# American Association on Health & Disability

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

CQL | The Council on Quality and Leadership

HSRI Human Services Research Institute

LAKESHORE

NHMH.org
No Health without Mental Health

August 9, 2018

## Re: National Quality Forum: Quality Partners Action Team on Serious Mental Illness – Statement of Interest

Dear National Quality Forum SMI Action Team:

Our collaborative national organizations, concerned with the health and wellness of persons with serious mental illness, submit this statement of interest. A brief description of each submitting collaborative member follows at the end of this statement of interest. Mental health and addiction currently top the lists of the most costly and debilitating conditions in the United States.
It has been well documented that the overall quality of mental health care in the United States is quite poor, compared to other medical conditions. One contributing factor is the lack of uniform methods for measuring quality. What few behavioral health measures exist, they are mostly narrow clinical measures for particular diagnoses. AAHD has completed the NQF on-line SMI statement of interest survey form (as a NQF member).

## Beneficiary Experience, Satisfaction, and Choice

One of the National Quality Strategy triple aim is improving the patient experience of care (including quality and satisfaction). In July 2012, the Consortium for Citizens with Disabilities (CCD) Task Force on Long-Term Services and Supports (LTSS) identified six gaps in existing quality standards as they directly relate to persons with disabilities and persons dually eligible for Medicare and Medicaid. Two were/are:

1. Consumer Choice and Participant-Directed Services
2. Satisfaction: Individual Experience with Services and Supports

These concepts and goals have been addressed, as major gaps, in multiple NQF reports, including persons dually eligible for Medicare and Medicaid), Medicaid adult measures, patient engagement, and home and community-based services. The NQF action team on serious mental illness needs to expand the application of these measures to persons with serious mental illness (SMI). This collaborative statement of interest identifies several existing experience-satisfaction-choice measure instuments.

### ECHO

The National Quality Forum has explored the potential of ECHO (The Experience of Care and Health Outcomes). The measure steward has failed to report on ECHO implementation experience and use data; thus, NQF has not endorsed this behavioral health instrument.

Experience measures in both inpatient and home and community-based settings are both desperately needed and not available. People who are patients in inpatient psychiatric treatment facilities are vulnerable, all too often subject to abuse and neglect, and often feel that they have

no meaningful voice or control of treatment decisions. The ECHO needs to be expanded and actually implemented in terms of reported use data.

**PROMIS**

For person-reported outcomes, we are interested in cross-cutting measures of improvements in social functioning that promote effective team-based care and/or population health management. One possible example of an existing well-developed person-reported outcome item bank is the NIH Patient Reported Outcome Measurement Information System (PROMIS). Several mental health associations - Mental Health America (MHA), with support from the National Alliance on Mental Illness (NAMI), the Depression and Bipolar Support Alliance (DBSA), and the American Foundation for Suicide Prevention (AFSP) - have submitted to CMS a proposal to incorporate a behavioral measure into PROMIS: Mental Health Response at Twelve Months – Progress Toward Recovery.. The proposal submitted by MHA and colleagues would expand the Patient Health Questionnaire (PHQ-9) into PROMIS.

**Personal Outcome Measures**

The Personal Outcome Measures was originally developed based on focus groups about quality of life priorities with people with a wide range of disabilities, including mental illness, and their families. The Personal Outcome Measures® is designed to be used by people with disabilities receiving long term services and supports (LTSS). The overwhelming majority of people interviewed with the Personal Outcome Measures® are on Medicaid. While the majority of the Council for Quality and Leadership (CQL) current data is with people with intellectual and developmental disabilities, the Personal Outcome Measures® is also used with people with mental illness, older adults, and children and youth.

The Personal Outcome Measures is well suited for working with people with multiple disabilities or co-occurring conditions. The majority of people who participated in the Personal Outcome Measures between 2015 and 2016 had more than one diagnosis (70%). Moreover, almost one-fourth of our sample from these two years (23%) had co-occurring disabilities and chronic-illnesses. (The chronic-illnesses currently tracked quantitatively are Alzheimer's, dementia, and epilepsy so the number could actually be higher.) Almost half (40%) of our sample from the past two years had a co-occurring disability and mental illness.

Hundreds of organizations across the United States currently utilize the Personal Outcome Measures®. The Personal Outcome Measures® has been used with over 15,000 people with disabilities by certified interviewers alone. POM has been presented to several NQF committees and work groups.

**National Core Indicators**

The National Core Indicators™ has been in use for over 20 years by states to assess the performance of state systems by gathering outcomes of services provided to people with intellectual and developmental disabilities and their families. It was developed as a partnership between Human Services Research Institute (HSRI) and the National Association of State

Directors of Developmental Disability Services (NASDDDS). At present, 46 states plus the District of Columbia participate in National Core Indicators, collecting surveys from individuals who receive services, families, and from providers of services regarding staff stability. Not all states collect data in each survey year however there is broad representation by states. For example, in the 2016-2017 data collection cycle, 39 states participated in the NCI In-Person-Survey, completing valid surveys from 21,625 individuals.

Background information collected prior to the NCI In-Person-Survey identifies chronic and co-occurring health conditions. Results from the 2016-2017 data collection cycle indicate that 47.6% of respondents were identified as having a mood disorder, anxiety disorder, psychotic disorder, or 'other mental illness or psychiatric diagnosis'. Additionally, 48% of the sample reviewed were identified as taking medication for mood, anxiety and/or psychotic disorders.

