



American Association on Health & Disability

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AAHD - Dedicated to better health for people with disabilities through health promotion and wellness



LAKESHORE

May 7, 2020

Re: National Quality Forum - Measure Feedback Loop, Pilot: April 27, 2020 Draft Final Report for Comment

The American Association on Health and Disability and the Lakeshore Foundation appreciate the opportunity to provide comments on the draft report on a measure feedback loop.

The American Association on Health and Disability (AAHD) (www.aahd.us) is a national non-profit organization of public health professionals, both practitioners and academics, with a primary concern for persons with disabilities. The AAHD mission is to advance health promotion and wellness initiatives for persons with disabilities.

The Lakeshore Foundation (www.lakeshore.org) mission is to enable people with physical disability and chronic health conditions to lead healthy, active, and independent lifestyles through physical activity, sport, recreation and research. Lakeshore is a U.S. Olympic and Paralympic Training Site; the UAB/Lakeshore Research Collaborative is a world-class research program in physical activity, health promotion and disability linking Lakeshore's programs with the University of Alabama, Birmingham's research expertise.

We fully support the NQF objective (page 7) that a standard pathway for generating and collecting measure feedback be established. We agree with the (page 5) NQF observations that "user experience" and "information about the negative and positive unintended consequences of implementing the measure in practice" are important components.

We are gravely disappointed that totally missing from the report is recognizing, incorporating, and prioritizing the experience of persons, patients, consumers, family members, program participants, and program beneficiaries.

It was the disability independent living movement of the 1970s that first articulated the philosophy and practice – Nothing About Us, Without Us. The federal centers for independent living program was legally authorized in the Rehabilitation Act Amendments of 1978.

The draft NQF report (pages 8-10) outlines the process of NQF collaboration with target organizations to publicize feedback opportunities. The report (page 10) identifies “such as, specialty societies, measure developers, health systems, and federal agencies.” Missing – the importance of state government administering agencies, such as Medicaid, mental health, and intellectual disability/developmental disability. And totally missing from this section and the entire report - **the experience of persons, patients, consumers, family members, program participants, and program beneficiaries.**

Given all of the previous NQF work over the past decade and the avowed importance of the person-consumer-patient voice in health and health related decision making, this is unfathomable.

Thank you for the opportunity to comment. If you have any questions please contact Clarke Ross at clarkeross10@comcast.net.

Sincerely,



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Member, National Quality Forum (NQF) workgroup on Medicaid adult measures (December 2017-present), Medicaid-CHIP Scorecard Committee (October 2018-present) and Measure Sets and Measurement Systems TEP (June 2019-present). Member, National Quality Forum (NQF) workgroup on persons dually eligible for Medicare and Medicaid (July 2012-July 2017) and

NQF population health task force (2013-2014) <http://www.qualityforum.org/>) and NQF representative of the Consortium for Citizens with Disabilities (CCD) Task Force on Long Term Services and Supports (<http://www.c-c-d.org/>). 2017 member, NQF MAP workgroup on Medicaid adult measures. 2016-2017 NQF duals workgroup liaison to the NQF clinician workgroup. 2015-2016 and 2014-2015 NQF duals workgroup liaison to the NQF PAC/LTC workgroup. Member, NQF Medicare Star Ratings Technical Expert Panel (June-November 2019). AAHD Representative to the CMS-AHIP-NQF Core Quality Measures Collaborative (2019-present). Member, ONC (Office of the National Coordinator for Health Information Technology) Health IT Policy Committee, Consumer Workgroup, March 2013-November 2015; Consumer Task Force, November 2015-April 2016. (<http://www.healthit.gov/policy-researchers-implementers/federal-advisory-committees-facas/consumer-empowerment-workgroup>). Member, SAMHSA Wellness Campaign National Steering Committee – January 2011-September 2014. (<http://promoteacceptance.samhsa.gov/10by10/>).

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