6 (adjusted CAHPS, or AHPPPAL, has been field tested and validated and provides an important new tool); Mastal, M., Palsbo, S., "Measuring the Effectiveness of Managed Care for Adults with Disabilities" (Center for Health Care Strategies, Inc., 2005), p. 19, http://www.chcs. org/usr doc/CCOMeasures final.pdf ; http://www.chcs.org/resource/assessment-of-health-plans-and-providers-by-people-with-activitv-limitations/ 4 http://hin.com/blog/2012/04/27 /new-hcahps-measure-would-evaluate-guality-of-care-transitions/ ; Coleman, E., Parry, C., Chalmers, S., Chugh, A., Mahoney, E., "The Central Role of Performance Measurement in Improving the Quality of Transitional Care," Home Health Care Services Quarterly, Vol. 26, Iss. 4, 2007 5 Axon, R. N., Williams, M.V., "Eliminating Hospital Readmissions" National Quality Measures Clearinghouse, June 25, 2012, http://www. gualitvmeasures.ahrg.gov/expert/expert-

		commentar:y.aspx?id=37 562 6 http://www.nationalcoreindicators. org/indicators/domain/system-performance/service-coordination 7 http://www.hosonline.org/surveys/hos/download/HOS 2012 Survey.pdf 8 Jones, N., Jones, S., Miller, N., "The Medicare Heath Outcomes Survey program: Overview, context, and near- term prospects" Health Quality Life Outcomes, 2:33, July 12, 2004, http://www.ncbi.nlm.nih.gov/pmc/articles/PMC4 79698/ 9 Biennan AS, Clancy CM. "Health Disparities Among Older Women: Identifying Opportunities to Improve Quality of Care and Functional Health Outcomes," Journal of the American Medical Women's Association Fall 2001. 200I;56: 155-160. 10 Mastal, M., Palsbo, S., "Measuring the Effectiveness of Managed Care for Adults with Disabilities" (Center for Health Care Strategies, Inc., 2005), p. I 9, http://www.chcs.org/usr doc/CCOMeasures final.pdf
Nicole T. Jorwic	The Arc of the United States	Thank you for the opportunity to comment on the second interim report from the National Quality Forum "Addressing Performance Measure Gaps in Home and Community-Based Services to Support Community Living: Synthesis of Evidence and Environmental Scan." We commend the research and leadership on this issue. We support the overall framework. These comments are submitted on behalf of The Arc of the United States. The Arc is the largest national community-based organization advocating for people with intellectual and developmental disabilities (I/DD) and their families. In reviewing the evidence and environmental scan there are several resources, particularly the National Core Indicators (NCI) and the Council on Quality Leadership (CQL)'s personal outcome measures, that are imperative to capturing the quality of life of an individual with intellectual

		disabilities. These resources are particularly useful in looking at the following domains that were includes in the interim report: • Consumer Voice • Choice and Control • Human and Legal Rights • Effectiveness/Quality of Services • Health and Well Being • Community Inclusion • Equity Because of the unique needs of individuals with intellectual and developmental disabilities, we encourage NQF to continue to develop measures for capturing the quality of those domains.

