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January 19, 2016

National Quality Forum  
HCBS Measure Gap Project  
1030 15th Street, NW, Suite 800  
Washington, DC 20005

Dear Project Leader,

Community Catalyst respectfully submits the following comments to the National Quality Forum in response to the second interim report "Addressing Performance Measure Gaps in Home and Community-Based Services to Support Community Living - Synthesis of Evidence and Environmental Scan."

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. The Center works directly with consumer advocates to increase the skills and power they have to establish an effective voice at all levels of the health care system. We collaborate with innovative health plans, hospitals and providers to incorporate the consumer experience into the design of their systems of care. We work with state and federal policymakers to spur change that makes the health system more responsive to consumers.

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](http://www.communitycatalyst.org/resources/tools/mmltss)"<sup>1</sup> and "[Meaningful Consumer Engagement: A Toolkit for Plans, Provider Groups and Communities](http://www.communitycatalyst.org/resources/tools/meaningful-consumer-engagement)."<sup>2</sup> 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.

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<sup>1</sup> Community Catalyst. Strengthening Long-Term Services and Supports. <http://www.communitycatalyst.org/resources/tools/mmltss>

<sup>2</sup> Community Catalyst. Meaningful Consumer Engagement: A Toolkit for Plans, Provider Groups and Communities. <http://www.communitycatalyst.org/resources/tools/meaningful-consumer-engagement>

We appreciate the opportunity to provide comments on the synthesis of evidence, environmental scan, and compilation of measures, which is an important step forward in identifying and filling measurement gaps.

NQF's report makes clear that we have a misalignment in the proliferation of 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, manageable set of measures in each of the domains that is simple, meaningful and can be universally adopted. This means winnowing down measures in some of the domains that are overrepresented. It also means that in three domains in which the scan found few or no existing measures, measure concepts or instruments, NQF should identify next steps to help spur measure development to fill key gaps. Those are: **Consumer Voice, Equity and Community Inclusion**. These domains are crucial to the goal of measurement – ensuring HCBS enable consumers to live with dignity and as much independence and community participation as possible.

**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 truly responsive to their needs, consumers must be at the decision-making tables for design, implementation, oversight and evaluation of HCBS programs. 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 that are participating. Community Catalyst has extensive experience in facilitating consumer voice and would be pleased to meet with NQF workgroup members to share ideas for measure concepts. The financial alignment demonstrations, which include HCBS, can provide several measure concepts for this domain.

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 received by people based on their race, ethnicity, income and disability status. NQF's own [report on health disparities and cultural competencies](#)<sup>3</sup> can provide a starting point for development of HCBS-specific measures of reduction in health and service disparities. The equity domain measures must include access to a broad range of services, not just housing.

Underlying any measurement of disparities is the critical need for data that is disaggregated by age, race, ethnicity, primary language, gender identity and sexual orientation and disability status. This is needed across all the domains. For example,

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<sup>3</sup> National Quality Forum. Healthcare Disparities and Cultural Competency Consensus Standards. 2012. [http://www.qualityforum.org/projects/Healthcare Disparities and Cultural Competency.aspx](http://www.qualityforum.org/projects/Healthcare_Disparities_and_Cultural_Competency.aspx)

examining data from the Choice and Control domain measures by race and ethnicity may be a way to identify equity or inequity.

Another very important element of equity is the extent to which the workforce is racially and ethnically representative of the people receiving LTSS and is culturally and linguistically competent. These measures are currently part of the workforce domain and should be prioritized as well.

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.

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.

Please contact Alice Dembner, senior policy analyst for long-term services and supports, with any questions about these comments.

Sincerely,



Robert Restuccia  
Executive Director