

Community Participation and Inclusion:

SHIFTING PERSPECTIVES ON QUALITY MEASURES

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Requests for training, technical assistance, or other inquiries related to this monograph should be directed to The Temple University Collaborative on Community Inclusion for Individuals with Psychiatric Disabilities (TU Collaborative) at tucollab@temple.edu.

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The importance of quality measures that identify the impact of mental health care has been a hot (if not the hottest) topic at industry-facilitated meetings over the last few years. It's no secret that advocacy, practitioner, and professional groups regularly hold meetings on this topic that are supported through industry partnerships. In fact, [Otsuka America Pharmaceutical, Inc.](#), the sponsoring organization for the April 28, 2015 Mental Health Quality Summit, which is the subject of this monograph, held other quality-focused events in 2013 and 2014. But the event detailed herein was quite notable in that by the end of the afternoon-long meeting there was a pronounced policy perspective turnabout for those in attendance.

The changed perspectives belonged to a group of well-informed individuals from influential organizations, including a senior advisor at the Center for Medicare and Medicaid Services, which carries significant responsibilities in the quality measures arena. In large part this shift in perspective was in response to the issues discussed in a presentation from one of the panelists, Richard Baron, Co-Director of Knowledge Translation at the [Temple University Collaborative on Community Inclusion of Individuals with Psychiatric Disabilities](#) (TU Collaborative), which focused on the importance of including community inclusion outcomes as part of mental health systems' emphasis on quality measures.

The TU Collaborative is a National Rehabilitation Research and Training Center, funded by the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR), where their research and knowledge translation activities emphasize the importance of community inclusion for individuals with psychiatric disabilities. As aptly put by the Center's TU Collaborative Director Mark Salzer, PhD, the TU Collaborative works to create opportunities for individuals with psychiatric disabilities "to live in the community, and be valued for one's uniqueness and abilities, like everyone else" (2006).ⁱ

In addition to Mr. Baron, the other invited speakers at the summit were an accomplished group, each with impressive credentials and expertise related to quality measurement in behavioral health: Jeffery Buck, PhD, who is Senior Advisor for Behavioral Health in the CMS [Center for Clinical Standards and Quality](#) and also the program lead for the [Inpatient Psychiatric Facility \(IPF\) Quality Reporting Program](#); Samantha Shugarman, M.S., Deputy Director of Quality for the [American Psychiatric Association \(APA\)](#), and one of the authors of a very pertinent recent article, [Measuring Quality in Psychiatry: A Call to Action](#);ⁱⁱ and Michael R. Lardieri, LCSW, a recognized expert in implementing Health Information Technology (HIT) strategies to improve care quality in settings that integrate physical and behavioral health. Currently, he serves as the Assistant Vice President for Strategic Program Development at [Northwell Health \(formerly the North Shore-LIJ Health System\)](#), which is the fourteenth largest health system in the country.

Lastly, there was Ron Manderscheid, PhD. Dr. Manderscheid is the Executive Director of the [National Association of County Behavioral Health and Developmental Disability Directors \(NACBHD\)](#). Dr. Manderscheid is viewed by many as the grandfather of promoting recovery, peers, and family supports. His career includes serving as a director at, if not the founder of, several important behavioral health and global healthcare organizations and coalitions. These include serving at [NIMH](#) and [SAMHSA](#) and founding or cofounding entities such as [ACMHA](#):

[The College of Behavioral Health Leadership](#) and the [Coalition for Whole Health](#). He also sits on a number of advisory boards that shape national policy, including the [FrameWorks Institute](#), the [Council on Quality and Leadership](#), and the [National Research Institute](#). Dr. Manderscheid is also an Adjunct Professor at the [Department of Mental Health, Bloomberg School of Public Health at Johns Hopkins University](#), where he shares his expertise with students, many of whom are community behavioral health leaders from around the country. Dr. Manderscheid is perhaps most renowned for doing the research that has resulted in powerful policy data interpretations and statistics. In the behavioral health field, people know about and use Dr. Manderscheid's work to facilitate policy and systems change, even if they do not realize that the research is attributable to him, including the oft-quoted statement, "People with serious mental illnesses (SMI) die 25 years younger than other Americans."ⁱⁱⁱ

