



## 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 30, 2022

### **Re: Inpatient Mental Health Experience of Care RFI**

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CAHPS RFI

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The American Association on Health and Disability and the Lakeshore Foundation appreciate the opportunity to provide comments on the AHRQ RFI.

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.

Our responses to a few of the RFI questions follow:

1. What are the highest priority aspects of patient experiences with inpatient mental healthcare that should be included in measures and surveys?
  - a. Why are these aspect(s) of patient experience a high priority for inclusion within assessment tools?
  - b. What other topic area(s) should new measures and/or surveys assessing patient experiences with inpatient mental healthcare address?

**Inpatient program placement should not be an excuse to ignore the fundamental and elementary priority aspects used in Medicaid home-and-community-based services and supports programs, and used in person-centered, individualized, respectful, and responsive disability movement and mental illness approaches and current practices. Mental illness should not be an excuse to ignore the current general and other specialized (such as inpatient rehabilitation hospital) standards and practice, which includes patient surveys. The absence of patient surveys in inpatient mental health settings can only be interpreted as a form of discrimination (underlying misunderstandings and bias).**

**Inpatient mental health settings should not be excused from the overwhelming trend in all of health care – PRO-PMs (Patient-Reported Outcomes-Performance Measures). Inpatient mental health settings patient surveys should be completely consistent with the NQF, CMS, and ACL approaches and elements to person-centered quality measurement, as outlined in the reports below:**

**Inpatient mental health patient surveys should be consistent with:**

**The CMS “Meaningful Measures” initiative (August 9, 2021 CMS to NQF MAP Coordinating Committee; MM 2.0) has 5 goals; one is” prioritize outcome and patient reported measures.” The center-piece is the “consumer and caregiver voice,” that includes 8 domains - person-centered care; chronic conditions; behavioral health; wellness and prevention; safety; seamless care coordination; equity; affordability and efficiency.**

**The CMS National Quality Strategy (2022 CMS annual quality conference) “focuses on a person-centric approach as individuals journey across the continuum of care and across payer type.”**

**The National Quality Forum (NQF) is in their second year of a “Building a Roadmap from Patient-Reported Outcome (PRO) Measures To Patient-Reported Outcome Performance Measures (PRO-PMs)” project – reflecting the HHS and CMS PRO-PM priority. The June 1, 2020 NQF draft PROs: Best Practices report for public comment observed: “Patient-**

**reported outcomes (PROs) are increasingly being used for a variety of healthcare-related activities, including care provision, clinical health services.....” PROs are defined as “any report of the status of a patient’s health condition, health behavior, or experience with healthcare that comes directly from the patient...”**

**The National Quality Forum (September 2, 2020 Patient-Reported Outcomes: Best Practices on Selection and Data Collection final technical report) states: “The word ‘patient’ is intended to be inclusive of all persons, including patients, families, caregivers, and consumers more broadly, and is intended to cover all persons receiving support services, such as persons with disabilities.”**

**The National Quality Forum (July 31, 2020 final Person-Centered Planning and Practice Project report) defines: “person-centered planning is facilitated, individual-directed, positive approach to the planning and coordination of a person’s services and supports based on individual aspirations, needs, preferences, and values. The goal of person-centered planning is to create a plan that would optimize the person’s self-defined quality of life, choice, and control, and self-determination through meaningful exploration and discovery of unique preferences and needs and wants in areas including, but not limited to, health and well-being, relationships, safety, communication, residence, technology, community, resources, and assistance. The person must be empowered to make informed choices that lead to the development, implementation, and maintenance of a flexible service plan for paid and unpaid services and supports.”**

**The Administration for Community Living (ACL) Person-Centered Planning and Practice Project (May 3, 2019 orientation meeting) defines: “person-centered planning (PCP) allows individuals to be engaged in the decision making process about their options, preferences, values, and financial resources....The PCP approach identifies the person’s strengths, goals, preferences, needs, and desired outcomes. The role of staff, family, and other team members is to enable and assist the person to identify and access a unique mix of paid and unpaid services to meet their needs, and to provide support during the planning and implementation....The best person-centered planning helps people to live better lives, with support to do the things most important to them.” PCP is “an approach to assessment, planning, and coordination of services and supports that is focused on the individual’s goals, needs, preferences, and values.”**