Submitter Name	Submitter Organization	Comment
Peter Notarstefano	LeadingAge	Medically-oriented Measures We suggest NQF highlight the importance of the more medically-oriented measures currently being used by HCBS providers, and Managed Care organizations. MedPAC has estimated that 76 percent of 30-day readmissions for Medicare beneficiaries overall were due to five potentially preventable conditions (heart failure, electrolyte imbalance, respiratory infection, sepsis, and urinary tract infection (MedPAC 2007). A 2006 Duke University study on reasons why individuals were placed in an institutionincluded (a) the need for more skilled care (65%); (b) the caregivers' health (49%); (c) the patients' dementia-related behaviors (46%); and (d) the need for more assistance (23%).[2] The medically-oriented measures address many of the reasons why individuals may have poor outcomes that result in institutionalization. Recommendation:We do not believe that because a measure contains a medical focus, NQF should deem it not appropriate for HCBS. Two of the aims of the National Quality Strategy are to provide Better Care: Improve the overall quality, by making health care more patient-centered,reliable, accessible, and safe; and Healthy People/Healthy Communities: Improve the health of the U.S. population by supporting proven interventions to address behavioral, social and, environmental determinants of health in addition to delivering higher-quality care.An important priority of the National Quality Strategy is “Promoting the most effective prevention and treatment practices for the leading causes of mortality, starting with cardiovascular disease”. In the Project Overview of the Second Interim Report, the purpose of this project is to “advance the aims and priorities of the Affordable Care Act, the NQS, and the previous work of the HHS Community Living Council. The use of medically-oriented measures aligns with the project’s purpose. Draft NQF Domains and Subdomains of HCBS Quality Measurement : Equity There are statewide variations in HCBS due to the state’s LTSS delivery system, approved Medicaid waivers and state plan services, as well as state regulations. Rural and frontier parts of our country have a challenge with the lack of affordable transportation, and provider

		options. Recommendation:We suggest NQF review the information on the CMS Data metrics and Medicaid Access to Care request. CMS asked for feedback on whether and what core access measures thresholds and access resolution techniques would be useful inimproving compliance with Medicaid access requirements.[5] The RFI includes information on the impact of provider reimbursement and geography (rural, frontier) on access to care, including HCBS. Again, LeadingAge appreciates the opportunity to comment on this interim report. We look forward to our continued work with you on this and related issues. Sincerely, Cheryl Phillips, MD Senior VP Public Policy and Advocacy
Jill Kagan	ARCH National Respite Network and Resource Center	I support the comments from LeadingAge about the importance of including caregiver outcomes and appropriate meaningful measures. Thank you for including the ARCH document Measuring Systems Change and Consumer Outcomes: Recommendations for Developing Performance Metrics for State Lifespan Respite Programs, 2014, in your Annotated Bibliography. This document proposed suggested caregiver, care recipient and system change outcomes resulting from respite care use that were carefully based on the work of a prestigious Data Workgroup and also taken from the work of many of the current Lifespan Respite grantees. A comprehensive menu of sample measurement tools are included as well. In addition, I wanted to call your attention to a new ARCH document, A Research Agenda for Respite Care: Deliberations of an Expert Panel of Researchers, Advocates and Funders. This report includes a respite research agenda developed by the ARCH Expert Panel on Respite Research convened in collaboration with the Administration for Community Living. Their recommendations call for improvements and expansion of respite research, prinicipally to develop an evidence base for family caregiver, care recipeint, family and societal outcomes resulting from respite use, used alone or as a compenent of more comprehensive caregiver supports. Of particular importance to the work of the National Quality Forum, the report includes a suggested research framework and a schema for possible outcomes (pp 15-20) that builds on the work done in the previous document. The Expert Panel based their deliberations

		on gaps and methodological issues in respite research that were identified by a literature review and summarized in an Annotated Bibliography of Respite and Crisis Care Studies, that may also prove useful in the NQF's efforts. All of these documents can be found on the ARCH website at http://archrespite.org/productspublications. Thank you for providing the ARCH National Respite Network and Resource Center the opportunity to comment.
E. Clarke Ross	Consortium for Citizens with Disabilities	AAHD & Lakeshore Foundation acknowledge the Council for Quality Leadership (CQL) submitted to NQF comment: "We recommend person-centered (vs system-centered or service-centered langauge in domain descriptions, emphasizing the outcome for the individual rather than the action of the service or system." We concur while recognizing the value of system-centered measures. The fundamental starting and core items should be person-centeredness. The balance between the themes (person and system) should be discussed by the NQF HCBS committee. Clarke Ross, American Association on Health and Disability and Lakeshore Foundation
Lindsay Schwartz	American Health Care Association/National Center for Assisted Living	AHCA/NCAL appreciates the opportunity to comment on this interim report and looks forward to continued work with NQF on HCBS quality measures. The compendium of measures was comprehensive and well-organized.