In addition to the invited speakers, summit participants included members of the Otsuka Government Affairs Team and five prominent national mental health organizations. There were two trade groups and three advocacy organizations, and while they have much in common, they do represent specific interests and somewhat differing perspectives about behavioral health quality measures. Nonetheless, representatives from these disparate, yet complementary, organizations have a long history of working together as a formal Mental Health Advocacy Coalition. Participants in the program included representatives from:

- The [American Psychiatric Association \(APA\)](#) represents the interests of their 36,000 member psychiatrists and has the most clinically-focused perspective of all the coalition members. However, APA's mission, vision and goals are quite simpatico with those of the other summit participants. APA promotes access to the highest quality care for individuals with mental illness (including substance use disorders), prevention, sensitivity towards people with mental health and substance use conditions, and compassion for their families.^{iv}
- The [National Council for Behavioral Health](#) represents community mental health and substance use providers, and is pioneering community-based models for integrated care through the [SAMHSA-HRSA Center for Integrated Health Solutions](#). The National Council has 2,500 member organizations, serving more than eight million adults and children living with mental illnesses and addiction disorders.^v

The other members of the Mental Health Advocacy Coalition, [Mental Health America \(MHA\)](#), the [National Alliance on Mental Illness \(NAMI\)](#), and the [Depression and Bipolar Support Alliance \(DBSA\)](#), represent many facets of the needs and perspectives of people touched by mental health conditions.

- NAMI, founded in 1979 by family members of individuals living with mental illnesses, defines itself as being "dedicated to building better lives for the millions of Americans affected by mental illness."^{vi} NAMI focuses on the needs of those with mental illnesses, as well as their families and caregivers. NAMI has a network of state and local affiliates and volunteer leaders who work in local communities across the country to raise awareness and provide essential and free education, advocacy, and support group

programs.

- DBSA's stated primary goal is to make life better for those experiencing mood disorders. Since its inception in 1985, DBSA has always been an organization based on providing peer support to people experiencing depression and bipolar disorder. Its chapters have more than 700 independent peer-run support groups in communities across the county.^{vii}
- MHA is the oldest national mental health organization with more than one hundred years of experience advocating from the viewpoint of those who have lived experience with mental health conditions. MHA has more than 200 affiliates nationwide, many of which are also service providers and well-regarded advocates in their local regions. MHA is "committed to promoting mental health as a critical part of overall wellness, including prevention for all, early identification and intervention for those at risk, integrated health, behavioral health and other services for those who need them, and recovery as a goal."^{viii} MHA is a collaborator in the Temple Collaborative on Community Inclusion of Individuals with Psychiatric Disabilities.^{ix}

Planning for the April 28, 2015 Quality Summit began several months before the event. Speakers were suggested and invited, and a survey was sent out by the Otsuka Government Affairs team. Respondents included summit participants from Mental Health Advocacy Coalition organizations. The survey responses were compiled and presented at the summit by a member of the Otsuka Government Affairs team. With only seven respondents, the "n" was very small, but the bar charts did illustrate rankings pretty clearly.

Responses demonstrated deep agreement that robust mental health quality measures were important to survey participants, and that the [National Quality Forum \(NQF\)](#) was the most trusted organization to validate and support measures. Questions in the survey were posed from a clinical perspective and thus responses regarding importance and usefulness were consistent with that perspective. For example, provider-reported outcomes and medication adherence were ranked important or very important. Clinical process/effectiveness ranked as the most useful aspect of mental health quality development. This clinical perspective was also reflected in the predominate choice regarding which organizations should play a role in the development of quality measures. All of the respondents thought that the entities should include the [Centers for Medicaid Services \(CMS\)](#) and the [American Medical Association Physician Consortium for Performance Improvement \(AMA-PCPI\)](#). Eighty percent of respondents thought that SAMHSA should also have a role. Survey participants also ranked the development of care coordination, services, and measures that drive patient-reported outcomes as being very high in importance.