**The National Quality Forum [2017 revised conceptual framework for HCBS (home-and-community-based services) outcome measurement] includes 13 domains: community inclusion; workforce; employment; holistic health and functioning; consumer leadership and system development; service delivery and effectiveness; equity; choice and control; human and legal rights; transportation; person-centered planning and coordination; system performance and accountability; and caregiver support. The final NQF report on HCBS Quality Measure Framework was publicly released September 2016.**

**November 13, 2020 Consortium for Citizens with Disabilities (CCD) and November 18, 2020 Disability and Aging Collaborative (DAC) comments to CMS RFI on a possible “HCBS (Home and Community Based Services) Core Quality Measure Set”: “HCBS**

quality measures are essential to ensure Medicaid enrollees, including people with disabilities and older adults, receive services that meet their needs, goals, and preferences, and help them thrive in the community.”

Inpatient mental health settings should not be excused from the overwhelming trend in all of health care – PRO-PMs. Inpatient mental health settings patient surveys should be completely consistent with the NQF, CMS, and ACL approaches and elements to person-centered quality measurement, as outlined on the reports above.

See our reply to question #6 – existing surveys in use and their areas of focus.

6. What measures and surveys that assess the experience of patients in inpatient mental health settings are currently being used?

Inpatient mental health settings patient surveys should use the philosophy, approach, and practices used for persons with disabilities and mental illness currently used in community-based settings. These include:

The **CAHPS (Consumer Assessment of Healthcare Providers and Systems) HCBS (home-and-community-based services)** survey addresses the following eight domains (using 21 questions) : planning your time and activities; personal safety; unmet needs; staff are reliable and helpful; staff listen and communicate well; care manager is helpful; choosing the services that matter to you; and transportation to medical appointment.

The **National Core Indicators (NCI)** (for persons with ID-DD including persons with co-occurring ID-DD and mental illness) and **NCI-AD (National Core Indicators-Aging and Disability, includes persons with mental illness)** focus on roughly 15 indicators in 3 domains: individual outcomes (employment; community participation; choice and decision making; personal relationships); family outcomes (choice and control; family involvement; information and planning; access, community connections; response); and health, wellness, and system (health and wellness; respect for rights; medications; safety; service coordination; staff stability). There are differences between the NCI and NCI-AD. Both are used in state home-and-community-based services systems, particularly Medicaid HCBS programs.

The Council for Quality and Leadership (CQL) **“Personal Outcome Measures”** uses 21 indicators focused on 5 factors – my human security, my community, my relationships, my choices, and my goals. POMs was initially designed for persons with ID-DD and is now applicable to persons with mental illness.

The CAHPS Health Plan Survey whose core composite measures are: getting needed care; getting care quickly; how well doctors communicate; and the health plan information and customer service.

The NIH-National Cancer Institute **PROMIS (Patient-Reported Outcomes Measurement Information System)** is used in inpatient treatment programs using brief, precise, valid, reliable, fixed or tailored tools for patient-reported health status in physical, mental, and

**social well-being for adult and pediatric populations. The focus is on inpatient clinical treatment settings. In reference to mental illness, PROMIS are administered to persons with primary diagnosis of depression and anxiety.**

**Consideration and analysis could be applied to the CMS and NQF Inpatient Rehabilitation Facility measures. These are limited but do have a history with a variety of persons with significant physical disability challenges.**

**ECHO: The Experience of Care and Health Outcomes: many individuals with behavioral health challenges and their advocates cite and support use of the ECHO. The questions are appropriate and helpful. However, the National Quality Forum determined that the administrators of ECHO fail to meet the core responsibilities of a measure steward. Further, we understand that AHRQ is analyzing reconsideration and revision of the ECHO given these measure steward failures. Consideration should be given to merging CAHPS HCBS and ECHO questions, as determined appropriate for an inpatient setting stay.**

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,



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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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