Lindsay Schwartz	American Health Care Association/National Center for Assisted Living	AHCA/NCAL appreciates the opportunity to comment on this interim report and looks forward to continued work with NQF on HCBS quality measures. The compendium of measures was comprehensive and well-organized. Workforce: We are pleased that turnover was included as it has been shown to be directly related to quality of care in skilled nursing centers (Castle, N. G., Engberg, J., & Men, A., 2007). Retention is also an important measure in assessing the stability of the workforce and should be considered as a measure, or possibly a gap in HCBS measurement. AHCA/NCAL has been measuring retention of the long term care workforce with its annual staffing survey. Consumer Voice – Consider changing the name of this domain (possibly consumer participation) as this is an organization's name and could cause confusion among consumers and providers. Caregiver Support – The measures identified seem to focus only on informal (unpaid) caregivers. Measures that should be considered for formal caregivers include employee satisfaction, employee wellness or other support, educations/training, and engagement. Effectiveness – There is considerable overlap between the effectiveness/quality of services domain, service delivery and the system performance domain, with such outcomes as hospital admissions or vaccines. This may be an opportunity to combine domains for simplicity. Castle, N. G., Engberg, J., & Men, A. (2007). Nursing home staff turnover: impact on nursing home compare quality measures. The Gerontologist, 47(5), 650-661. doi: 47/5/650 [pii]

Kimberly Austin-Oser	SEIU Healthcare	The overall compendium of measures provides a comprehensive and well-organized selection of relevant metrics across the identified domains that seems generally useful for our project purposes. The primary focus of our review was around the workforce portion of the compendium. While we recognize this is a representative sampling of what is currently utilized in this particular domain, we found the measures to be limited and inadequate for assessing systemic planning and performance relating to workforce sufficiency, preparedness, protections, and sustainability. We strongly urge the committee to concentrate domain and sub-domain contents pertaining to the frontline workforce to include the following: overall workforce system planning that ensure practices meet healthcare workforce needs and is coordinated across all relevant organizations; recruitment and retention practices including measures pertaining to turnover and vacancy rates; preparedness methods including but not limited to initial and on-going skill development requirements and opportunities that are both relevant for the population being served as well as the development needs of the workforce; workforce safety and protections; career advancement prospects; opportunity for engagement with professional and/or advocacy related workforce organization(s); funding and provider rate sufficiency and sustainability; actual workforce wage data; and, access to health insurance and other benefits.
Abby Marquand	PHI	As stated in our comments on the first interim report, PHI believes that the direct-care workforce is unique in the world of health and human service delivery. Access to high-quality services hinges on a sufficient supply of workers to meet the growing demand, but also their level of skill and preparedness, their likelihood of remaining on the job, and their ability to make ends meet for their own families. Across much of the country, consumer advocates, provider organizations, and direct-care workers themselves point to the various gaps in policy and practice that create barriers to meeting the growing demand for services. The instability in the workforce providing HCBS resulting from poverty level wages, lack of access to employment benefits or labor protections, in particular, if continued, will have a detrimental impact on the system of service delivery. PHI agrees with the Committee's recognition of the central significance of the workforce in HCBS quality. To that end, PHI is encouraged to see several of our proposed workforce subdomains addressed in the compendium of measures, specifically related to workforce vacancy,

		turnover, access to health insurance, and paid leave. However, major gaps exist among validated measures and concepts that we hope will be addressed in the next phase of the Committee’s work. For example, although outside of the scope of psychometrically validated quality measures, economic data related to workforce capacity will be essential to ensure access to HCBS, which relies on a sufficient number of qualified workers to provide essential supports and services. This data includes standardized assessment of workforce volume relative to demand, turnover and vacancy rates, and wages and compensation relative to competing industries. Measurement gaps also exist related to: High-quality, pre-service and ongoing training that addresses person-centered care, independent Living, and cultural and linguistic competence. Proper compensation with a living wage Career advancement opportunities (e.g. advanced roles in care coordination, specialty roles) Predictable and stable work schedules Supportive supervision Job satisfaction and intent to leave Workforce labor protections

