



July 15, 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 the third interim report, “Address performance Measure Gaps in Home and Community-Based Services to Support Community Living: Priorities for Measure Development.”

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 U.S. 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 enhance their skills and power 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, producing tools for consumer advocates to use in state-based advocacy as well as tools for use by other stakeholders.

We provided [comments on the second interim report](#)¹ in January and appreciate the opportunity to provide comments on the gaps in quality measurement as well as the recommendations for prioritization.

We are encouraged by the Committee’s emphasis that all measurement domains should be person-centered, promote community living, and improve consumer outcomes. We especially appreciate the multilevel approach to measurement wherein HCBS quality measures are developed from individual-, service-, and systemic-level data. While we applaud the

¹ Community Catalyst. Comments on the second interim report of the National Quality Forum HCBS Measure Gap Project. http://www.communitycatalyst.org/resources/comment-letters/document/Comments-on-NQF_HCBS_2nd_interim_report_Community_Catalyst__final.pdf

Committee's recognition of the need to prioritize quality measurement work across all domains and subdomains in the conceptual model, we are concerned with the recommended categories and their implications for filling measurement gaps in a timely manner.

We recommend that the Committee prioritize the following three domains for measure development: **Consumer Leadership in System Development, Community Inclusion, and Equity**. These domains are critical to the goal of measurement – ensuring HCBS consumers are able to live with dignity and as much independence and community participation as possible. The second interim report made clear that measures and measure concepts for these domains are less developed, emphasizing the need to focus efforts and prioritize these domains. We also believe there is a sense of urgency for these three domains to be prioritized and developed. Recent CMS final regulations on Medicaid Managed Care require states to include quality measures on rebalancing, community integration, and quality of life. Developed measures for consumer leadership, community inclusion, and equity will assist states, health plans, and advocates implementing the new CMS regulations and ensure consumer perspectives and experiences are included. We urge the Committee to consider the following recommendations and elevate these domains as priority areas as the project's final report is prepared and distributed in September.

Consumer Leadership in System Development

We appreciate the Committee's renaming of the Consumer Leadership domain and its stated underscoring of the importance of active and meaningful participation. Without Consumer Leadership, it is extremely unlikely that HCBS will fully reflect consumer goals, preferences and needs. We realize developing structure and process measures to assess the subdomains will take some time; therefore, we strongly urge prioritization of measure development in this domain. We believe that process measures on the types and amount of support offered to support consumer leadership, such as stipends, travel reimbursement, and training in the subject area, could be implemented immediately while further testing occurs. We believe there are helpful existing [models](#)² and [toolkits](#)³ for meaningful consumer leadership that could be used for measure, measure concept, and instrument development. Changes in service patterns resulting from new initiatives developed from consumer input, as well as improved communication and educational materials for consumers based on feedback from consumers can serve as evidence for meaningful consumer involvement. We believe it is possible to immediately begin collecting data on these types of outcomes and develop quality measures for meaningful consumer involvement. We would be pleased to offer our support to NQF to further develop measures for this domain.

² Lomerson, N., McGaffigan, E., O'Connor, D., & Wambach, K. (2007). *When CPIGs Fly: Meaningful Consumer Involvement in Systems Change* [PowerPoint slides]. Retrieved from <http://www.nasuad.org/sites/nasuad/files/hcbs/files/108/5357/CPIGS.pdf>

³ Community Catalyst. Meaningful Consumer Engagement: A Toolkit for Plans, Provider Groups and Communities. <http://www.communitycatalyst.org/resources/tools/meaningful-consumer-engagement>

Community Inclusion

We strongly agree with the Committee's statement that performance measures could be developed from consumer surveys such as CMS's **Money Follows the Person Quality of Life Survey** and the **National Core Indicators – Aging and Disabilities Survey (NCI-AD)**. We also believe the **HCBS Experience Survey** is a potential source for measures. These surveys make use of broad measures for social connectedness, relationships, and meaningful activity measurement, which are more effective at gathering meaningful consumer responses. Using specific activities, such as, whether a person went to the movies or ate in restaurant to assess community inclusion can limit or misrepresent consumer experiences. Broad measures ensure that personal preferences for different activities are considered and more effectively capture how a person feels about their access to community and relationships. Some of the questions in the NCI-AD survey seem particularly suited for swift adoption as measures:

- Are you as independent as you would like to be?
- Do you feel in control of your life?
- Are you lonely?
- Are you doing things inside and outside the home when you want to?
- Do you like how you spend time during the day?
- Are you able to see friends and family?
- Do you need more/different services to live in your choice of setting?

Without effective measures for Community Inclusion, HCBS will fall short of the *Olmstead* ruling of the US Supreme Court and the requirements of new federal Medicaid managed care regulations. We urge the Committee to prioritize translation of these surveys into measures as a short-term recommendation rather than as an intermediate recommendation.

Equity

We urge the Committee to expand the short-term recommendation beyond just housing and homelessness. The equity domain measures must assess a broad range of services. Administrative data exists that can be tapped immediately to measure the extent of disparities by race, ethnicity, age, and primary language in service delivery and in outcomes, where outcomes measures already exist. The Department of Health and Human Services released an [action plan to reduce health disparities](#)⁴ that emphasized the need for a multifaceted health disparities data collection strategy to build effective monitoring and reporting systems. Furthermore, data collection disaggregated by age, race, ethnicity, primary language, gender identity, sexual orientation, and disability should be prioritized across all the domains.

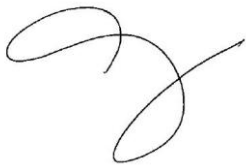
⁴ Department of Health & Human Services. HHS Action Plan to Reduce Racial and Ethnic Health Disparities: A Nation Free of Disparities in Health and Health Care. http://minorityhealth.hhs.gov/npa/files/plans/hhs/hhs_plan_complete.pdf

Finally, Community Catalyst would like to commend the Committee members for acknowledging the crucial role of the direct care workforce in the HCBS System, and the need to recognize and support these workers – who deliver the vast majority of direct-touch HCBS care. The six subdomains address what are clearly major steps forward in measuring quality for HCBS services as 80-90 percent of the services are delivered by front line workers. Given the importance of turnover and the evidence of how continuity of care affects quality, we would recommend that you at a minimum move “sufficient numbers, dispersion and availability” into your short term category. NQF could do this by analyzing the average annual turnover rate by setting and job title (percent of direct care workers that left their position as a proportion of total staff employed during the reporting period), broken out by setting and job title, and the percent of workers retained during the reporting period; as well as the average amount of time it takes for consumers to find workers/services.

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.

Please contact Alice Dembner (adembner@communitycatalyst.org), senior policy analyst for long-term services and supports, with any questions about these comments.

Sincerely,

A handwritten signature in black ink, appearing to be 'Ann Hwang', with a stylized, flowing script.

Ann Hwang, MD
Director, Center for Community Engagement in Health Innovation