Interdepartmental Serious Mental Illness Coordinating Committee

The Way Forward: Federal Action for a System That Works for All People Living With SMI and SED and Their Families and Caregivers

December 13, 2017

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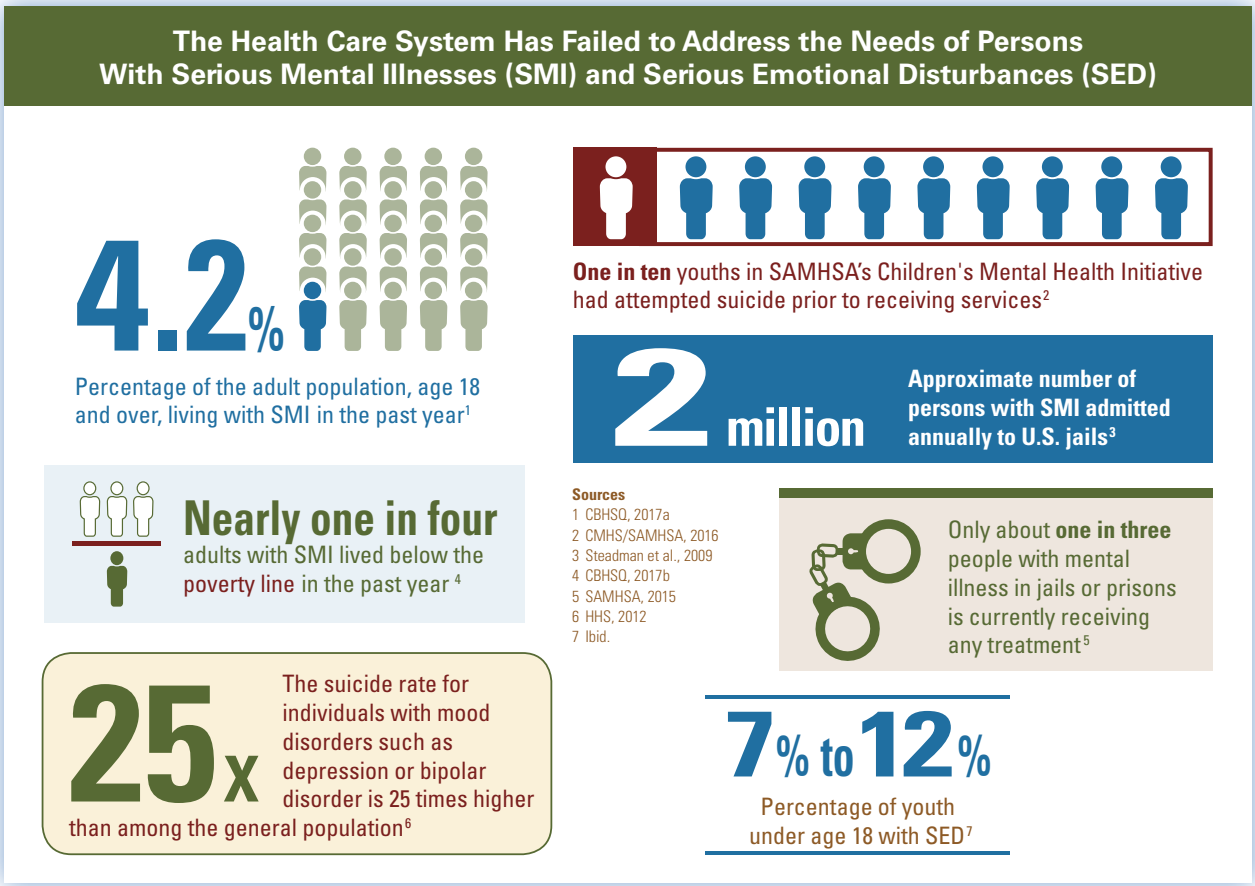
Introduction

In 2003, the President's New Freedom Commission on Mental Health concluded that America's mental health service delivery system was in shambles. The Commission's final report stated that "for too many Americans with mental illnesses, the mental health services and supports they need remain fragmented, disconnected and often inadequate, frustrating the opportunity for recovery." A number of the recommendations of the President's New Freedom Commission on Mental Health were not implemented or have only been partially realized. Since then, quality of life has not fundamentally changed for adults with serious mental illnesses (SMI) and children and youth with serious emotional disturbances (SED) and their families in the United States (Figure 1).

Figure 1. Estimates and Unmet Needs of Persons With Serious Mental Illnesses and Serious Emotional Disturbances



Poor social supports, unemployment, comorbid medical problems, and addiction challenges abound. We have continued to defer to law enforcement services, criminal justice systems, hospital services, public education systems, and homeless services as the primary solutions, overtaxing these services and systems while contributing to poor outcomes such as unnecessary incarceration and long waits in hospital emergency departments. Failure to succeed in school or to access higher education, housing, or employment remain all too common. Tragically, people with SMI and SED die of suicide at extremely high rates, and in rare circumstances violence has led to unspeakable pain for families and our communities.

> "My adult son has cycled 13 times through mental hospitals over a 3-year period. He is taking his medications but continues to have psychotic thoughts not based in reality, and is greatly disabled by them. What has transpired since the closing of psychiatric care facilities is a travesty: incarceration, multiple cycles through hospitals or ERs, and homelessness, and often deaths. Without access to adequate care, many family members are caught in impossible situations, become distraught, or give up entirely. We need a federal standard and community solutions to provide care for highly disabled, mentally ill people like my son."
>
> — *Marilyn (submitted through public comments to the ISMICC)*

Negative attitudes and discrimination remain a painful part of every setting, including school, work, and health care, preventing children, youth, and adults with serious mental health conditions from being embraced and valued in their communities. When individuals and their families don't seek help because of negative attitudes and discrimination, they don't access services and supports that could improve their situations, and this prevents them from exercising their legal rights under the Americans with Disabilities Act and the Individuals with Disabilities Education Act.

Role of the ISMICC

The 21st Century Cures Act (Public Law 114-255) authorizes the Interdepartmental Serious Mental Illness Coordinating Committee (ISMICC) to enhance coordination across federal agencies to improve service access and delivery of care for people with SMI and SED and their families. The ISMICC is charged to:

- Report on advances in research on SMI and SED related to prevention, diagnosis, intervention, treatment and recovery, and access to services and supports;
- Evaluate the effect federal programs related to SMI and SED have on public health, including outcomes across a number of important dimensions; and
- Make specific recommendations for actions that federal departments can take to better coordinate the administration of mental health services for adults with SMI or children with SED.

The ISMICC is chaired by Dr. Elinore F. McCance-Katz, Assistant Secretary for Mental Health and Substance Use. This position brings a new level of authority, experience, and expertise to the coordination of efforts at the Department of Health and Human Services (HHS) to address the needs of people with SMI and SED. Dr. McCance-Katz and other federal members on the Committee will work across HHS and the federal government so Americans with SMI and SED are able to improve their lives and have access to the highest possible standard of care—care that is deeply informed by our knowledge of science and medicine.

The ISMICC is a historic chance to address SMI and SED across federal departments and the systems that they represent. Each of the eight departments supports programs that address the needs of people with SMI and SED. Their collaboration will be informed and strengthened by the participation of non-federal members, including national experts on health care research, mental health providers, advocates, and people with mental health conditions and their families and caregivers. The ISMICC is currently authorized through 2022, at which time the Secretary of HHS will submit a recommendation to Congress about whether to extend the ISMICC.

Federal Department and Agency Representation on the ISMICC

- Secretary of the Department of Health and Human Services
- Assistant Secretary for Mental Health and Substance Use
- Attorney General, Department of Justice
- Secretary of the Department of Veterans Affairs
- Secretary of the Department of Defense
- Secretary of the Department of Housing and Urban Development
- Secretary of the Department of Education
- Secretary of the Department of Labor
- Administrator of the Centers for Medicare & Medicaid Services
- Commissioner of the Social Security Administration

The non-federal ISMICC members have firsthand experience with the mental health service system, and knowledge of what barriers exist for people who are seeking help. Moreover, the non-federal members bring on-the-ground solutions and innovative ideas that can promote change and improve lives, in partnership with the federal members.

Together, ISMICC members bring the experience needed to develop a better understanding of what is working and what needs to be changed within the current systems of care. (See Appendix A for the full ISMICC membership.) This cross-sector, public-private partnership provides a unique opportunity to share and generate solutions not previously considered or implemented.

By strengthening federal interdepartmental leadership and coordination, we can change federal policy to improve the availability and quality of care for people served. Improvement will come not just through the provision of more health care services, but through a more holistic approach—a true continuum of care that makes sense for each unique person. We seek to build a system where treatment and services work and individuals with SMI and SED can recover and live happier, healthier, more productive, and more connected lives.

The 2017 ISMICC Report to Congress

The work of the ISMICC is just beginning. This 2017 ISMICC Report to Congress includes information presented in the first ISMICC meeting in August 2017 and from ongoing dialogue with the ISMICC members. This report will set the stage for work by the ISMICC in the years ahead.

The ISMICC identified five major areas of focus for fulfilling the Committee's vision. The five areas will guide the Committee's work. We know that important treatment advances are on the horizon. Research is identifying new and powerful ways to improve the ability to diagnose and identify risk factors for the course of mental illnesses. Sensitive to emerging science, the ISMICC members plan to revisit this report, its charge, and the areas of focus periodically in the coming years.

Five ISMICC Areas of Focus

1. Strengthen federal coordination to improve care
2. Access and engagement: Make it easier to get good care
3. Treatment and recovery: Close the gap between what works and what is offered
4. Increase opportunities for diversion and improve care for people with SMI and SED involved in the criminal and juvenile justice systems
5. Develop finance strategies to increase availability and affordability of care

The final ISMICC report to Congress is due December 2022 and will provide more complete information on what the ISMICC has accomplished and will identify future opportunities for improving the lives of those with SMI and SED. The ISMICC will develop interim reports and other documents as needed to further the progress of the Committee's work.

The ISMICC will serve as a model for cross-sector coordination and will promote partnerships to address the needs of people with SMI and SED and their families and caregivers. We anticipate that the work of the ISMICC will stimulate change across federal and non-federal sectors. Federal efforts will help build new relationships and partnerships across public sectors, agencies, and levels of government. A commitment to coordinate and collaborate at the federal, state, tribal, county, and local levels will lead to systems that are easy to navigate, appropriate, and tailored to the individual needs of each person and their family and caregivers.

ISMICC Vision Statement

Federal interdepartmental leadership, with genuine collaboration and shared accountability of all federal agencies, and in partnership with all levels of government and other stakeholders, supports a mental health system that successfully addresses the needs of all individuals living with SMI or SED and their families and caregivers, effectively supporting their progress to achieve healthy lives characterized by autonomy, pride, self-worth, hope, dignity, and meaning.

Recommendations From the Non-Federal Members Summary[1] (See Chapter 4 for Full Recommendations)

Focus 1: Strengthen Federal Coordination to Improve Care

1.1. Improve ongoing interdepartmental coordination under the guidance of the Assistant Secretary for Mental Health and Substance Use.

1.2. Develop and implement an interdepartmental strategic plan to improve the lives of people with SMI and SED and their families.

1.3. Create a comprehensive inventory of federal activities that affect the provision of services for people with SMI and SED.

1.4. Harmonize and improve policies to support federal coordination.

1.5. Evaluate the federal approach to serving people with SMI and SED.

1.6. Use data to improve quality of care and outcomes.

1.7. Ensure that quality measurement efforts include mental health.

1.8. Improve national linkage of data to improve services.

Focus 2: Access and Engagement: Make It Easier to Get Good Care

2.1. Define and implement a national standard for crisis care.

[1] These recommendations reflect the views of the non-federal ISMICC members. Federal members were consulted regarding factual concerns and federal processes, but the final list of recommendations are the product of the non-federal members. These recommendations do not represent federal policy, and the federal departments represented on the ISMICC have not reviewed the recommendations to determine what role they could play in the future activities of the departments. The recommendations should not be interpreted as recommendations from the federal government.

2.2. Develop a continuum of care that includes adequate psychiatric bed capacity and community-based alternatives to hospitalization.

2.3. Educate providers, service agencies, people with SMI and SED and their families, and caregivers about the Health Insurance Portability and Accountability Act of 1996 (HIPAA) and other privacy laws, including 42 CFR Part 2, in the context of psychiatric care.

2.4. Reassess civil commitment standards and processes.

2.5. Establish standardized assessments for level of care and monitoring of consumer progress.

2.6. Prioritize early identification and intervention for children, youth, and young adults.

2.7. Use telehealth and other technologies to increase access to care.

2.8. Maximize the capacity of the behavioral health workforce.

2.9. Support family members and caregivers.

2.10. Expect SMI and SED screening to occur in all primary care settings.

Focus 3: Treatment and Recovery: Close the Gap Between What Works and What Is Offered

3.1. Provide a comprehensive continuum of care for people with SMI and SED.

3.2. Make screening and early intervention among children, youth, transition-age youth, and young adults a national expectation.

3.3. Make coordinated specialty care for first-episode psychosis available nationwide.

3.4. Make trauma-informed, whole-person health care the expectation in all our systems of care for people with SMI and SED.

3.5. Implement effective systems of care for children, youth, and transition-age youth throughout the nation.

3.6. Make housing more readily available for people with SMI and SED.

3.7. Advance the national adoption of effective suicide prevention strategies.

3.8. Develop a priority research agenda for SED/SMI prevention, diagnosis, treatment, and recovery services.

3.9. Make integrated services readily available to people with co-occurring mental illnesses and substance use disorders, including medication-assisted treatment (MAT) for opioid use disorders.

3.10. Develop national and state capacity to disseminate and support implementation of the national standards for a comprehensive continuum of effective care for people with SMI and SED.

Focus 4: Increase Opportunities for Diversion and Improve Care for People With SMI and SED Involved in the Criminal and Juvenile Justice Systems

4.1. Support interventions to correspond to all stages of justice involvement. Consider all points included in the sequential intercept model.

4.2. Develop an integrated crisis response system to divert people with SMI and SED from the justice system.

4.3. Prepare and train all first responders on how to work with people with SMI and SED.

4.4. Establish and incentivize best practices for competency restoration that use community-based evaluation and services.

4.5. Develop and sustain therapeutic justice dockets in federal, state, and local courts for any person with SMI or SED who becomes involved in the justice system.

4.6. Require universal screening for mental illnesses, substance use disorders, and other behavioral health needs of every person booked into jail.

4.7. Strictly limit or eliminate the use of solitary confinement, seclusion, restraint, or other forms of restrictive housing for people with SMI and SED.

4.8. Reduce barriers that impede immediate access to treatment and recovery services upon release from correctional facilities.

4.9. Build on efforts under the Mentally Ill Offender Treatment and Crime Reduction Act, the 21st Century Cures Act, and other federal programs to reduce incarceration of people with mental illness and co-occurring substance use disorders.

Focus 5: Develop Finance Strategies to Increase Availability and Affordability of Care

5.1. Implement population health payment models in federal health benefit programs.

5.2. Adequately fund the full range of services needed by people with SMI and SED.

5.3. Fully enforce parity to ensure that people with SMI and SED receive the mental health and substance abuse services they are entitled to, and that benefits are offered on terms comparable to those for physical illnesses.

5.4. Eliminate financing practices and policies that discriminate against behavioral health care.

5.5. Pay for psychiatric and other behavioral health services at rates equivalent to other health care services.

5.6. Provide reimbursement for outreach and engagement services related to mental health care.

5.7. Fund adequate home- and community-based services for children and youth with SED and adults with SMI.

5.8. Expand the Certified Community Behavioral Health Clinic (CCBHC) program nationwide.

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Chapter 1: The Current Needs of Americans With Serious Mental Illnesses and Serious Emotional Disturbances

This report focuses on issues related to adults with serious mental illnesses (SMI) and children and youth with serious emotional disturbances (SED).

Defining SMI[2]

Serious mental illness (SMI) refers to individuals 18 or older, who currently or at any time during the past year have had a diagnosable mental, behavioral, or emotional disorder of sufficient duration to meet diagnostic criteria specified in the diagnostic manual of the American Psychiatric Association and that has resulted in functional impairment, that substantially interferes with or limits one or more major life activities.

Major life activities include basic daily living skills (e.g. eating, bathing, dressing); instrumental living skills (e.g., maintaining a household, managing money, getting around the community, taking prescribed medication); and functioning in social, family, and vocational/educational contexts.

Serious Mental Illnesses

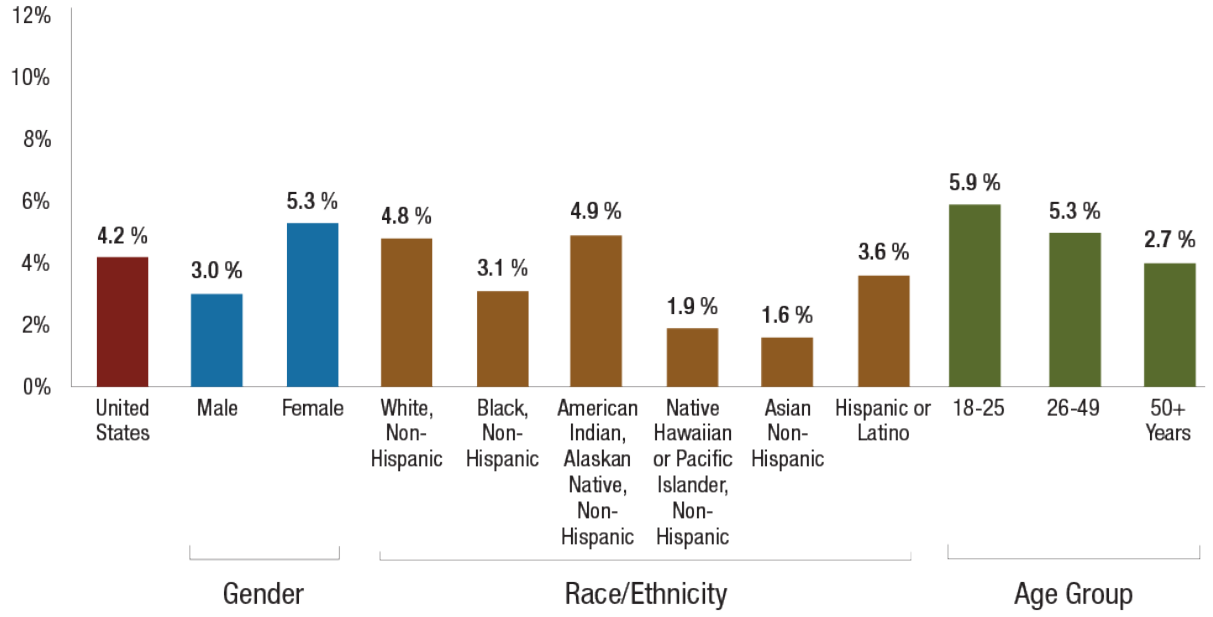
The definition of SMI includes one or more diagnoses of mental disorders combined with significant impairment in functioning. Schizophrenia, bipolar illness, and major depressive disorder are the diagnoses most commonly associated with SMI, but people with one or more other disorders may also fit the definition of SMI if those disorders result in functional impairment.

About 1 in 25 adults has an SMI in a given year. In 2016, 4.2 percent of U.S. adults age 18 or older (an estimated 10.4 million adults) had an SMI in the past year (CBHSQ, 2017a). This estimate includes new and existing cases of SMI. The percentage of SMI in the past year was higher for sexual minority adults (13.1 percent) than for sexual majority adults (3.6 percent) (Medley et al., 2016). Across racial and ethnic groups, people of two or more races (7.5 percent) and Non-Hispanic Whites (4.8 percent) had higher percentages of SMI in the past year than the national average (4.2 percent) (Figure 1.1). In 2016, women accounted for 65.4 percent of adults with SMI (CBHSQ, 2017a).

The percentage of SMI in the past year also varies across age groups, with those 50 and older (2.7 percent) having lower rates than those aged 18 to 25 (5.9 percent) or those aged 26 to 49 (5.3 percent). The lower prevalence in older adults may be impacted by the increased risk of earlier death among people with SMI.

2 For the precise wording of the definition, see https://www.samhsa.gov/sites/default/files/federal-register-notice-58-96-definitions.pdf. Note that impairment resulting from a primary diagnosis of substance use disorder does not qualify a person as having a serious mental illness. This report does not address Alzheimer's disease or related disorders that are listed in the Diagnostic and Statistical Manual of Mental Disorders and cause functional impairment. The ISMICC has noted the need for consistent definitions of SMI and SED and is considering how best to address these definitional issues moving forward.

Figure 1.1. Past Year Serious Mental Illness (SMI) Among Adults Age 18 or Older in the United States, by Gender, Race/Ethnicity, Age Group: 2016



Source: Center for Behavioral Health Statistics and Quality. (2017). *Results from the 2016 National Survey on Drug Use and Health: detailed tables.* Rockville, MD: Substance Abuse and Mental Health Services Administration.

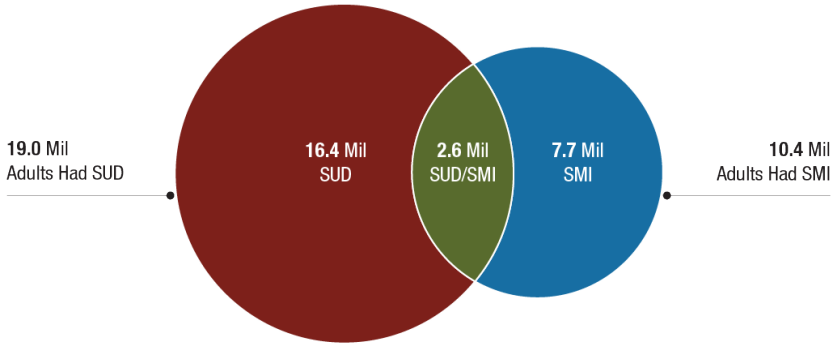
Adults with SMI often have multiple chronic conditions and general health issues. As stated by the Institute of Medicine[3] (Daniels, England, Page, and Corrigan, 2005), "Mental and substance-use problems and illnesses seldom occur in isolation. They frequently accompany each other, as well as a substantial number of general medical illnesses such as heart disease, cancers, diabetes, and neurological illnesses. … Because of this, mental, substance-use, and general health problems and illnesses are frequently intertwined, and coordination of all these types of health care is essential to improved health outcomes, especially for chronic illnesses." People with co-occurring disorders often experience difficulty seeking and receiving services, which leads to poorer health outcomes overall and utilization of high-cost services such as inpatient and emergency room care. These individuals need to receive integrated care in settings equipped to diagnose and treat these complex and interrelated disorders (SAMHSA, 2002).

Nearly three-quarters of adults with SMI are diagnosed with two or more mental disorders (Kessler, Chiu, Demler, & Walters, 2005). About a quarter of adults with SMI (25.4 percent, an

[3] Now known as the National Academy of Medicine

estimated 2.6 million adults) have a substance use disorder (Figure 1.2) (CBHSQ, 2017b), and approximately one in six (16.1 percent) misused opioids in the past year (CBHSQ, 2017c). Adults with SMI and substance use disorders "show more severe symptoms of mental illness, more frequent hospitalizations, more frequent relapses, and a poorer course of illness than patients with a single diagnosis, as well as higher rates of violence, suicide, and homelessness" (Bellack, Bennett, Gearon, Brown, & Yang, 2006). Nearly half of people with SMI used tobacco in the past year (49 percent) (CBHSQ, 2017d). A growing body of research shows that quitting smoking can improve mental health and addiction recovery outcomes (SAMHSA, n.d.-a); for example, smoking cessation is associated with a decreased risk of anxiety and mood disorders (Cavazos-Rehg et al., 2014).

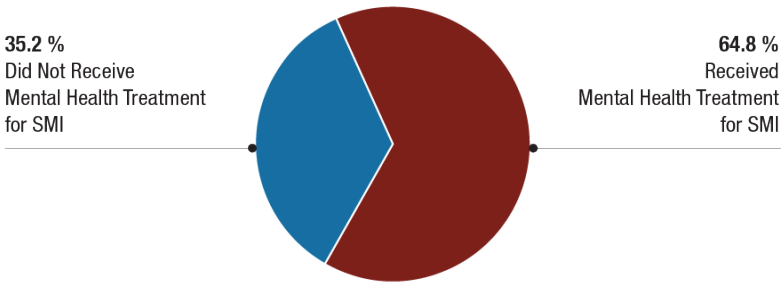
Figure 1.2. Past Year Substance Use Disorder (SUD) and Serious Mental Illness (SMI) Among Adults Age 18 or Older: 2016



Source: Adapted from Figure 69 of: Substance Abuse and Mental Health Services Administration. (2017). *Key substance use and mental health indicators in the United States: Results from the 2016 National Survey on Drug Use and Health* (HHS Publication No. SMA17-5044, NSDUH Series H-52). Retrieved from http://www.samhsa.gov/data.

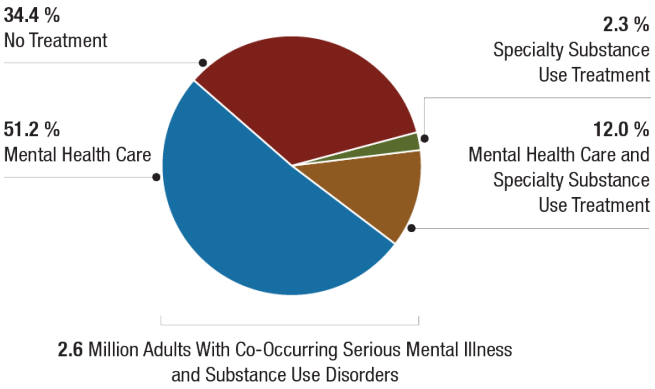
Relatively few adults with SMI receive effective treatments. Treatments that are demonstrated to be effective for SMI may include some combination of prescription medications, other supports (e.g., inpatient treatment, respite care, assertive community treatment, coordinated specialty care, supported employment), and psychotherapy (e.g., cognitive behavioral therapy, cognitive remediation therapy). About two-thirds of adults with SMI (64.8 percent, an estimated 6.7 million adults) (CBHSQ, 2017e) reported receiving mental health treatment in 2016 (Figure 1.3). Most treatment is offered in outpatient settings, with only 7.6 percent (an estimated 789,000 adults) receiving inpatient mental health treatment/counseling in the past year (CBHSQ, 2017f). Nearly a third (32.6 percent, 2.2 million adults) of those who get treatment receive medications only, with no psychosocial or psychotherapeutic services (CBHSQ, 2017g). Among adults with co-occurring SMI and substance use disorders, nearly two-thirds (63.2 percent) received mental health care, but only 14.3 percent received specialized substance use treatment (Figure 1.4).