Alice Dembner	Community Catalyst	Community Catalyst is a national non-profit advocacy organization dedicated to quality affordable health care for all. Since 1997, Community Catalyst has been working to build the consumer and community leadership required to transform the American health system. Our new Center for Consumer Engagement in Health Innovation is a hub devoted to teaching, learning and sharing knowledge to bring the consumer experience to the forefront of health. We have been working to improve home and community based services for consumers for the last five years, with a particular focus on Medicaid managed care and populations dually eligible for Medicaid and Medicare. We have produced tools for consumer advocates to use in state-based advocacy as well as tools for use by other stakeholders. These tools include "Strengthening Long-Term Services and Supports" and "Meaningful Consumer Engagement: A Toolkit for Plans, Provider Groups and Communities," both of which can be accessed on our website: http://www.communitycatalyst.org/resources/tools. The significant gaps in quality measurement for HCBS are inhibiting our efforts and those of many other stakeholders to ensure that HCBS fully serves the needs of consumers. We appreciate that NQF is taking on the important area of quality in HCBS. We believe that NQF could contribute to improvements in HCBS by driving measure development in the critical gap areas of Consumer Voice, Equity, and Community Inclusion. At the same time, we note that the sheer number of measures identified by NQF in this study is overwhelming (over 10,000 in the 1915(c) waivers alone). We believe that the high volume of measures is counter-productive and deeply problematic for achieving the important goal of better health for consumers who are in need of HCBS. We would urge NQF to use this opportunity to push toward a small set of measures in each of the domains that is simple, meaningful and universally adopted.

Carmella Bocchino	America's Health Insurance Plans	The domains of measurement should be more balanced and should be mutually exclusive. While the existing domains are important to measure, other areas and measures that assess effectiveness of care and system performance are important and should be included (e.g., cost effectiveness, appropriateness of setting, timeliness of service delivery, and management of physical/behavioral health). Additionally, there are numerous measures recommended in the report, yet the purpose or goal of such measurement is unclear. Finally, implementation of these measures and related domains could pose challenges because the domains are not mutually exclusive. The domains need to be revaluated and NQF should strive to create mutually exclusive domains. Finally, in the future additional discussions and analytic work need to be conducted to ensure robust implementation of measures in this area including issues pertaining to how the domains will be weighted.
Fay Gordon	Justice in Aging	Dear HCBS Committee, NQF Project Staff, and HHS Advisory Group: Justice in Aging appreciates the opportunity to comment on the Home and Community-Based Services Quality Second Interim Draft. Please see http://www.justiceinaging.org/resources-for-advocates/comment-letters for our full comments on the compendium. We commend NQF's impressive effort in creating this compendium. While NQF's HCBS work will take time, in the immediate term, we urge states to utilize the HCBS measure compendium to begin evaluating HCBS access and quality at the state level. We suggest the following additions to the compendium subdomains: Workforce—Dementia Care: We appreciate the example of a dementia training measure in the compendium of workforce measures. Our recent report, Training to Serve People with Dementia: Is our Health Care System Ready?, found 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. We recommend NQF prioritize dementia training measures in the Workforce domain and build upon the example measure in the final draft. Human and Legal Rights—Nondiscrimination Protections: We are concerned the current

		Human and Legal Rights domain does not adequately address nondiscrimination protections. The Department of Health and Human Services (HHS) is finalizing regulations to implement Section 1557 of the Affordable Care Act. Section 1557 prohibits health care providers from discriminating against individuals on the basis of sex, gender identity, race, national origin and disability. As health care entities, service providers in the HCBS delivery system are held to these requirements. If nondiscrimination measures exist, we recommend their inclusion in the final draft. Service Delivery—Access to Supplemental Services: In our experience with state transitions to MLTSS, consumers struggle to access supplemental services. Without existing metrics for supplemental service delivery quality and access, stakeholders struggle to identify ways to improve access problems. We suggest NQF prioritize identifying measures to evaluate access to quality supplemental services. Caregiver Support—Voluntary Support: We support the prioritization of caregiver support as a core domain, and strongly support the subdomains of caregiver assessment and caregiver compensation. System performance—Effective Management: We recommend NQF adopt Australia's measure standard, "effective management." State eligibility IT systems, as well as provider payment systems, are frequently cited by consumer advocates as an impediment to service delivery. We strongly recommend NQF's measure recommendations include standardizing data on the effectiveness of state information management systems. Thank you for the opportunity to comment.