The final survey question asked how recovery should be considered when measuring quality. Respondents were asked to indicate their preferences between a number of well-known scales, including the [Sheehan Disability Scale \(SDS\)](#), the [WHO-5 Well-Being Scale](#), and what was identified only as Social Determinants of Health (without naming a particular scale). The

rankings for all three resulted in a bar chart with three bars of equal height. What was notable, however, was that the clear preference was indicated by a bar that was twice as tall for a category labeled “other.”

Before Rick Baron stepped in to define this “other” category, the group also briefly reviewed parts of a PowerPoint presentation that the Otsuka team had prepared for a quality focused meeting in 2014.^x The review noted that, through a series of incentives and penalties set into law under the [Patient Protection and Affordable Care Act \(ACA\)](#), Medicare providers will have to collect data and report on outcomes related to quality. The ACA also established a [National Quality Strategy \(NQS\)](#) in order to improve outcomes based on quality and value. An important component of the NQS is the [Physician Quality Reporting System \(PQRS\)](#) – formerly called the Physician Quality Reporting Initiative (PQRI).^{xi} The PQRS measures for mental health are focused on Major Depressive Disorder (MDD) and Substance Use Disorder (SUD). They include measures for medication management for MDD, and measures for screening for MDD and SUD.

Additionally, the group reviewed Medicare measures for inpatient hospitals and inpatient psychiatric facilities. These measures included the time between arrival in an emergency department and departure of admitted patients, the use of medications, reporting on restraint and seclusion, and the creation of follow-up plans. The group also briefly looked at some of the [Healthcare Effectives Data and Information Set \(HEDIS\)](#) measures, which are designed for commercial insurance plans. HEDIS measures look beyond discharge, and include monitoring for comorbidities, such as diabetes and thyroid or cardiac conditions that commonly effect people with serious mental illnesses who are taking antipsychotic medications. Lastly, [National Quality Forum \(NQF\)](#) measures were reviewed. NQF measures move the bar even further than the HEDIS measures by assessing and screening for behaviors such as smoking and alcohol and substance use, as well as monitoring body-mass index and blood pressure for people with mental illnesses. Before moving on to the presentations by Jeff Buck, Samantha Shugarman, and Michael Lardieri, several meeting participants noted that thus far every measure spoken about concerned only clinically-focused outcomes.

Jeff Buck began by discussing a fact that had become familiar to the summit participants and is presently unfolding, changing the landscape for the funding and delivery of services. “The recession dealt a deft blow to traditional funding streams,” Buck stated, quickly explaining that, “the ACA was stepping in to the rescue.” From Dr. Buck’s standpoint at CMS, where he presently focuses on Medicare, the payment system incentives, Pay for Reporting (PFR) and Pay for Performance (PFP), will be game-changers. Through a series of incentives and penalties set into law under the ACA, he explained, Medicare providers will have to collect data and report on outcomes related to quality. Dr. Buck further explained that even though most people with mental health conditions are covered under Medicaid and increasingly by private insurance (owing to the [Mental Health Parity and Addiction Equity Act \(MHPAEA\)](#) and the parity provisions of the ACA), we should all be paying close attention to what happens in Medicare. This is because Medicare is the model for other federal insurance programs and for private plans.

Samantha Shugarman spoke about how the APA is deeply involved in advocating for quality measures in behavioral health. Her presentation focused on the article she had recently co-authored, [*Measuring Quality in Psychiatry: A Call to Action*](#).^{xii} Shugarman explained that the APA would like to establish a registry of best care practices.

Michael Lardieri told participants about using his experience in community behavioral health and as an IT expert during his tenure on the Behavioral Health Measures Subcommittee of the NQF. He believes that the growing use of Health Information Technology (HIT) systems will facilitate the building of more comprehensive systems of care.

Rick Baron's turn to speak began with an explanation of the purposes and activities of the TU Collaborative and then went on to make a very compelling case for what the measure that had been labeled "other" should be – community inclusion. He strengthened his case by suggesting that, "Community inclusion is what recovery is for."