Figure 1.3. Receipt of Mental Health Services in the Past Year Among Adults Age 18 or Older With Serious Mental Illness (SMI): Percentages, 2016



Source: Adapted from Table 8.33 of: Center for Behavioral Health Statistics and Quality. (2017). *2016 national survey on drug use and health: Detailed tables. Rockville, MD: Substance Abuse and Mental Health Services Administration.*

Figure 1.4. Receipt of Mental Health Care and Specialty Substance Use Treatment in the Past Year Among Adults Age 18 or Older Who Had Past Year Serious Mental Illness and Substance Use Disorders: Percentages, 2016



Source: Adapted from Figure 73 of: Substance Abuse and Mental Health Services Administration. (2017). *Key substance use and mental health indicators in the United States: Results from the 2016 National Survey on Drug Use and Health* (HHS Publication No. SMA17-5044, NSDUH Series H-52). Retrieved from http://www.samhsa.gov/data.

Effective treatment models exist, but are not widely available. States report annually on the implementation of select evidence-based practices (EBPs) in their systems. EBPs are practices that are based on rigorous research that has demonstrated effectiveness in achieving the outcomes that the practices were designed to achieve. State mental health systems often serve those with mental health conditions, including SMI and SED, who are Medicaid eligible and whose conditions require levels of care not paid for by private insurance. The percentage of the population who have access to these EBPs remains low and varies widely across states, recognizing that not all EBPs are appropriate for all people with SMI or SED (Table 1.1). For example, assertive community treatment, an intensive team-based care model that is a long-established best practice for adults with SMI, is provided to only 2.1 percent of the people served in state systems nationwide. Similarly, the individual placement and support model of supported employment, which should be provided to all adults with SMI who have a goal of employment, also is provided to only 2.1 percent of adults in state systems.

Table 1.1. Populations Receiving Select Evidence-Based Practices in Selected State Mental Health Systems in 2016[4]

Evidence-Based Practice	Target Population for Service	Percent of State MH Population Who Receive Practice in States that Report Data
Medication management	Adults and youth with SMI/SED	32.0%
Illness self-management	Adults with SMI	19.0%
Dual diagnosis treatment	Adults with SMI and SUD	10.5%
Assertive community treatment	Adults with SMI	2.1%
Supported employment	Adults and transition-age youth with SMI	2.1%
Supported housing	Adults and transition-age youth with SMI	3.1%
Therapeutic foster care	Children and youth with SED	1.5%
Multi-systemic therapy	Children and youth with SED	3.6%
Functional family therapy	Children and youth with SED	6.9%
Family psychoeducation	Families of people with SMI	1.9%

Most counties in the United States face shortages of mental health professionals. In 96 percent of the counties in the nation, there is a shortage of psychiatrists who prescribe medications for people with SMI (Thomas, Ellis, Konrad, Holzer, & Morrissey, 2009). From 2003 to 2013, the number of practicing psychiatrists decreased by 10 percent when adjusted for population size (Bishop, Seirup, Pincus, & Ross, 2016). Many psychiatrists are shifting to private practice, accepting only cash for reimbursement. In part, this may reflect low reimbursement

[4] From SAMHSA Uniform Reporting System Data - https://wwwdasis.samhsa.gov/dasis2/urs.htm. These figures only represent a subset of states that provided data.

for psychiatric services from state Medicaid programs and Medicaid-contracted managed care payers, cuts to federal and state funding for public sector programs, and inadequate rate setting for psychiatric services (Bishop, Press, Keyhani, & Pincus, 2014; National Council Medical Director Institute, 2017). The greatest shortages are in poorer and more rural counties. The need for child psychiatrists is even greater than the shortage of psychiatrists for adults with SMI (Thomas & Holzer, 2006). The lack of access to psychiatric services creates several issues, such as long wait times for scheduled appointments, often leading to emergency department visits and hospitalizations (National Council Medical Director Institute, 2017).

Expanding the workforce by allowing advanced practice registered nurses to practice to the full extent of their training, broadening the scope of practice of psychologists to prescribe some medications, and educating more advanced practice registered nurses and psychiatric-mental health physician assistants, are examples of strategies to address the shortage. Tele-mental health is widely accepted as a mechanism that can address shortages in some geographic areas. One county in five also has a shortage of non-prescriber mental health professionals, defined as psychologists, advanced practice psychiatric nurses, social workers, licensed professional counselors, and marriage and family therapists (Thomas, Ellis, Konrad, Holzer, & Morrissey, 2009). Also, there are categories of mental health service providers, including licensed professional counselors and marriage and family therapists, whose services are not eligible for reimbursement by Medicare (CMS, 2015). Peer support can play an important role in a functioning mental health system and should be included as a part of a full continuum of services, whenever possible (Myrick & del Vecchio, 2016). Peer support services have been demonstrated to promote recovery and resiliency through the generation of hope, engagement in treatment services, and activation for improved health outcomes (Repper & Carter, 2011). Youth and family peer support services have also generated notable outcomes in this area (Center for Health Care Strategies, 2013).

Most states report insufficient psychiatric crisis response capacity as well as insufficient numbers of inpatient psychiatric hospital beds. It is critical that every state have adequate bed capacity to respond to the needs of people experiencing both psychiatric crises and those who are in need of longer periods of inpatient care, such as people in forensic care (care that is provided because of involvement in the criminal or juvenile justice systems). In many areas, bed shortages have led to long delays in gaining access to treatment and an increase in individuals waiting for competency restoration services needed to restore competency to participate in legal proceedings (NASMHPD, 2017a). A report by the National Association of State Mental Health Program Directors Research Institute (NASMHPD, 2017b) found that most states (35 of the 46 who responded) have shortages of psychiatric hospital beds. The configuration of available beds and the number of beds per 100,000 population varies substantially across states, but few states report they have adequate numbers of inpatient beds to meet needs. Use of a variety of strategies, such as building psychiatric respite bed capacity, may help to address these capacity issues.

Adults with SMI are more likely to be jailed or involved with the criminal justice system. It is estimated that approximately two million people with SMI are admitted annually to U.S. jails (Steadman, Osher, Robbins, Case, & Samuels, 2009). Among these admissions, 72 percent also meet criteria for co-occurring substance use disorders (Hyde, 2011). In 2016, among U.S. adults age 18 or older with SMI, 9.5 percent were on probation and 9.7 percent were on parole or supervised release (CBHSQ, 2017h). By comparison, 2.9 percent of the general U.S. adult population is currently under some form of criminal justice supervision (SAMHSA, 2015). Too few jails and prisons offer screening and treatment programs for mental and substance use disorders, leading to longer incarceration stays (SAMHSA, 2015). All states require efforts to restore legal competence after a person is determined to be incompetent to stand trial, a process that typically takes place in state hospitals. However, a lack of available hospital beds for competency restoration can lead to waits for pretrial jail detainees that may average weeks, or even a year or longer (Fuller, Sinclair, Lamb, Cayce, & Snook, 2017). Only about one in three people with mental illness in jails or prisons receives any treatment (Bronson & Berzofsky, 2017). These factors contribute, in turn, to higher rates of recidivism. Specialty courts for people with mental or substance use disorders are promising, but their availability is extremely limited.

> "Successful reentry into the community is a challenge for returning inmates with SMI. They are more likely than returning inmates without SMI to experience homelessness and are less likely to find employment."
>
> — *Conclusions from a systematic review by the Agency for Healthcare Research and Quality (AHRQ, 2012)*

Many adults with SMI are unemployed. Only 36 percent (CBHSQ, 2017a) of people with SMI have full-time employment, while most would prefer to work (McQuilken, Zahniser, Novak, Starks, Olmos & Bond, 2003). SMI also is a major driver of disability: 24.55 percent of adult disability applications in Federal Fiscal Year 2016 to the Social Security Administration were based on mental health, as were 64.56 percent of childhood disability applications (Social Security Administration, 2017).

Nearly twice as many adults with SMI have incomes below the poverty level as in the general population (22.8 percent, compared to 13.5 percent) (CBHSQ, 2017i; U.S. Census Bureau, n.d.).

SMI is common among people experiencing homelessness. The Department of Housing and Urban Development (HUD) and SAMHSA (SAMHSA, n.d.-b) estimate that about one in five people (nearly 108,000 people)(HUD, 2016) experiencing homelessness has an SMI, and a similar percentage have a chronic substance use disorder. The Office of National Drug Control Policy reports that approximately 30 percent of people who are chronically homeless live with an SMI (Office of National Drug Control Policy, n.d.).

Most adults with SMI have private insurance or Medicaid. About one-quarter (24.9 percent) of adults with SMI were enrolled in Medicaid at some time during 2015, while slightly more than

half (51.5 percent) had private insurance during the year. For some period of the year, more than 1 in 10 (12.5 percent) had no insurance (CBHSQ, 2017i). However, individuals with insurance may still face challenges in accessing treatment. For example, many individuals with SMI still lack a usual source of care or delay medical care because of cost (Sherrill & Gonzales, 2017). An analysis of the 2016 Affordable Care Act Marketplaces demonstrated that, of those practicing in a given state-level market, plan networks included mental health care providers at a much lower rate (11.3 percent) in comparison to primary care providers (24.3 percent) (Zhu, Zhang, & Polsky, 2017).

Adults with SMI are at particularly high risk of death by suicide. A suicide occurs in the United States about every 13 minutes (Centers for Disease Control and Prevention [CDC], 2015); more than 44,000 suicides occurred in 2015 (CDC, 2017). According to the Surgeon General's National Strategy for Suicide Prevention (HHS, 2012), the rate of death by suicide for people with mood disorders such as depression or bipolar disorder is estimated to be 25 times higher than among the general population. Among adults diagnosed with schizophrenia, 1 in 20 dies by suicide, a rate 20 times higher than for the general populations (Hor & Taylor, 2010).

> "My 39-year old son killed himself today. He hung himself in a solitary confinement cell in a prison. He died alone, afraid, and powerless. He needed help. Instead, he got punishment. Like all mothers, I had dreams for my children – dreams that didn't include mental illness or prison."
>
> — *Anne (submitted through public comments to the ISMICC)*

Mental illnesses lead to high medical costs. Health care costs are increased by two to three times for people with mental illness, even if their conditions are not among the most serious (Melek, Norris & Paulus, 2014). It is noteworthy that most of these higher costs for people with mental disorders result from medical spending for chronic health conditions, not for behavioral health medications or services. A high proportion of the most costly patients served by the health care system have mental or substance use disorders (Boyd et al., 2010). High medical costs are often incurred at hospitals, due to emergency department visits and hospitalizations. Between 2006 and 2014, the rate of mental health/substance abuse-related emergency department visits increased approximately 44 percent (Moore, Stocks, & Owens, 2017). In 2014, people diagnosed with schizophrenia or mood disorders made 10.8 million visits to emergency departments (HCUP, 2014a). Hospitalizations for people with schizophrenia or mood disorders cost $27.7 billion nationwide (HCUP, 2014b).

Adults with mental illness receive a disproportionate share of opioid prescriptions. While people with any mental health condition represent only 17.9 percent of the population, a recent study concluded: "Adults with mental health conditions receive 51.4 percent (60 million of 115 million prescriptions) of the total opioid prescriptions distributed in the United States each year" (Davis, Lin, Liu, & Sites, 2017).

Most civil commitment statutes fall short of adequately protecting patients or communities. In many jurisdictions, civil commitment criteria focus primarily on the immediate

threat of harm to self or others and do not consider patient history or capacity to make informed decisions about the need for or benefits of treatment (Goldman, 2014). This results in many patients being unable to access care when decompensated until they have done something which may lead to their arrest. Although virtually all states have legal provisions for the use of assisted outpatient treatment (AOT), this form of court-ordered outpatient treatment is realistically available in few areas in the nation currently. AOT can be valuable to help ensure that people with SMI who are at high risk of damaging behavior are engaged at some level with treatment services. SAMHSA currently is working with the HHS Assistant Secretary for Planning and Evaluation and the National Institute of Mental Health to evaluate the effect of various aspects of AOT implementation in 17 communities throughout the United States. Other strategies may be considered to address some of these issues, such as advance directives and other forms of consumer-directed care planning such as wellness recovery action plans.

> "If assisted outpatient treatment had been available to my paranoid schizophrenic son, countless heartaches and dangers could have been averted over the course of the 25 years he has endured this cruel disease. No, instead we have had to wait until our psychotic loved ones became a danger to self or others. There are red flags that maybe only family members can see, but still we have to wait until it is too late. My son has been homeless, dangerous, and now in prison. I have not heard from him in 3 years because I "know" he's been off meds, but he has a right to refuse treatment! He is lost! And I can get no information because of HIPAA. We need assisted outpatient treatment, revised HIPAA, and more hospital beds instead of jail cells."
>
> — *Judy (submitted through public comments to the ISMICC)*

Caregivers of people with mental illness face complex situations and a high burden of care. A study of unpaid caregivers by the National Alliance for Caregiving estimates that nearly 8.4 million Americans provide care to an adult with an emotional or mental health issue, mainly related to SMI (NAC, 2016). It found that, for nearly one in five mental health caregivers, taking care of a loved one is equivalent to a full-time job. Approximately one in three caregivers provides care for more than 10 years (NAC, 2016). Many people with SMI are financially dependent on family and friends. Caregivers also bear a significant emotional burden, and often report feeling isolated and stigmatized because of their loved one's illness. This stress can lead to physical health problems, as nearly 4 in 10 caregivers report difficulty taking care of their own health, and about half cite caregiving as a cause of worsening health (NAC, 2016). Caregivers also face logistical challenges in coordinating care for their loved one, such as finding appropriate providers, managing medications, handling paperwork and finances, and accessing community services

(NAC, 2016). Despite their involvement in day-to-day disease management, many caregivers report they are often excluded from care conversations and cannot speak to the provider about the patient's condition. Parents caring for an adult child face these challenges more frequently, as 77 percent have been told they cannot speak to a provider and 69 percent feel they have been left out of care conversations (NAC, 2016).

Serious Emotional Disturbances

The definition of SED is similar to SMI, but applies to children and youth; it requires the presence of a diagnosable mental, behavioral or emotional disorder and substantial functional impairment. While some of the diagnoses that contribute to meeting criteria for SED are the same as for SMI, some are different. Diagnoses that are more commonly seen in children than adults include disruptive behavior disorders, and others that are less commonly seen in children than adults, include bipolar disorder and schizophrenia.

As with SMI, individuals with SED can also have substance use disorders and intellectual/developmental disabilities that co-occur with their mental disorders. Those whose sole diagnosis is a substance use disorder or an intellectual/developmental disorder are not considered to have SED. The type of functional impairment in SED also reflects the nature of childhood; role functioning in family, school, and community naturally varies depending on the age of the child.

Defining SED[5]

Serious emotional disturbance (SED) refers to children and youth who have had a diagnosable mental, behavioral, or emotional disorder in the past year, which resulted in functional impairment that substantially interferes with or limits the child's role in family, school, or community activities.

The members of the ISMICC have concerns about the term "serious emotional disturbance." The use of the word "emotional" does not capture the reality that mental disorders experienced by children and youth often have cognitive or behavioral aspects. The word "disturbance" also does not seem fitting for diagnosable disorders that are just as important to address in young people as disorders experienced by adults. As a result, ISMICC members plan to examine this issue and propose alternative language as the group moves forward.

Many children and youth have an SED. It has been challenging to assess functional impairment across age groups, as no national survey currently estimates the prevalence of SED. SAMHSA estimates prevalence ranging between 6.8 and 11.5 percent, based on published studies that differ on the study design and ages of children and youth included.

Reviews of the literature have produced some estimates. According to a 2013 CDC review of population-level information, estimates of the number of children with a mental disorder range from 13 percent to 20 percent (CDC, 2013). A recent meta-analysis of U.S. epidemiological studies concluded that 10 percent of children meet the criteria of significant impairment in one domain of role functioning (family, school, peers, community, or school) (Williams, Scott, & Aarons, 2017).

[5] Adapted from Federal Register, Vol. 58, No. 96, pages 29422-29425; for detail on the criteria for emotional disturbance under IDEA, see http://idea.ed.gov/explore/view/p/,root,regs,300,A,300.8,.html.

The National Comorbidity Survey – Adolescent Supplement (NCS-A), was a large-scale national survey of youth ages 13 to 18 conducted between 2001 and 2004 (Merikangas, He, Burstein, Swanson, Avenevoli, Cui & Swendsen, 2010). Interviews of 10,123 youth used an instrument that generated DSM-IV diagnoses. The overall prevalence of disorders with severe impairment and/or distress was 22.2 percent. Lifetime prevalence of mood disorders (including major depressive disorder, dysthymia, and bipolar I and II) with severe impairment was the most common class of disorders (11.2 percent). Lifetime prevalence of behavior disorders (including conduct disorder and oppositional defiant disorder) with severe impairment was found at a rate of 9.6 percent, and the rate of anxiety disorder with severe impairment was 8.3 percent. By any measure, the problem is substantial, and addressing it is important for the healthy development of our nation's youth.

Children and youth have a range of SED diagnoses. SAMHSA's Children's Mental Health Initiative (CMHI) provides funds to a limited number of public entities to promote recovery and resilience for children and youth who have an SED and their families by providing comprehensive services for mental and substance use disorders using the system of care framework. Systems of care refers to a coordinated network of community-based services and supports organized to meet the challenges of children and youth and their families. Among youth entering the CMHI program in 2015, the five most common diagnoses were mood disorders (such as depression, 29.3 percent), attention deficit hyperactivity disorder (ADHD, 24.9 percent), oppositional defiant disorder (15.8 percent), adjustment disorders (15.3 percent), and post-traumatic stress disorder (PTSD) or acute stress disorder (12.6 percent) (CMHS/SAMHSA, 2016). Data from the 2016 National Survey of Children's Health (NSCH), shown in Table 1.2, indicate reported diagnoses for younger children, ages birth to 11, as well as for older youth. It should be noted that the NSCH methodology involves asking a parent about the statements made by a doctor or health provider, an approach that may be less precise and result in lower estimates than a diagnostic interview.

On average, 15 percent of young children (ages 2-8) in the United States have a parent-reported mental, behavioral, or developmental disorder (MBDD) diagnosis, which includes ADHD, depression, anxiety problems, behavioral or conduct problems such as oppositional defiant disorder or conduct disorder, Tourette syndrome, autism spectrum disorder, learning disability, intellectual disability, developmental delay, or speech or other language problems.1 The percentage of children with diagnosed MBDD is similar for small rural and urban areas, at 18.6 percent and 15 percent, respectively (Robinson et al., 2017).

Table 1.2. Weighted Data From 2016 National Survey of Children's Health

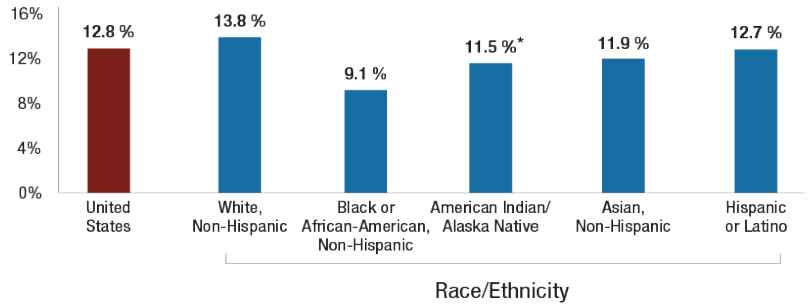
Condition	Percentage by Age Category: Age 0-11 (N=48,534,964)	Age 12-17 (N=24,815,076)
Doctor/health provider ever said child had anxiety problems	4.4	12.4
Doctor/health provider ever said child had depression	1.1	8.2
Doctor/health provider/educator ever said child had behavioral/conduct problems	7.1	10.1

* Missing data excluded from denominator

Racial and ethnic differences among youth. The NCS-A study found few differences across racial and ethnic groups in the major classes of mental disorders (mood, anxiety, or behavior disorders), except that the rates of anxiety disorders were higher and rates of substance use disorder were lower among Non-Hispanic Black or African-American adolescents, compared to Non-Hispanic White adolescents, and there were higher rates of mood disorders among Hispanic adolescents compared to Non-Hispanic Whites.

SAMHSA's ongoing National Survey of Drug Use and Health estimates the rate of major depressive disorder annually among youth. In 2016, 12.8 percent of youth in this age group (an estimated 3.1 million youth) experienced a major depressive episode (CBHSQ, 2017j). There were differences in the rate of major depressive episodes across ethnic groups, with Non-Hispanic Black or African-American youth having lower rates and Non-Hispanic White youth having higher rates (Figure 1.5).

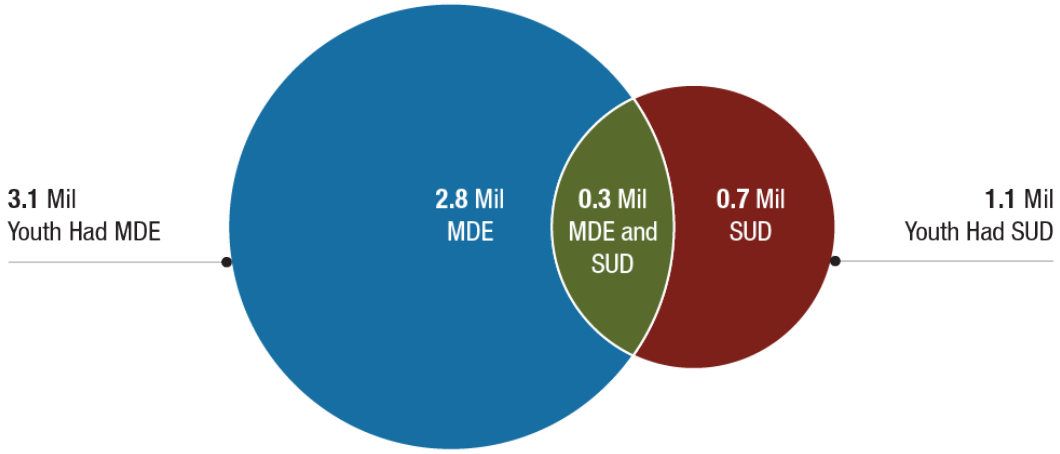
Figure 1.5. Past Year Major Depressive Episode Among Adolescents Ages 12 to 17 in the United States, by Race/Ethnicity: 2016



Source: Based on Table 9.7B of: Center for Behavioral Health Statistics and Quality. (2017). *Results from the 2016 National Survey on Drug Use and Health: detailed tables*. Rockville, MD: Substance Abuse and Mental Health Services Administration.

Youth with SED often have multiple disorders. The NCS-A study found that 6 percent of youth had disorders in two or more major classes of mental disorders (i.e., mood, anxiety, or behavior disorders). Among youth with a past year major depressive episode, 12.1 percent (an estimated 333,000) also had a substance use disorder (CBHSQ, 2017k). An estimated 333,000 adolescents ages 12 to 17 had both a substance use disorder and a major depressive episode in the past year (Figure 1.6). Children and youth with SED also have increased rates of co-occurring health conditions such as obesity (Pastor & Reuben, 2011), asthma (Goodwin et al., 2014), and the onset of cigarette smoking (Blum, Kelly, & Ireland, 2001).

Figure 1.6. Past Year Substance Use Disorder (SUD) and Major Depressive Episode (MDE) Among Youth Ages 12 to 17: 2016



Source: Adapted from Figure 66 of: Substance Abuse and Mental Health Services Administration. (2017). *Key substance use and mental health indicators in the United States: Results from the 2016 National Survey on Drug Use and Health* (HHS Publication No. SMA17-5044, NSDUH Series H-52). Retrieved from http://www.samhsa.gov/data.

Early intervention is crucial to address development of mental disorders. The vast majority of individuals who will develop a mental health disorder in their lifetime do so before age 24 (Kessler et al., 2005). Strong prevention and early intervention efforts should occur at these ages, but occur far too rarely. There are many standards for assessing mental health conditions in children and adolescents up to age 18 in pediatric care (U.S. Preventive Services Task Force, n.d.). There are also consensus-based guidelines for care of children and adolescents, such as Bright Futures: Guidelines for Health Supervision of Infants, Children, and Adolescents (Hagan, Shaw, & Duncan, 2017). These guidelines call for regular screening for a variety of mental health conditions, and include recommendations for pediatric screening of those up to age 21. Medicaid's Early and Periodic, Screening, Diagnosis, and Testing (EPSDT) benefit requires mental health assessment of all covered children. Other expert groups have developed guidelines for screening for a broader array of mental health conditions in children and adolescents (Weitzman et al., 2015). However, screening is recommended only when systems are in place to ensure accurate

diagnosis, treatment, and follow-up, so screening efforts must be accompanied by an expansion of access to mental health care. Low uptake of screening procedures likely reflects the shortage of mental health care for children and youth, the stigmatizing nature of these conditions, and cultural variations in views of mental health needs (Wissow et al., 2013). Mental health screening for children and adolescents can be conducted in schools (Essex et al., 2009), but the vast majority of schools do not conduct universal screening, as they face many of the same challenges as screening in pediatric care settings, and have limited resources to do so.

As youth enter young adulthood, mental health screening and early intervention continues to be limited. Screening rates are very low (IOM & NRC, 2014). Screening tools and processes have not been developed explicitly for 18- to 26-year-olds (Ozer, Scott, & Brindis, 2013). This is a critical age at which screening for development of the most serious mental illnesses (i.e., psychotic illness) can substantially reduce the impact of these disorders. Yet screening for early psychosis rarely takes place outside mental health clinics affiliated with early psychosis research programs. The following recommendation was issued by the National Academy of Science, Engineering, and Medicine (IOM & NRC, 2014): "The U.S. Preventive Services Task Force should develop a consolidated set of standardized evidence-based recommendations for clinical preventive services such as screenings, counseling services, and preventive medications specifically for young adults ages 18-26. Behavioral and oral health should be included in these recommendations." This is an important step toward achieving a system of care that ensures screening for youth during this critical time.