Michael Feore		No agencies in Alabama have ever reported on client/family choices or desires. This is also true of all advocacy groups including our State DD Council and ADAP Offices. The only effort made along these lines is to invite all stakeholders to any outreach effort which when scheduled during working hours results in a very low percentage of families and clients ever attending any out reach meetings. Additionally, no effort has ever been made to compile and seperated client family wishes from the larger group. This results in no available data reflecting client/family wishes. In addition, no findings of advocacy groups, including the DD Council and ADAP activities has ever been presented to the State Medicaid Agency for their consideration in managing and guiding the HCBS waiver progams. Also the State Medicaid Agency, in conjunction with their contracting agency, DD Dept of Mental health, have consistantly held that assisted living is not a valid Medicaid HCBS Choice inspite of being shown HCBS DD Waiver documentation to the contrary. Please feel free to contact me at 251 454-5976 for furthern explanation. Michael Feore 12 South McGregor Ave Mobile, Alabama , 36608

Submitter Name	Submitter Organization	Comment
Peter Notarstefano	LeadingAge	Draft NQF Domains and Subdomains of HCBS Quality Measurement: Caregiver Support There were few measures, measure concepts, and instruments that fall into the domain of caregiver support (n=18), even though the involvement of a caregiver has a positive impact on helping the frail older adult remain in the community. 51 percent of family caregivers report that the medical/nursing tasks they provided for their family member helped them avoid nursing home placement.[3] The draft specifications for the Discharge to Community Quality Measure for Skilled Nursing Facilities, Inpatient Rehabilitation Facilities, Long-Term Hospitals and Home Health Agencies include the availability of a caregiver. Nearly 34 million family caregivers care for frail elders.[4] This "informal" care of individuals with chronic illnesses or conditions that prevent them from handling daily activities such as bathing, managing medications or preparing meals on their own is a major determinant of achieving the aim of Better Care within the National Quality Strategy. A caregiver also decreases the chance of social isolation that can occur, as well as providing a safe environment for the individual with chronic illnesses or conditions. Recommendation: More work needs to be done on measures, measure concepts, and instruments that fall into the domain of caregiver support. Sincerely, Cheryl Phillips, MD Senior VP Public Policy and Advocacy [1] Centers for Medicare & Medicaid Services, Office of Information Products & Data Analytics. Medicare and Medicaid research Review, 2014: Volume 4, Number 3 online at https://www.cms.gov/mmrr/Downloads/MMRR2014_004_03_b01.pdf [2]The Gerontologist, Caregivers' Reasons for Nursing Home Placement: Clues for Improving Discussions With Families Prior to the Transition Vol. 46, Issue 1, pp. 52-61. Online at

		http://gerontologist.oxfordjournals.org/content/46/1/52.full [3] AARP’s Public Policy Institute; HOME ALONE: Family Caregivers Providing Complex Chronic Care; October 2012. Online at http://www.aarp.org/content/dam/aarp/research/public_policy_institute/health/home-alone-family-caregivers-providing-complex-chronic-care-rev-AARP-ppi-health.pdf [4]National Alliance for CaregivingCaregiving in the U.S. 2015 at http://www.caregiving.org/caregiving2015/ [5] (RFI)—Data Metrics & Medicaid Access to Care RFI (CMS-2328-NC)
E. Clarke Ross	Consortium for Citizens with Disabilities	Role of NCI - Thank you for incorporating the role of the National Core Indicators - pages 12, 14, 17, and 24. The NCI staff can comment on the correlation of domains and topics within the NCI instrucments. Clarke Ross: American Association on Health and Disability and Lakeshore Foundation Role of CQL POM - Thank you for incorporating the role of the Personal Outcome Measures. AAHD & Lakeshore repeat the CQL observation on the correlation of POM with domains and topics: CQL submitted to NQF: "To clarify, the POM covers the domains listed (choice and control; effectiveness; and quality of services), but also includes your domains of human and lega rights, community inclusion, amd service delivery." Clarke Ross, AAHD & Lakeshore Fd

