Measuring the Performance of State Systems

Anyone living with a serious mental illness knows that recovery can take many years. The milestones are familiar: the onset of symptoms, an initial diagnosis, an *accurate* diagnosis, beginning treatment, and, hopefully, effective evidence-based treatments. Tragically, too many people are never diagnosed or accurately diagnosed, and many never receive effective treatments.

The data are staggering: one study showed 60 percent of people with a mental disorder received no services in the preceding year;[1] another revealed that the time between symptom onset and receiving any type of care ranged from six to 23 years.[2] The situation is even worse for traditionally underserved groups, such as people living in rural/frontier areas, the elderly, racial/ethnic minorities, and those with low incomes or without insurance.

There are many reasons public mental health systems are failing to reach and care for their target population, but a single problem is at the root: an alarming lack of reliable data that can accurately reflect states activities and help guide improvements.

To design and implement high-quality mental health systems, states and localities must be able to accurately identify the needs in their communities, and track the use of services currently in place. Put simply, if you can't see the problems, how can you fix them? Further, in an environment of limited (and increasingly shrink-

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[1] Ronald C. Kessler et al., "Prevalence and Treatment of Mental Disorders, 1990 to 2003," *New England Journal of Medicine* 352 (2005): 2515.

[2] Philip S. Wang et al., "Failure and Delay in Initial Treatment Contact After First Onset of Mental Disorders in the National Comorbidity Survey Replication," *Archives of General Psychiatry* 62 (2005): 603.

ing) resources, funding anything but the most effective services is simply not sustainable. Yet how can states appropriately target their funding if they don't know what works and what doesn't? With *Grading the States*, NAMI is unequivocally asserting that funding for mental health treatment services must be tied to performance and outcomes.

Understanding the Information Gap

The gaps in states' collection, compilation, and monitoring of data regarding mental illness and mental health services are both wide and deep.

Service Availability and System Capacity are Often Unknown

Many states are unable to report even basic information about their mental health services. Many do not know, for example, the total number of inpatient psychiatric beds in their systems, how long it takes to get such a bed following an emergency room stay, or how many people receive evidence-based treatments, such as ACT.

"Recovery, not stability, is more than an acceptance of the illness—it is an embracing of the situation, making the best of it, and living the fullest life possible with the limitations given. It is like learning to dance with a broken leg."

—Consumer from Illinois

Data like these should be collected in every state (as well as at the county level where services are often managed and delivered). But often there are no systems in place for accomplishing this.

Service Effectiveness is Truly a Mystery

Compiling trustworthy data about the level of available services is just the first step. States must also be able to measure how well those services meet the needs for quality mental health care: are a person's physical and mental wellbeing improving with the services and supports received? Are they reaching their educational and vocational goals? Do they have adequate income and affordable housing? Are unnecessary hospitalizations and arrests decreasing? Too often, states do not know the answers to these types of questions.

Available Data are Not Standardized Within or Across States

In order for data to truly drive system improvements, individual service providers and provider groups must consistently collect information that can be aggregated to the community and county levels and then to the state level. Unfortunately, even among those states that *do* collect some data in this manner, the variety of definitions and measures they use makes accurate—and therefore useful—comparisons across states extremely difficult.[3] At the state level, part of the problem is outdated information technology (IT) systems in use by many state mental health agencies. In addition, the persistence of paper health records decreases the likelihood that data can and will be standardized. Updating technology and adopting electronic record-keeping should ultimately facilitate the collection of outcome data that can be used for rigorous program evaluations and system performance assessments.

Unfortunately, once data are compiled at the federal level they are of limited use for cross-state analysis. Despite its name, SAMHSA's Uniform Reporting System (URS) gathers administrative data that are far from uniform because of significant differences in how states define variables, variable categories, and collect the data. SAMHSA itself warns analysts not to use the data to compare states, presumably because of these inconsistencies. The quality of the URS data appears to be improving, and SAMHSA's adoption of a subset of the URS to be used as National Outcome Measures (NOMS) is a step in the right direction. However, none of these data are currently reliable or robust enough to support the ongoing performance measurement NAMI and others in the mental health community need and expect, nor is it clear if they will be in the future.

Federal Agencies Give Mental Health Data Collection Low Priority

Data collection efforts, like direct service provision, reflect values and priorities. Across key federal agencies, mental health- and mental illness-related data collection is often given short shrift.