Children and youth with SED often have challenging life circumstances (CMHS/SAMHSA, 2016). Caregivers of youth entering the CMHI program reported that 4 in 10 (39.7 percent) children and youth had been exposed to domestic violence at some point in life, and one in five (21.7 percent) had been exposed to such violence during the prior six months. More than one in five of these youth were missing school frequently, and nearly half (47.2 percent) had been suspended or expelled from school. Nearly three-quarters of these youth (73.5 percent) lived with someone who had shown signs of depression in the six months before entering services, and nearly half (48.4 percent) had a family member with a mental illness other than depression (CMHS/SAMHSA, 2016). These types of adverse childhood experiences increase the likelihood of developing SED and later SMI (Dube, Anda, Felitti, Chapman, Williamson & Giles, 2001; Chapman, Whitfield, Felitti, Dube, Edwards & Anda, 2004).

"Three years ago, I took in my cousin because my uncle and aunt are both SMI and they could no longer care for him. His mom was in jail and his father was in a long-term community placement. At only 8 years old, he was very much out of control due to a number of abuses and a general lack of a nurturing environment. We quickly pulled together the services and supports we thought he needed in school, in the community, and in our home. He was still failing miserably in all of his life domains. This year, I sat down with every provider he had ever used and we developed strategies, services, and supports that cut across all of his programs as a team. We developed new approaches that were customized to his unique needs and life experiences. Here we are today, I am finalizing his adoption and he is starting to mesh into our family and community. He is a survivor; but the system had to work collaboratively to throw him the lifelines he needed."

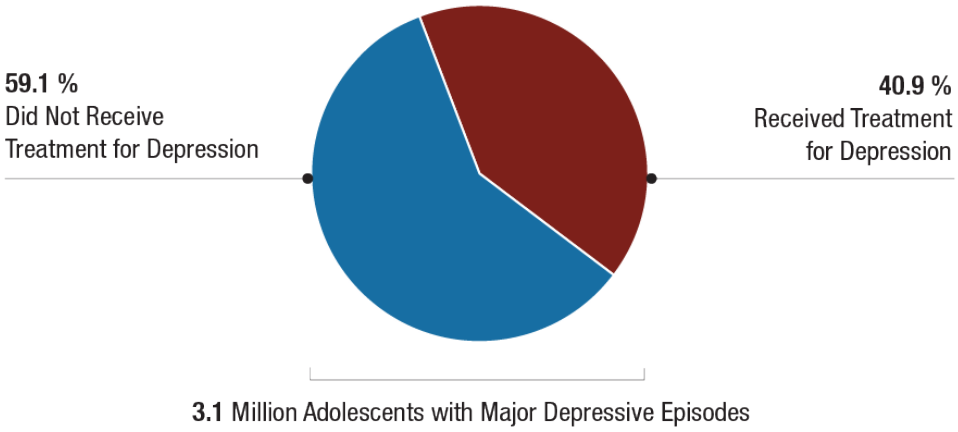
— SJ

Effective treatments are available. There are a wide range of evidence-based treatments for many mental disorders that children and youth experience (e.g., anxiety, depression, ADHD, autism, eating disorders, obsessive compulsive disorder [OCD], exposure to traumatic events, disruptive behavior, substance abuse) (Silverman & Hinshaw, 2008). Psychotherapeutic or psychosocial services such as cognitive behavioral therapy and social skills training are evidence-based interventions that may be provided independently or along with medications. Coordinated specialty care is an evidence-based approach to working with youth nearing or in early adulthood who experience a first episode of psychosis. Psychotropic medications are commonly given for disorders such as anxiety, depression, psychosis, ADHD, and OCD, among others, and should be used for children and youth in keeping with the latest research and guidelines. Prescribers should be careful, as psychotropic medications have been overused in some populations of young people in ways that are not supported by research or practice guidelines (American Academy of Child and Adolescent Psychiatrists, 2015). In addition, the system of care approach continues to evolve to reflect advances in research and service delivery. The core values of community-based, family-driven, youth-guided, and culturally and linguistically competent services are widely accepted. The guiding principles calling for a broad array of effective services, individualized care, and coordination across child-serving systems are extensively used as the standards of care throughout the nation (Stroul & Friedman, 2011).

Most children and youth with SED do not receive treatment. Identifiable mental health problems are common, but few children receive services for those problems. The lack of services received by these young, multi-challenged children is a services systems and social policy failure (McCue Horwitz et al., 2012). About 4 in 10 (40.9 percent) of youth ages 12 to 17 with major depressive episodes (1.2 million youth) received treatment of any kind in 2016 (Figure 1.7) (CBHSQ, 2017j). This is similar to the findings from the NCS-A study, that 36.2 percent of adolescents with mental disorders received treatment across diagnostic groups. However, that study also reported that treatment rates were higher for adolescents with attention deficit hyperactivity disorder (59.8 percent) and behavior disorders, such as oppositional defiant disorder and conduct disorder (45.4 percent), but lower for those with anxiety disorders (17.8 percent), while children and youth with mood disorders had received treatment 37.7 percent of the time (Merikangas, He, Burstein, Swendsen, Avenevoli, Case, & Olfson, 2011). Among youth in 2016 with a past year major depressive episode who received treatment for depression, only 18.9 percent saw or talked to a health professional and also took prescription medication (CBHSQ, 2017l).

> "The last 10 months of our lives have been filled with a life-altering and horrific change as my beloved youngest son had a psychotic break and was diagnosed with schizophrenia. Like many other families, we were naïve. We have been screaming for help and information, waiting on services, and watching my son slowly fade away. Things need to change. It is evident that mental illness is still treated with casual effort and not as a true and serious medical illness."
>
> — *Charlene (submitted through public comments to the ISMICC)*

Figure 1.7. Past Year Treatment for Depression Among Adolescents Ages 12 to 17 With Major Depressive Episodes in the United States: 2016



Source: Substance Abuse and Mental Health Services Administration. (2017). *Key substance use and mental health indicators in the United States: Results from the 2016 National Survey on Drug Use and Health* (HHS Publication No. SMA17-5044, NSDUH Series H-52). Retrieved from http://www.samhsa.gov/data.

Transition-age youth face particular challenges. Youth with SED encounter problems as they age from adolescence to adulthood, and undergo the transition from youth-oriented systems of care to the adult behavioral health system. Exact definitions of the transition period ages have been described broadly (ages 14 to 30) to more narrowly (ages 17 to 25). Regardless of the exact age range, this is a developmentally critical stage, i.e., transition from childhood into adult responsibilities. It is also the age range during which many adult SMI diagnoses first become apparent (Kessler et al., 2005; Hafner et al., 1994). Program structures, eligibility criteria, expectations related to family participation in treatment and sharing of information, and expectations for adult functioning can change substantially, based solely on the passage of a birthday (Davis, 2003; Davis & Koroloff, 2005). For these and other reasons, many of these youth drop out of services when they reach adulthood. The adult outcomes for most youth who enter adulthood with SED or SMI are bleak; many don't finish high school, college enrollment and completion is low, unemployment is high, and they are at increased risk of homelessness (Davis & Vander Stoep, 1997; Rinaldi et al., 2010; Wagner & Newman, 2012). As with the general population, substance use peaks during these ages, as does justice system involvement (Sheidow, McCart, Zajac, & Davis, 2012; Davis, Banks, Fisher, Gershenson, & Grudzinskas, 2007). Evidence-based practices such as supported employment and supported housing have been adapted and shown promising results for transition-age youth. The coordinated specialty care model also shows great promise for people who experience a first episode of psychosis in late adolescence or early adulthood (Kane et al., 2016). A review of health care and services for young adults by the Institute of Medicine and National Research Council[6] (2014) describes the variety of evidence-based interventions and recommends steps for increasing the use of evidence-based approaches for young adults.

> "My son was treated for serious psychiatric disorders as a child. At age 17, in an attempt to escape the discrimination of his peers, he refused treatment. It was not long before he quickly became aggressively psychotic. My husband and I were encouraged to file a beyond control petition in civil court, just 6 months prior to our son's 18th birthday—hoping to save his life and us from his reckless and often dangerous behavior. Instead, he was ordered to jail, punished for behaviors that were symptoms of his untreated brain disease! None of my son's medical records and history transitioned to the adult system. My son was homeless, desperate for food, and still refused treatment. When we petitioned him to a hospital, he was not held long enough to stabilize. Many times, he threatened homicide or suicide. We have felt powerless, as we have watched his brain disease deteriorate year after year from countless psychotic episodes."
>
> — *Regina (submitted through public comments to the ISMICC)*

[6] Now known as the National Academy of Medicine and the National Academies of Science, Engineering, and Medicine.

Many children and youth with SED are living in poverty. More than one in five (20.2 percent) youth with major depressive episodes (CBHSQ, 2017m), and almost one in three (29.8 percent) of special education students with emotional disturbance (Wagner et al., 2003) have family incomes below the poverty line. Almost two-thirds (65.1 percent) of children and youth with SED who receive services from SAMHSA's CMHI program live below the poverty line (CMHS/SAMHSA, 2016).

> "Our mentally ill are filling up our jails and living homeless in our streets. Why would we let a 20-year-old suffering from a disease with many of the same symptoms as dementia wander around the streets without care and treatment? People suffering from serious mental illness have loving families but are often too psychotic to remember that, and they don't have the capacity to realize they need to be in a hospital. If our children were stricken with diabetes or cancer, we would not be waiting until they reached stage 4 in the disease, or became a danger to themselves or others, before being able to access treatment. I cannot think of a single disease, other than serious mental illness, where this would happen. Mental illness is not a crime yet the criminalization of mental illness is an epidemic of national proportion."
>
> *— Jeanne (submitted through public comments to the ISMICC)*

Children and youth account for nearly a quarter of people experiencing homelessness. The Department of Housing and Urban Development (HUD) estimates that more than 120,000 people experiencing homelessness are age 18 or under (HUD, 2016), with most being accompanied by a parent. Estimates of those with SED are not currently available. SAMHSA notes that lesbian, gay, bisexual, and transgender (LGBT) youth are at high risk for homelessness and SED (SAMHSA, n.d.-b). A national survey found that as many as 40 percent of youth experiencing homelessness self-identify as LGBT (Durso & Gates, 2012).

Most children and youth with past year major depressive episode do have health insurance. More than one-third (34.9 percent) of children or youth were enrolled in Medicaid or the Children's Health Insurance Program at some time during 2016, while 6 in 10 (60.1 percent) had private insurance. Only 5.2 percent had no health insurance (CBHSQ, 2017m).

Youth with SED are at high risk for suicide. Among youth entering the CMHI program in 2015, almost one-fifth (19.4 percent) had thought about committing suicide, and almost 1 in 10 (9.1 percent) had attempted suicide prior to receiving services (CMHS/SAMHSA, 2016). In particular, youth involved in the juvenile justice and child welfare systems are at higher risk for suicide, and often have a history of mental health and/or substance use disorders and traumatic experiences (HHS, 2012). One study found that adolescents in foster care were almost four times more likely to have attempted suicide in the previous year than those who had never been in foster care (Pilowsky & Wu, 2006). In addition, the CDC has found that the prevalence of having seriously considered attempting suicide was higher among gay, lesbian, and bisexual students (42.8 percent) than heterosexual students (14.8 percent) and that the prevalence of having attempted suicide was higher among gay, lesbian, and bisexual students (29.4 percent) than heterosexual students (6.4 percent) (Kann et al., 2016).

While the highest rates of death by suicide are among middle-aged adults, especially males, suicide rates have increased among Black or African-American children. While the suicide rate among young children has remained relatively stable, a recent study shows that the number of Black or African-American children between the ages of 5 and 11 who die by suicide has almost doubled since 1993. The research shows that from 1993 to 2012, a total of 657 U.S. children in that age group killed themselves; 84 percent were boys and 16 percent were girls. Over the nearly 20-year period, the rate among Black or African-American children significantly rose while the rate among White children dropped (Bridge et al., 2015).

Compared with early adolescents who died by suicide, children who died by suicide were more commonly male, Black or African-American, died by hanging, strangulation, suffocation, and died at home. Among suicide decedents with known mental health problems, childhood decedents more often experienced attention deficit disorder with or without hyperactivity and less often experienced depression/dysthymia compared with early adolescent decedents (Sheftall et al., 2017).

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Chapter 2: Improving Practice Related to Serious Mental Illness and Serious Emotional Disturbances

This chapter highlights some key advances in research on serious mental illnesses (SMI) and serious emotional disturbances (SED). It also includes strategies to improve services for people with SMI and SED that were highlighted in the first ISMICC meeting. This is an exciting time, and many innovations are available to help federal departments, states, and providers meet the needs of people with SMI and SED and their families.

The first ISMICC meeting occurred on August 31, 2017, at the Department of Health and Human Services headquarters at the Hubert H. Humphrey Building in Washington D.C. Federal and non-federal experts were invited to present information on relevant advances for addressing the needs of people with SMI and SED. This chapter reflects the content of the presentations, discussion during the meeting, and later input from ISMICC members.

The advances included in this chapter come directly from the presentations of the federal leaders and national experts. All of the advances are relevant to SMI and SED populations. Each advance has a substantial evidence base and has been tested in real-world settings. The order in which the information is summarized within the chapter corresponds to the order of the ISMICC meeting presentations. Within the chapter, attention is given to the areas outlined in the Congressional legislation regarding the ISMICC:

- Prevention
- Diagnosis
- Intervention
- Treatment and recovery

Federal Leaders Who Presented on Federal Advances in Addressing the Needs of People With SMI and SED

Joshua Gordon, Director, National Institute of Mental Health (NIMH)

Paolo del Vecchio, Director, Center for Mental Health Services (CMHS), Substance Abuse and Mental Health Services Administration (SAMHSA)

John McCarthy, Director, Serious Mental Illness Treatment Resource and Evaluation Center (SMITREC), Department of Veterans Affairs (VA)

Ruby Qazilbash, Associate Deputy Director, Bureau of Justice Assistance (BJA), Department of Justice

National Experts Who Presented on Non-Federal Advances in Addressing the Needs of People With SMI and SED

Lynda Gargan, Executive Director, National Federation of Families for Children's Mental Health

Lisa Dixon, Professor of Psychiatry, Columbia University Medical Center; Director, Division of Behavioral Health Services and Policy Research

Sergio Aguilar-Gaxiola, Professor of Clinical Internal Medicine, University of California, Davis; Director, Center for Reducing Health Disparities; Director, Community Engagement Program, Clinical and Translational Science Center

Joseph Parks, Medical Director, National Council for Behavioral Health

- Access to services and supports

The presentations do not cover the full breadth of current advances. The chapter ends with additional advances that ISMICC members identified as areas that warrant further exploration by the ISMICC.

As with the other chapters in this report, we expect to build on the foundation outlined in this chapter. Moving forward, the ISMICC will update and consider the range of evidence-based practices and advances that should be available to people with SMI and SED.

The advances highlighted in this chapter come from experts invited by the ISMICC to present at the ISMICC inaugural meeting, August 31, 2017.

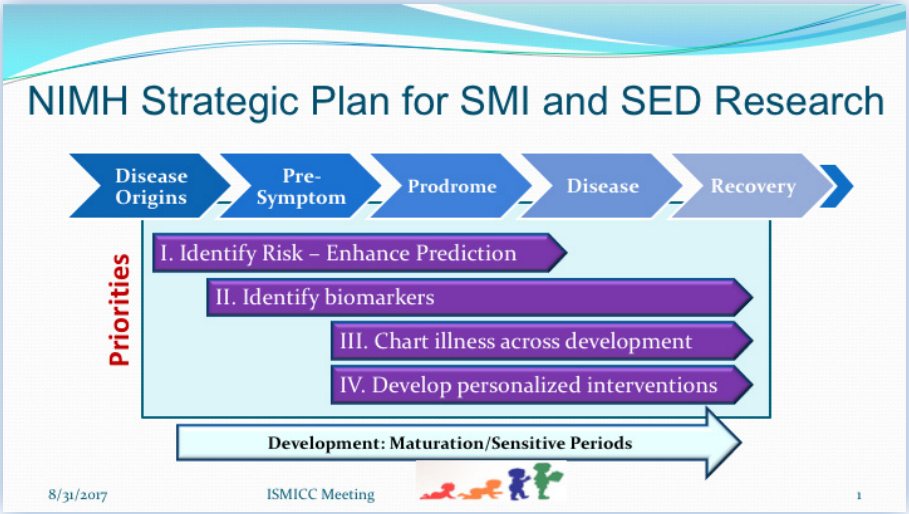
Additional advances and innovations are listed at the end of this chapter.

Federal Presentations

National Institute of Mental Health: Support of Advances to Address Challenges of SMI and SED

Joshua A. Gordon, Director, National Institute of Mental Health (NIMH)

Dr. Gordon noted that NIMH priorities include: (1) identify risk and enhance our ability to predict the development of SMI, (2) identify biomarkers that help predict risk and follow the course of disease, (3) chart the illness throughout development, and (4) develop personalized interventions. NIMH seeks to understand SMI across the entire cycle of development.



The growth of genetic knowledge provides indicators for predicting risk. However, genetic risk is only one part. There is a need to understand the environmental factors and developmental factors that play a role in the development of SMI.

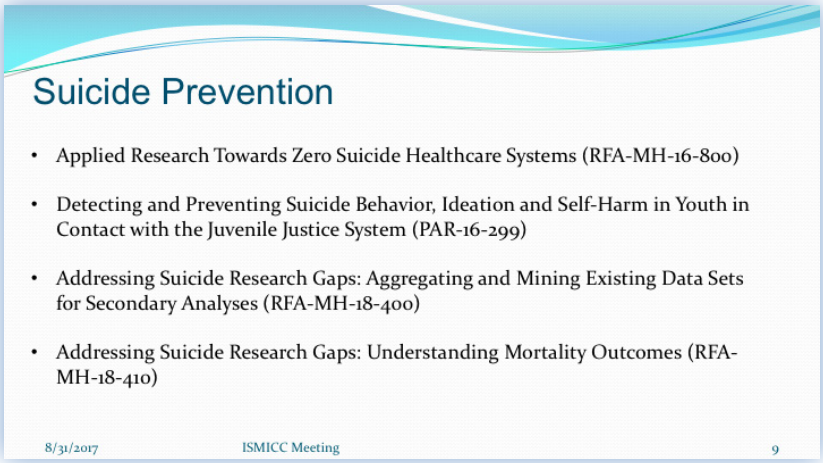
Dr. Gordon remarked that biomarkers may someday make it possible to chart the course of the illness. NIMH avoids studying simple individual diagnoses, but instead pools data on people with SMI across diagnostic domains. Researchers are looking at "deep phenotyping," which includes measurement of a combinations of factors such as behavior, brain activity, and symptoms. Using this approach, researchers seek to group people with psychosis according to common anatomic and/or biologic origins. This may better predict their disease course and response to treatment.

Early/Personalized Intervention

- Reducing Treatment Delays in First Episode Psychosis (PAR16-264/-265)
- Research to Improve the Care of Persons at Clinical High Risk for Psychotic Disorders (RFA-MH-14-210/-211/-212)
- Advanced Laboratories for Accelerating the Reach and Impact of Treatments for Youth and Adults with Mental Illness (ALACRITY) Research Centers (PAR-16-354)
- Exploratory Clinical Trials of Novel Interventions for Mental Disorders (RFA-MH-16-406)
- Temporal Dynamics of Neurophysiological Patterns as Potential Targets for Treating Cognitive Deficits in Brain Disorders (PAR-14-153)
- Pragmatic Strategies for Assessing Psychotherapy Quality in Practice (RFA-MH-17-500)
- Effectiveness Trials for Post-Acute Interventions and Services to Optimize Longer-term Outcomes (PAR-17-272)
- Reducing Medical Comorbidities Among Youth (RFA-MH-16-600) and Adults with SMI (RFA-MH-14-060)

Longitudinal studies that use multiple modalities—including neuroimaging and neuropsychological measures—allow the development of predictive tools and methods for charting illness progression. The Recovery After an Initial Schizophrenia Episode (RAISE) project was a research initiative of the NIMH. RAISE studied coordinated specialty care (CSC), an integrated approach to care for patients who experience their first episode of psychosis, including psychotherapy, family education and support, supported employment, education, and medication. Patients who received CSC had better outcomes. SAMHSA and NIMH are collaborating closely to implement CSC in community settings via the Mental Health Block Grant 10 percent set-aside for early serious mental illness, including psychotic disorders. Several related NIMH research efforts aim to reduce treatment delays in first-episode psychosis by identifying people at high risk, improving the care of those high-risk people in community mental health centers, and developing novel approaches to treating youth and adults. The evidence shows that diagnoses are not sufficient predictors of response to treatment; an individualized approach is needed. Understanding the relationship between patterns of brain activity and treatment will help develop novel treatments aimed at patterns of dysfunctional brain activity.

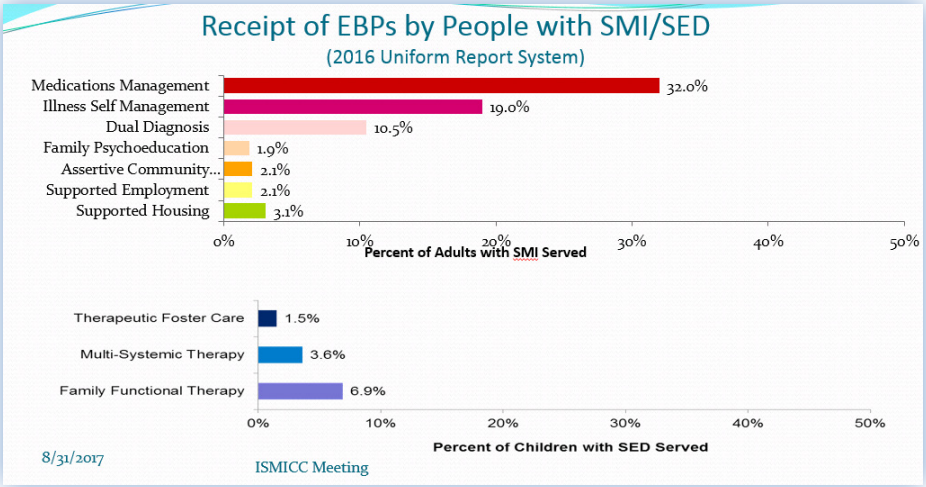
NIMH is also focused on predicting which people are at high risk of suicide, and approaches for treatment. In collaboration with the Department of Justice and other partners, NIMH is studying people who are particularly at high risk for suicide following release from jail or prison. The research aims to improve understanding of mortality outcomes. The use of data sets can ultimately make it possible to identify those at highest risk, so that appropriate services can be accessed efficiently.



Substance Abuse and Mental Health Services Administration: Support of Advances to Address Challenges of SMI and SED

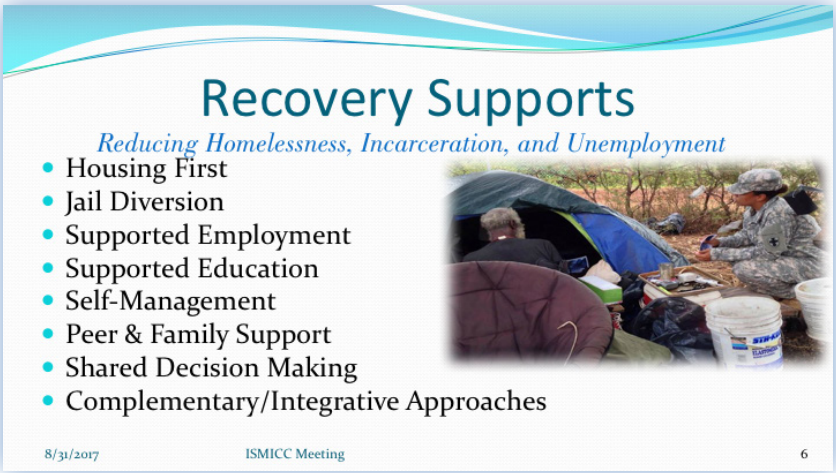
Paolo del Vecchio, Director, Center for Mental Health Services (CMHS), Substance Abuse and Mental Health Services Administration (SAMHSA)

Mr. del Vecchio focused on the central issue of access to evidence-based treatments. Data from 2016 show that most people who receive public mental health services for SMI or SED do not receive evidence-based practices such as medication management, assertive community treatment, supported employment, and family psychoeducation.



Research shows that the most effective way to provide services is through comprehensive, coordinated, and collaborative care. Meeting the complex needs of people with SMI and SED requires a multidisciplinary approach that often includes medication, therapy, and community recovery supports.

Only 2 percent of public mental health clients have access to effective therapeutic approaches such as cognitive behavioral therapy. Similarly, few are receiving evidence-based approaches such as dialectical behavior therapy and cognitive remediation therapy. People with SMI need access to effective psychiatric care, including diagnostic examination, medication, and psychotherapeutic interventions.



Of the 70 percent of people with SMI who are unemployed and want to work, only 2 percent receive evidence-based supported employment. Similarly, few have access to supportive housing, despite the link between housing and reduced symptoms, decreased criminal justice and juvenile justice systems involvement, and increased employment. Jail diversion programs have also demonstrated effectiveness. Major advances have been made in recent decades to promote peer and family support, with 40 states including this as a billable Medicaid optional service. As a part of recovery support services, and given the elevated rates of mortality, attention to self-care and general health by people with SMI and SED is also important. Studies show the benefits of exercise, healthy diet, and other self-management activities.

Coordinated care approaches are critical. Through a partnership across the Centers for Medicare & Medicaid Services (CMS), SAMHSA, and the Assistant Secretary for Planning and Evaluation (ASPE), over 70 Certified Community Behavioral Health Clinics in eight states have enhanced Medicaid federal match to provide comprehensive, coordinated care as a result of the Section 223 Demonstration Program to Improve Community Mental Health Services. Equally promising is the collaboration involving SAMHSA, ASPE, and NIMH to look at the impact of assisted outpatient treatment on engagement in effective care in 17 representative communities throughout the United States.

An estimated 50 percent of clients stop engaging in treatment in the first six months. People must be engaged in their care, and providers should be trained to deliver individualized and personalized approaches that address individual goals and strengths as well as culture, age, sexual orientation, and geography.

For an estimated 50 percent of people, the onset of mental illness happens before age 15; onset happens before age 25 for 75 percent of people. It is critical that problems be identified early in educational and health settings, and that children and youth have access to a range of services.

There is a critical need to standardize and increase data collection. Further work is needed to address privacy rights and offer protections against the abuse and neglect that continue for this vulnerable population.