Reiterating TU Collaborative Director Dr. Mark Salzer's explication that the basis of community inclusion is having the opportunity to live in community like everybody else, Baron described many of the ways in which this is decidedly still not happening for people with psychiatric disabilities. He focused on several key aspects of community life:

"Employment" – Mr. Baron noted that the unemployment rate for people with psychiatric disabilities has remained steady, for several decades, at 80 to 85 percent, even though most people report that they want to work. He also noted that much of this work is often in part-time and low-wage jobs, despite the capacities and interests of the individual worker.

"Housing" – He reminded the summit participants that both high rates of homelessness and the segregation of housing programs for people with mental illnesses in poorer communities continues as well. What we need to do, he explained, is build pathways for people to access mainstream housing in the location of their choosing.

"Adult Roles" – Mr. Baron reminded attendees that social relationships for people with psychiatric disabilities are often attenuated in fundamental ways. For example, many people report that their only friends are their therapist, case manager, or, at best, other people with psychiatric disabilities with whom they engage in programs and services. It is still common, as well, for civil rights of individuals with a history of mental health conditions to be restricted, including in the area of one of the most fundamental social roles – parenting (and large numbers of people with mental illnesses are parents). Mothers with mental illnesses still regularly lose custody of their children solely because of a history of emotional difficulties.

"Religious and Spiritual Engagement" – Another area of life that people with psychiatric disabilities report as being extremely important to their recovery is their active engagement in the life of religious congregations and spiritual groups of their choice. Individuals often suggest they while they may attend religious services, they are not active participants in

congregational life. As Mr. Baron explained, “People are interested in both the faith and the fellowship aspect of congregational life.”

Mr. Baron suggested that the continued isolation of individuals with mental health conditions from everyday life called for a new generation of interventions, services, and supports that “must help people move beyond the warm embrace of the mental health system, building pathways from segregated services to mainstream settings that are accessible by everyone.”

Mr. Baron affirmed that this can be done, but only by removing structural barriers, retraining providers, staff, and consumers, and engaging everyone to work together to build communities that are truly welcoming. Barriers include funding based solely on traditional medical necessity requirements and outcome measures focused mainly on reducing hospitalization and increasing medication adherence, safety, and stability.

Baron offered a few examples and places in which some of this is happening. He cited the [Pioneer Center](#) in McHenry, Illinois, where there are staff positions such as a Community Inclusion Manager, who supervises a team of Community Inclusion Specialists. He gave other examples of programs that foster community inclusion, including one that has garnered national and international attention,^{xiii} the [Consumer Recovery Investment Fund Self Directed Care Program \(CRIF\)](#) at the [Mental Health Association of Southeastern Pennsylvania \(MHASP\)](#). The CRIF program employs [Certified Peer Specialists \(CPS\)](#) as peer coaches who help consumers strengthen their recovery by using mental health system dollars to increase their community inclusion. Previously, these dollars would likely have been used on high cost services such as inpatient care and intensive case management. Baron gave examples of how what are called “freedom funds” might be used, including purchasing monthly passes for public transportation, taking music lessons, gym memberships, and obtaining clothes for job interviews.

Mr. Baron also offered an available resource, accessible online, where state and local mental health entities, provider agencies, and managed care organizations and other payers can learn about how to increase community inclusion for those for whom they provide services – [The College of Recovery and Community Inclusion](#).

But, Baron continued, we need to move from clinical quality to accountability in consumer-driven ways, using something that can measure the ways in which consumers are engaged in living their lives. He argued that “quality measurement must illustrate community inclusion principles to be meaningful,” reflecting the consumer voice, and most importantly demonstrably illustrating the degree to which a person is engaged in community life.

Mr. Baron drew participants’ attention to one tool for measuring outcomes in the category previously known as “other” – [The TU Community Participation Measure](#). This tool measures the state of and changes to the frequency, importance, and sufficiency of individuals self-reported participation in various activities denoting their own personal inclusion in the community. The 26 questions contained therein include questions specific to people with

behavioral health issues, such as engagement with programs like Alcoholics Anonymous, Narcotics Anonymous, and NAMI or other self-help groups. It also asks about everyday activities that strongly signify recovery for people for whom these activities may have become anomalous. Every summit participant could relate to most of the items measured by the tool, including: running errands, like shopping and going to the library or bank; attending services at church, synagogue, or mosque; going to a concert or sporting event; and participating in family gatherings. Increasing the number of times people with psychiatric disabilities engage in these common activities is an outcome that signifies recovery.

