



## American Association on Health & Disability

110 N. Washington Street Suite 328-J Rockville, MD 20850  
T. 301-545-6140 F. 301-545-6144 www.aahd.us

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



# LAKESHORE

October 29, 2019

### **Re: Patient-Reported Outcomes – Best Practices on Selection and Data Collection: An Environmental Scan**

October 15 National Quality Forum draft report for public comment

Submitted to NQF through the NQF website portal:

[http://www.qualityforum.org/Patient\\_Reported\\_Outcomes\\_Best\\_Practices\\_on\\_Selection\\_and\\_Data\\_Collection.aspx](http://www.qualityforum.org/Patient_Reported_Outcomes_Best_Practices_on_Selection_and_Data_Collection.aspx)

Dear Colleagues:

The American Association on Health and Disability and the Lakeshore Foundation appreciate the opportunity to provide comments on this important topic – person-reported outcomes.

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.

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.

Our comments:

## **Terminology: Patient, or Person, or Both**

**We suggest that the final PRO scan report include a quote from the NQF MAP May 30, 2014 draft report - Finding Common Ground for Healthcare Priorities: Families of Measures for Assessing Affordability, Population Health, and Person-and-Family-Centered Care:** (page 21) - “one single term cannot apply to all individuals in all situations; in actuality, an individual with many needs may self-identify as a person, client, or patient at a single point in time...” “The task force agreed to use the word ‘person’ as an over-arching term to encompass the health and healthcare needs of all individuals, regardless of age, setting, or health status.”

This draft report was subsequently finalized. I simply don’t easily have the exact report text easily copied. NQF typically does “not” cross-reference other NQF reports, products, and projects; this is highly frustrating – meaningful previous and current NQF work not mentioned in new NQF projects.

## **Person-Centeredness**

The draft report description of person-centeredness (pages 8 &9) is adequate and accurate. In reviewing NQF reports and products since 2012, NQF typically does “not” cross-reference other NQF reports, products, and projects. The NQF is currently implementing an Administration for Community Living (ACL) funded project to better define and suggest practice implementation guidance on “person-centeredness.” The draft PRO environmental scan should acknowledge, reference, and quote from this current work. NQF previous reports, such as Home-and-Community-Based Services, Medicaid adult measures, and persons dually eligible for Medicare and Medicaid, are helpful NQF referenced resources.

## **Challenges to PRO Collection - Proxies**

Thank you for acknowledging the challenge of proxies (page 11). For some persons with severe disabilities, including some persons with significant intellectual disabilities and serious mental illness, the additional supplemental input of families and other proxies is helpful and appropriate. Proxy responses do “not” replace the direct voice and lived experience of the person with a disability, but is also a helpful additional PRO information point. The National Association of State Directors of Developmental Disabilities Services (NASDDDS)-Human Services Research Institute (HSRI) developed and administered National Core Indicators has two decades of implementation experience with PRO by persons with severe disabilities and their family members (as supplemental proxies).

## **Missing – PRO in the Area of Disability and in the Medicaid Home-and-Community-Based Services Program and Arena.**

Missing – completely – from the environmental scan is the 20 years experience with PRO in the area of disability and HCBS. NQF typically does “not” cross-reference other NQF reports, products, and projects. Previous and current NQF projects have analyzed and written about PRO in the area of disability and HCBS, but the draft report does not mention this work.

The environmental scan should identify and discuss in some detail: the National Core Indicators; the National Core Indicators-Aging and Disability; Personal Outcome Measures; and the recent and NQF endorsed CMS-AHRQ CAHPS HCBS Experience Survey. Past and existing NQF reports have discussed these instruments and approaches. The October 15 draft PRO environmental scan includes numerous pages of details on the use of PRO in burns, trauma, joint replacement, and heart failure (while being silent of disability and HCBS). Please – please – integrate and include previous NQF work and products on disability and HCBS.

Thank you for the opportunity to comment. If you have any questions please contact Clarke Ross at [clarkross10@comcast.net](mailto:clarkross10@comcast.net).

Sincerely,



**E. Clarke Ross, D.P.A.**

Public Policy Director

American Association on Health and Disability

[clarkross10@comcast.net](mailto:clarkross10@comcast.net)

Cell: 301-821-5410

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-October 2019). 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/>).

**Roberta S. Carlin, MS, JD**

Executive Director

American Association on Health and Disability  
110 N. Washington Street, Suite 328J  
Rockville, MD 20850  
301-545-6140 ext. 206  
301 545-6144 (fax)  
[rcarlin@aahd.us](mailto:rcarlin@aahd.us)

**Amy Rauworth**  
Director of Policy & Public Affairs  
Lakeshore Foundation ([www.lakeshore.org](http://www.lakeshore.org))  
4000 Ridgeway Drive  
Birmingham, Alabama 35209  
205.313.7487  
[amyr@lakeshore.org](mailto:amyr@lakeshore.org)