Department of Veterans Affairs: Support of Advances to Address Challenges of SMI and SED

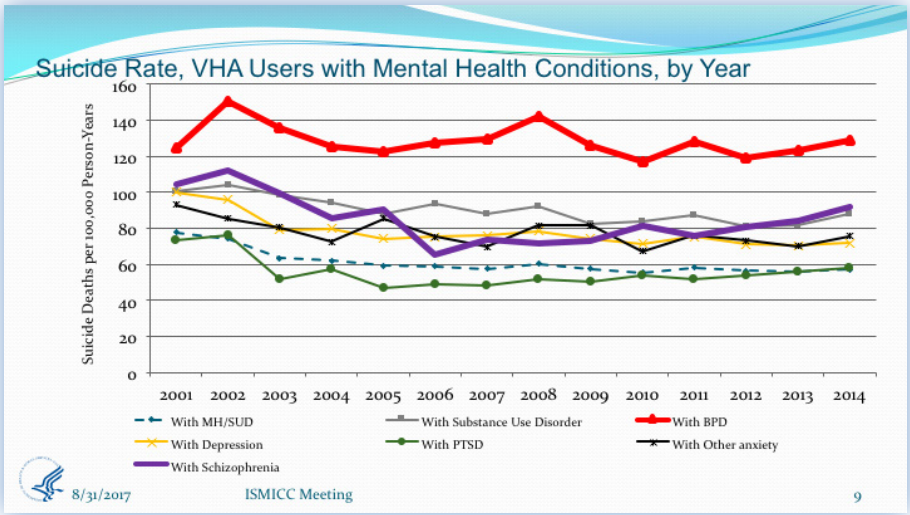
John McCarthy, Director, Serious Mental Illness Treatment Resource and Evaluation Center, Department of Veterans Affairs (VA)

Dr. McCarthy noted that the VA has substantially increased its capacity to meet the needs of veterans with mental health conditions. Veterans Health Administration (VHA) users with schizophrenia and bipolar disorder constitute a small proportion of the patient population, yet they generate disproportionate expenditures and service utilization.

In response, the VA established the National Psychosis Registry in 1999, which generates data about patients with schizophrenia, bipolar disorder, or other psychoses. The VA's SMI Re-Engage Initiative identifies people with schizophrenia or bipolar disorder who experience a gap in VHA services lasting a year or more, and provides outreach in an effort to bring them back into VHA care.

The number of people receiving care for bipolar disorder increased steadily between 1999 and 2016. The data also reflects a decrease in the prevalence of patients diagnosed with schizophrenia. Changes from 2015 to 2016 may be related to the transition from ICD-9 to ICD-10 diagnosis coding.

From 1999 through 2016, the percentage of VHA patients receiving inpatient psychiatric care has decreased, whereas receipt of non-psychiatric inpatient care has been relatively stable. For people with SMI, the decrease may be associated with changes in treatment practices and the success of outpatient programs such as the Mental Health Intensive Case Management Program, VHA's version of assertive community treatment. Data related to outpatient utilization for people with SMI shows more encounters in non-mental health clinic settings than in mental health settings.



The VA has conducted comprehensive suicide monitoring and analysis. Among those who received VHA care since 1999, suicide rates through 2006 were elevated, with the highest rates among those with bipolar disorder, but the rates have declined somewhat since then. Among VHA patients from 2001 through 2014, suicide rates have stayed high among people with bipolar disorder, despite VA efforts such as the Mental Health Enhancement Initiative and the development of suicide prevention coordinators on the crisis line. However, suicide rates have decreased somewhat for VHA users with schizophrenia, and overall among people with mental or substance use disorders. Suicide risks are particularly high after inpatient discharges, especially among people with depressive disorder, followed by bipolar disorder and schizophrenia.

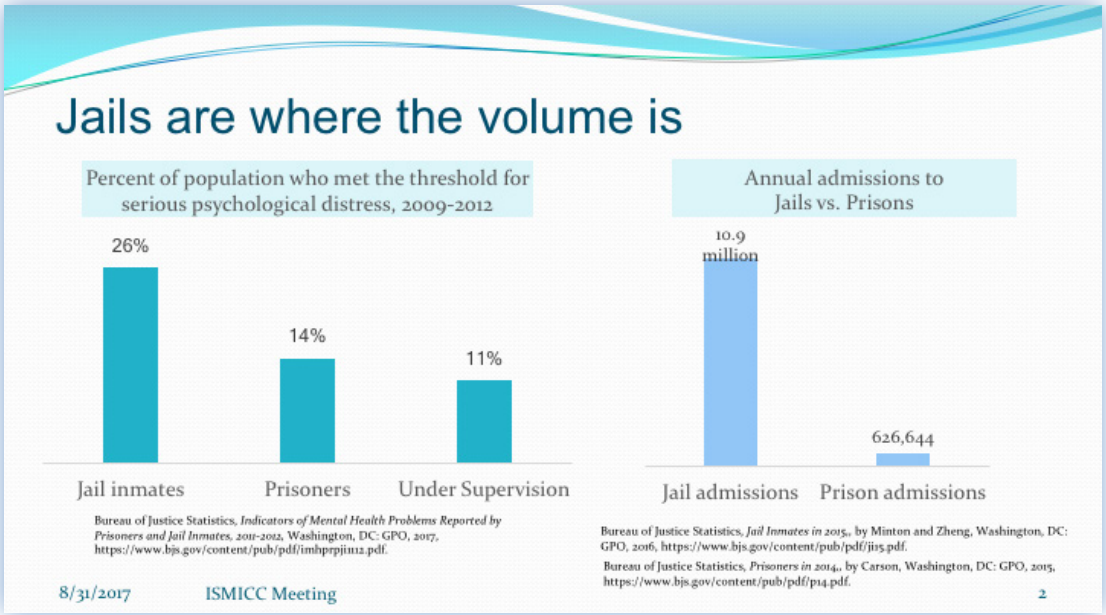
Suicide prevention for people with SMI is an important priority. REACH VET (Recovery Engagement And Coordination for Health—Veterans Enhanced Treatment) uses a suicide predictive model based on information in the VA's electronic health record system to identify and engage veterans at high risk for suicide, particularly among those with SMI. Strategic partnerships—such as the one between the Veterans Administration, CMS, SAMHSA, and the Administration for Community Living—are critical given the substantial numbers of veterans who die of suicide and who are not recent users of VHA care or otherwise connected with the VA.

Department of Justice: Support of Advances to Address Challenges of SMI and SED

Ruby Qazilbash, Associate Deputy Director, Bureau of Justice Assistance (BJA), Department of Justice

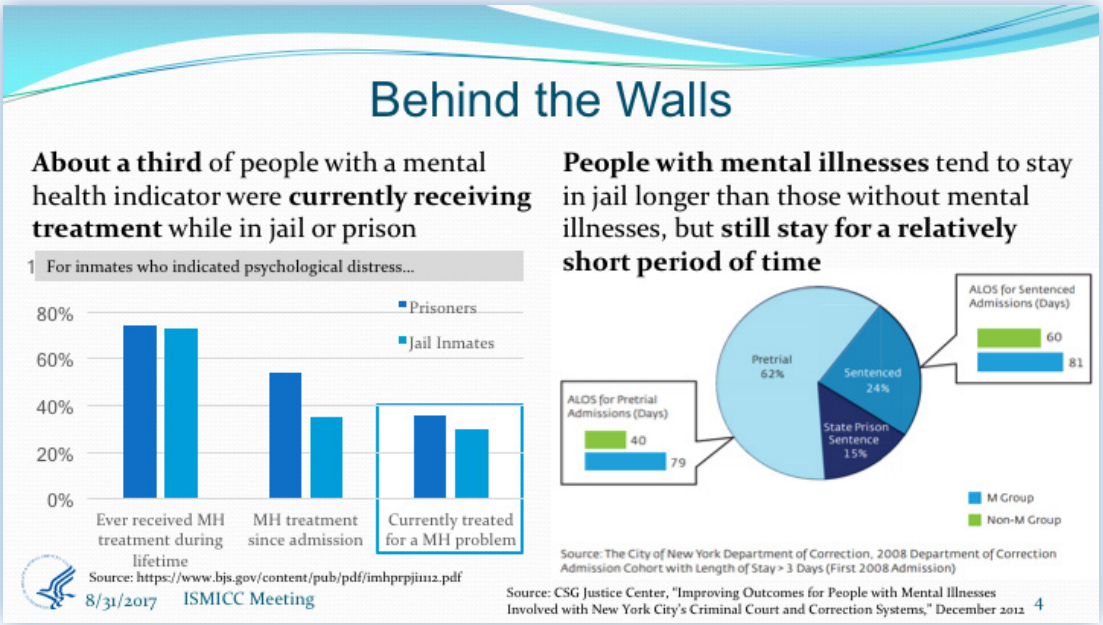
With close to 11 million people being processed through jails each year, compared with approximately 625,000 being admitted into the nation's prisons, jails house the majority of the inmate population with SMI. BJA policy focuses on helping local jails use validated screening instruments consistently in order to understand and reduce SMI prevalence rates within a

jurisdiction's jail, and to connect people who are cycling in and out of jails to services within the community.

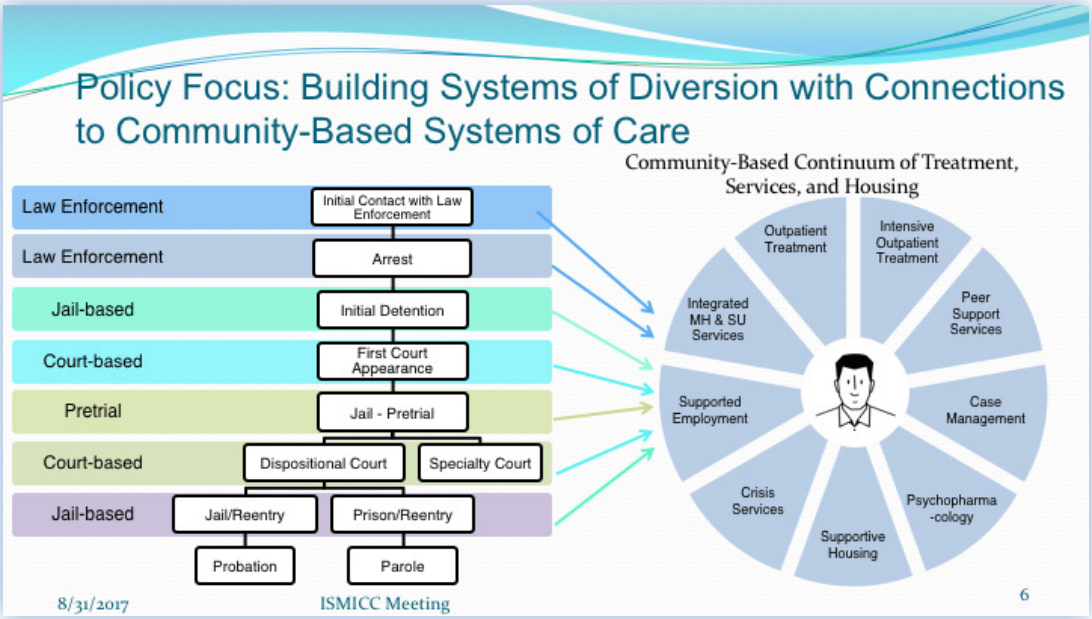


Law enforcement agencies and officers have become first responders for people in mental health crises, as well as for their family members. The volume of calls to law enforcement involving people with SMI appears to be increasing, with one Florida report indicating that 1 in 10 calls is mental health-related. Similarly, law enforcement agencies in Deschutes County, Oregon, have reported sharp increases in recent years in mental health-related service calls. Generally, service calls involving mental health issues take much longer to resolve than other calls. These individual communities reflect the state of systems across the nation.

Bureau of Justice Statistics surveys show that approximately one-third of inmates with a mental health indicator are receiving treatment, and local studies supported by BJA show that people with mental illnesses stay longer in jail. Research shows that providing connections to community-based services, particularly case management services, increases length of time in the community following release. Yet only a fraction of people—at the point of court, jail diversion, or reentry from the jail or prison back into the community—are getting connected to that care. For example, in the Franklin County, Ohio, jail population, out of 10,523 bookings into the jail, 969 people were flagged with an SMI, and of those, only 609 received follow-up treatment in the community. According to the national estimates previously mentioned, as many as 1,700 people with SMI in that county were not connected to community treatment but likely needed it. Of those not connected to services, estimates suggest that more than half are at moderate to high risk for reoffending.



In 2012, BJA and the Council of State Governments Justice Center released a shared framework for reducing recidivism and promoting recovery for adults with behavioral health needs who are under correctional supervision. The framework reflects a consensus with SAMHSA, the National Institute of Corrections, and major associations representing state directors of corrections, probations and parole, substance use services, and mental health services. The outcome was that there is a need for risk and needs assessments for people under correctional control who have behavioral health needs. People with low criminogenic risk need to be connected to community services and medical care. People with moderate to high criminogenic risk need intensive supervision with a combination of supports. The shared framework is part of the Justice and Mental Health Collaboration Program funded by the Bureau of Justice Assistance, which is adding 55 new grantees in 2017 to help communities apply the framework and allocate resources appropriately.



The Stepping Up Initiative focuses on reducing the prevalence of people with SMI in jails. Stepping Up works to increase community efforts to support law enforcement and create effective systems and processes that connect people with SMI to services in the community. To date, at least 384 county boards (representing 115 million people) have passed resolutions committing to the Stepping Up Initiative. The initiative's "Six Questions" ask counties to answer key questions and track four measures: (1) the percent of people within the jail population who have an SMI (which necessitates screening and assessment), (2) the average length of stay in jail for people with SMI as compared to the general jail population, (3) the rate of connection to care upon release, and (4) the recidivism rate for this population, compared to a general release cohort.

The Police and Mental Health Collaboration Toolkit launched by BJA provides information about how to build a police and mental health collaboration, provide training, track data and outcome measures, and evaluate progress. The toolkit features six learning sites, their policies, and memoranda of understanding. The sites accept site visits and are on call to help other jurisdictions. A 2017 Congressional appropriation for a National Training and Technical Assistance Center to Improve Law Enforcement Responses to People with Mental Illness and Intellectual and Developmental Disabilities will operationalize more supports to law enforcement agencies.

Non-Federal Stakeholder Presentations

Challenges and Opportunities in Improving Children's Mental Health Care

Lynda Gargan, Executive Director, National Federation of Families for Children's Mental Health

Prevalence data show that approximately 20 percent of children under age 18 (approximately 7.5 million) will have a significant mental health issue sometime in life.

Dr. Gargan emphasized that stigma associated with mental illness is real. She compared the rally around families whose children developed catastrophic medical illnesses with the silence and prejudice surrounding mental illness. To help our children, there is a need to reject stigma, identify children's behavioral health as a public health crisis, and support a system that will help our teachers teach. Children are not little adults, so data cannot be extrapolated from what works for adults, and then applied to children. She noted the example of medications that are dispensed without longitudinal data or Food and Drug Administration indications for children. Prescriptions should not be the first line of response. Culturally responsive supports are needed.

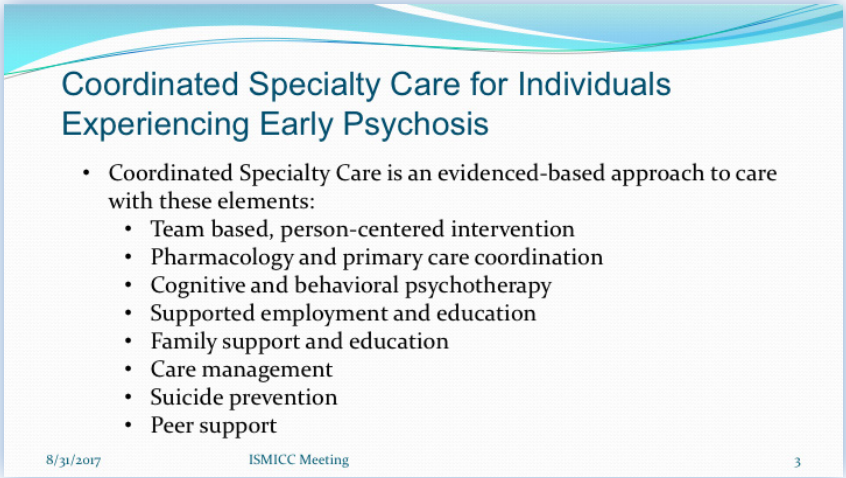
Peer support services constitute a valuable tool in supporting families. For families, a peer is a person who possesses the lived experience of having parented a child who experiences mental/behavioral health challenges. Because families trust families, peers offer guidance and support that cannot be matched by professionals. Peers act as cultural translators, navigators, and advocates for families.

Key Advances in the Clinical Care of People With SMI and SED

Lisa Dixon, Professor of Psychiatry, Columbia University Medical Center; Director, Division of Behavioral Health Services and Policy Research

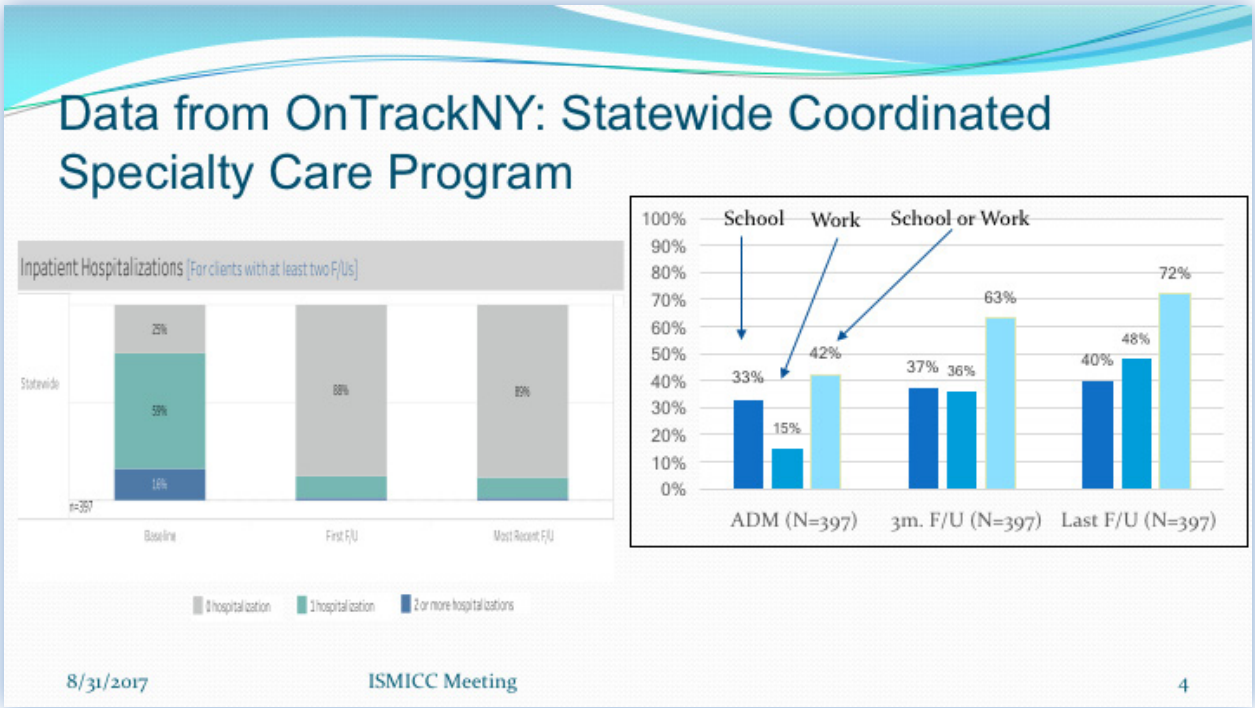
Dr. Dixon emphasized the need for partnerships of the federal, state, local, and private sectors to achieve progress. This effort requires ongoing attention to engagement and a continuum of integrated care that includes evidence-based pharmacologic treatment, recovery support and a person-centered approach.

She reported on a recent example of an advance in the treatment of people with first-episode psychosis. Research shows improved outcomes in people with a shorter duration psychosis compared to those with a longer period of not being in treatment. Emerging evidence supports coordinated specialty care (CSC), a package of interventions delivered by a team of providers and focused on transition-age youth with early psychosis. Based on the positive outcomes associated with CSC, Congress has asked states to set aside funds to provide CSC services through the SAMHSA-administered Mental Health Block Grant program. In many states, state and local government provide additional support to further the development of this evidence-based intervention.



The Mental Health Block Grant and the contributions of states and localities have promoted advances from research to practice. For example, providers in New York State have enrolled over 800 young adults across 20 sites. This has led to dramatic reductions in hospitalization.

Upon entry into the New York program, only about 40 percent of youth worked or were in school. This rate increased to 72 percent at the last or most recent follow-up. Studies show that most youth and adults want to work or go to school, and see that as an essential part of recovery. A no-exclusion, integrated approach to evidence-based supported employment, with the goal of competitive employment, has consistently been demonstrated as more effective than traditional vocational rehabilitation and other rehabilitative approaches.



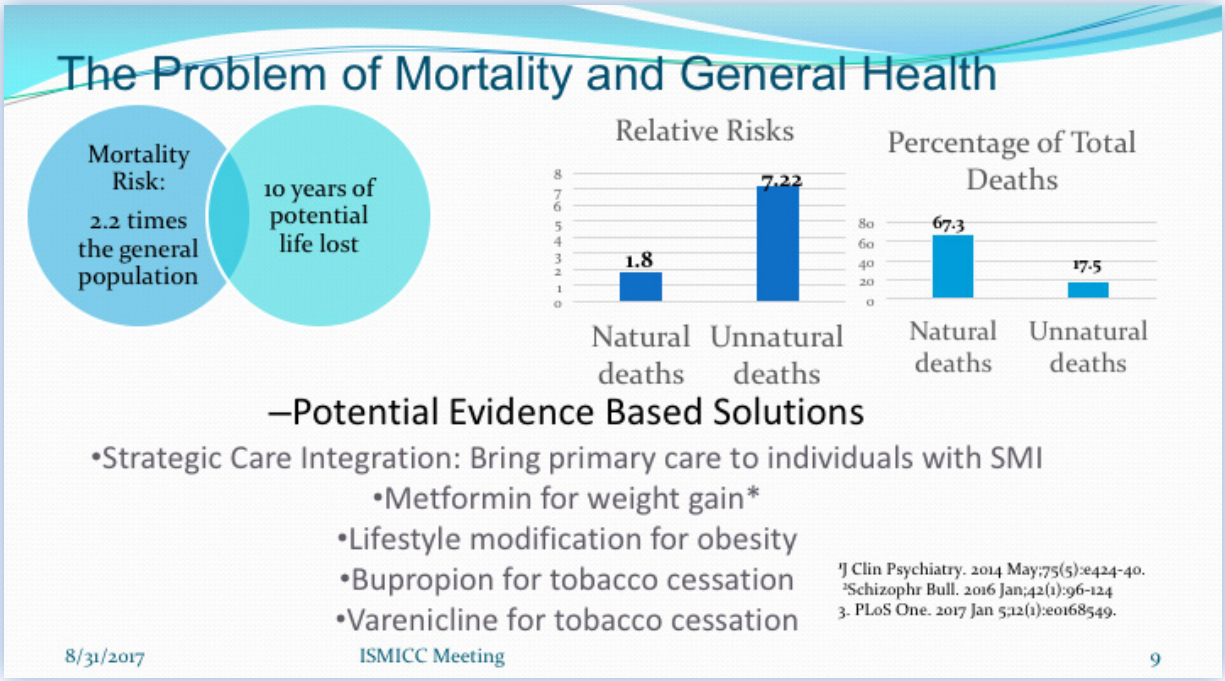
Early psychosis treatment is critical, as is peer support. Peer support has an emerging evidence base demonstrating reduced use of acute services, decreased substance abuse, and increased engagement.

Approximately 5-20 percent of people with SMI die by suicide. The highest risk follows discharge from an emergency department or inpatient hospitalization. Effective strategies that reduce risk during the post-discharge period include:

- Systematized safety planning prior to discharge,
- Follow-up outreach (phone, text, home visits), and
- Suicide-specific psychotherapies (e.g., cognitive therapy for suicide prevention, dialectical behavior therapy).

Knowledge about detecting and treating suicidality (i.e., selective prevention) is not routinely employed in health care systems.

Data show that people with SMI die roughly 10 years earlier than their age-matched counterparts who do not have SMI. Strategic care integration, attention to health behaviors, and high-quality services is needed to address this issue.



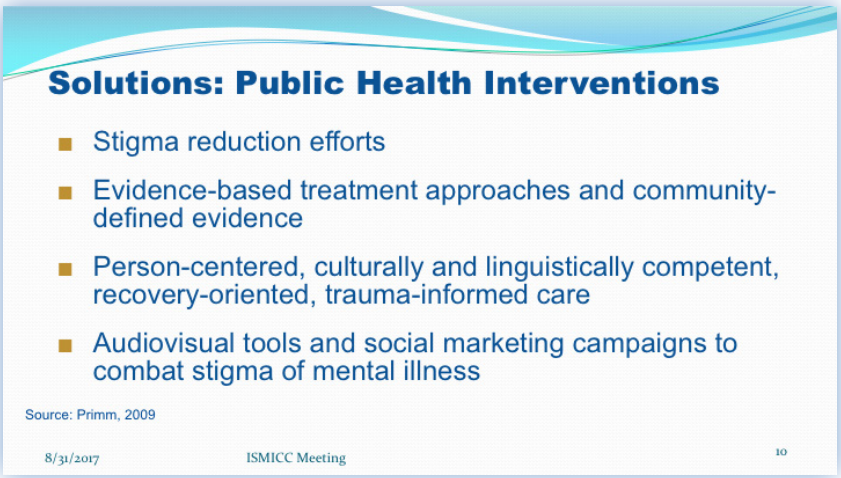
Disparities and Closing the Treatment Gap

Sergio Aguilar-Gaxiola, Professor of Clinical Internal Medicine, University of California, Davis; Director, Center for Reducing Health Disparities; Director, Community Engagement Program, Clinical and Translational Science Center

Dr. Aguilar-Gaxiola focused on the difficulty of people accessing care—the treatment gap—especially for traditionally underserved populations. National data on the treatment gap reveals that 50 to 90 percent of those in need of mental health treatment are not receiving services.

