



## American Association on Health & Disability

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



# LAKESHORE

June 4, 2021

### **Re: Building a Roadmap From Patient-Reported Outcome Measures To Patient-Reported Outcome Performance Measures – June 1, 2021 draft interim report for public comment**

The American Association on Health and Disability and the Lakeshore Foundation appreciate the opportunity to provide comments. We write to endorse the June 3 submitted comments of the Council on Quality and Leadership (CQL). In addition to the CQL submitted comments, we also strongly encourage the NQF to fully integrate and reference in some detail two NQF previously published reports – Person-Centeredness (July 2020) and Home and Community-Based Services (September 2016).

The June draft PRO-PMs report, page 5, raises the question: “Whether a PROM is well-suited for performance measurement”? The CQL comments answer yes and explain the importance to beneficiaries and recipients of services and supports (including patients of health services programs).

The American Association on Health and Disability (AAHD) ([www.aahd.us](http://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. AAHD is specifically dedicated to integrating public health and disability into the overall public health agenda.

The Lakeshore Foundation ([www.lakeshore.org](http://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.

**AAHD & Lakeshore Fd Endorse June 3 Council on Quality and Leadership (CQL) submitted comments:**

CQL | The Council on Quality and Leadership  
100 West Road, Suite 300  
Towson, MD 21204

National Quality Forum  
1099 14th Street NW  
Suite 500  
Washington DC 20005

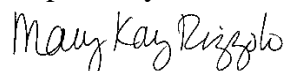
We would like to commend the National Quality Forum on their efforts to recognize patient-reported outcome performance measures. We represent the Council on Quality and Leadership (CQL), an international not-for-profit organization dedicated to the definition, measurement, and improvement of personal quality of life, through a world of dignity, opportunity, and community for all people. For over 50 years, CQL has taken the leadership initiative in developing progressive measures and indicators of quality in services and supports, personal quality of life outcome measures, and social capital. CQL emerged from national efforts to improve conditions in public institutions in the late 1960s. CQL established the first and subsequent sets of standards and performance indicators for children and adults that were later adopted as Federal Standards by HCFA (now the Centers for Medicare and Medicaid Services). CQL's standards were incorporated in the historic *Wyatt v. Stickney* decision and the federal courts later incorporated CQL's standards into legal settlements in Texas, North Dakota, California, Alaska, and West Virginia. CQL has collaborated with state systems for over five decades to design and deliver statewide quality management models that are person-centered, integrated, and evidence based. CQL models have been shown to empower states to build capacity and utilize data to hold systems accountable while targeting limited resources. CQL has a proven track record in partnering with states and providers to enhance systems and practices.

Based on our experience, background, and research, we would like to draw attention to the following important aspects of quality for your consideration as you build a Roadmap for PRO-PMs (Patient-Reported Outcome Performance Measures).

A quality service system necessitates a *truly* person-centered outcome performance measurement process. The person-centered measures should be designed to assist the person to achieve personally defined outcomes, while also contributing to the assurance of their health and welfare. To truly be person-centered, outcome measurement must reflect people's meaningful priorities/goals, reflect their desires, and include informed choice.

It is important that quality metrics are not utilized simply because they are easy to measure. In addition, whenever possible, it is important to avoid utilizing process-based assessments and metrics. We believe that quality assurance metrics should incorporate metrics that capture the extent to which person-centered outcomes are infused throughout the provision of clinical services. Person-centered outcomes not only recognize each person's unique individuality, systems and organizations promote health when they incorporate the person's wants and needs in the provision of services and supports.

We wish you much success as build a roadmap to patient-report outcome performance measures. Please do not hesitate to reach out if you have any questions or would like further clarification. Respectfully,



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**AAHD & Lakeshore Fd also strongly encourage the NQF to fully integrate and reference in some detail two NQF previously published reports – Person-Centeredness (July 2020) and Home and Community-Based Services (September 2016).**

NQF projects and reports typically are silo focused, reflecting the expertise of the particular technical expert panel and committee engaged on a project. NQF excels at multi-stakeholder engagement and analysis and prototype public transparency and engagement; however, many products still reflect a particular silo. We strongly encourage the NQF PRO-PMs report to fully integrate and reference in some detail two previously published reports; these reinforce and are totally consistent with the CQL comments. The two reports:

1. "Person-Centered Planning and Practice" (July 31, 2020)
2. "Quality in Home-and-Community-Based Services To Support Community Living: Addressing Gaps in Performance Measurement" (September 2016)

Thank you for the opportunity to comment. If you have any questions please contact Clarke Ross at [clarkeross10@comcast.net](mailto:clarkeross10@comcast.net).

Sincerely,



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National Quality Forum (NQF) Involvement includes: Medicare Hospital Star Ratings Technical Expert Panel (June-November 2019 and September-October 2020); workgroup on Medicaid adult measures (appointed December 2017); Medicaid-CHIP Scorecard Committee (appointed October 2018); Measure Sets and Measurement Systems TEP (June 2019-August 2020); workgroup on persons dually eligible for Medicare and Medicaid (July 2012-July 2017); and NQF population health task force. Clarke was the NQF representative of the Consortium for Citizens with Disabilities (CCD) Task Force on Long Term Services and Supports (2012-2017). Dr. Ross was the 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. Clarke is the AAHD Representative to the CMS-AHIP-NQF Core Quality Measures Collaborative (2019-present).

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