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[3] While we have no way of assessing overall state performance in this area, states receiving federal Transformation State Incentive Grants (TSIG)—Connecticut, Hawaii, Maryland, Missouri, New Mexico, Ohio, Oklahoma, Texas, and Washington—are clearly making additional investments in their mental health data infrastructures.

What are Electronic Health Records?

Electronic Health Records (EHRs) compile comprehensive information about an individual's health in a format based on nationally recognized standards. An EHR is typically created and managed by authorized health care professionals in a variety of settings, such as a provider's office, pharmacy, emergency room, or laboratory. An EHR provides "real time" patient health information and an immediate health history for providers. As a result, EHRs can help reduce adverse drug reactions, decrease duplicate testing, increase medication compliance, and improve benefit and claim management. For people with mental illnesses and/or substance use problems, who often interact with large numbers of providers, EHRs facilitate information exchange that increases the efficiency of care.

A Personal Health Record (PHR) is also a comprehensive electronic record of an individual's health information based on nationally recognized standards. While similar to an EHR, a PHR is typically managed and controlled by the individual, who can download health information. PHRs can empower consumers by increasing their understanding of, and sense of control over, their health, and facilitate communication with providers. As the technology and standards for EHRs and PHRs develop, it is essential that security measures to protect the privacy of individuals as well as the confidentiality of their information be in place. Without such safeguards, people with serious mental illnesses are at risk of further exclusion and discrimination.

For more information, see the National Alliance for Health Information Technology's *Report to the Office of the National Coordinator for Health Information Technology on Defining Key Health Information Technology Terms,* April 28, 2008. Available at http://www.nahit.org/images/pdfs/HITTermsFinalReport_051508.pdf.

Within SAMHSA, resources devoted to the collection and analysis of mental health and mental illnesses pale in comparison to investments on the substance abuse side. For example, unlike SAMHSA's National Survey on Drug Use and Health (NSDUH), the size and budget of its Client/Patient Sample Survey (which covers mental health) is too small to support state-level estimates. The major national psychiatric epidemiological surveys also preclude the development of state- and small-area estimates of mental illness.[4]

SAMHSA's support to states to collect data through the Behavioral Risk Factor Surveillance System (BRFSS) has also declined in recent years. The BRFSS is a unique population health surveillance tool designed to gather information on behavioral risk factors and conditions for chronic diseases, injuries, preventable infectious diseases, and health care access at the state and local levels.[5] It includes multiple optional modules (with standard sets of questions developed by the CDC and/or its partners) that each state decides to include based on priori-

ties and funding. A major strength of BRFSS is that it has individual- and state-level data on both mental and physical health. Unfortunately, not all states opt to include modules that include mental health information. The number of states collecting mental illness-related information through BRFSS declined from 39 states (including Washington, D.C.) in FY 2006, to 35 states in FY 2007, to only seven states (Arizona, Colorado, New York, Idaho, Illinois, Massachusetts, and Ohio) in FY 2008.[6]

Medicaid administrative data are another potentially rich source of information on state mental health systems, but they are rarely systematically analyzed on a state-by-state basis for mental health-related purposes. This is likely because the data are highly complex (the unit of analysis is usually a claim, not a person or a provider) and analyses would need to be tailored to each state's program since Medicaid itself varies considerably from one state to another.[7]

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[4] These surveys are sponsored by NIMH and include the National Comorbidity Survey (NCS) and the Collaborative Psychiatric Epidemiology Surveys (CPES), which includes the National Comorbidity Survey Replication (NCS-R), the National Survey of American Life (NSAL), and the National Latino and Asian American Study (NLAAS). More information about these surveys is available at www.hcp.med.harvard.edu/ncs and www.icpsr.umich.edu/CPES/.

[5] BRFSS is a telephone survey conducted by state health departments with technical and methodological assistance provided by the federal Centers for Disease Control and Prevention (CDC).

[6] This decline is in spite of improved measures that were built into the BRFSS beginning in 2006. These measures are the Physician Health Questionnaire-8 (PHQ-8), a validated screening instrument for current symptoms of depression, and the K-6, a measure of whether a person has serious mental illness. The BRFSS alternates between these two measures each year. SAMHSA reports that in FY 2009, the number of participating states will increase to 15.