**National Core Indicators – Aging and Disability (NCI-AD)**

The National Core Indicators for Aging and Disability is a separate survey tool, collecting outcome and satisfaction information from a representative state sample of adults receiving services for age-related disabilities and physical disabilities. It was developed and is administered by HSRI and the National Association of States United for Aging and Disability (NASUAD) beginning data collection in 2014. Currently, NCI-AD has over 20 states participating. In the 2015-2016 survey results summary including respondents from 11 states, an average of 35% of respondents reported they had a chronic psychiatric or mental health diagnosis. In addition, an average of 40% reported that they 'take medication to help feel less sad or depressed'.

**In both the NCI and NCI-AD,** the items described, combined with self or proxy reported measures of health and service outcomes such as community engagement and employment, provide an effective means to understand outcomes of people with disability and co-occurring mental illness.

Both National Core Indicators and National Core Indicators for Aging and Disability were developed and validated with individuals with disabilities, and use standard training, implementation and reporting protocols. Measures from these two tools are being developed for submission to NQF for endorsement, as has been discussed in several presentations with NQF and at the national NQF conference.

**Proposal: Needed ACL, SAMHSA, CMS, AHRQ funded project: measure by measure and procedure by procedure comparison of:**

CAHPS HCBS Experience Survey
NCI – National Core Indicators (HSRI)
POM – Personal Outcome Measures (CQL)
ECHO – Experience of Care and Health Outcomes
NCQA Individual Health Care Experience

The CAHPS HCBS Experience Survey is endorsed by the NQF and copyrighted by AHRQ as part of the CAHPS (Consumer Assessment of Healthcare Providers and Systems) portfolio. The

CAHPS HCBS is currently used by 17 state Medicaid programs. NCI-POM-ECHO have previously been summarized. With foundation support, NCQA is testing a health plan experience survey. There is an immediate need for a measure-by measure and procedure by procedure detailed and precise comparison of these and similar/related experience measures. SAMHSA and CMS should be part of the funding sponsorship so that specific application to persons with serious mental illness can be fully and adequately analyzed.

## Integration of Behavioral Health and Primary Care; Interface Between Medical and Behavioral Health

The current draft NQF report on Medicaid adult measures (pages 19 & 43) recognize the need for quality measures on the integration of behavioral health and physical health/primary care. As documented in NQF committee on behavioral health reports, existing behavioral health quality measures are inadequate and modest, as well as almost exclusively clinically focused.

Some of the new quality measures being developed, to evaluate integration services performance by medical practices starting to integrate medical-BH services, which can act as a basis for payment, are:

-- performing a repeat PHQ-9 depression screen after the initial baseline PHQ-9;

-- contact w/ patient (call, visit, email, text) within 4 weeks of clinical encounter where depression diagnosis made;

-- patient visit with an external BH provider within 60 days of referral;

-- provider/care team communication or follow-up with external BH provider referral;

-- action by the medical practice to bill or receive revenue for BH screening work.

Another need is to prioritize within the Treatment/Services/Support Team, the need for the specialty BH practitioners who treat persons with serious mental illness, to keep up with and incorporate the changes now beginning to take shape integrating care, i.e. they need to apply behavioral integration in medical venues best practices into medical integration in BH specialty settings. Co-occurring behavioral health and medical issues, usually chronic medical conditions, are largely neglected.

### Social Determinants of Health

Multiple National Quality Forum reports address social determinants of health. Needed is a precise focus on social determinants and serious mental illness.

### Collaborating Associations: Brief Description

**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. Since 2012, AAHD has served as the liaison between the NQF and the Consortium for Citizens with Disabilities (CCD), Task Force on Long Term Services and Supports (LTSS).

**Council on Quality and Leadership (CQL)** (www.thecouncil.org) . For over 45 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 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) and their standards were incorporated into the historic *Wyatt v. Stickney* decision as well as legal settlements in TX, ND, CA, AK, and WV.

**Human Services Research Institute (HSRI) (www.hsri.org)** : A nonprofit organization based in Cambridge, Massachusetts. HSRI was founded in 1976 to improve the availability and quality of behavioral, developmental, and physical health services. HSRI works across the fields of intellectual and developmental disabilities, substance use and prevention, mental health, child and family services, and health data.

**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.

**NHMH - No Health without Mental Health**, www.nhmh.org is a 501(c)(3) tax-exempt mental health advocacy nonprofit formed in California in 2007, and with an office in Washington, D.C. since 2011. NHMH's mission is focused exclusively on one issue: getting effective mental health care services into medical settings such as primary care. NHMH is also involved in numerous clinical trials around the country serving on stakeholder committees as a voice for patients and families. These research projects are aimed at helping primary care practices begin to implement evidence-based mental health and substance use disorder services. And develop multiple models of integrated medical-behavioral care for medical settings.

**Thank You**

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

Sincerely,

E. Clarke Ross

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Member, National Quality Forum (NQF) workgroup on Medicaid adult measures (December 2017-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) and NQF representative of the Consortium for Citizens with Disabilities (CCD) Task Force on Long Term Services and Supports to the workgroup on persons dually eligible. 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, 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. Member, SAMHSA Wellness Campaign National Steering Committee – January 2011-September 2014.

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