American Association on Health & Disability

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

LAKESHORE

October 11, 2022

Re: NQF Technical Guidance Draft 2 – Building a Roadmap From Patient-Reported Outcome Measures To Patient-Reported Outcome Performance Measures

The American Association on Health and Disability and the Lakeshore Foundation appreciate the opportunity to provide comments on draft #2 PRO-PM.

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. AAHD is specifically dedicated to integrating public health and disability into the overall public health agenda.

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.

The purposes of our comments are:

1. Reinforce the report's recognition of the importance of patient/beneficiary/program participant/consumer engagement (and their caregivers, families, and advocates).

2. Advocate for greater focus on health equity in the report's work and recommendations.
3. Advocate for more substantial and ongoing involvement by public program administrators who have actual experience implementing PROs and PRO-PMs in the public domain.
4. Raise the question of the balance between promoting the whole-person health and wellness of persons with disabilities vs use of PROs/PRO-PMs in targeted (siloed) public programs, particularly Medicaid and Medicare.
5. Observe, as we have done previously, that the major PROs/PRO-PMs currently serving persons with disabilities are missing as reference points and lessons learned.
6. Question who gets left out with the report, CMS, and NQF emphasis on digital quality measures.

Reinforce the report's recognition of the importance of patient/beneficiary/program participant/consumer engagement (and their caregivers, families, and advocates).

We appreciate the Roadmap intent to be both a guide for measure developers and "a catalyst to elevate patients' voices" (page 30). We agree with the observation (page 5) that patients, in general, lack awareness about the benefits of PRO-PMs.

We support the recommended establishment of stakeholder advisory groups (pages 14 and 15). Yes, the composition of the stakeholder advisory group will depend on the measure. It is important that the report states that the stakeholder advisory group must include representation from the patients, patient advocacy groups, caregivers, and (or) consumer groups. We suggest the report delete "or" and exclusively use "and."

We further endorse the page 15 recommendation of the importance of ensuring stakeholders can submit feedback in a timely manner throughout the development life cycle. We support the suggestion that stakeholders identify a consensus definition for the measure concept-desired outcomes, "that will be monitored." We strongly concur with the pages 15-16 statement that PRO-PMs must be meaningful to patients and/or caregivers and must be meaningful to the program's target population. As above, we recommend both patients and caregivers, not "or." Please delete "or."

Advocate for greater focus on health equity in the report's work and recommendations.

We appreciate and agree with the page 15 observation: Health equity is the attainment of the highest level of health for all people, and it warrants consideration throughout the measure development process. However, this observation ignores the current priority focus of much of the health care field; advocates, patients, families; most of the quality measurement entities; and federal agencies such as ACL, AHRQ, CDC, CMS, HRSA, and SAMHSA. Addressing health equity requires much greater attention. We note the page 24 observation that guidance on risk adjustment is evolving. But the urgency and importance of health equity is missing.

Advocate for more substantial and ongoing involvement by public program administrators who have actual experience implementing PROs and PRO-PMs in the public domain.

Page 19 lists candidate PRO-PMs from lists of academics and quality measure specialists. MISSING – public program administrators. While most public program administrators bring a conservatism based on available resources, budgeting and other factors, they have the experience and lessons of using PRO-PMs in actual use (and limitations and barriers). In the area of disability, public program administrators of Medicaid, especially Medicaid Home and Community-Based Services (HCBS), special Medicare programs, and state government service delivery systems including agencies serving persons with ID/DD, mental illness, and related behavioral health conditions.

We agree with the observations (page 24) regarding attribution – for which providers is the patient outcome a signal of the quality of care? Attribution is used in quality measurement to assign accountability for a patient's outcomes to the accountable entity being assessed by the measure. MISSING: the public program administrators.

Raise the question of the balance between promoting the whole-person health and wellness of persons with disabilities vs use of PROs/PRO-PMs in targeted (siloed) public programs, particularly Medicaid and Medicare.

In 2020, 7.5 million people (persons with disabilities, mental illnesses, and aging with challenges) received Medicaid home-and-community-based services (HCBS) through both Medicaid waiver programs and state plan benefits. [CMS; Medicaid Beneficiaries Who Use LTSS; July 22, 2022.] In 2020, HCBS expenditures accounted for $125 billion, or 62%, of the $199 billion spent nationally on Medicaid LTSS (CMS: SMD 22-003, HCBS Quality Measures Set, July 22, 2022]. In addition to these 7.5 million persons served, 39 states have HCBS waiting lists of 665,015 persons, largely persons with disabilities. [Kaiser Family Foundation: State Policy Choices About Medicaid HCBS Amid the Pandemic; March 4, 2022.]

So, the report does not address the major programs that serve persons with disabilities, mental illnesses, aging with challenges, and related life situations.

Persons with disabilities and mental illnesses are served by the general health care system. But there are few appropriate individualized services and supports for such persons. Additionally, many of these persons face lack of accessibility and accommodation, discrimination, lack of privacy and confidentiality, and lack of provider knowledge. General health services and specialized behavioral health and disability services are rarely coordinated, much less integrated. These factors are not mentioned in the report. PRO-PMs need expertise and experience in addressing the whole-person health and wellness of these special populations. And, largely missing are bridges between specialized Medicaid and Medicare programs (silos) and the general health care arena.

Observe, as we have done previously, that the major PROs/PRO-PMs currently serving persons with disabilities are missing as reference points and lessons learned.

Medicaid home-and-community-based services (HCBS) programs have over 20 years PRO-PM experience in multiple states through the National Core Indicators (NCI) and Personal Outcome Measures (POMs). During the past several years, almost 20 states have implemented a new HCBS-CAHPS (Consumer Assessment of Healthcare Providers and Systems) PRO-PMs. These programs have been discussed, documented, and even endorsed by the NQF. This experience is missing from the NQF PRO-PM guide. The Administration for Community Living (ACL) sponsors several projects examining these HCBS-based PRO-PMs.

Question who gets left out with the report, CMS, and NQF emphasis on digital quality measures.

The report emphasizes the Roadmap for the Development of a Digital PRO-PM (page 12), and need for machine-readable specifications (page 23), and measures captured and transmitted electronically (page 42). Digital measures is the hot/buzz topic and development in health care delivery, led by CMS and NQF. But rarely do the advocates, including the NQF PRO-PM report ask: who gets left out? The entire Medicaid HCBS enterprise, the public mental illness and substance use systems largely do not have such digitally based systems – left out by silo thinking and lack of attention. The few operational HCBS systems generally lack any inter-operability. The report should acknowledge this challenge and situation.

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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And
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National Quality Forum (NQF): Member, NQF Measure Applications Partnership (MAP) Coordinating Committee (July 2021-present); NQF Medicare Hospital Star Ratings Technical Expert Panel (June-November 2019 and September-October 2020); workgroup on Medicaid adult measures (appointed 2016 and 2017); Medicaid-CHIP Scorecard Committee (appointed October 2018); and Measure Sets and Measurement Systems TEP (June 2019-August 2020).

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/). 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 Technical Expert Panel for Social and Functional Risk Adjustment Within Quality Measurement (April 2022-present). AAHD Representative to the CMS-AHIP-NQF Core Quality Measures Collaborative (CQMC) (2019-present). Member: National Committee on Quality Assurance (NCQA) Consumer Advisory Council (2022-2024).

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