Measuring Specific Mental Illness Diagnoses with Functional Impairment

Discussion Brief

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Introduction:

SAMHSA is interested in expanding the agency's behavioral health data collections and in obtaining input on an approach for providing estimates of specific mental illness diagnoses with functional impairment. The goal is to directly estimate mental disorders and impairment associated with each of the disorders, including more disorders than what SAMHSA is able to include in its existing procedures of estimating Serious Mental Illness (SMI). This document summarizes the authors' perspectives on some lessons learned based, in part, on a workshop[1] that explored this topic in detail, and discusses possible current and future options for SAMHSA. Many of the concepts and potential directions may apply to other constructs of interest to SAMHSA as well.

Why is this important?

The federal government has historically provided funds to states to care for poor and uninsured individuals with the most disabling mental illnesses. In the 1992 ADAMHA Reorganization Act (P.L. 102-321), Congress directed the Secretary of Health and Human Services to develop a federal definition of SMI to aid in the estimation of state-level rates of SMI. These rates are used to allocate block grants to states through the Community Mental Health Services Block Grant (MHBG) program.

The 1993 definition defines adults with a serious mental illness as persons: (1) age 18 and over, (2) who currently or at any time during the past year, (3) have a diagnosable mental, behavioral, or emotional disorder of sufficient duration to meet diagnostic criteria specified within the Diagnostic and Statistical Manual of Mental Disorders, (4) that has resulted in functional impairment which substantially interferes with or limits one or more major life activities. (Federal Register Volume 58 No. 960, 1993).

[1]See: National Academies of Sciences, Engineering, and Medicine. (2016). *Measuring Specific Mental Illness Diagnoses with Functional Impairment: Workshop Summary*. J. C. Rivard and K. Marton, rapporteurs. Committee on National Statistics, and Board on Behavioral, Cognitive, and Sensory Sciences, Division of Behavioral and Social Sciences and Education. Board on Health Sciences Policy, Institute of Medicine, Washington, DC: The National Academies Press.

What are the data needs?

SAMHSA's Center for Behavioral Health Statistics and Quality is charged with producing state-level estimates of SMI to Congress each year. SAMHSA's National Survey on Drug Use and Health (NSDUH) is used to generate these annual statistics. Approximately 4 percent of the population in the United States meets the definition of a serious mental illness using these criteria.

State level estimates of SMI: SAMHSA is required by statute to develop state-level estimates of SMI through P.L. 102-321. These estimates are used to determine the level of state funding for state block grants. Because the NSDUH's sample design was not set up to be representative of all 50 states and the District of Columbia, the annual sample sizes in many states are too small to produce direct survey estimates, SAMHSA uses a small-area estimation (SAE) methodology to produce estimates using the most recent 2 years of pooled NSDUH data. As of 2011, there was considerable variation across states, from 3.1 percent prevalence in New Jersey to a 5.5 percent rate in West Virginia.

What are the epidemiological sources of variation in rates of serious mental illnesses across states? Socio-contextual factors, such as poverty, crime rates, or urbanicity could potentially drive higher rates of depressive or anxiety symptoms. These social factors could also lead to lower functioning (e.g., ability to hold a job) among symptomatic individuals. Migration patterns could also attract individuals with mental disorders to areas with better treatment options. Differences in diagnostic capabilities across settings could also influence treated prevalence rates of conditions. Many of these factors are likely to operate at the neighborhood or census tract level, with a high degree of heterogeneity within any state.

SAMHSA uses many of these socio-contextual factors to calculate state-level SMI rates. Income and poverty statistics are drawn from the U.S. Census Bureau and the Bureau of Economic Analysis; other demographic factors from the 5-year American Community Survey; crime reports from the Federal Bureau of Investigation; unemployment rates from the Bureau of Labor Statistics (BLS), However, other potential contributing factors are likely left unmeasured in the model and could potentially lead to misspecification and bias in the SAE estimates.

Frequency of data collection: SAMHSA is required to provide annual estimates of SMI to Congress (as well as distributing block grants); however, these rates tend to be very stable over time. Neither NSDUH nor other major surveys (e.g., National Comorbidity Survey

Replication) have found major secular trends in national rates of SMI or specific mental disorders (with the exception of substance use disorders) from year to year. We are not certain of the potential state to state variation by year.

What are the dimensions that need to be measured? The two key dimensions that need to be captured for a diagnosis of SMI are diagnosis/symptomatology and impairment. During the period 2008-2012, NSDUH SMI estimates were validated using clinical interview data collected on a subset of adult NSDUH respondents who completed a past 12-month version of the Structured Clinical Interview for the DSM-IV-TR Axis I Disorders (SCID). The SCID measures symptoms using DSM criteria and a Global Assessment of Functioning (GAF), which describes overall functioning without attribution to particular mental or substance use disorders. Clinical data from the National Mental Health Services Survey were used to develop this model to estimate SMI and apply it to the full sample of NSDUH participants, using the K-6 and the WHO Disability Assessment Schedule (WHODAS). The K-6 primarily measures depressive and anxiety symptoms, and the WHODAS captures self-reported functioning in cognition, mobility, self-care, interactions with others, life activities, and community participation. As with the GAF, problems in functioning are not attributed to particular mental or medical disorders.

The NSDUH is not able to capture psychotic illnesses or personality disorders, because of the complexity of assessment and, in the case of psychotic conditions, their low prevalence rates in the general population.

Issues and potential opportunities for Center for Behavioral Health Statistics and Quality, SAMHSA, and federal policymakers

There are several themes that emerged from the workshop. These centered on how to combine or complement NSDUH with other data sources; periodicity and state-level variation; and the definition of SMI, in particular functional status. Each of these issues has potential implications for the Center for Behavioral Health Statistics and Quality, which is charged with generating SMI estimates; SAMHSA, whose mission is to reduce the impact of substance abuse and mental illness on America's communities; and federal regulators, whose role is to establish the definition of SMI and determine how federal dollars are used to care for populations with serious mental illness.