[7] For a preliminary examination of these issues see James Verdier et al., *Administration of Mental Health Services by Medicaid Agencies* (Rockville, MD: Department of Health and Human Services Publication No. SMA 07-4301, Substance Abuse and Mental Health Services Administration, Center for Mental Health Services, 2007). Available at http://mentalhealth.samhsa.gov/publications/allpubs/sma07-4301/.

Finally, the Bureau of Justice Statistics (BJS) has dropped all mental health questions from its periodic census of state and federal adult correctional facilities.[8] The agency's inmate survey, which alternates between jails and prisons every two years and *does* include questions on mental illness, only supports national estimates.[9]

Missed Opportunities

States, inpatient and outpatient provider groups, and individual practitioners have a great deal to learn from one another. Policies and practices that are successful in one state or community can be replicated or adapted in other places. Knowing what works around the country, and how different jurisdictions compare to one another, can also push state and local governments to increase and improve resource allocation, and tackle issues in their own systems. Without reliable data these important opportunities will continue to be missed.

"Recovery for me means having the ability to function in society without having to take a yearly 'vacation' in the mental ward."

—Consumer from Kentucky

NAMI's *Grading the States* Report

Americans have come to expect regular scorecards on a variety of key public issues: child well-being (*Kids Count*), education (*Leaders and Laggards*), and mainstream healthcare (*America's Health Rankings*), among others. The popularity of these scorecards reflects a growing demand for transparency and accountability in public sector systems. By making factual information widely available, the scorecards have improved the quality of public debate, increased government oversight, and in many cases have led to better decision making.

In 2006, NAMI launched an effort to bring this kind of information-gathering and reporting to the mental health field to help fill the information gap that is putting people who live with serious mental illnesses at risk. The 2006 *Grading the States* report was NAMI's first comprehensive effort to assess state mental health systems in more than 15 years. Overall, the national grade was a dismal D.

In August 2008, NAMI surveyed state mental health agencies in preparation for this 2009 report (the survey questions are reproduced in the appendix). While covering similar topic areas, this latest edition of the survey has evolved in several ways:

- *More Detail-Oriented Questions:* Questions have been structured to draw out clearer and more detailed information. States were also encouraged to offer clarifications and additional comments to their responses.
- *Supplemental Information Requested:* For this report, NAMI asked states to provide a variety of supporting materials and planning documents, including those covering cultural competence, housing, and workforce development. NAMI was able to review many of these to assess if the plans were comprehensive and well crafted.
- *Direct Consumer and Family Input:* NAMI conducted (in English and Spanish) a Web-based survey of consumers and family members, seeking input on their experiences with state mental health systems. Using a "snowball sample," in which mental health system users participated and were then asked to forward the survey to other eligible people, more than 13,000 responses were received from across the country. These findings are not statistically representative and were not scored, but they allowed NAMI to confirm that many of the issues and measures that *are* scored are indeed of great importance to consumers and family members. This direct consumer and family input will also help NAMI refine questions and measures for future editions of *Grading the States*. Finally, these real-world experiences and personal stories serve as powerful reminders of why it is so important to assess how well states are providing critical mental health services. First-person accounts from this survey can be found throughout this report and in each state narrative in Chapter 5.

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[8] Until 2000, this survey identified, for each state, the number of facilities that provided mental health screening and treatment, and the number of prisoners receiving these screenings and treatment services.

[9] This survey has also been widely criticized for overestimating the prevalence of mental illness in incarcerated settings; BJS is currently working with NIMH, SAMHSA, and others to correct this.

■ *Some New Sources of Information:* As in 2006, most of the data for assessing states in this report came from NAMI's survey of state mental health agencies. However, three secondary sources of information were used for state estimates on these measures: (1) the number of adults living with serious mental illnesses (based on work by Charles E. Holzer, III, Ph.D., of the University of Texas Medical Branch in Galveston, Texas, and Hoang T. Nguyen, Ph.D., of LifeStat LLC[10]); (2) the extent of shortages in the mental health workforce (based on work by Joseph P. Morrissey, Ph.D., Thomas R. Konrad, Ph.D., Kathleen C. Thomas, Ph.D., and Alan R. Ellis, M.S.W., of the Cecil G. Sheps Center for Health Services Research at the University of North Carolina at Chapel Hill); and (3) hospital-based inpatient psychiatric bed capacity (based on annual survey data from the American Hospital Association). Other information sources were used to identify states with ongoing federal investigations and lawsuits involving public sector programs' treatment of adults living with serious mental illnesses. *For more information about NAMI's questionnaire, scoring methodology, and these secondary data sources, see the appendix.*