There is a need to work with community-based organizations to capture the effectiveness of practices and programs used for diverse populations. An initiative in California called the Mental Health Services Act generated over $2 billion for services last year, especially for those experiencing disparities. Other examples include the statewide stigma reduction campaign called Each Mind Matters that includes materials tailored to specific ethnic groups, and the California Reducing Disparities Project focused on reducing stigma and discrimination.

Engaging people with SMI and SED and their families in the treatment process is key. Engagement is an iterative process in which clinicians and investigators reach out to the client and his/her family and continually evaluate their efforts. Incorporating the family in a culturally appropriate fashion within routine clinical settings improves access to treatment, client participation in care, integration of care, and ultimately, clinical outcomes for populations with SMI and SED. Public health interventions should include audiovisual tools and social marketing campaigns to reduce stigma, promote evidence-based treatment approaches, and disseminate community-defined evidence. Public health messaging should be inclusive and respectful of diversity.

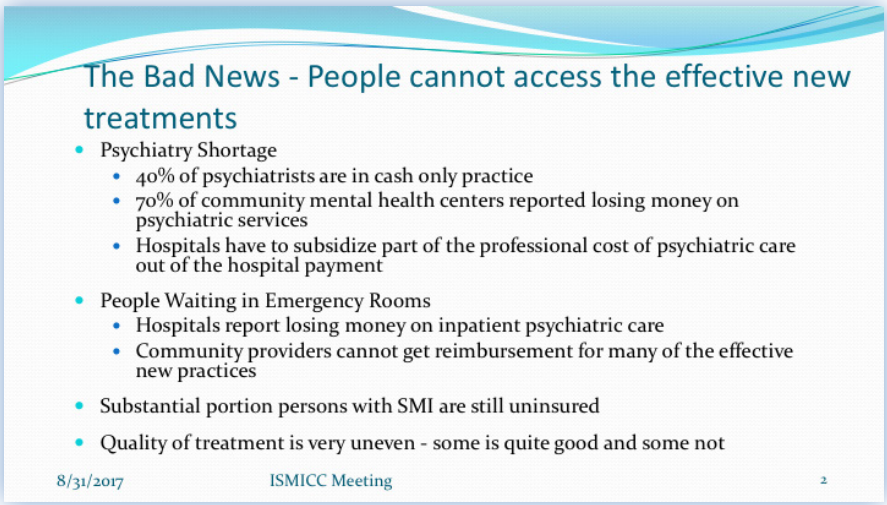


The Challenges and Opportunities for Improving the System That Supports the Care of People With SMI and SED

Joseph Parks, Medical Director, National Council for Behavioral Health

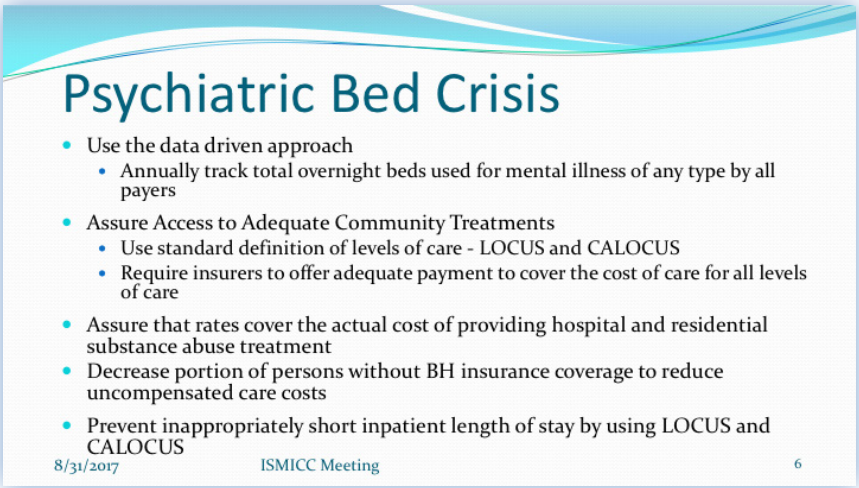
Dr. Parks indicated that many effective services are available for people with SMI. Peer support and population health management services are especially important.

The bad news is that most people with SMI have approximately three or four behavioral health disorders and three or four physical health disorders. They often have deficits in memory, concentration, executive functioning, and ability to organize information. Yet they are expected to figure out what they need and when they need it.



Dr. Parks noted that there are many effective treatments for addressing the needs of people with SMI. Yet there are not enough psychiatrists to treat people. Additionally, there is a lack of resources to address the needs of people with SMI and SED in crisis. Generally, the availability and quality of treatment and services vary by state and community. A substantial number of people with SMI are uninsured.

The psychiatry shortage is particularly severe. Reports indicate a shortage of available psychiatric treatment, with hospitals closing beds or not providing care due to financial loss.



Community providers also report that they are unable to obtain reimbursement for new practices that are not reflected in Current Procedural Terminology (CPT) coding and available billing streams. The payments for behavioral health services need to be actuarially sound—meaning that the amount of the payment is sufficient to cover the actual cost of what is done, plus a reasonable profit. Comparing payment rates in behavioral health to the rates in general medical care to identify possible parity concerns is also critical, as well as assessing the adequacy of provider panels by secret shopper to see if someone actually answers the phone and if appointments are available.

The new Certified Community Behavioral Health Clinic (CCBHC) demonstration program may provide strategies for addressing these issues. The CCBHC program covers the full range of evidence-based services, but it remains a demonstration program operating in only eight states and limited to just two years.

What Is a Certified Community Behavioral Health Clinic?

Section 223 of the Protecting Access to Medicare Act (PAMA) creates and evaluates a 2-year demonstration program for states to certify community behavioral health clinics. Certified clinics must meet specific criteria emphasizing high-quality care and integration across community services to address the holistic needs of people with SMI and SED, and others. Learn more about the CCBHC program at https://www.samhsa.gov/section-223.

Dr. Parks discussed the importance of level of care assessment instruments that include scores for social determinants. These instruments may help address the bed crisis by reflecting appropriate lengths of stay. For example, after Missouri required the use of LOCUS (Level of Care Utilization System) and CALOCUS (Child and Adolescent Level of Care Utilization System), which assess housing and other social determinants, insurers enhanced coverage for evidence-based services.

Finally, Dr. Parks outlined technical ways to address psychiatric service shortages, such as revising the Conrad 30 Waiver Program, which allows medical doctors to apply for a waiver for the 2-year residence requirement upon completion of the J-1 exchange visitor program, so waivers provided to psychiatrists do not count toward the ceiling of 30 slots; revising the Group on Educational Affairs (Association of American Medical Colleges) graduate medical education calculation for supporting psychiatry residents to be the same as for obstetrician- gynecologists or primary care physicians; revising redistribution requirements for unused Medicare direct graduate medical education training slots so the psychiatry slots cannot be reduced; and removing regulatory barriers to telepsychiatry. Dr. Parks noted that success will largely be a question of willingness to exert executive powers in areas such as payments rates and performance measurement.

Areas to Be Explored by the ISMICC

The federal and expert presentations described above provide an important overview of key areas of opportunity and innovation for application on the federal level and in the broader behavioral health field. Table 2.1 summarizes other areas that the ISMICC will consider in the future.

Table 2.1. Areas for the ISMICC to Explore During Future Meetings

Focus Area	Advances, Including Evidence-Based and Promising Practices
Diagnosis	• Deep phenotyping/biomarkers to provide indicators for predicting genetic risk, along with understanding of environmental/developmental factors • Neuroimaging/neuropsychological measures to allow for the development of predictive tools for charting illness progression • Implementation of American Psychiatric Association practice guidelines • Jail-based Mental Health Screening
Intervention: Adults	• Assertive community treatment • Cognitive behavioral therapy (CBT); trauma-focused CBT • Dialectical behavioral therapy • Cognitive remediation therapy • Social rhythm therapy • Brief interpersonal therapy • Problem-solving therapy • Dialogic therapy • Coordinated specialty care for adults with first-episode psychosis • National Association of State Mental Health Program Directors, core strategies for reduction of restraint and seclusion
Intervention: Children and Youth	• High-fidelity wraparound • CBT; trauma-focused CBT • Interpersonal therapy for adolescents with depression • Coordinated specialty care for youth with first-episode psychosis • Exposure and response prevention for obsessive-compulsive disorder • Trauma-informed and trauma-specific services, including Promising Path to Success (New Jersey Division of Children's System of Care) • Multisystemic therapy • Behavioral classroom management; • Behavioral parent training • Intensive behavioral peer intervention for attention deficit hyperactivity disorder • Family-based treatments
Intervention: Criminal Justice	• Jail diversion • Mental health courts • Drug courts • Civil commitment laws, including compulsory treatment • Crisis intervention team training • Forensic assertive community treatment • Cognitive behavioral therapy, cognitive skills training (Reasoning and Rehabilitation Program) • Re-entry programs with navigational assistance and links to community health • Trauma-informed officers • Sequential intercept model • Strategies and approaches included in the Stepping Up Initiative
Treatment and Recovery	• Findings from CATIE (NIMH-funded Clinical Antipsychotic Trials of Intervention Effectiveness); STAR*D (NIMH-funded Sequenced Treatment Alternatives to Relieve Depression); PORT (Schizophrenia Patient Outcomes Research Team) • Veterans Administration Uniform Mental Health Standards • Medication treatment and management • Medication optimization • Medication development • Exploration of levels of care and their place in the treatment of SMI

Table 2.1. Areas for the ISMICC to Explore During Future Meetings (continued)

Focus Area	Advances, Including Evidence-Based and Promising Practices
Treatment and Recovery (continued)	• Exploration of need for inpatient beds in different settings • Telemedicine • Use of mobile applications and social media • American Diabetes Association and American Psychiatric Association consensus report on antipsychotic drugs and obesity and diabetes • Georgia model of crisis call center engagement and support • Family psychoeducation; family consultation; caregiver respite • Shared decision-making; supported decision-making; therapeutic alliance; advance directives • Assisted outpatient treatment • Wellness coaching to address co-occurring disorders • Peer-led engagement; peer groups; programs such as Hearing Voices Network • Complementary approaches (e.g., mindfulness, diet, exercise) • Supportive housing • Supported employment • Supported education • Housing first
Access to Services and Supports	• System of care approach for children's behavioral health • Comprehensive coordinated care; integration approaches • Standards included in the Certified Community Behavioral Health Clinic demonstration • Specialized services and cultural competence training to address disparities among underserved groups such as people of color, and lesbian, gay, bisexual and transgender individuals • Health navigator programs such as the Peer Bridger Program and other family- and youth-led programs • Findings from Meadows Mental Health Policy Institute continuum of crisis services, and related adult and child crisis stabilization services • Arizona model for connecting law enforcement to facility-based crisis stabilization • Use of secret shopper surveys to assess network adequacy • Level of care instruments such as LOCUS and CALOCUS

Additionally, advances in our understanding of genetic, environmental, and developmental factors across the lifespan hold great promise for earlier diagnosis of SMI and SED. Research on early intervention and treatment demonstrates the potential to improve the course of the illnesses.

There have not been many significant recent advances in the biologic treatment of people with SMI. Decades of experience with second-generation antipsychotic medications have yielded medications with much better tolerability, but little improvement in effectiveness. Even though this class of medications often avoids the more debilitating side effects of older antipsychotic medications (such as sedation, movement disorders, and cardiac conduction abnormalities), the newer medications have more silent side effects such as blood glucose elevation, blood lipid elevation, and obesity. One of the second-generation antipsychotic agents, clozapine, continues to stand out as potentially effective in individuals who have not responded to other medications. However, this medication is underutilized in the United States. SAMHSA has engaged in several recent projects to develop interventions to highlight underutilization of clozapine.

Recent advances in drug development have included a focus on delivery mechanisms, so that more agents are available in long-acting injection forms that can be administered monthly, or even once every three months (for at least one product). Lithium and clozapine can reduce the intensity of suicidal ideation in people with SMI, and other medicines such as antidepressants, mood stabilizers, and anxiety medications are often used to augment the effects of antipsychotics. We remain hopeful that advances in understanding the biologic underpinnings of psychosis and other elements of SMI symptomology will result in new opportunities to develop better pharmacotherapeutic interventions.

Many people have concurrent issues that are not adequately addressed, including physical health issues, intellectual or developmental disabilities, substance use, trauma, homelessness, justice involvement, and other challenges. Many of the evidence-based practices include a team approach that recognizes the importance of interdisciplinary and cross-sector support, as well as client and family involvement. The ISMICC will continue to explore and capture the broad range of effective treatments and services to meet the needs of people with SMI and SED across the lifespan. The ISMICC will also work to understand and define the resources needed to effectively serve Americans living with SMI and SED and their families and caregivers.

Chapter 3: Setting the Stage for Evaluation of Federal Programs Related to SMI and SED

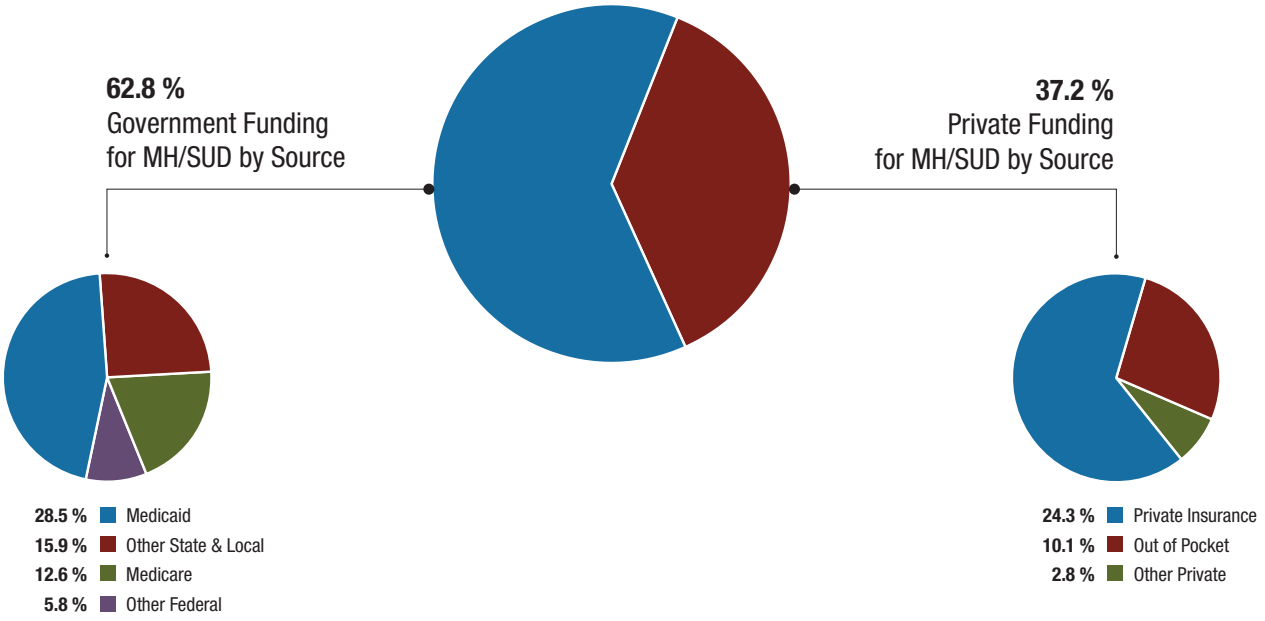
The central charge of the ISMICC is to improve the lives of Americans with serious mental illnesses (SMI) and serious emotional disturbances (SED) and their families. This is to be achieved in part by enhancing coordination across federal departments to improve service access and delivery of care. Working with leaders of the eight departments that serve on the ISMICC, committee members will inform efforts to evaluate the effect that federal policies and programs related to SMI and SED have on public health outcomes. The ISMICC will develop specific recommendations for actions that federal departments can take to better coordinate the administration of mental health services for adults with SMI and children and youth with SED.

Those efforts begin now. Over the next five years, the ISMICC will work in collaboration with federal interdepartmental leadership to build shared accountability for a system that provides the full range of treatments and supports needed by individuals and families living with SMI and SED.

This will be a challenging undertaking. ISMICC members recognize that it will require partnerships with all levels of government and a diverse array of other stakeholders. Mental health care and treatment is not solely a federal responsibility, but rather one shared across federal, state, tribal, and local governments; private insurers; diverse provider organizations; advocates; caregivers; families; and people with SMI and SED. Figure 3.1 illustrates this point by showing the complexity of funding for treatment of mental health and substance use disorders in the United States.

In the course of their deliberations, ISMICC members have emphasized that this review of federal initiatives must rise above the level of simply looking at individual programs. The ISMICC vision calls for federal interdepartmental leadership in collaboration with others to build responsive and effective systems of care that meet the needs of people with SMI and SED and their families. Members have stressed the importance of focusing not only on prevention and treatment, but also on key social determinants of health such as housing, employment, education, and transportation.

Figure 3.1. Government and Private Funding Sources for Mental Health (MH) and Substance Use Disorder (SUD) Treatment



Source: Mark, T. L., Levit, K. R., Yee, T., & Chow, C. M. (2014). Spending on mental and substance use disorders projected to grow more slowly than all health spending through 2020. Health Affairs, 33(8), 1407-1415.

Each of the eight departments represented on the ISMICC supports programs that address the needs of people with SMI and SED. Programs differ according to each department's mission, its population of focus, its authorizing legislation and level of funding, and the performance metrics through which it is held accountable to Congress and its constituents. For example, the Department of Veterans Affairs serves veterans and the Department of Defense (DoD) serves active duty military and their families, while the Department of Health and Human Services (HHS) has public health agencies such as the Substance Abuse and Mental Health Services Administration (SAMHSA) and the Centers for Medicare & Medicaid Services that have components related to the health of the nation at large.

Five other agencies represented on the ISMICC—Housing and Urban Development (HUD), Education, Labor, Justice, and Social Security—have missions that are highly relevant to the target population, but are more broadly focused and tied to their mission and authorizing legislation. The same is true for other components of the HHS that are not specifically represented on the ISMICC, such as the Administration for Children and Families, the Health Resources and Services Administration, and the Indian Health Service. These departments all have programs that contribute in important ways to supporting the delivery of effective prevention, treatment, and recovery support services for people with SMI and SED.

The review of federal initiatives must include the large federal health insurance and disability programs such as Medicare, Medicaid, the Children's Health Insurance Program, and Social Security disability programs that serve a broad and diverse population, including many people with SMI and SED. These insurance and disability programs are of critical importance and serve as a major source of funding for treatment and recovery support services for people with SMI and SED. School-based services in affiliation with the Department of Education play a central role in the lives of children and youth with SED. HUD-funded housing is also critically important. ISMICC members have stressed that it is essential to include these programs in any meaningful analysis of population health outcomes for people with SMI and SED.

The formation of the ISMICC marks the first time in many years that an interdepartmental group has come together to coordinate their efforts related to the broad spectrum of issues that impact people with SMI and SED. It is the first time that such a group has been chaired by an Assistant Secretary for Mental Health and Substance Use. This newly created position brings a new level of authority, experience, and expertise to the coordination of efforts at HHS to address the needs of people with SMI and SED. The Assistant Secretary must work across HHS and the federal government so people with SMI and SED receive the highest possible standard of care—care that is deeply informed by our knowledge of science and medicine.

These eight departments have made a commitment to align their policies, assess their programming, and improve care for people with SMI and SED. Their collaboration will be informed and strengthened by the participation of non-federal ISMICC members, including national experts on health care research, mental health providers, advocates, and people with mental health conditions and their families.

Direct and Indirect Levers of Federal Influence

As the ISMICC undertakes the challenging work of evaluating and recommending ways to strengthen federal policies and programs, a key goal will be to ensure that changes made at the federal level actually lead to better lives for people with SMI and SED throughout the nation. As Figure 3.1 illustrates, there are many contributors to our complex national system for mental health care. All federal sources combined account for almost half of all spending on mental and substance use disorders (46.9 percent; Mark, Levit, Yee & Chow, 2014). It is important to note that the data in Figure 3.1 includes little if any of the spending that occurs for housing, disability payments, vocational training, educational services, etc., much of which also reflects a combination of federal, state, tribal, local, and private resources.

The ISMICC process will examine the various approaches that can be used to improve population health for people with SMI and SED, using the broad range of direct and indirect levers of federal influence. The goal of this process is to improve collaboration of federal agencies that provide services, such as:

- **Government-operated systems run by the Veterans Health Administration (VHA) and DoD health care facilities.** VHA and DoD have done promising work in areas such as integration of health and behavioral health care, suicide prevention, and ongoing outreach to people with SMI and SED. This work improves the care of active duty service members and veterans and—importantly—serves as a model to be emulated in other systems.

- **Medicare, TRICARE, and the Indian Health Service.** These are examples of programs where the federal government directly reimburses health care providers for services provided to eligible enrollees or works with intermediaries to provide health coverage. These programs are highly influential, not only for the impact on enrollees and their ability to access care, but also because they often serve as a model for private insurers. Making their policies and programs more effective at addressing the needs of people with SMI and SED could have widespread benefits, particularly through the Medicare program because of its great reach.

- **Medicaid and the Children's Health Insurance Program (CHIP).** Medicaid, a federal/state partnership for reimbursement of services, is the largest payer for behavioral health services, and frequently offers the most comprehensive array of services relevant to people with SMI and SED. Because Medicaid is jointly operated by the federal and state governments, the configuration of reimbursable services and methods of payment for services can vary substantially from one state to the next. The mix of mandated and optional services provides extensive opportunities for the creative exercise of the principles of federalism, and allows each state (and counties in some states) to tailor its service system. An example of this is the Medicaid Health Home program, which often serves people with SMI and SED, an optional benefit under Medicaid. States differ widely in the extent to which this flexibility has been used to create a responsive and effective system of services for people with SMI and SED. CHIP, like Medicaid, is a federal/state partnership. CHIP provides low-cost health coverage, including behavioral health services, to uninsured children in families that earn too much to qualify for Medicaid. In some states, CHIP also covers pregnant women. Medicaid and CHIP policy can greatly influence the range and types of services available in communities throughout the nation, but cannot always overcome disparities in local economies and circumstances.

- **Social Security disability programs.** These programs have long played a major role in the lives of adults with SMI and children and youth with SED. One facet of the role of the Social Security Disability Insurance (SSDI) and Supplemental Security Income (SSI) programs is that they provide an entitlement to Medicare or Medicaid eligibility. Another is the direct income support and other services they provide to recipients with SMI and SED. Demonstration programs currently underway are assessing whether enhanced access to supported employment and evidence-based treatment can

enable people with SMI to avoid enrolling in the programs and move to competitive employment instead.

The federal government also provides a diverse mix of other services and functions that influence the lives of people with SMI and SED and their families. A partial list of examples would include:

- **Basic and applied research that helps us better understand the course of a disorder and the means to prevent, cure, or lessen its impact.** This includes the work of the National Institute of Mental Health that aims to unravel the causes and course of SMI and to assess the effectiveness of models such as coordinated specialty care for first-episode psychosis.

- **Surveys and other surveillance programs that provide information on the incidence, prevalence, and distribution of disorders.** SAMHSA, the Agency for Healthcare Research and Quality, and the Centers for Disease Control and Prevention conduct ongoing major national surveys to help us understand patterns and prevalence of a broad range of health and behavioral health disorders, patterns of care, as well as some of the contributing social factors.

- **Demonstrations and evaluations of prevention, treatment, and support models that can improve the lives of people with SMI and SED.** SAMHSA, the Office of the Assistant Secretary for Planning and Evaluation, and the Centers for Medicare & Medicaid Services have collaborated on relevant demonstration programs, such as the Certified Community Behavioral Health Clinic (CCBHC) program that provides alternative payment models and more integrated, comprehensive care for people with SMI and SED. The Center for Medicare and Medicaid Innovation has implemented and is assessing an extensive roster of alternative delivery and payment programs, including many that impact health and behavioral health care for people with SMI and SED.

- **Time-limited grant programs to fund development of promising models at the state, tribal, and local levels.** This widely used tool encourages widespread implementation of promising models through time-limited federal funding. Examples include suicide prevention initiatives, efforts to develop trauma-informed systems, expansion of mental and substance use disorder treatment in federally qualified health centers, and many others. A general concern with this strategy is whether gains achieved are retained over the longer term after the grant funding ends.

- **Longer-term formula-funded programs.** These include block grants and other funding streams that support critical infrastructure and system capacity. They may be used to ensure a focus on specific issues, such as the focus on intervening early for serious mental illness included in the Community Mental Health Services Block Grant.

- **Technical assistance and support.** Many technical assistance centers address a wide variety of topics relevant to people with SMI and SED, and provide education, tools, and supports to aid implementation of effective models at state, tribal, and local levels. For example, SAMHSA and the Departments of Justice, Education, and Labor fund several such programs.

- **Quality measurement and reporting.** These are required for receipt of a wide variety of federal grants, as well as reimbursement funding streams from Medicare, Medicaid, and other insurers. These requirements have the potential to shape service delivery in ways that can improve responsiveness and effectiveness. However, many providers complain about the costs and burden associated with these requirements, while advocates tend to push for additional, more specific measures and reports.

The evaluation of this diverse array of federal policies and programs will be an enormous undertaking. The ISMICC will support coordination across the participating departments and agencies to advance evaluation of the federal system of services and supports for people with SMI and SED. Examining these policies and programs, and the ways in which they can serve as beneficial influences on practices at the community level, will be a major focus of the committee in the years ahead.

The ISMICC Role in Evaluating Federal Programs and Enhancing Coordination to Improve Outcomes

The ISMICC is newly formed and this evaluation will require an extended process. Since the first ISMICC meeting, we have begun to collect information about federal programs serving people with SMI and SED in order to inform the development of this evaluation.

The ISMICC proposes to examine the information obtained from the request to federal members, and from a Government Accountability Office (GAO) report that was released in 2014 and based on data from 2013, Mental Health: HHS Leadership Needed to Coordinate Federal Efforts Related to Serious Mental Illness, as a first step in developing a high-level perspective on the array of federally supported services.

A deeper examination of this broad array of federal programs should attempt to answer common evaluation questions such as the following:

1. **How effective are federal policies and programs in addressing the needs of people with SMI and SED?** Consider and examine the full spectrum of services and supports necessary to make possible an acceptable quality of life for people with SMI and SED and their families. Are there important gaps—areas that are not being addressed at all, or not being adequately addressed? What areas could benefit from new, innovative approaches to meet the needs across the full range of health,

behavioral health, education, employment, income supports, housing, or other areas?