Ron Manderscheid spoke next, and both his prepared and spontaneous remarks strongly reinforced what Mr. Baron had just put forth. Dr. Manderscheid pointed out to the group that the conversation and the perspectives in the room “had moved from systems to people,” and declared that “we must push the reset button on quality.” He stated that before the ACA, quality measures were “going nowhere,” reiterating that they were clinical and reflected only the point of view of providers. Manderscheid also affirmed that measures were still less reflective of where they need to go with respect to guiding payers and managed care organizations. Dr. Manderscheid boldly asserted that peers will be 25 percent of workforce in the coming years as healthcare delivery systems transform. Manderscheid claimed that quality must be tied to outcomes, and that “quality measurement must come from the peer point-of-view,” measuring what matters to people living with behavioral health conditions, not just measuring what systems are or are not doing.

Jeff Buck jumped in to offer the very last words of the day, specifically directed to the advocacy groups in the room. He implored them to mobilize their consumer constituencies and to take every opportunity to give him “huge pushback.” Dr. Buck called for the advocacy and consumer communities to take every opportunity to respond to public [requests for comment](#) from Medicare and Medicaid. Comments, he insisted, must promote specific quality assessments that measure outcomes that go beyond what is being done now – outcomes such as community inclusion.

ⁱ Salzer, M.S., & Baron, R.C. (2006). Community integration and measuring participation. Philadelphia, PA: University of Pennsylvania Collaborative on Community Integration. Available online at www.upennrrtc.org.

ⁱⁱ Giled, S; Stein, B; McGuire, T; Robinson-Beal, S; Firoozman-Duffy, F; Shugarman, S; and Goldman, H. (2015) Measuring Quality in Psychiatry: A Call to Action, *Psychiatric Services*, Volume 66 Issue 8, August 01, 2015, pp. 872-878

ⁱⁱⁱ Manderscheid, R.W (2006) Behavioral Healthcare, We can help people with serious mental illness live longer, happier lives. Accessed at <http://www.behavioral.net/article/saving-lives-and-restoring-hope>

^{iv} APA's Vision, Mission, Values, and Goals. (2015). Retrieved December 22, 2015, from <http://www.psychiatry.org/about-apa/vision-mission-values-goals>

^v About the National Council. (2015). Retrieved December 22, 2015, from <http://www.thenationalcouncil.org/about/>

^{vi} About NAMI. (2015). Retrieved December 22, 2015, from <http://www.nami.org/About-NAMI>

^{vii} About Support Groups and Chapters. (n.d.). Retrieved December 22, 2015, from http://www.dbsalliance.org/site/PageServer?pagename=peer_chapters_support_groups

^{viii} About Us. (2015). Retrieved December 22, 2015, from <http://www.mentalhealthamerica.net/about-us>

^{ix} Collaborators. (2014, January 24). Retrieved December 22, 2015, from <http://tucollaborative.org/about-us/collaborators/>

^x Otsuka America Pharmaceutical, Inc. (2014) Quality Landscape in Mental Health

^{xi} Unpublished work ©2013. American College of Physicians, Inc.

https://www.acponline.org/advocacy/where_we_stand/assets/iii9-medicare-pay-for-reporting.pdf

^{xii} Giled, S; Stein, B; McGuire, T; Robinson-Beal, S; Firoozman-Duffy, F; Shugarman, S; and Goldman, H. (2015) Measuring Quality in Psychiatry: A Call to Action, *Psychiatric Services*, Volume 66 Issue 8, August 01, 2015, pp. 872-878

^{xiii} Welder, L, Maula, E. Diamond, B. Baron, R. Salzer, M A Guide to Creating Self-Directed Care Programs: The Delaware County CRIF CSD Model <http://tucollaborative.org/wp-content/uploads/2015/09/SDC-Manual-draft-94.pdf>