State Scorecards and Survey Methodology

All states except South Dakota responded to NAMI's survey for this 2009 *Grading the States* report.[11] The information was scored and weighted in four broad categories:

  I. Health Promotion and Measurement
 II. Financing and Core Treatment/Recovery Services
III. Consumer and Family Empowerment
IV. Community Integration and Social Inclusion

Individual questionnaire items in each category were first given a "raw" or unweighted score (zero to 10 points depending on the number of levels needed to distinguish between state responses) and then these scores were weighted to reflect NAMI's judgment of the relative importance of the measure.[12] State grades—both overall and for each of the four categories listed above—are based on these weighted scores. The nation's grade was calculated by averaging the weighted state scores. The measures and weights used in each category, and information sources used, are described below.

Category I: Health Promotion and Measurement

In NAMI's survey of state mental health agencies, states were asked to report a variety of basic information, such as the number of programs delivering evidence-based practices, emergency room wait-times, and the quantity of psychiatric beds by setting. The number of states unable to provide this type of data was troubling. Unfortunately, inconsistencies in the way states reported these data (among those that did) prohibited cross-state comparisons. As a result, in this category NAMI scored states only on their *ability* to provide seemingly accurate data on a variety of services, *not* on whether they provide enough evidence-based practices, have an *adequate* number of inpatient psychiatric beds, or provide *timely* access to those beds, etc. (two of these measures were further analyzed in Category II using estimates and external sources).

Other components of Category I include state performance on seclusion and restraint, state insurance parity laws, programs for the uninsured, and plans and activities in the areas of mortality reduction, health promotion, and workforce development (see Table 2.1).

> *"Recovery means I have many 'identities' not only my mental illness. I am a wife, mother, sister, daughter, friend, nana. My illness is not the first thing I think about when I wake up in the morning."*
>
> —Consumer from Pennsylvania

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[10] The estimates used in this study are available online at psy.utmb.edu. For a description of the general methodology used to derive these estimates, see Charles E. Holzer, III et al., "Horizontal Synthetic Estimation: A Strategy for Estimating Small Area Health Related Characteristics," *Evaluation and Program Planning* 4 (1981): 29.

[11] The survey was sent by U.S. mail and electronically on August 4, 2008. States were given six weeks to complete it.

[12] For three measures, NAMI divided states into four equal groups (or quartiles) and scored them on a scale of 1 to 4: (1) the share of adults with serious mental illnesses (SMI) served by state mental health agencies, (2) the number of non-federal psychiatric hospital beds per 1,000 people with SMI, and (3) the extent of shortage in the mental health workforce (with lower shortage states receiving higher scores). These raw quartile scores were then weighted in the same way as the other measures.

Table 2.1	Health Promotion & Measurement, Category I (25 percent)		
		Domain Weight	Overall Weight
Workforce Development Plan (Questionnaire Item 47)		15.0%	3.8%
State Mental Health Insurance Parity Law (Item 9)		8.1%	2.0%
Mental Health Coverage in Programs for Uninsured (Item 18)		8.1%	2.0%
Quality of Evidence-Based Practices Data (Item 23)		8.1%	2.0%
Quality of Race/Ethnicity Data (Item 4)		8.1%	2.0%
Have Data on Psychiatric Beds by Setting (Item 27)		8.1%	2.0%
Integrate Mental and Primary Health Care (Item 41)		8.1%	2.0%
Joint Commission Hospital Accreditation (AHA)		4.0%	1.0%
Have Data on ER Wait-times for Admission (Item 26)		4.0%	1.0%
Reductions in Use of Seclusion & Restraint (Item 33)		4.0%	1.0%
Public Reporting of Seclusion & Restraint Data (Item 34)		4.0%	1.0%
Wellness Promotion/Mortality Reduction Plan (Item 39)		4.0%	1.0%
State Studies Cause of Death (Item 38)		4.0%	1.0%
Performance Measure for Suicide Prevention (Item 40)		4.0%	1.0%
Smoking Cessation Programs (Item 42)		4.0%	1.0%
Workforce Development PlanDiversity Components (Item 47)		4.0%	1.0%
		100.0%	25.0%

This category accounts for 25 percent of a state's overall score.