2. **How effectively are federal departments collaborating and coordinating policies and programs to enhance the quality of life for people with SMI and SED?** In addition to the ISMICC, what structures are in place to develop and sustain coordination on an ongoing basis? What accountability measures exist or are needed to ensure that efforts to improve policy and programmatic coordination are achieving desired public health outcomes?

3. **Do current policies and programs have sufficient reach to serve all of the people with SMI and SED who could benefit?** A concern is that programs may be designed, accidentally or intentionally, to restrict the number of people who can participate and consequently exclude vulnerable populations or those with limited access such as people in rural areas. This may occur inadvertently through the construction of program eligibility criteria that fail to acknowledge all relevant circumstances. It also may occur simply as the result of inadequate funding—a universally important consideration that may be difficult to address. What can be done to expand the reach of policies and programs to all of those who are in need?

4. **Are there important gaps in knowledge or information that make it difficult to assess the extent to which we are achieving goals related to public health outcomes for people with SMI and SED?** Given the context of our complex system in which federal, state, tribal, local, and private players hold important roles, there are many important concerns about which information is not yet readily available to assess key issues or progress in resolving problems. What can be done to improve access to public health indicators in such areas? For example, the need to involve the criminal justice system is widely viewed as a sign of failure of community treatment systems, yet we have no way to obtain comprehensive information on such incidents. In other cases, programs that serve people with SMI and SED do not collect information that allows identification of that segment of program participants.

5. **How effectively do policies and programs meet the needs of the people they serve or impact?** As currently constructed and operated, do they advance the goal of improving care and quality of life for people with SMI and SED? Do they incorporate adaptations to cultural, linguistic, and local circumstances? Do they address health disparities and vulnerable populations in the areas served? Has the effectiveness of the

program been evaluated, or are there plans to evaluate it? Has the program undergone improvements in response to evaluation recommendations? Does current program design align with the nature of SMI and SED? For example, do disability programs create incentives to work and provide the necessary support for people with episodic or cyclical illnesses?

6. **Does the policy or program reflect the state of the science and our knowledge about what has been shown to improve outcomes for people with SMI and SED?** A good deal is known about practices and models of care that have a track record of success in meeting the needs of people with SMI and SED. Are policies and programs being implemented in a manner consistent with those models, with appropriate adaptation to cultural, linguistic, and local circumstances?

7. **Does the policy or program apply the principles of population health management in its operations?** Is there an approach to monitoring the proportion of those who could benefit from services who are receiving them? Does it take active steps to increase the reach of the program and participation in the program? Are registries used as a tool to maintain contact with participants, monitor their progress, and ensure that they receive needed services? Are there active, meaningful quality assurance initiatives so that operations and outcomes can be improved over time?

8. **For direct treatment programs, does the program apply the principles of measurement-based care?** Is the program using validated rating scales appropriate to the population served to track progress over time, and to adapt the intervention in a person-centered manner if the person is not progressing?

9. **Are there areas where clearer guidance for regions or states implementing jointly funded programs could improve access and outcomes?** For example, could there be better guidance related to termination of Medicaid or disability benefits upon institutionalization or incarceration, and reinstatement of benefits upon release?

10. **Are there areas in which data collection could be harmonized across departments to improve our knowledge of changes in key outcome measures?** Many program measures are set through regulation or law and may be difficult to change, but others could be changed administratively to allow better comparisons across departments and programs. This could facilitate the collection of data relevant to tracking progress on public health outcomes relevant to the SMI and SED populations.

11. **Could existing large-scale federal data collection efforts be better used to provide information about population health outcomes relevant to the SMI and SED populations?** Could reasonable and affordable changes to these data collection efforts be feasible and beneficial? Several federal databases are relevant to people with SMI and SED and could provide information about gaps to address, such as Medicaid and Medicare claims data, electronic health record data from the VHA, and data from surveys such as the National Survey on Drug Use and Health and the Medical Expenditure Panel Survey. Is it feasible to use these data to monitor the effectiveness of efforts to improve the care and quality of life for SMI and SED populations over time?

It will be critical to identify gaps that occur either through the absence of essential policies or programs, or through programs that fail to reach all of those in need. The 21st Century Cures Act created new programs and initiatives to address the needs of people with SMI and SED. If Congress provides funding to implement or continue these programs, the ISMICC can examine them to assess what is working and where additional improvements are called for.

This work will require a level of commitment from the departments that participate in the ISMICC process, and will benefit from the expertise and guidance of the full membership. A key concern will be how to ensure that improvements developed at the federal level are implemented comprehensively throughout the states, tribes, and localities across the nation. Given the complex and multilayered federal, state, and local funding streams that support services needed by the SMI and SED populations, careful attention to principles of implementation science will be very important.

What Is Known to Date About Federal Programs

Table 3.1 is a listing of programs in each of the eight departments that serve on the ISMICC, compiled by committee staff. This list includes programs that focus on SMI and SED, as well as programs that serve a broader population but provide services that are important to people with SMI and SED. An initial call has gone to all the departments for basic information about these programs, and that data collection process is ongoing.

Another source of basic descriptive information for many of these programs is available from the 2014 GAO report cited above.

In the months ahead, the ISMICC will, with staff support, continue existing data collection efforts and begin the process of a broader evaluation of federal policies and programs, and their impact nationally.

Table 3.1. Federal Programs Related to SMI and SED Programs That Can Support People With SMI and SED

Department of Defense
• Army Behavioral Health Residential Treatment Facilities
• Direct Care (DC) System Mental Health Services
• In-Transition
• Overcoming Adversity and Stress Injury Support (OASIS)
• Naval Hospital Jacksonville, Substance Abuse Rehabilitation Program (SARP)
• TRICARE

Department of Education
• Early Intervention Program for Infants and Toddlers with Disabilities (Part C of Individuals with Disabilities Education Act (IDEA)
• Elementary and Secondary School Counseling Program
• IDEA Parent Information
• IDEA Technical Assistance and Dissemination
• Project SERV (School Emergency Response to Violence)
• School Climate Transformation Grants
• Services for School Aged Children: (Part B of IDEA)
• Special Education – Personnel Development to Improve Services and Results for Children with Disabilities
• State Supported Employment Program
• State Vocational Rehabilitation Services Program
• Student Support and Academic Enrichment Formula Grant
• Vocational Rehabilitation Services

Table 3.1. Federal Programs Related to SMI and SED Programs That Can Support People With SMI and SED (continued)

Department of Health and Human Services
Administration for Children and Families
• National Center on Domestic Violence, Trauma, and Mental Health
• Temporary Assistance for Needy Families
• Title IV-E Foster Care
Administration for Community Living
• Advanced Research Training Program in Employment and Vocational Rehabilitation of Persons with Psychiatric Disabilities
• Aging and Disability Resource Centers
• Creating a Multidimensional Model of Engagement for Young Adult with Psychiatric Disabilities in Adult System Team-Based Community Outreach and Support Services
• Customized Employment for Individuals with Serious Psychiatric Disabilities
• Development Center to Enhance Evidence-Based Supportive Employment with a Technology-Based Management System
• Empowering Parents: National Research Center for Parents with Disabilities and their Families
• Enhancing the Community Living and Participation of Individuals with Psychiatric Disabilities
• Evaluating the Impact of Employment Services in Supportive Housing
• Identifying Enabling Environments Affecting Adults with Psychiatric Disabilities
• Increasing Community Participation Among Adults with Psychiatric Disabilities Through Intentional Peer Support
• Increasing Community Participation in Adults with Schizophrenia
• Integrated Program to Improve Competitive Employment in Dually Diagnosed Clients
• Integrated Scaling Approach: A Model for Large Scale Implementation of Effective Interventions for Employment.
• Manual and Training Program to Promote Career Development Among Transition Age Youth and Young Adults with Psychiatric Conditions
• Recovery 4 US – Development of a Photovoice-Based Social Media Program to Enhance the Community Participation and Recovery of Individuals with Psychiatric Disabilities
• Rehabilitation Research and Training Center on Improving Employment Outcomes for Individuals with Psychiatric Disabilities
• Rehabilitation Research and Training Center on Self-Directed Recovery and Integrated Health Care
• Research and Training Center for Pathways to Positive Futures: Building Self-Determination and Community Living and Participation
• Temple University Rehabilitation Research and Training Center on Community Living and Participation of Individuals with Psychiatric Disabilities
• TEST – Translating Evidence to Support Transitions: Improving Outcomes of Youth in Transition with Psychiatric Disabilities by Use and Adoption of Best Practice Transition Planning
• The Learning and Working During the Transition to Adulthood Rehabilitation Research and Training Center
• Weight Management and Wellness for People with Psychiatric Disabilities
• Workers with Psychiatric Disabilities and Self-Employment Through Microenterprise
• WorkingWell: Developing a Mobile Employment Support Tool for Individuals with Psychiatric Disabilities

Table 3.1. Federal Programs Related to SMI and SED Programs That Can Support People With SMI and SED (continued)

Department of Health and Human Services (continued)
Agency for Healthcare Research and Quality
• Academy for Integrating Behavioral Health and Primary Care
Assistant Secretary for Preparedness and Response
• Ensuring that the needs of people with SMI are integrated into broader public health preparedness, response, and recovery practices
Centers for Disease Control and Prevention
• LET'S CONNECT
• Senior Connection Research Study
• National Violent Death Reporting System
• Preventive Health and Health Services Block Grant
• Centers for Medicare & Medicaid Services
• Medicare
• Care Management and Coordination Services
• Medicaid
• Selected Programs Focused on SMI
– Certified Community Behavioral Health Clinics
– Guidance on Opportunities for Innovation
– Health Homes
– Medicaid Innovation Accelerator Program – SMI Data Analytic Tool
– Medicaid and CHIP Quality Measurement and Improvement Program
– Study of Medicaid Managed Care Coverage of Treatment in Institutions for Mental Diseases
– Home- and Community-Based Services
• Children's Health Insurance Program (CHIP)
• Center for Medicare and Medicaid Innovation Demonstration Projects
Food and Drug Administration
• Critical Path Initiative: Optimizing schizophrenia trial design elements and establishment of exposure-response relationship based on efficacy findings of immediate-release and long acting injectable antipsychotic formulations sharing the same active moiety
Health Resources and Services Administration
• Health Center Program
• Specialized Health Care Service Grants
– Healthy Start Program
– Home Visiting Program
Ryan White HIV/AIDS Program
• Title V Maternal and Child Health Block Grant
• Training/Workforce Programs
– Nurse Education, Practice, Quality and Retention: Behavioral Health Integration Program
– Behavioral Health Workforce Education and Training Program

Table 3.1. Federal Programs Related to SMI and SED Programs That Can Support People With SMI and SED (continued)

Department of Health and Human Services (continued)
– Teaching Health Center Graduate Medical Education Program
– National Health Service Corps
Indian Health Service
• Behavioral Health Integration Initiative (BH2I)
• Mental Health Direct Care Services
• Zero Suicide Initiative
National Institute of Mental Health
• Addressing Suicide Research Gaps: Aggregating and Mining Existing Data Sets for Secondary Analyses (R01)
• Addressing Suicide Research Gaps: Understanding Mortality Outcomes (R01)
• ALACRITY – Advanced Laboratories for Accelerating the Reach and Impact of Treatments for Youth and Adults with Mental Illness (Research Centers (P50)
• Applied Research Towards Zero Suicide Healthcare Systems (R01)
• Bipolar-Schizophrenia Network for Intermediate Phenotypes
• Detecting and Preventing Suicide Behavior, Ideation and Self-Harm in Youth in Contact with the Juvenile Justice System (R01)
• Effectiveness Trials for Post-Acute Interventions and Services to Optimize Longer-term Outcomes (R01 and R34)
• Exploratory Clinical trials of Novel Interventions for Mental Disorders (R61/R33)
• Improving Health Outcomes and Reducing Premature Mortality in Serious Mental Illness
• North American Prodrome Longitudinal Study
• Pilot Studies to Detect and Prevent Suicide Behavior, Ideation, and Self-Harm in Youth in Contact with the Juvenile Justice System (R34)
• Products to Support Applied Research Towards Zero Suicide Healthcare Systems (R43/R44)
• Psychiatric Genomics Consortium
• RAISE Recovery after an Initial Schizophrenia Episode
• Reducing the Duration of Untreated Psychosis in the United States (R01 and R34)
• Temporal Dynamics of Neurophysiological Patterns as Potential Targets for Treating Cognitive Deficits in Brain Disorders (R01)
• Using the NIMH Research Domain Criteria (RDoC) Approach to Understand Psychosis (R21/R01)
Office of Civil Rights
• 21st Century Cures Act: HIPAA Compassionate Communications
• Disability nondiscrimination under Section 504 of the Rehabilitation Act, Title II of the Americans with Disabilities Act and Section 1557 of the Affordable Care Act.
Substance Abuse and Mental Health Services Administration
• Assisted Outpatient Treatment
• Children's Mental Health Initiative
• Circles of Care
• Cooperative Agreements to Implement the National Strategy for Suicide Prevention
• Community Mental Health Services Block Grant

Table 3.1. Federal Programs Related to SMI and SED Programs That Can Support People With SMI and SED (continued)

Department of Health and Human Services (continued)
• Cooperative Agreements to Benefit Homeless Individuals
• Garrett Lee Smith Campus Suicide Prevention Program
• Garrett Lee Smith State and Tribal Youth Suicide Prevention Program
• Healthy Transitions
• Homeless and Housing Resource Network
• Jail Diversion
• Minority AIDS Initiative
• National Child Traumatic Stress Initiative
• National Consumer and Consumer Supporter Technical Assistance Centers
• National Suicide Prevention Lifeline
• National Suicide Prevention Lifeline Crisis Center Follow-Up Grants
• National Technical Assistance Center for Trauma-Informed Practice and Alternatives to Restraint and Seclusion
• Native Connections
• Primary and Behavioral Health Care Integration/ Promoting Integration of Primary and Behavioral Health Care
• Programs to Achieve Wellness
• Projects for Assistance in Transition from Homelessness
• Protection and Advocacy for Individuals with Mental Illness
• Recovery to Practice Task 4 Workgroup: Clinical Decision Making with People who have SMI
• SAMHSA's Behavioral Health and Justice Transformation Center
• SAMHSA Social Inclusion and Public Education Program (VOICE)
• Service Members, Veterans, and their Families – Technical Assistance Center
• Statewide Consumer Networks
• Statewide Family Networks
• Suicide Prevention Resource Center
• The National Consumer and Consumer Supporter Technical Assistance Centers (CCSTAC)
• Transforming Lives Through Supported Employment Grant Program
• Zero Suicide Grants
Department of Housing and Urban Development
Office of Community Planning and Development
• Continuum of Care
• Emergency Solutions Grant
• Housing Opportunities for Persons with AIDS
Office of Housing
• Section 811 Supportive Housing for Persons with Disabilities
Office of Public and Indian Housing
• HUD – VA Supportive Housing

Table 3.1. Federal Programs Related to SMI and SED Programs That Can Support People With SMI and SED (continued)

Department of Justice
Bureau of Justice Assistance
• Justice and Mental Health Collaboration
• Second Chance Act Reentry
• Stepping Up Initiative
Bureau of Prisons
• Dual Diagnosis Residential Drug Abuse Program
• Mental Health Step Down Unit
• Resolve
• Skills Program
• Steps Toward Awareness, Growth, and Emotional Strength
• Office of Juvenile Justice and Delinquency Prevention
• Juvenile Drug Treatment Court Program
• Formula Grants
• Juvenile Accountability Block Grant
• Second Chance Act Reentry
Department of Labor
Office of Disability Employment Policy
• Campaign for Disability Employment
• Job Accommodation Network
• State Leadership Mentoring Programs
• Workforce Recruitment Program
Employment and Training Administration
• American Job Center Network
• Employer Technical Assistance Center
• Reentry Employment Opportunities
• State Leadership Mentoring Program
• Workforce Innovation and Opportunity Act Programs
• YouthBuild
Veterans' Employment and Training Service
• Homeless Veterans Reintegration Program
• Jobs for Veterans State Grants Program
Department of Veterans Affairs
Veterans Health Administration
• General Outpatient Mental Health Services
• Inpatient Mental Health

Table 3.1. Federal Programs Related to SMI and SED Programs That Can Support People With SMI and SED (continued)

Department of Veterans Affairs (continued)
• Intensive Community Mental Health Recovery Services
• Mental Health Enhancement Initiative
• Mental Health Residential Rehabilitation Treatment
•
• National Psychosis Registry
• Primary Care – Mental Health Integration
• Psychosocial Rehabilitation and Recovery Center
• REACH VET – Recovery Engagement And Coordination for Health --Veterans Enhanced Treatment
• Re-Engaging Veterans with Serious Mental Illness
• Specialized Homeless Services
• Substance Use Disorder Treatment
• Therapeutic and Supported Employment Services
Social Security Administration
• Homeless with Schizophrenia Presumptive Disability*
• Military Casualties/Wounded Warriors
• PROMISE – Promoting Readiness of Minors in SSI
• Protection and Advocacy
• SOAR – SSI/SSDI Outreach Access and Recovery
• Social Security Disability Insurance
• Supplemental Security Income
• Supported Employment Demonstration
• Work Incentives Planning and Assistance

Future Work of the ISMICC to Evaluate Federal Programs

Fulfilling the responsibilities outlined in the ISMICC charter will require an extensive effort by each of the federal departments, in collaboration with the membership of the ISMICC. This is the work of the next several years. The committee looks forward to the opportunity to document concrete improvements in the proportion of people with SMI and SED who receive the evidence-based services they need to live in recovery and experience an improved quality of life. The ISMICC will strive to do everything possible to improve the direction and coordination of federal programs in support of this goal and the committee's vision.

Chapter 4: Recommendations From Non-Federal ISMICC Members

This chapter was developed solely by the non-federal members of the ISMICC. We, the non-federal members, have created a list of recommendations that reflects our hope that federal departments will better align and coordinate their efforts to support people with serious mental illnesses (SMI) and serious emotional disturbances (SED). Our goal is to advance the development of a comprehensive continuum of treatments and supports that have been demonstrated to improve outcomes for people of all ages with SMI and SED. We envision the establishment of standards of care for mental health treatment and supports across the full continuum, in communities nationwide. We intend to promote evidence-based practices and strong community-based systems of care, and to end travesties such as unnecessary incarceration and "boarding" of people with acute psychiatric conditions in emergency departments for hours or days. We hope that coordinated federal efforts will enable our partners in states and communities to strengthen their efforts in support of these goals.

On the following pages we present these recommendations. The recommendations call for specific actions that we see as important and achievable. The recommendations are grouped into five areas of focus. For each recommendation, we indicate whether we believe it could be achieved in 1 year or less (short term), 2-3 years (medium term), or 4-6 years (longer term).

All of the recommendations call for actions to be taken by federal departments represented on the ISMICC. Realization of the broader vision will also require changes at the state, tribal, and local levels, with assistance from federal policies and programs, and through support and legislative action from Congress.

Source of Recommendations

These recommendations reflect the views of the non-federal ISMICC members. Federal members were consulted regarding factual concerns and federal processes, but the final list of recommendations are the product of the non-federal members. These recommendations do not represent federal policy, and the federal departments represented on the ISMICC have not reviewed the recommendations to determine what role they could play in the future activities of the departments. The recommendations should not be interpreted as recommendations from the federal government.

While drafting this report, we received hundreds of recommendations from diverse sources, many of which had merit and are worthy of attention in due time. The carefully selected set of recommendations included in this first report, however, were chosen to provide critical points of deliberation within the ISMICC. They will help shape the activities of the ISMICC in the years to come, and we anticipate that they will be refined and amended as the ISMICC moves forward.

The final ISMICC Report to Congress will include data on what has been accomplished. The final report also will include further recommendations to guide federal coordination in future years.

Full Recommendations

Focus 1: Strengthen Federal Coordination to Improve Care

1.1. **Improve ongoing interdepartmental coordination under the guidance of the Assistant Secretary for Mental Health and Substance Use.** Develop procedures and guidelines for ongoing coordination between federal departments to focus on SMI and SED populations. Activities, planning, and policies must focus on improving outcomes for people with SMI and SED, and will include the following. *[Short-term recommendation]*

a. Obtain commitment by all ISMICC federal departments to participate in interdepartmental meetings. Department representatives should be empowered to actively participate.

b. Conduct regularly occurring interdepartmental meetings of federal ISMICC members. Invite sub-agencies such as the Bureau of Prisons and the Office of Special Education and Rehabilitative Services as needed.

c. Conduct quarterly ISMICC meetings of federal and non-federal ISMICC members. Federal members will update the group on progress within focus areas. These meetings are working sessions, and include the two public sessions as required under the ISMICC charter.

d. Content-specific subgroups with federal and non-federal ISMICC members will address specific recommendations from this report. Outside experts may be invited to participate in workgroup meetings.

e. Draft an annual report due by July 1 following each calendar year of the ISMICC that describes how federal agencies have progressed in addressing the recommendations in this report.

f. Budget adequate resources for the level of federal staffing support and committee effort needed to operationalize the ISMICC processes over full term of the committee.

1.2. **Develop and implement an interdepartmental strategic plan to improve the lives of people with SMI and SED and their families.** Building on the foundation of this report, ISMICC federal departments will develop a joint federal strategic plan for improving services and outcomes for people with SMI and SED. The plan should be consistent with the "strategic planning" language in the 21st Century Cures Act, extend to all the federal ISMICC partners, and be complete by September 30, 2018, in conjunction with the strategic plan required under the 21st Century Cures Act. The plan must include measurable activities and outcomes for each participating department, as well as for all departments operating collectively. Though the development and implementation of the strategic plan, the Assistant Secretary for Mental and Substance Use shall review and propose modifications to federal programs that serve people with SMI and SED. *[Short-term recommendation]*

1.3. **Create a comprehensive inventory of federal activities that affect the provision of services for people with SMI and SED.** The list of federal programs will include federal leadership efforts, regulations, policies, contracts, grants and other programs that focus on people with SMI and SED or play a significant role in the service system for people with SMI and SED. *[Short-term recommendation]*

1.4. **Harmonize and improve policies to support federal coordination.** The federal departments participating in the ISMICC will address specific issues that impede coordination and effectiveness. Activities include but are not limited to the following. *[Short-term recommendation]*

a. Establish uniform definitions of SMI and SED and a shared lexicon across federal departments to promote understanding, coordination, and integration of services and supports for people with SMI and SED. Include definitions that support inclusion of individuals who have SMI or SED with co-occurring substance use disorders, developmental disabilities, and traumatic brain injury.

b. Identify federal policies or other barriers across federal departments that preclude or impede access to services, treatments, or continuity of care. Assess whether federal program designs align with what is known from implementation research about effective ways to promote lasting practice change and improve systems.

c. Identify age-based barriers to services in the federal policies of the ISMICC federal departments that impede access to needed treatments and services that support the transition to adulthood for 16- to 25-year-olds with or at risk of SED or SMI.

d. Align eligibility and benefits systems across federal departments to facilitate system navigation and continuity of care for people with SMI and SED.

1.5. **Evaluate the federal approach to serving people with SMI and SED.** Evaluate systems, services, and supports for people with SMI and SED, and assess effectiveness. Routinely measure, evaluate, and improve the federal government's efforts. Identify areas where the federal government is failing to meet the needs of people with SMI and SED. Support evaluation and accountability for individual federal programs. See how federal programs fit within the larger support system. Identify and reduce non-coordinated duplication across departments. *[Short-term recommendation]*

1.6. **Use data to improve quality of care and outcomes.** Review and improve federal and national data sets relevant to the lives of people with SMI and SED to incorporate tracking of SMI/SED information and outcomes. Include all relevant federal data such as those focused on health, education, criminal justice, labor, military personnel, and veterans. Use the findings from data sets to reduce across-department variation and to establish national benchmarks for making progress on core recovery measures which address key issues for the ISMICC, including reduction in health disparities, and improvements in access, employment, education, decriminalization of mental illness, and community integration. Establish a national dashboard including this set of core recovery measures by which federal agencies, states, tribes, and counties can measure progress transparently. The measures included in this dashboard should be included in all federal health care quality measurement programs, and dashboard results should be regularly published for all federal health programs for children and youth experiencing SED and for adults experiencing SMI. *[Medium-term recommendation]*

1.7. **Ensure that quality measurement efforts include mental health.** Use existing bodies, such as the National Quality Forum and/or the HHS Measurement Policy Council, to harmonize and coordinate development and adoption of behavioral health quality measures across HHS divisions and other departments. Examine existing quality measures, such as those that track rehospitalization and emergency department use, to ensure that behavioral health data is not excluded, and encourage the inclusion of peers and family members in measure development. Through this work, improve the use of measures for populations, such as younger children, for whom mental health quality measures do not widely exist. *[Medium-term recommendation]*

1.8. **Improve national linkage of data to improve services.** Promote national adoption by public and private health care systems of routine linking of SMI and SED populations to mortality data, including tracking cause/manner of death, and analysis of survival rates after suicide attempts, emergency department presentation, and inpatient hospital discharge. Standardize similar data gathering across all state and local systems for SMI and SED populations within the justice system. *[Longer-term recommendation]*

Focus 2: Access and Engagement: Make It Easier to Get Good Care

2.1. Define and implement a national standard for crisis care. Through federal departmental coordination, establish standards consistent with those defined in the SAMHSA publication, *Crisis Services: Cost Effectiveness and Funding Strategies*.[7] Develop standards that are person-centered, youth-guided, family-driven, and responsive to the circumstances and developmental needs of children, youth, and adults. Include a minimum standard for stabilization under the Emergency Medical Treatment and Labor Act (EMTALA). Once established, ensure that federal programs support the standards, and enable and incentivize states and communities to support and sustain adequate crisis care systems. *[Longer-term recommendation]*

2.2. Develop a continuum of care that includes adequate psychiatric bed capacity and community-based alternatives to hospitalization. Through partnerships at the federal, state, and local levels, build the capacity of the mental health system to provide a continuum of services that includes inpatient psychiatric care, when needed, with community-based resources also available. Ensure that people with SMI and SED receive care in the least-restrictive safe setting available that meets their mental health service needs. *[Longer-term recommendation]*

2.3. Educate providers, service agencies, people with SMI and SED and their families, and caregivers about the Health Insurance Portability and Accountability Act of 1996 (HIPAA) and other privacy laws, including 42 CFR Part 2, in the context of psychiatric care. There is a need for clarification and guidance regarding the value and need for communication with family members and caregivers. For example, there are permitted disclosures of protected health information in the context of psychiatric crises. There is justification for engaging families and caregivers in responding to the needs of their loved ones. Technical assistance and training is needed on how to involve family members and loved ones when a person with SMI or SED is in crisis and unable to make their own decisions. This work should include strategies for involving families while empowering people with SMI to direct their own care, such as psychiatric advance directives. *[Short-term recommendation]*

2.4. Reassess civil commitment standards and processes. Through federal coordination, reexamine current standards and develop model standards that both protect individual rights and enable greater flexibility for families, caregivers, and mental health providers to provide care, when necessary. Consider standards for inpatient civil commitment, assisted outpatient treatment, short-term "holds," and longer-term civil commitment. Help states adopt standards. *[Medium-term recommendation]*

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[7] Substance Abuse and Mental Health Services Administration. Crisis Services: Effectiveness, Cost-Effectiveness, and Funding Strategies. HHS Publication No. (SMA)-14-4848. Rockville, MD: Substance Abuse and Mental Health Services Administration, 2014.