E. Clarke Ross	Consortium for Citizens with Disabilities	Role of CAPHS and CMS HCBS Experience Survey. Thank you for incorporating the role of CAPHS, particularly the CMS HCBS experience survey. We encourage NQF to strongly encourage CMS to publicly share the lessons and learnings from the CMS HCBS experience survey. Further, as previously discussed and shared with NQF staff, the report should discuss the work of the NIDILRR funded Westchester Institute for Human Development to modifiy and adapt the CAHPS for persons with signficant intellectual disabilities. Clarke Ross, American Association on Health and Disability and Lakeshore Foundation
Lindsay Schwartz	American Health Care Association/National Center for Assisted Living	AHCA/NCAL realizes the goal of this project was to identify non-medical measures but HCBS participants utilize medical services, which at times can be a large part of their services received. AHCA/NCAL was pleased to see medically-focused outcomes in the domains as they do have an impact on a recipient's quality of life and care. These are also important measures for payers such as Medicare, Medicaid, Managed Care (which includes Medicaid), and Accountable Care Organizations. AHCA/NCAL appreciates the opportunity as an NQF member to comment on the work of this committee and recognizes that the general public also has the opportunity to comment. AHCA/NCAL informs their members (which includes providers) of these opportunities. Even with great outreach efforts to HCBS recipients and providers, it is likely comments are not well-represented from these groups. With the importance of the work of the committee, it would be helpful to have input from providers and recipients of HCBS care. NQF may want to consider focus groups of the different providers of HCBS and recipients/family members to ensure that the areas identified as lacking are truly meaningful to HCBS recipients.

Abby Marquand	PHI	The first interim report did well to articulate the relationship between home and community based service delivery and quality of life, based on individual preferences and goals. To that end, evaluation of quality should engage with individualized measures (of individualized goals and whether HCBS allows individuals to meet those goals) that include consumer and worker input rather than traditional, quantifiable, validated measures. The examination of select state and international approaches for examining HCBS quality are worthwhile, but should not be limited to include only measures and concepts that met the criteria of the NQF for inclusion in the compendium. Rather, we argue in favor examination of the measures in earlier stages of development within these systems, especially those that assess non-medical aspects of service delivery and quality.
Carmella Bocchino	America's Health Insurance Plans	The measures domains identified and the measures listed in Table 2 do not take into account differences in populations in regard to appropriate measurement, nor do they address measures that cross the domains of Consumer Voice, Equity, Community Inclusion, and Caregiver Support. While we support the need for fewer well-harmonized measures that work accross settings and populations, the report has a one size fits all approach which is not appropriate to meet the needs of what are really different sub-populations, i.e., physically disabled, intellectual and developmental disability, serious mental illness, self-directed patients, and frail elderly. For instance, the measures, such as Caregiver Support or Consumer Voice, cannot be applied equally to patients that are self versus non-self directed with their care as there will be wide variation in performance between these groups. We recommend the report include greater emphasis and identification of performance measurement in the identified areas lacking measurement and address appropriate measurement for sub-populations in the domains identified in the report.

COMMENTS ON THE ANNOTATED BIBLIOGRAPHY

Submitter Name	Submitter Organization	Comment

E. Clarke Ross	Consortium for Citizens with Disabilities	Suggested Additional Appendix - NQF Workgroup on Persons Dually Eligible for Medicare and Medicaid "High Priority Measure Gaps." Very relevant to the work of the NQF HCBS is the work of the NQF workgroup on persons dually eligible. We suggest an additional appendix identifying these 7 gaps - available in 2013, 2014, 2015 NQF repots submitted to CMS. We also suggest that the 2015 NQF report to CMS list of 4 participant survey finding of priorities (consistent with the 7 high priority gaps) be included in the appendix. Clarke Ross, American Association on Health and Disability and Lakeshore Foundation