Category II: Financing and Core Treatment/Recovery Services

Category II includes a variety of financing measures, such as whether Medicaid reimburses providers for all, or part, of important evidence-based practices; if the state charges outpatient co-pays; and if access to antipsychotic medications is restricted in any way.

Category II also includes some measures that capture the extent of service delivery in each state: the share of adults with serious mental illnesses served by the state mental health system and availability of ACT per capita. For this measure, NAMI used state reports on the number of people served with ACT (estimated for states reporting numbers of ACT *teams* only) and calculated what share of people with serious mental illnesses in the state would have access to ACT. For two other measures NAMI turned to external sources of data and analyses: the number of inpatient psychiatric beds per 1,000 adults with serious mental illnesses based on annual survey data from the American Hospital

Table 2.2	Financing & Core Treatment/Recovery Services, Category II (45 percent)		
		Domain Weight	Overall Weight
Workforce Development Plan (Questionnaire Item 47)		15.0%	3.8%
Workforce Availability (Sheps Center)		8.0%	3.6%
Inpatient Psychiatric Bed Capacity (AHA)		8.0%	3.6%
Cultural Competence–Overall Score (Questionnaire Items 35–37)		8.0%	3.6%
Share of Adults with Serious Mental Illness Served (Item 2)		5.0%	2.3%
Assertive Community Treatment (ACT) —per capita(Item 23)		5.0%	2.3%
ACT (Medicaid pays part/all) (Item 10)		4.0%	1.8%
Targeted Case Management (Medicaid pays) (Item 10)		4.0%	1.8%
Medicaid Outpatient Co-pays (Item 11)		4.0%	1.8%
Mobile Crisis Services (Medicaid pays) (Item 10)		3.0%	1.4%
Transportation (Medicaid pays) (Item 10)		3.0%	1.4%
Peer Specialist (Medicaid pays) (Item 10)		3.0%	1.4%
State Pays for Benzodiazepines (Item 12)		3.0%	1.4%
No Cap on Monthly Medicaid Prescriptions (Item 14)		3.0%	1.4%
ACT (availability) (Item 22)		3.0%	1.4%
Certified Clubhouse (availability) (Item 22)		3.0%	1.4%
State Supports Co-occurring Disorders Treatment (Items 6–8)		2.0%	0.9%
Illness Self Management & Recovery (Medicaid pays) (Item 10)		2.0%	0.9%
Family Psychoeducation (Medicaid pays) (Item 10)		2.0%	0.9%
Supported Housing (Medicaid pays part) (Item 10)		2.0%	0.9%
Supported Employment (Medicaid pays part) (Item 10)		2.0%	0.9%
Supported Education (Medicaid pays part) (Item 10)		2.0%	0.9%
Language Interpretation/Translation (Medicaid pays) (Item 10)		2.0%	0.9%
Telemedicine (Medicaid pays) (Item 10)		2.0%	0.9%
Access to Antipsychotic Medications (Item 13)		2.0%	0.9%
Clinically-Informed Prescriber Feedback System (Item 16)		2.0%	0.9%
Same-Day Billing for Mental Health & Primary Care (Item 17)		2.0%	0.9%
Supported Employment (availability) (Item 22)		2.0%	0.9%
Integrated Dual Diagnosis Treatment (availability) (Item 22)		2.0%	0.9%
Permanent Supported Housing (availability) (Item 22)		2.0%	0.9%
Housing First (availability) (Item 22)		2.0%	0.9%
Illness Self Management & Recovery (availability) (Item 22)		1.0%	0.5%
Family Psychoeducation (availability) (Item 22)		1.0%	0.5%
Services for National Guard Members/ Families (Item 25)		1.0%	0.5%
		100.0%	45.0%

Association, and the severity of shortages in the mental health workforce based on recent pioneering analysis by researchers at the Cecil G. Sheps Center for Health Services Research at the University of North Carolina at Chapel Hill.[13]

This category also includes measures of: the availability of specific evidence-based practices in parts of the state or statewide; state policies and practices that deal with co-occurring mental health and substance abuse treatment needs; and state mental health agency programs for individuals and families involved in the National Guard. It also includes a multi-faceted measure of state planning and activities to develop cultural competence (see Table 2.2). This category, Financing and Core Treatment/Recovery Services, is the most heavily weighted of the four, accounting for 45 percent of each state's overall score.