2.5. **Establish standardized assessments for level of care and monitoring of consumer progress.** Through partnership with states and localities, support the use of standardized assessment tools such as the Level of Care Utilization System (LOCUS) and the Child and Adolescent Level of Care Utilization System (CALOCUS) to create a common methodology across the nation to assess the need for level of care for people with SMI and SED receiving services. The use of validated instruments will allow for consistent metrics for adequacy of system capacity, as well as systematic monitoring of patient progress and response to treatment. *[Medium-term recommendation]*

2.6. **Prioritize early identification and intervention for children, youth, and young adults.** Develop standards that help educational institutions identify signs of mental illnesses, especially early psychosis. Enhance the Individuals with Disabilities Education Act (IDEA) so that children and youth with SED are identified regardless of the impact to learning. Develop policies that provide for educational staff and school-based clinics to have appropriate systems (such as standardized assessments) and expertise (such as participation by mental health professionals and family support specialists in individualized education program [IEP] meetings for students with SMI and SED). Provide transition planning for all students ages 16-25 with SED/SMI or first-episode psychosis, to ensure that they have access to treatment, services, and supports as they move into adulthood. Coordinate transition planning with state vocational rehabilitation agencies, in accordance with the Workforce Innovation and Opportunity Act and IDEA. *[Longer-term recommendation]*

2.7. **Use telehealth and other technologies to increase access to care.** Establish standards for the use of telehealth to provide mental health and other support services for people with SMI and SED and increase access to care, specifically for rural populations. Change regulations that inhibit provision of mental health services by telemedicine (e.g., cross-state licensure issues, requiring presence in a "clinic" setting, and requiring face-to-face meetings for payment). Apply telehealth to models of care such as the collaborative care model and Project ECHO (Extension for Community Healthcare Outcomes) to build workforce capacity and make better use of scarce professional resources. Support research, testing, and dissemination of new technology-based behavioral health services and supports so that people with SMI and SED and their families have access to accurate information regarding the use of these technologies. *[Medium-term recommendation]*

2.8. **Maximize the capacity of the behavioral health workforce.** Through federal interdepartmental planning, find ways to increase the capacity of the behavioral health workforce to meet the needs of people with SMI and SED and their families. *[Longer-term recommendation]*

a. Include coverage of peer and family support specialists in federal health benefit programs.

b. Incentivize providers to obtain education and continuing education on evidence-based treatments and team-based care models.

c. Provide tuition reimbursement to encourage mental health professionals in roles where there are severe shortages, such as child psychiatry and in addressing underserved populations.

d. Remove exclusions that disallow payment to certain qualified mental health professionals, such as marriage and family therapists and licensed professional counselors, within Medicare and other federal health benefit programs.

e. Remove reimbursement and administrative burdens associated with psychiatric care within Medicare, Medicaid, and other federal health benefit programs.

f. Explore how to fully implement integrated team models that are the most effective in addressing the needs of people with SMI and SED.

g. Enable health care providers to practice to the full extent of their education and training. For example, remove barriers that prevent advanced practice registered nurses from prescribing medication.

h. Develop a workforce that is representative of the populations served (including racial and ethnic minorities, people in rural areas, and populations facing health disparities such as lesbian, gay, bisexual, or transgender individuals) and able to provide services in a culturally competent manner.

i. Develop standards for network adequacy in health plans, and identify and implement processes to monitor access to services and adherence to established standards.

2.9. **Support family members and caregivers.** Develop and disseminate programs for non-professional caregivers of children with SED and adults with SMI. Programming should be similar to those that exist for caregivers of people with intellectual disabilities, people with developmental disabilities, and older adults. Include caregiver respite, family consultation, system navigation, caregiver training, and family psychoeducation. Provide technical assistance and financial support for education programs by and for families and other caregivers. *[Medium-term recommendation]*

2.10. Expect SMI and SED screening to occur in all primary care settings. Expand access and facilitate early initiation of treatment for people with SMI and SED through identification and engagement in primary care settings. Develop routine expectations that behavioral health consultation occurs in primary care, using collaborative care models, and then proactively monitor behavioral health provider network adequacy for all payers in all communities. This will ensure that those listed as providing services are actually available to accept new referrals. *[Longer-term recommendation]*

Focus 3: Treatment and Recovery: Close the Gap Between What Works and What Is Offered

3.1. Provide a comprehensive continuum of care for people with SMI and SED. Develop standards that include a full spectrum of integrated, complementary services known to be effective and to improve outcomes. Standards should be appropriate to phases of development and aging. Give attention to service disconnections that can occur as children and youth transition into adult systems. These standards must include at least the following. *[Medium-term recommendation]*

a. Guidance on effective use of psychopharmacological medications, including taking immediate action to promote the appropriate use of clozapine and long-acting injectable antipsychotic medications;

b. Supportive services, such as supportive housing, employment, and education;

c. Team-based models of care delivery that are interdisciplinary and incorporate peer and family support specialists as a matter of routine practice;

d. Recovery-oriented models of team-based care to be used in conjunction with outpatient civil commitment and assisted outpatient treatment;

e. Bidirectional integrated mental health and primary care services;

f. Integrated services for people with co-occurring SMI/SED and substance use disorders;

g. Psychiatric crisis response using least-restrictive appropriate settings in communities and psychiatric hospitals, and eliminating “psychiatric boarding” in hospital emergency departments;

h. Trauma-informed systems of care;

i. Systems of care that provide family-driven, youth-guided, and culturally and linguistically responsive services; and

j. Comprehensive and integrated systems of care for people who need varying levels of intensive services and supports on an ongoing basis, including community-delivered services.

3.2. Make screening and early intervention among children, youth, transition-age youth, and young adults a national expectation. Develop and implement interdepartmental guidelines for detecting and treating early signs of SED in children and youth, and of SMI in transition-age youth and young adults, in a wide range of settings, including primary care, day care, school- and college-based health clinics, public health clinics, juvenile justice facilities, jails, and emergency departments. In this work, pay special attention to vulnerable populations facing health disparities. *[Medium-term recommendation]*

3.3. Make coordinated specialty care for first-episode psychosis available nationwide. Incentivize universal access to coordinated specialty care services in all federal health benefit programs, including Medicaid, Medicare, Department of Defense, the Veterans Administration, and TRICARE. Continue the SAMHSA block grant set-aside requirements, and provide guidance to facilitate payment by all public and private insurance programs. *[Medium-term recommendation]*

3.4. Make trauma-informed, whole-person health care the expectation in all our systems of care for people with SMI and SED. Adverse childhood experiences and trauma play a tremendously important role in the development of SMI and SED, and trauma-informed treatment is increasingly recognized as essential to enable recovery. People with SMI and SED commonly experience problems with health, substance use disorders, and the need for supportive housing, employment, and education. To address the mortality gap, we must provide access to integrated health and behavioral health care that identifies and addresses all health and social determinants in every treatment setting. *[Longer-term recommendation]*

3.5. Implement effective systems of care for children, youth, and transition-age youth throughout the nation. This must include the following. *[Longer-term recommendation]*

a. Support national implementation of the SAMHSA System of Care model.

b. Provide strong supports for students with or at risk of SED/SMI through special education and Section 504 of the Rehabilitation Act services and supports, including the requirement of a school-based mental health professional and family support specialist at all IEP and 504 planning meetings that include a student with SED/SMI or its early forms, and identification or development of payment mechanisms through Medicaid or other health care coverage for health care services in IEP and 504 plans.

c. Through collaboration between SAMHSA, Centers for Medicare & Medicaid Services, the Health Resources and Services Administration, and the Department of Education, establish school-based clinics with Medicaid-billable behavioral health assessment and treatment capacity integrated with physical health services in all public schools.

d. Improve postsecondary transition outcomes of all students with or at risk of SED/SMI. Expand policies and guidelines that require transition planning for all students ages 16-22 with SED/SMI or first-episode psychosis, including those not covered within special education programs, to ensure that they have a student-centered plan that identifies treatment, services, and supports to achieve their best mental health and successful assumption of adult roles, including state vocational rehabilitation and other employment options.

3.6. Make housing more readily available for people with SMI and SED. Housing is an essential prerequisite for effective treatment and a life in recovery. Develop consistent federal policies to support and require adequate housing as a standard part of recovery-oriented treatment for people with SMI and SED, with special emphasis on providing housing, including supported housing, to those exiting jails and prisons, youth who have been estranged from their families, those who experience homelessness, and those aging out of foster care. Have the Department of Housing and Urban Development issue guidance for state and local housing authorities on establishing tenant selection preferences for non-elderly people with SMI, consistent with federal fair housing requirements. Target resources such as Housing Choice Vouchers for individuals with SMI experiencing chronic homelessness or transitioning from settings such as correctional facilities, nursing homes, or board and care homes. *[Medium-term recommendation]*

3.7. Advance the national adoption of effective suicide prevention strategies. All federal departments, including VA and DoD, should adopt Zero Suicide as a model for suicide reduction, and agree to develop and implement strategic plans with achievable and transparent targets for progress. Consider ways to widely disseminate and universally apply these strategies in the public health system. *[Medium-term recommendation]*

3.8. Develop a priority research agenda for SED/SMI prevention, diagnosis, treatment, and recovery services. *[Medium-term recommendation]*

a. Increase funding for research at the National Institute of Mental Health, commensurate with prevalence rates of SED/SMI, the direct and indirect costs of these conditions, and the burden of disease they impose.

b. Establish a public-private partnership for discovering biomarkers and breakthrough disease-modifying interventions for the treatment of people with SMI and SED.

3.9. Make integrated services readily available to people with co-occurring mental illnesses and substance use disorders, including medication-assisted treatment (MAT) for opioid use disorders. Despite the high rate of co-occurring mental illness and substance use disorders and the disproportionate share of opioid prescriptions that go to people with mental illnesses, people with SMI and SED often do not have access to necessary MAT and other substance use disorder treatment services. Co-occurring treatment for mental illnesses and substance use disorders must be available in all treatment settings. In guidance accompanying federal funds to address the opioid crisis, clarify that those services and resources are to be made fully available on an ongoing basis to people with SMI and SED, with attention to housing, as well as mental and primary health needs. *[Medium-term recommendation]*

3.10. Develop national and state capacity to disseminate and support implementation of the national standards for a comprehensive continuum of effective care for people with SMI and SED. The challenges of implementation are well known, but rarely adequately addressed. As a consequence, we find a huge gap between what is known to be effective and what is available in communities throughout the nation. Several states (including New York, Ohio, and Vermont) have used block grant funds to develop technical assistance centers to support widespread implementation of effective practices. Implement these models more widely with national support, to bring implementation of evidence-based and effective practices to scale. *[Medium-term recommendation]*

Focus 4: Increase Opportunities for Diversion and Improve Care for People With SMI and SED Involved in the Criminal and Juvenile Justice Systems

4.1. Support interventions to correspond to all stages of justice involvement. Consider all points included in the sequential intercept model. Pay particular attention to the "zero intercept"—the avoidance of initial arrest. Provide funding opportunities for communities to map their systems, develop programs and services, and promote diversion of people with SMI and SED along the continuum of the sequential intercept model.[8] *[Medium-term recommendation]*

8 Substance Abuse and Mental Health Services Administration. (2016). Turning Point: Criminal Justice to Behavioral Health. SAMHSA News, July 18, 2016. Retrieved from https://newsletter.samhsa.gov/2016/07/18/criminal-diversion-programs-resources.

4.2. **Develop an integrated crisis response system to divert people with SMI and SED from the justice system.** Community-based mental health services must be in place to address the crisis needs of people with SMI and SED. A crisis response system should include services such as 24/7 access to crisis line services staffed by clinicians; warm lines staffed by certified peer specialists, including family and youth support specialists; non-law enforcement crisis response teams of clinicians and other behavioral health providers able to respond independently to nonviolent crisis situations, and to co-respond with law enforcement when needed; and dedicated crisis triage centers. A person with SMI or SED who is in crisis should be able to get adequate mental health care in the community without contact with law enforcement. However, until that goal is achieved, there must be plans for information sharing between crisis service providers and law enforcement personnel. Sustaining an adequate crisis response system must be addressed through an interdepartmental group, including SAMHSA, the Centers for Medicare & Medicaid Services, the Veterans Health Administration, and other federal departments. *[Longer-term recommendation]*

4.3. **Prepare and train all first responders on how to work with people with SMI and SED.** Ideally, crises among people with SMI and SED should be resolved without involving law enforcement. When the crisis system fails, or the level of dangerousness warrants, law enforcement and other first responders should be prepared to respond safely and effectively to people with SMI and SED. All law enforcement staff should be aware of the symptoms and needs of people with SMI and SED and have training to de-escalate mental health crisis situations. A select cadre of law enforcement officers in a patrol capacity within every community must receive specialized training in working with community behavioral health resources, and in-depth training on mental health and substance abuse issues. Officers who receive this specialized training will then be a resource for the community and fellow patrol officers, and be able to engage people within local justice diversion programs. *[Longer-term recommendation]*

4.4. **Establish and incentivize best practices for competency restoration that use community-based evaluation and services.** Develop federal guidelines and work with states to ensure that people with SMI wait no more than 5 days, on average, for initiation of competency services. Support the use of mathematically based planning tools to develop evidence-based strategies for reducing forensic bed waitlists. For people with SMI and SED charged with nonviolent crimes, use jail diversion options whenever possible instead of holding people in jails to await competency evaluations. Give consideration to pre-arrest, post-arrest, and post-competency phases. *[Longer-term recommendation]*

4.5. **Develop and sustain therapeutic justice dockets in federal civilian, state, and local courts for any person with SMI or SED who becomes involved in the justice system.** This includes support of therapeutic court models at local and federal levels, therapeutic justice dockets, and probationary units with specialized capacity to work with

people with mental illness. Examples include mental health courts, accountability courts, veterans courts, and juvenile courts. Through coordination between federal departments and state and local agencies, community-based services for people with SMI and SED should support diversion programs. Federal financing should incentivize states to adopt and expand wraparound services such as case management; forensic assertive community treatment; cognitive skills training; and peer, family, and youth mentoring programs so courts and probation systems can connect people with SMI and SED to effective services. *[Longer-term recommendation]*

4.6. Require universal screening for mental illnesses, substance use disorders, and other behavioral health needs of every person booked into jail. Use evidence-based screening tools to screen for SMI, SED, co-occurring substance use disorders, cognitive disabilities, and suicide risk when the person is booked, and later if indicated. When people screen "positive" for mental illnesses or substance use disorders, conduct a comprehensive assessment of mental and substance use disorder treatment needs, in accordance with procedures developed in the Stepping Up Initiative.[9] Establish procedures for serving people identified through the screening process, including immediate crisis response for those with a high risk of suicide, diversion services to behavioral health services for lower severity offenses, and adequate jail-based behavioral health services for those who remain incarcerated. *[Longer-term recommendation]*

4.7. Strictly limit or eliminate the use of solitary confinement, seclusion, restraint, or other forms of restrictive housing for people with SMI and SED. Develop and implement a plan to reduce and eventually eliminate the use of solitary confinement and other forms of segregation, seclusion, restraint, and isolation of people with SMI within Federal Bureau of Prison facilities. This plan must include implementation of mental and substance use disorder treatment services to alleviate symptoms and, when appropriate, to help prepare people to reenter communities. Build on this policy to support similar measures for people with SMI and SED in state and local jurisdictions, while ensuring that effective mental health services are available within juvenile and adult correctional facilities. *[Longer-term recommendation]*

[9] Stepping Up Initiative. (n.d.). Stepping Up: A National Initiative to Reduce the Number of People with Mental Illnesses in Jails. Website home page. Retrieved from https://stepuptogether.org.

4.8. Reduce barriers that impede immediate access to treatment and recovery services upon release from correctional facilities. Criminal charges that are related to symptoms of SMI and SED should not impede a person's ability to get housing, education, employment, and community living. Work at the federal level and help states to adopt policies that enable immediate access to benefits (such as Medicaid, Supplemental Security Income, and Social Security Disability Income) upon release from correctional facilities, including services such as supported employment. Encourage states to suspend, rather than terminate, Medicaid coverage and access to disability benefits for people who are incarcerated less than 18 months. Help states discontinue the practice of changing the Medicaid status of a person who has been arrested, confined but not convicted, or on probation or parole. Likewise, support forgiveness of criminal charges, including felonies, and actions related to symptoms of SMI and SED. *[Longer-term recommendation]*

4.9. Build on efforts under the Mentally Ill Offender Treatment and Crime Reduction Act, the 21st Century Cures Act, and other federal programs to reduce incarceration of people with mental illness and co-occurring substance use disorders. As part of a federal interdepartmental strategy, review the language of the Mentally Ill Offender Treatment and Crime Reduction Act and the 21st Century Cures Act to identify opportunities to maximize resources and provide services. Review federal programs such as the Byrne Justice Assistance Grant program and other relevant federal programs for juveniles and adults to identify opportunities to coordinate at the state and local level to maximize resources and provide services. *[Short-term recommendation]*

Focus 5: Develop Finance Strategies to Increase Availability and Affordability of Care

5.1. Implement population health payment models in federal health benefit programs. Such models provide support for integrated population health care that addresses the range of complexity and co-occurring conditions experienced by people with SMI and SED. People with SMI and SED often experience co-occurring substance use disorders, intellectual and developmental disabilities, and chronic physical health conditions. To measure effectiveness and quality of care, federal departments should employ outcome and quality measures at the individual and population levels. *[Longer-term recommendation]*

5.2. Adequately fund the full range of services needed by people with SMI and SED. Federal health benefit programs (including Medicaid, Medicare, VA, and TRICARE) should cover outreach services, bidirectional integration of physical and behavioral health care, care coordination, consultation, supported housing and employment services, family and peer support services, and other services needed by people with SMI and SED. Payment models should make it easy to reimburse providers for services. Fund such services directly or through models such as health homes, accountable care organizations, and managed care organizations. Federal departments should partner with private health plans, and with state and local governments, to promote similar approaches. *[Longer-term recommendation]*

5.3. Fully enforce parity to ensure that people with SMI and SED receive the mental health and substance abuse services they are entitled to, and that benefits are offered on terms comparable to those for physical illnesses. Fully implement the October 2016 recommendations from the White House Parity Task Force and the recommendations made by the President's Commission on Combating Drug Addiction and the Opioid Crisis for improving the implementation and enforcement of the Mental Health Parity and Addiction Equity Act (MHPAEA).[10] These recommendations include enacting legislation to provide the Department of Labor the authority to impose civil monetary penalties for findings of noncompliance, authority to enforce MHPAEA directly against health plan insurance issuers, and additional funding to increase parity enforcement efforts. Review and implement the recommendations from the Coalition for Whole Health on parity implementation and enforcement, as documented in an August 10, 2017, letter to the Office of the Assistant Secretary for Planning and Evaluation.[11] Ensure that the services needed by people with SMI and SED are covered by health insurance and available at the same level as for other health conditions, with attention to parity in payment rate setting processes. *[Medium-term recommendation]*

5.4. Eliminate financing practices and policies that discriminate against behavioral health care. Identify and eliminate programs, practices, and policies that make it hard to deliver good mental health care. This includes ending the exclusion for reimbursement of services to adults under age 65 in Institutions for Mental Diseases (IMD exclusion) and ending the 190-day lifetime limit on Medicare psychiatric inpatient hospitalization. In addition, provide incentives for behavioral health providers to adopt electronic health records similar to incentives that other health care providers have received. *[Medium-term recommendation]*

5.5. Pay for psychiatric and other behavioral health services at rates equivalent to other health care services. In many states, reimbursement by public programs for mental health services is lower (as a percentage of cost) than reimbursement for other health services. This forces providers to offer critical services (including psychiatric care and hospitalization) at a loss. As a result, many mental health service providers do not participate in public programs, leading to widespread mental health workforce shortages. Medicare, Medicaid, and other benefit programs should provide adequate reimbursement for the full range of services needed by people with SMI and SED, at rates equivalent to rates for other types of health care services. *[Longer-term recommendation]*

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10 Executive Office of the President of the United States. (2016). The Mental Health & Substance Use Disorder Parity Task Force: Final Report, October 2016. Retrieved from https://www.hhs.gov/sites/default/files/mental-health-substance-use-disorder-parity-task-force-final-report.pdf.

11 Coalition for Whole Health. (2017). Letter to Office of the Assistant Secretary for Planning and Evaluation, August 10, 2017. Retrieved from https://www.aahd.us/wp-content/uploads/2017/09/CWHparitylisteningsessioncomments.pdf.

5.6. Provide reimbursement for outreach and engagement services related to mental health care. The public health care system must cover outreach and engagement services that are an essential part of so many effective mental health treatment models. More than one-third of adults with SMI and most children and youth with SED received no treatment in the past year. Outreach and engagement services allow mental health providers to meet with people with SMI and SED and their families in the community and in their homes. These activities help ensure that people with SMI and SED get the care they need. Outreach and engagement should be supported through financing models that are designed to support population health. *[Longer-term recommendation]*

5.7. Fund adequate home- and community-based services for children and youth with SED and adults with SMI. Through federal departmental coordination, help states meet the needs of people with SMI and SED. Medicaid waivers and options can be used to expand the availability of evidence-based services. Streamline the waiver approval and state plan amendment processes so states can easily make changes to better serve people with SMI and SED. To support states in this work, highlight best practices across states and make technical assistance and materials available, such as model managed care contract language. *[Medium-term recommendation]*

5.8. Expand the Certified Community Behavioral Health Clinic (CCBHC) program nationwide. The CCBHC program provides a framework to support effective services in a population health framework and offers a sustainable payment model. Evaluate the effectiveness of the CCBHC model and, if needed, modify the model to improve the reach and quality of services and outcomes. Help interested states to move toward similar models of care delivery, even states not funded by the CCBHC program. *[Medium-term recommendation]*

Appendix A

U.S. Department of Health & Human Services Interdepartmental Serious Mental Illness Coordinating Committee Members

Federal Members

Elinore F. McCance-Katz, M.D., Ph.D.
Assistant Secretary for Mental Health and Substance Use

Eric D. Hargan, Esq.
Acting Secretary of the Department of Health and Human Services

Benjamin Carson, Sr., M.D.
Secretary of the Department of Housing and Urban Development

Terry Adirim, M.D., M.P.H., F.A.A.P.
Deputy Assistant Secretary of Defense for Health Services Policy and Oversight, Office of the Assistant Secretary of Defense for Health Affairs, Department of Defense

Kimberly Brandt, J.D.
Principal Deputy Administrator for Operations, Centers for Medicare & Medicaid Services

Stephen Cox, J.D.
Deputy Associate Attorney General, Department of Justice

Captain Robert DeMartino, M.D.
Lead Medical Officer, Office of Health Services Policy and Oversight, Department of Defense

Thomas McCaffery, M.P.P.
Deputy Assistant Secretary of Defense for Health Affairs, Department of Defense

John McCarthy, Ph.D., M.P.H.
Director, Serious Mental Illness Treatment Resource and Evaluation Center, Department of Veterans Affairs

Ruby Qazilbash, M.P.A.
Associate Deputy Director, Bureau of Justice Assistance, Department of Justice

Kimberly M. Richey, J.D.
Deputy Assistant Secretary and Acting Assistant Secretary for Special Education and Rehabilitative Services, Department of Education

Jennifer Sheehy, M.B.A.
Deputy Assistant Secretary, Office of Disability Employment Policy, Department of Labor

Melissa Spencer
Deputy Associate Commissioner, Office of Disability Policy, Social Security Administration

Non-Federal Members

Linda Beeber, Ph.D., P.M.H.C.N.S.-B.C., F.A.A.N.

Linda Beeber, Ph.D., P.M.H.C.N.S.-B.C., F.A.A.N., is a doctorally prepared advanced practice psychiatric mental health nurse with over 40 years of experience in practice and over 20 years of research experience in mental health. Funded through federal grants and private foundations, Dr. Beeber and her colleagues have conducted community-based research focused on reducing maternal depressive symptoms and enhancing parenting in populations of high-risk mothers of infants and toddlers. Her work has shown that reduction of barriers and provision of culturally and contextually tailored, evidence-based interventions can effectively reduce maternal depressive symptoms and improve parenting. Dr. Beeber has experience as an educator, academic administrator, and psychiatric nursing leader. Through her work with the American Psychiatric Nurses Association (APNA) as the Chair of the Research Council, and more recently as President-Elect, and as the past Co-Chair of the Psychiatric Mental Health and Substance Abuse Expert Panel of the American Academy of Nursing, she advocates to reduce the risk factors that threaten mental health, and to improve the lives of people living with symptoms of mental illness through models of recovery, culturally congruent symptom management, social support mobilization, and healthy lifestyle patterning. Dr. Beeber has disseminated her work through peer-reviewed papers, national and international presentations, and service on national policymaking panels.