1. Harmonizing NSDUH with other data sources: NSDUH's large sample size and representative sampling strategy are assets for providing population-based estimates of SMI. However, there are also limitations of using the NSDUH alone for these estimates. NSDUH does not capture psychotic illnesses or personality disorders, which are among the most prevalent, burdensome, and costly conditions treated in the public mental health sector. Surveys do not routinely capture institutionalized populations or the criminal justice system. Furthermore, as with other national polls and surveys, response rates are declining over time and samples may be becoming less representative of the broader population, particularly missing those with SMI.

Other national datasets may help fill some of these gaps. The NESARC includes diagnostic questionnaires for personality disorders, BRFSS is designed to produce state-level estimates, and the planned NIMH National Mental Health Survey (if implemented) will provide updated epidemiology and detailed service use data. It will be important to consider strategies of how best to harmonize these data in developing estimates of SMI.

Insurance claims information are also an important set of data about public sector service users. These include Medicaid MAX and state files, Medicare data, state mental health authority data, and private claims databases such as MarketScan and the Health Care Cost Institute. While public sector claims databases only capture service users, most individuals with the most serious mental illnesses will use some sort of mental health services. Furthermore, these databases may capture individuals who have a disabling condition but are successfully treated and not currently symptomatic. The large samples make it possible to understand variations in treated prevalence rates of rare conditions such as schizophrenia.

- Implications for the Center for Behavioral Health Statistics and Quality: It may be possible to expand internal capacity to analyze other data sources, in particular claims data from Medicaid/Medicare, commercial claims data, and data from state mental health authorities. As a starting point it would be useful to examine the correlation between state- and county-level estimates of SMI as measured in NSDUH and other datasets to better understand the degree of overlap across these different definitions and sources of data. For instance, how do state-level estimates of SMI correlate with state-level estimates of individuals treated for SMI diagnoses in the Medicaid disability program?
- Implications for SAMHSA: These different surveys and datasets are currently not planned or analyzed in a coordinated fashion. As the primary agency tasked with mental health

surveillance, SAMHSA has the opportunity to coordinate efforts across surveys and datasets to identify areas of unmet need as well as duplication.

- Implications for federal policymakers: Estimates of SMI defined using population surveys may not fully map onto needs for block grant funding. Surveys largely capture populations with high levels of distress; these individuals are not necessarily the high users of inpatient, outpatient, and pharmaceutical services.

2. Periodicity and small area variation: For the NSDUH and other national surveys, rates of mental illnesses (with the exception of substance use) appear to be relatively constant over time. State-level variation may have less to do with different ambient rates of mental illness and more to do with differences in the underlying populations, but this is still to be definitely ascertained.

- Implications for the Center for Behavioral Health Statistics and Quality: Annual prevalence estimates for SMI are likely not needed. This would potentially free resources to conduct more in-depth analyses of other topics. Given that there were no changes found in epidemiological prevalence of common mental disorders in the 10-year gap between the NCS and the NCS-R, prevalence estimates every five years would probably be more than sufficient.
- State-level estimates could further rely on synthetic estimates using national estimates of SMI projected to states using county-level factors such as urbanicity, poverty, etc.
- Implications for SAMHSA: Other factors such as use of services are likely to change more frequently than epidemiological estimates. SAMHSA may be able to redeploy resources from more frequent epidemiological estimates and larger sample sizes needed for state estimates to an expanded focus on tracking these high priority areas.
- Implications for policymakers: As noted above, state-level estimates of mental health symptomatology may not be the best proxy for service needs and block grant funding. Information including public sector claims datasets may better capture funding needs than survey-based estimates. For instance, states that are treating comparatively larger numbers of uninsured individuals in their public sector may need more financial support.

3. Defining Serious Mental Illness: From a public health perspective, functioning may be an important proxy for need for funding. Similarly, recovery, another important construct examined

as part of SAMHSA's efforts to expand behavioral health data collections[2], is the notion that individuals may be symptomatic but still be highly functional. Taken together, these observations suggest expanding the current measures of functioning as part of SAMHSA's data collection efforts.

- Implications for the Center for Behavioral Health Statistics and Quality: It would be useful to supplement the WHODAS measure of function with other measures such as the Sheehan disability scale. Additionally, it may be possible to reverse the order in which diagnoses and function are assessed, focusing diagnostic/symptom questions among individuals with functional impairment. Attributing these functional limitations to particular mental disorders is difficult and probably not necessary; however, it is important to be able to assess whether the limitations are primarily due to mental or physical conditions.
- Implications for SAMHSA: A more systematic assessment of the prevalence, predictors, and trajectories of functional status among individuals with mental disorders would provide useful information for SAMHSA. Ideally, this would utilize a longitudinal design. The focus on functioning would be consistent with SAMHSA's mission to measure and support recovery. Enhanced measures of functioning could be used to track these constructs over time.
- Implications for policymakers: The current legal definition of serious mental illness was developed 23 years ago. Since that time there have been developments in epidemiology and treatment, and major changes in the service delivery system. This could be an opportune time for the Department of Health and Human Services to revisit and update this definition.

[2]National Academies of Sciences, Engineering, and Medicine. (forthcoming). *Measuring Recovery from Substance Use or Mental Disorders: Workshop Summary.* K. Marton, Rapporteur. Committee on National Statistics and Board on Behavioral, Cognitive, and Sensory Sciences, Division of Behavioral and Social Sciences and Education. Board on Health Sciences Policy, Health and Medicine Division. Washington, DC: The National Academies Press.