Category III: Consumer and Family Empowerment

Category III consists of a variety of measures that NAMI views as top priorities. It includes results from the Consumer and Family Test Drive (CFTD), an original research instrument developed by NAMI in 2006 that measures how well people with serious mental illnesses and their family members are able to access essential information about conditions and treatment resources from state mental health agencies.

This category also measures whether there is a written mandate that consumers or family members sit on the state Pharmacy and Therapeutics (P&T) Committee, and if the state promotes consumer-run programs, peer services, and other important educational and support resources such as family and peer education programs and provider education programs with significant consumer involvement. Finally, Category III measures the extent to which consumers and family members monitor conditions in inpatient and community-based mental health treatment programs (see Table 2.3). This category accounts for 15 percent of a state's overall score.

Table 2.3	Consumer/Family Empowerment, Category III (15 percent)		
		Domain Weight	Overall Weight
Consumer & Family Test Drive (CFTD)		25.0%	3.8%
Consumer & Family Monitoring Teams (Questionnaire Item 32)		15.0%	2.3%
Consumer/Family on State Pharmacy (P&T) Committee (Item 15)		10.0%	1.5%
Consumer-Run Programs (availability) (Item 22)		10.0%	1.5%
Promote PeerRun Services (Item 24)		10.0%	1.5%
State Supports Family Education Programs (Item 28)		10.0%	1.5%
State Supports Peer Education Programs (Item 29)		10.0%	1.5%
State Supports Provider Education Programs (Item 30)		10.0%	1.5%
		100.0%	15.0%

Category IV: Community Integration and Social Inclusion

Category IV includes activities that require collaboration among state mental health agencies and other state agencies and systems. It covers topics such as the suspension and restoration of Medicaid benefits during and after incarceration; the availability of jail diversion, re-entry programs, and mental health courts; state public education campaigns and activities; and efforts to plan for, and secure, the resources needed to address long-term housing for people with mental illnesses (see Table 2.4). This category accounts for 15 percent of a state's overall score.

Table 2.4	Community Integration & Social Inclusion, Category IV (15 percent)		
		Domain Weight	Overall Weight
Housing—Overall Score (Questionnaire Items 43–44)		25.0%	3.8%
Suspend/Restore Medicaid Post-Incarceration (Items 19–20)		10.7%	1.6%
Jail Diversion Programs (availability) (Item 22)		10.7%	1.6%
Reentry Programs (availability) (Item 22)		10.7%	1.6%
Mental Illness Public Education Efforts (Item 31)		10.7%	1.6%
State Supports Police Crisis Intervention Teams (CIT) (Item 45)		10.7%	1.6%
Mental Health Courts—Overall Score (Item 46)		10.7%	1.6%
Mental Health Courts—per capita (Item 46)		10.7%	1.6%
		100.0%	15.0%

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[13] Joseph P. Morrissey et al., "Development of a New Method for Designation of Mental Health Professional Shortage Areas," unpublished report prepared under contract HHSH-230200532038C with the Bureau of Health Professions, Health Resources and Services Administration, U.S. Department of Health and Human Services, December 2007.

Challenges in Assessing a Complex System

Our nation's public mental health system is complex, bridging inpatient and community-based health services, housing and economic support programs, vocational and social supports, and the criminal justice system, among others. Because of this complexity, it is extraordinarily challenging to accurately assess not only its overall quality, but also the effectiveness of each component and the extent to which the components successfully interact.

As noted earlier, the lack of reliable outcome data generally limits the ability to measure the effectiveness of state services. Plans and policies may exist, but they do not necessarily translate to implementation. Evidence-based practices may be intended, but fall short of fidelity standards.

With those caveats in mind, this report provides the best comprehensive, comparative assessment of state mental healthcare systems to date. State-by-state narratives in Chapter 5 go beyond existing state data and shed light on each state's qualitative performance.

The following chapter provides a summary of NAMI's findings. It outlines national trends in mental health system performance, common strengths and weaknesses, the unique challenges faced by some states, and some exciting areas of innovation.