Ron L. Bruno

Ron L. Bruno is a Utah law enforcement officer with over 22 years of experience. Mr. Bruno has dedicated much of his career working with adult and child populations dealing with serious mental illness and emotional disturbances. Mr. Bruno is a founding board director of CIT International and currently is the corporation's second vice president; a founding board director of CIT Utah, Inc. and the corporation's Executive Director; and the Director of CTS Services, LLC, an organization that provides de-escalation training for law enforcement officers and other disciplines throughout the country. Mr. Bruno has worked with national organizations such as the National Alliance on Mental Illness in developing its CIT for Youth Implementation Manual; the International Association of Chiefs of Police in developing and conducting Law Enforcement Leadership Institutes on Juvenile Justice; and the Council of State Governments with its Learning Sites Program and its report on Statewide Law Enforcement/Mental Health Efforts. Within Utah, Mr. Bruno was instrumental in developing the fully integrated Salt Lake County crisis response system, and he continues to work with councils and committees for enhanced criminal justice and behavioral health services integration.

Clayton Chau, M.D.

Clayton Chau, M.D., is the Regional Executive Medical Director for the Mental Health Network, St. Joseph Hoag Health/Providence St. Joseph Health System in Orange County, California. He obtained his M.D. from the University of Minnesota and Ph.D. in clinical psychology from Chelsea University. Dr. Chau completed his psychiatry residency at the University of California, Los Angeles, San Fernando Valley, followed by a fellowship with the National Institute of Mental Health in psychoneuroimmunology focusing on substance use and HIV. Previously, he served as Senior Medical Director for Health Services at L.A. Care Health Plan, where he was Co-Principal Investigator for a multi-year Center for Medicare & Medicaid Services' health care innovation grant in transforming clinical practice. Dr. Chau also is a lecturer for the UCLA School of Public Health and an associate clinical professor of psychiatry at UC Irvine School of Medicine. Previously, he worked for the Orange County Health Care Agency Behavioral Health Services and was the Director of the Center of Excellence in Education, Training, Research and Advocacy for Reducing Health Disparities. Dr. Chau was named the 2012 Visionary Leader by the National Council for Behavioral Health and received the Warren Williams, M.D., Award from the American Psychiatric Association. He also has conducted international trainings in the areas of health care integration, health care system reform, cultural competency, veterans' health, trauma, homelessness, and mental health policy.

David Covington, L.P.C., M.B.A.

David Covington, L.P.C., M.B.A., is Chief Executive Officer and President of RI International (formerly Recovery Innovations). He is a partner in Behavioral Health Link, co-founder of CrisisTech 360, and leads the international initiatives "Zero Suicide," "Crisis Now," and "Peer 2.0." A licensed professional counselor, Mr. Covington received an M.B.A. from Kennesaw State and an M.S. from the University of Memphis. He previously served as Vice President at Magellan Health, CEO of Behavioral Health Link, and Director of Public Sector Quality Management at APS Healthcare. A recognized health care innovations global speaker and blogger, Mr. Covington is a two-time national winner of the Council of State Governments Innovations Award. He also competed as a finalist in Harvard's Innovations in American Government in 2009 for the Georgia Crisis and Access Line, and the program was subsequently featured in *Business Week* magazine. Mr. Covington is President-Elect of the American Association of Suicidology and has served on the National Action Alliance for Suicide Prevention Executive Committee since 2010. He is also the Chair of the National Suicide Prevention Lifeline SAMHSA Steering Committee. He has served on numerous committees and task forces on clinical care and crisis services, including the National Council for Behavioral Health Boards of Directors.

Maryann Davis, Ph.D.

Maryann Davis, Ph.D., is Research Associate Professor of Psychiatry (Psychology) and Director of the Systems and Psychosocial Advances Research Center and the Transitions Research and Training Center (RTC) at the Department of Psychiatry and the University of Massachusetts Medical School. A clinically trained research psychologist, she has spent her career studying transition-age youth and young adults with serious mental health conditions. Dr. Davis is a grant recipient of the National Institute of Mental Health; the National Institute on Disability, Independent Living, and Rehabilitation Research; the National Institute on Drug Abuse; and SAMHSA. She has collaborated with the Massachusetts Department of Mental Health in addressing the needs of transition-age youth for over 20 years. As Director of the Transitions RTC, she has extensive experience in sharing research-based knowledge with key stakeholders, including people with lived experience of serious mental health conditions and their families, administrators, policymakers, and service providers. Dr. Davis has provided expert testimony on transition-age youth with serious mental health conditions before Congress, and served on multiple committees of the National Academy of Sciences, Engineering, and Medicine.

Pete Earley

Pete Earley is a *New York Times* bestselling author and former reporter for *The Washington Post*. A 1973 graduate of Phillips University in Oklahoma, he previously worked for the *Emporia Gazette* in Kansas and the *Tulsa Tribune* in Oklahoma. From 1980 until 1986, Mr. Earley worked as a reporter at *The Washington Post* before writing books full-time. He is the author of six novels and 11 non-fiction books, including *Crazy: A Father's Search Through America's Mental Health Madness,* which was a finalist for the 2007 Pulitzer Prize. Mr. Earley is a member of the National Alliance on Mental Illness, serves on the board of the Corporation for Supportive Housing, and was appointed to a Virginia Supreme Court task force that recommended changes to that state's involuntary commitment laws and is currently serving on a committee investigating ways to improve Virginia jails. An advocate for mental health, Mr. Earley has testified five times before Congress, lectured in five foreign countries, spoken in every state except Hawaii, and toured a combined total of more than a hundred jails, prisons, treatment programs, and housing facilities.

Paul Emrich, Ph.D.

Paul Emrich, Ph.D., is Undersecretary of Family and Mental Health Services for the Chickasaw Nation, with responsibility for leading the integration of human services, addiction recovery, mental health, and medical care. Dr. Emrich received his training at Oklahoma State University and Oklahoma Baptist University, where he completed a postgraduate certificate in Medical Family Therapy, a Ph.D. in Human Development and Family Science, an M.S. in Marriage and Family Therapy, and a

B.A. in Family Psychology. Dr. Emrich is dually licensed as a licensed marital and family therapist (LMFT) and licensed professional counselor. He is also approved by the Oklahoma State Board of Behavioral Health Licensure to provide clinical supervision for license candidates. Dr. Emrich is a clinical fellow with the American Association for Marriage and Family Therapy and a member of the American Society for Addiction Medicine. He has served on Oklahoma's licensing board for LMFT and on the Tribal Technical Advisory Group on Behavioral Health for the Centers for Medicare & Medicaid Services. Having worked as a clinician, supervisor, administrator, researcher, advocate, and educator, Dr. Emrich has over 20 years of experience in the mental health field helping children, adults, and families experiencing serious emotional illnesses.

Mary Giliberti, J.D.

Mary Giliberti, J.D., is the Chief Executive Officer of the National Alliance on Mental Illness (NAMI). A native of North Bellmore, NY, she earned her B.A. at Harvard College and her J.D. at Yale Law School. During her tenure of over 20 years in the mental health field, Ms. Giliberti has served as disability counsel for the Senate Committee on Health, Education, Labor, and Pensions and as a senior attorney at the Bazelon Center for Mental Health Law. Before becoming CEO of NAMI, she worked as a section chief in the Office for Civil Rights at the Department of Health and Human Services. Prior to that, Ms. Giliberti served as the Director of Public Policy and Advocacy for federal and state issues at NAMI.

Elena M. Kravitz

Elena M. Kravitz is a community mental health provider and advocate. A resident of Old Bridge, NJ, she is a Certified Psychiatric Rehabilitation Practitioner and an active volunteer and provider who brings a lived experience of recovery. Ms. Kravitz manages a peer support wellness center for the Collaborative Support Programs of New Jersey, a nationally recognized peer-led mental health organization. She also served as coordinator and lead presenter of the Hearts and Minds for the National Alliance on Mental Illness (NAMI) New Jersey and assists NAMI as a trainer in the In Our Own Voice and NAMI Connection programs. A board member of Disability Rights–New Jersey and her county's Freeholder-appointed Mental Health Board, Ms. Kravitz supports legal protections for people pursuing recoveries. She is one of New Jersey's leading trainers on psychiatric advance directives, taking a leadership role in her own county on initiatives to bring law enforcement and mental health together, promoting the police crisis intervention team. As a former staff member of a peer-staffed crisis respite house and as a peer worker in a psychiatric emergency service, Ms. Kravitz works to assist people pursuing recoveries move beyond a medication- and hospitalization-based model of mental health care, helping to spread awareness of shared decision-making, trauma-informed care, wellness recovery action planning, and the recovery library.

Kenneth Minkoff, M.D.

Kenneth Minkoff, M.D., is a Senior System Consultant for ZiaPartners, Inc., a part-time Assistant Professor of Psychiatry for Harvard Medical School, and Director of Systems Integration for the Meadows MH Policy Institute in Dallas, TX. A recognized expert on integrated services and systems for individuals with co-occurring serious mental illnesses and substance use disorders, he is a Board-Certified Addiction Psychiatrist. In the 1990s, he chaired a SAMHSA Managed Care Initiative Panel on Co-occurring Disorders and developed a national model for integrated system design for individuals with co-occurring mental health and substance use disorders. For the past 17 years, Dr. Minkoff has worked with his consulting partner Christie A. Cline, M.D., M.B.A., to improve behavioral health systems all over the world. Dr. Minkoff also is active in policy and practice on a national and state level, serving as an emeritus board member of the American Association of Community Psychiatrists and currently as Chair of the Products and Services Plank. An active participant in designing SAMHSA's Recovery to Practice Curriculum for psychiatrists, he is co-chair of the Committee on Psychiatry and the Community for the Group for the Advancement of Psychiatry, and is an incoming board member for the College for Behavioral Health Leadership.

Elyn R. Saks, J.D., Ph.D.

Elyn R. Saks, J.D., Ph.D., is Orrin B. Evans Professor of Law, Psychology, and Psychiatry and the Behavioral Sciences at the University of Southern California Gould School of Law. Dr. Saks is also Director of the Saks Institute for Mental Health Law, Policy, and Ethics. She is an adjunct professor of psychiatry at the University of California, San Diego, School of Medicine, and faculty at the New Center for Psychoanalysis. Dr. Saks received her J.D. from Yale Law School, and a Ph.D. in Psychoanalytic Science from the New Center for Psychoanalysis. She writes extensively on law and mental health, having published five books and more than fifty articles and book chapters. Her memoir, *The Center Cannot Hold: My Journey Through Madness*, describes her struggles with schizophrenia and her managing to craft a good life for herself in the face of a dire prognosis. Dr. Saks has won numerous honors, including a 2009 John D. and Catherine T. MacArthur Fellowship and an honorary Doctor of Laws from Pepperdine University.

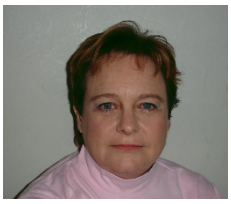
John Snook, J.D.

John Snook, J.D., is Executive Director of the Treatment Advocacy Center (TAC), an influential mental health advocacy organization. He received his J.D. from the George Mason School of Law in Virginia and his B.A. from Washington & Jefferson College in Pennsylvania. Mr. Snook brings to TAC nearly 20 years of policy and advocacy experience at both the federal and state levels. Prior to joining TAC, he worked on housing policy at the Mortgage Bankers Association and at Habitat for Humanity International, where he grew its state and local advocacy network into a driving nationwide force for affordable housing policy. Mr. Snook's passion has always been mental health reform. His focus on the issue began early, as he saw a loved one struggle with untreated serious mental illness. Mr. Snook championed mental illness reform, working first with the West Virginia Supreme Court on mental health issues and then at TAC. His return to TAC as Executive Director represents a homecoming in his work on these important issues.

Judge Rhathelia Stroud, J.D.

Judge Rhathelia Stroud, J.D., is a DeKalb County, Georgia Magistrate and as Chief Judge for the City of Decatur, GA, Municipal Court. A native of Atlanta, GA, she graduated from the University of Georgia and Georgia State University College of Law. As a magistrate, Judge Stroud presides over the DeKalb County Misdemeanor Mental Health Court and over Temporary Protective Order calendars as a superior court judge by designation. She has presided over the mental health court for 7 years. Judge Stroud has served as faculty for the Institute of Continuing Judicial Education eLearning 20-Hour Jail Diversion Online Course and for Emory University's School of Law Kessler-Eidson Trial Techniques Program. Before serving on the bench, Judge Stroud was a practicing attorney and partner with Mitchell Graham & Stroud, P.C., in Decatur, GA, and worked as Deputy General Counsel and Executive Director for the Department of Community Health and its Division of Health Planning, respectively. Her civic and professional affiliations include the State Bar of Georgia, DeKalb Lawyers Association's Community and Education Foundation, Georgia Association of Black Women Attorneys, Delta Sigma Theta Sorority, Inc., and the Providence Baptist Church Trustee Ministry.

Conni Wells



Conni Wells is a mental health consultant and advocate with over 30 years of lived experience. The parent and grandparent of children and young adults with health and mental health challenges, she served as a consultant and then Project Director of a National Technical Assistance Center, expanding the capacity of family- and consumer-run organizations serving children and youth with mental, emotional, and behavioral disorders. She was as a member of the Systems of Care Site Visit Team for three states, for which she also provided consulting on developing organizational capacity for family-run organizations. For 12 years, Ms. Wells directed the Florida Statewide Family Network, assisting the state in developing its system of care approach for vulnerable populations with mental health challenges. She also developed Florida's statewide family provider program for its Title V/CYSHCN Program, and served as a Senior Consultant at the Georgetown University National Center on Cultural Competence and as a Transformation Facilitator for the Georgetown University National Technical Assistance Center for Systems of Care. The former Chair for the National Certification for Parent Family Peers Commission, Ms. Wells currently works as a consultant on projects focusing on multiple systems of care values and has multiple publications, including *Straight Talk: Families Speak to Families about Child and Youth Mental Health*.

Appendix B

U.S. Department of Health and Human Services
Interdepartmental Serious Mental Illness Coordinating Committee
Glossary of Terms Used in Report

The terms within this glossary appear within the report. Many of the definitions have been taken verbatim or adapted from federal websites and reports.

Access to care: Having the timely use of personal health services to achieve the best health outcomes. Attaining good access to care requires three discrete steps: gaining entry into the health care system, getting access to sites of care where patients can receive needed services, and finding providers who meet the needs of individual patients and with whom patients can develop a relationship based on mutual communication and trust (AHRQ, 2011).

Acute care: Short-term care provided in intensive care units, brief hospital stays, and emergency rooms for those who are severely intoxicated or dangerously ill (CSAT, 2005).

Behavioral health: A state of mental/emotional being and/or choices and actions that affect wellness. Substance use and misuse are one set of behavioral health problems. Others include (but are not limited to) serious psychological distress, suicide, and mental illness (SAMHSA, n.d.).

Bipolar disorder: A mental condition in which a person has wide or extreme swings in mood. Periods of feeling sad and depressed may alternate with periods of being very happy and active, or being cross or irritable (MedlinePlus, n.d.-a).

Block grant: A noncompetitive, formula grant mandated by Congress. Eligible entities must submit an annual application to demonstrate statutory and regulatory compliance in order to receive the formula-based funding. SAMHSA is responsible for two block grant programs: the Substance Abuse Prevention and Treatment Block Grant (SABG) and the Community Mental Health Services Block Grant (MHBG) (SAMHSA, 2017b).

Coordinated care: Integrating the efforts of medical, behavioral health, and social service providers while addressing a person's health and wellness (CIHS, n.d.).

Cognitive behavioral therapy: A therapeutic approach that seeks to modify negative or self-defeating thoughts and behavior. CBT is aimed at both thought and behavior change—that is, coping by thinking differently and coping by acting differently (CSAT, 2005).

Comorbidity: The existence of two or more illnesses in the same person. These illnesses can be physical or mental (NIMH, n.d.).

Continuing care: Care that supports a client's progress, monitors his or her condition, and can respond to a return to substance use or a return of symptoms of mental disorder. It is both a process of post-treatment monitoring and a form of treatment itself. Sometimes referred to as "aftercare" (CSAT, 2005).

Co-occurring mental health and substance use disorder (a.k.a., co-occurring disorders): Co-existence of a substance use disorder and a mental health disorder at the same time (for example, alcohol dependence and depression). The combination of disorders can include any two or more of those identified in the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5). This condition is sometimes referred to as comorbidity (SAMHSA, n.d.).

Coordinated care: Integrating the efforts of medical, behavioral health, and social service providers while addressing a person's health and wellness (CIHS, n.d.).

Coordinated specialty care: A type of treatment for first-episode psychosis that uses a team of specialists who work with the client to create a personal treatment plan. The specialists offer psychotherapy, medication management, CSC case management, family education/support, and supported employment/education, depending on the person's needs and preferences. The client and the team work together to make treatment decisions, involving family members as much as possible (NIMH, n.d.).

Crisis services (also known as crisis care or crisis continuum): A continuum of services that are provided to people experiencing a psychiatric emergency. The primary goal of these services is to stabilize and improve psychological symptoms of distress and to engage people in an appropriate treatment service to address the problem that led to the crisis. Core crisis services include 24-hour crisis stabilization/observation beds, short-term crisis residential services and crisis stabilization, mobile crisis services, 24/7 crisis hotlines, warm lines, psychiatric advance directive statements, and peer crisis services (SAMHSA, 2014).

Cultural appropriateness: In the context of public health, sensitivity to the differences among ethnic, racial, and/or linguistic groups and awareness of how people's cultural background, beliefs, traditions, socioeconomic status, history, and other factors affect their needs and how they respond to services. Generally used to describe interventions or practices (SAMHSA, n.d.).

Culturally competent treatment: Cultural competence is the ability to interact effectively with people of different cultures. In practice, both individuals and organizations can be culturally competent. Culture is a term that goes beyond just race or ethnicity. It can also refer to such characteristics as age, gender, sexual orientation, disability, religion, income level, education, geographical location, or profession. Cultural competence means being respectful and responsive to the health beliefs and practices—and cultural and linguistic needs—of diverse population groups. Developing cultural competence is an evolving, dynamic process that takes time and occurs along a continuum (SAMHSA, 2016a).

Engagement: A client's commitment to and maintenance of treatment in all of its forms. A successful engagement program helps clients view the treatment facility as an important resource (CSAT, 2005).

Evidence-based practice: A practice that is based on rigorous research that has demonstrated effectiveness in achieving the outcomes that it is designed to achieve (SAMHSA, n.d.).

Fidelity: Occurs when implementers of a research-based program or intervention (e.g., teachers, clinicians, counselors) closely follow or adhere to the protocols and techniques that are defined as part of the intervention (SAMHSA, n.d.).

First-episode psychosis: The first time a person experiences an episode of psychosis (see definition for psychosis) (NIMH, n.d.).

Homelessness: Not being able to find a stable and safe place to stay. People experiencing homelessness may find themselves in one of the following groups:

- **Unsheltered:** Living on the streets, camping outdoors, or living in cars or abandoned buildings
- **Sheltered:** Staying in emergency shelters or transitional housing
- **Doubled up:** Staying with friends or family temporarily (SAMHSA, 2017c)

Implementation: A planned, coordinated group of activities, processes, and procedures designed to achieve a specific purpose. An intervention should have specified goals, objectives, and structured components (e.g., a defined curriculum, an explicit number of treatment or service hours, and an optimal length of treatment) to ensure the intervention is implemented with fidelity to its model (SAMHSA, n.d.).

Inpatient care: Health care that a person receives when admitted as an inpatient to a health care facility, such as a hospital or skilled nursing facility (CMS, n.d.).

Integrated treatment: Any mechanism by which treatment interventions for co-occurring disorders are combined within the context of a primary treatment relationship or service setting. It recognizes the need for a unified treatment approach to meet the substance abuse, mental health, and related needs of a client, and is the preferred model of treatment (CSAT, 2005).

Intervention: A strategy or approach intended to prevent an undesirable outcome (preventive intervention), promote a desirable outcome (promotion intervention), or alter the course of an existing condition (treatment intervention) (SAMHSA, n.d.).

Justice diversion program: A program that addresses the behavioral health needs of people involved in, or at risk of involvement in, the criminal justice system by providing an array of community-based diversion services designed to keep people with behavioral health issues out of the criminal justice system while also addressing issues of public safety (SAMHSA, 2015).

Justice system: Term meant to be inclusive of both the criminal justice and juvenile justice systems.

Juvenile justice system: Youth under age 18 who are accused of committing a delinquent or criminal act are typically processed through a juvenile justice system. While similar to the adult criminal justice system in many ways—processes include arrest, detainment, petitions, hearings, adjudications, dispositions, placement, probation, and reentry—the juvenile justice process operates according to the premise that youth are fundamentally different from adults, both in

terms of level of responsibility and potential for rehabilitation. The primary goals of the juvenile justice system, in addition to maintaining public safety, are skill development, habilitation, rehabilitation, addressing treatment needs, and successful reintegration of youth into the community (youth.gov, n.d.).

Major depression: A mood disorder. It occurs when feelings of sadness, loss, anger, or frustration get in the way of a person's life over a long period of time. It also changes how a person's body works (MedlinePlus, n.d.-b).

Outpatient: A structured service setting or program that provides ambulatory (not overnight) care delivered in a specialty mental health facility/hospital/center/clinic, specifically for the treatment of mental health clients. Care is generally provided for visits of 3 hours or less in duration and 1 or 2 days per week (SAMHSA, 2017a).

Outreach strategies (mental health): Approaches that actively seek out people in a community who may have substance use disorders and engage them in substance abuse treatment (CSAT, 2005).

Peer: In the context of peer support, a peer is a person who has lived experience with a psychiatric, traumatic, and/or addiction challenge, and may benefit from peer support (CIHS, n.d.).

Peer support: The process of giving and receiving nonclinical assistance to achieve long-term recovery from severe psychiatric, traumatic, or addiction challenges. This support is provided by peer supporters—people who have "lived experience" and have been trained to assist others in initiating and maintaining long-term recovery and enhancing the quality of life for people and their families. Peer support services are inherently designed, developed, delivered, evaluated, and supervised by peers in long-term recovery (CIHS, n.d.).

Person-centered care (also known as patient-centered care): Means consumers have control over their services, including the amount, duration, and scope of services, as well as choice of providers. Person-centered care also is respectful and responsive to the cultural, linguistic, and other social and environmental needs of the individual (SAMHSA, 2016b).

Poverty: The Census Bureau uses a set of income thresholds that vary by family size and composition to determine who is in poverty. If a family's total income is less than the family's threshold, then that family and every person in it is considered in poverty (United States Census Bureau, 2017).

Practice standards: Rules or guidelines used as the basis for informed decision-making about acceptable work performance and practices. They are established by an authoritative entity through a collaborative process with input from a wide range of people who perform the work. Standards are based on values, ethics, principles, and competencies. Having a core set

of standards is one important way to legitimize a field of practice. Practice standards generally have three basic components: 1) practice guidelines, 2) identification and description of core competencies, and 3) ethical guidelines or code of ethics (CIHS, n.d.).

Prevention strategies: Approaches that seek to prevent the onset of physical and behavioral health disorders. The Institute of Medicine has defined three types of preventions strategies:

- **Universal prevention strategies** address the entire population (such as national, local community, school, or neighborhood), with messages and programs to prevent or delay the development of behavioral health disorders.
- **Indicated prevention strategies** focus on preventing the onset or development of problems in people who may be showing early signs but are not yet meeting diagnostic levels of a particular disorder.
- **Selective prevention strategies** focus on specific groups viewed as being at higher risk for mental health disorders or substance use disorders because of highly correlated risk factors (for example, the children of parents with substance use problems) (SAMHSA, n.d.).

Primary care: The care provided by physicians specifically trained for and skilled in comprehensive first contact and continuing care for people with any undiagnosed sign, symptom, or health concern (the "undifferentiated" patient) not limited by problem origin (biological, behavioral, or social), organ system, or diagnosis (CIHS, n.d.).

Psychosis: A mental disorder that is characterized by distinct distortions of a person's mental capacity, ability to recognize reality, and relationships to others to such a degree that it interferes with that person's ability to function in everyday life (CSAT, 2005).

Recovery: A process of change through which people improve their health and wellness, live a self-directed life, and strive to reach their full potential. Through the Recovery Support Strategic Initiative, SAMHSA has delineated four major dimensions that support a life in recovery: health, home, purpose, and community (SAMHSA, n.d.).

Restrictive housing: Any type of detention that involves (1) removal from the general inmate population, whether voluntary or involuntary; (2) placement in a locked room or cell, whether alone or with another inmate; and (3) inability to leave the room or cell for the vast majority of the day, typically 22 hours or more. Even this definition, however, leaves substantial room for variation (DOJ, 2017).

Schizophrenia: A brain disorder that impacts the way a person thinks (often described as a "thought disorder"), and is characterized by a range of cognitive, behavioral, and emotional experiences that can include: delusions, hallucinations, disorganized thinking, and grossly disorganized or abnormal motor behavior. Although these symptoms are chronic and severe,

significantly impairing occupational and social functioning, recovery is possible (SAMHSA, n.d.).

Service utilization: A measure of whether the program is reaching the appropriate target population (SAMHSA, n.d.).

Serious emotional disturbance (SED): Refers to children and youth who have had a diagnosable mental, behavioral, or emotional disorder in the past year, which resulted in functional impairment that substantially interferes with or limits the child's role in family, school, or community activities (SAMHSA, 2017d).[12]

Serious mental illness (SMI): Refers to people age 18 or older, who currently or at any time during the past year have had a diagnosable mental, behavioral, or emotional disorder of sufficient duration to meet diagnostic criteria specified in the diagnostic manual of the American Psychiatric Association that has resulted in functional impairment, which substantially interferes with or limits one or more major life activities. Serious mental illnesses include major depression, schizophrenia, and bipolar disorder, and other mental disorders that cause serious impairment (SAMHSA, 2017d).

Solitary confinement: See "restrictive housing" (DOJ, 2017).

Stigma: A negative association attached to an activity or condition. A cause of shame or embarrassment (CSAT, 2005).

Sustainability: The long-term survival and continued effectiveness of an intervention (SAMHSA, n.d.).

Symptomatology: The combined symptoms or signs of a disorder or disease (SAMHSA, n.d.).

Transition-age youth: People between ages 16 to 25. People in this age group are at high risk for substance use and mental health disorders, but they are also among those least likely to seek help (Development Services Group, Inc., 2016).

Treatment guidelines: Descriptions of best practices for assessment or management of a health condition (CIHS, n.d.).

12 This is different from the IDEA definition of emotional disturbance; for detail on the criteria for emotional disturbance under IDEA, see http://idea.ed.gov/explore/view/p/,root,regs,300,A,300.8,.html.

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