



August 12, 2016

National Quality Forum
Person and Family Centered Care Project
1030 15th Street, NW, Suite 800
Washington, DC 20005

Re: Person and Family Centered Care, 2015-2016, Draft Report for Comment

Dear Project Leader:

The Center for Consumer Engagement in Health Innovation at Community Catalyst appreciates the opportunity to provide comments on the National Quality Forum (NQF) *Draft Report on Person and Family Centered Care, 2015-2016*.

Community Catalyst is a national non-profit advocacy organization dedicated to quality affordable health care for all. Since 1998, Community Catalyst has been working to build the consumer and community leadership required to transform the American health system. The 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.

Thus, working to ensure care is person and family centered is at the core of what we do. We have also been working to improve home and community-based services for consumers for the last five years, producing tools for consumer advocates and other stakeholders to use in seeking improvements, as well as weighing in with federal policymakers. It is this frame and experience that we bring to these comments to NQF.

We greatly appreciate the project's focus on prioritizing quality measures that focus beyond inpatient care and instead address increased consumer independence, functional improvement, interpersonal relationships, and patient and family engagement.

We are, however, writing to express our concern about the decision not to recommend endorsement of measure #2967, drawn from data in the Home and Community Based Services (HCBS) Experience of Care Survey. We request that the NQF committee reconsider its decision on measure #2967 as we believe that NQF's measure evaluation criteria were not applied appropriately in the evaluation of this measure.

We believe reconsideration of this measure is important for a number of reasons. For one, we agree with NQF's preference for outcome measures, as its Committee Guidebook (http://www.qualityforum.org/Measuring_Performance/Submitting_Standards/Steering_Committee_Guidebook.aspx) explains:

- outcomes (e.g., improved function, survival, or relief from symptoms) are the reasons patients seek care and why providers deliver care
- outcomes are of interest to purchasers and policymakers
- outcomes are integrative, reflecting the result of all care provided over a particular time period (e.g., an episode of care)
- measuring performance on outcomes encourages a "systems approach" to providing and improving care
- measuring outcomes encourages innovation in identifying ways to improve outcomes that might have previously been considered not modifiable (e.g., rate of central line infection)

We also note that there is a clear gap for patient reported outcomes measures, and for measures that assess HCBS quality. Many disability and aging advocates prioritize, as among the most important quality indicators, consumer choice, participant-directed services, individual experience and satisfaction with services and supports, shared decision-making, and beneficiary sense of control/autonomy/self-determination within a community integration and inclusion approach. The need for measures in these areas has been identified as a priority in numerous settings, including the Measures Application Partnership workgroup on persons dually eligible for Medicare and Medicaid and the HCBS committee. Given the clear need for patient-reported outcomes measures on HCBS, use of measure #2967 is supported by a broad array of consumer and disability advocates. We also note that this survey was just officially accepted to be part of the Consumer Assessment of Healthcare Providers and Systems (CAHPS).

We are concerned that in evaluating this measure, the committee inappropriately applied NQF's own criteria. In particular, we note the following:

1. Importance to Measure and Report: Subcriterion 1b (performance gap)

According to the Committee Guidebook, subcriterion 1b "is meant to address the question of whether there is actually a quality problem that is addressed by a particular measure" (page 38). We suggest that in the case of the HCBS Experience of Care measure, the need for this measure is clear because of (1) the shortage of alternative quality measures for this purpose, and (2) the need for monitoring of quality to detect problems that can occur with program and policy changes, such as the current shift to managed long-term services and support.

We believe that the concerns raised by the Committee about floor and ceiling effects in pilot data reflect measure *use*, not an intrinsic property of the measure itself.

We note that much of the Committee discussion around the criterion of importance did not address the criterion specifically, but discussed issues of accountability and possible uses. We

argue that this does not belong in the assessment of the importance of a measure, and should not have been allowed.

Finally, we suggest that the NQF definition of “importance” itself should be expanded to take into consideration consumer input into what information is most useful and relevant for consumers. Without this shift in approach, it will be difficult to achieve a truly person centered approach to quality measurement.

2. Scientific Acceptability: Subcriterion 2a (reliability)

The report notes that the Committee appears to have voted on reliability (criterion 2a) and not on validity (criterion 2b). In reviewing the notes of the Committee deliberation, we point out that the discussion appeared to address measure use, such as whether states had one program or multiple programs, and whether the use would be voluntary or not. We argue that these are factors that are out of place in a discussion of reliability.

The concerns that were tied more closely to measure reliability focused on sample size. The comments state that a sample size of 400 is necessary to achieve a reliability score of 0.7. We ask how the Committee determined to accept 0.7 as the correct level of reliability. We point out that NQF’s own criteria state, “NQF is not prescriptive about how empirical measure testing is done; similarly, NQF does not set minimum thresholds for reliability or validity testing results.” We believe that there should be further justification of this decision and the implied reliability threshold, including consumer input on what an appropriate level would be for reliability for this measure.

3. Feasibility

This did not appear to have been discussed in detail. We will note that the Committee’s request for more information is premised on a sample size of 400, and we again question why this threshold was selected, when NQF guidance does not stipulate a minimum threshold for the reliability score.

4. Usability and Use

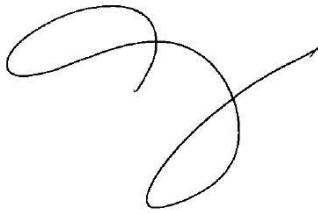
In this section, we are particularly troubled by the statement, “Given that for some patients, the only way to receive improved care would be to move to a different state with a better program, Committee members questioned how public reporting could be useful.”

We challenge not only the accuracy of this statement but question whether the composition of the Committee was appropriate for it to address this question. We work with consumers and advocates in a number of states who are playing a critically important role in improving state programs, and we argue that information about consumers’ experience of care is critical for understanding whether a state’s program is meeting the needs of its consumers.

Given these concerns, we respectfully request reconsideration of this measure and argue for a stronger role for consumers (particularly consumers who use HCBS) in evaluating this measure, particularly around the importance and the use criteria for this measure.

Thank you again for the opportunity to comment. Please contact me at AHwang@communitycatalyst.org with any questions about these comments.

Sincerely,

A handwritten signature in black ink, consisting of a large, stylized 'A' followed by a horizontal line that curves upwards and then downwards, ending in a small hook.

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