



# Interdepartmental Serious Mental Illness Coordinating Committee

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**Advances Through Collaboration:** Federal Action for a System That Works for All People Living with SMI and SED and Their Families and Caregivers

REPORT TO CONGRESS  
April 2022



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# INTRODUCTION

On August 31, 2017, the Interdepartmental Serious Mental Illness Coordinating Committee (ISMICC) was first convened. The meeting included leadership from 10 federal agencies and 14 non-federal public stakeholders. There was deep consensus among ISMICC members that too many people with serious mental illness (SMI) and severe emotional disturbance (SED) do not get the treatment and support that they need. They noted the challenges within a fragmented United States treatment delivery system that provides an incomplete array of needed services and does not always draw on available evidence. They acknowledged the needless suffering of individuals, and their families and caregivers, and the increased risk of incarceration, unnecessary institutionalization, homelessness, poor physical and mental health outcomes, and early death.

On December 13, 2017, the ISMICC submitted its first Report to Congress, ***The Way Forward: Federal Action for a System That Works for All People Living with SMI and SED and Their Families and Caregivers***. The report emphasized the importance of collaboration, coordination, and planning across federal agencies to ensure that Americans with SMI and SED are able to improve their lives and receive the highest possible standard of care. The report listed 45 recommendations across five areas of focus that were carefully crafted by the non-federal ISMICC members (see Appendix A).

Four years later, it is time to reflect on the advances the federal agencies have made in addressing the areas of focus and recommendations articulated in the 2017 ISMICC *The Way Forward* Report to Congress.

As anticipated, the recommendations helped shape the thinking and activities of federal members during the intervening years. Federal representatives participated in meetings, convened workgroups, revised policies, and developed national guidelines to advance the development of a comprehensive array of treatments and supports. There is little doubt that the ISMICC has stimulated new relationships and partnerships across federal agencies, and that the participating agencies have addressed, at least in part, most of the recommendations from the 2017 ISMICC *The Way Forward* Report to Congress.

## DEFINING SMI AND SED

**Serious mental illness (SMI)**<sup>1</sup> refers to a diagnosable mental, behavioral, or emotional condition of sufficient duration and functional impairment, and that substantially interferes with or limits one or more major life activities either currently or during the past year. The condition must meet criteria specified in the *Diagnostic and Statistical Manual of Mental Disorders (DSM-5)* and refers to individuals 18 or older. Major life activities include basic daily living skills (such as eating, bathing, and dressing); instrumental living skills (such as maintaining a household, managing money, getting around the community, and taking prescribed medication); and functioning in social, family, and vocational/educational contexts.

**Serious emotional disturbance (SED)**<sup>2</sup> refers to a diagnosable mental, behavioral, or emotional condition which results in functional impairment that substantially interferes with or limits a child's, adolescent's, or youth's role in family, school, or community activities.

Additionally, due to developments in the field, a global pandemic, and changes in the way people seek and receive behavioral health care, there are new and emerging focus areas for which recommendations may be appropriate.

This report reviews the advances made by federal agencies in addressing the recommendations articulated in the 2017 *The Way Forward* Report to Congress. This report also identifies emerging areas of focus that may be addressed through continued collaboration and coordination among federal agencies.

## ISMICC

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In December 2016, the 21<sup>st</sup> Century Cures Act was signed into law. Through this Act (Public Law 114-255), the ISMICC was established to enhance coordination across federal agencies and improve service access and delivery of care for people with SMI and SED, and their families and caregivers. ISMICC provides an opportunity for the federal government to promote and increase community living options for people with SMI and SED, in accordance with Title II of the Americans with Disabilities Act (ADA), 42 U.S.C. §§ 12131–12134, as interpreted by the Supreme Court in *Olmstead v. L.C.*, 527 U.S. 581 (1999), which requires public entities to administer services to individuals with disabilities in the most integrated setting appropriate to their needs.

In 2021, the Secretary of the U.S. Department of Health and Human Services (HHS) designated the Assistant Secretary for Mental Health and Substance Use, Dr. Miriam E. Delphin-Rittmon, to serve as the ISMICC chair. The ISMICC includes 10 federal agencies that support programs that address the needs of people with SMI and SED. The Substance Abuse and Mental Health Services Administration (SAMHSA) and the Centers for Medicare and Medicaid Services (CMS) are both agencies within HHS and were included as required members of the ISMICC by the legislation.

The collaboration among federal partners is informed and strengthened by the participation of 14 non-federal members, including national experts on healthcare research, mental health providers, advocates, and people with mental health conditions, and their families and caregivers (see Appendix B).

The ISMICC is currently authorized through March 2023 and continues to convene regularly. As stated in section 6031 of the 21<sup>st</sup> Century Cures Act, the HHS Secretary is required to submit a

### FEDERAL DEPARTMENTS AND AGENCIES REPRESENTATION ON THE ISMICC

- Centers for Medicare & Medicaid Services
- Department of Defense
- Department of Education
- Department of Health and Human Services
- Department of Housing and Urban Development
- Department of Justice
- Department of Labor
- Department of Veterans Affairs
- Social Security Administration
- Substance Abuse and Mental Health Services Administration

letter to Congress, recommending whether Congress should consider reauthorization of the ISMICC. The letter accompanies this Report and recommends reauthorization of the ISMICC.

### **2017 RECOMMENDATIONS CENTERED ON FIVE FOCUS AREAS**

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.

### **ISMICC Members**

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ISMICC has been fortunate in that all of the members have clear passion, expertise, and skills in addressing the needs of people with SMI and SED. Federal ISMICC members and their designees, who are knowledgeable about mental health care delivery and federal policy, embraced the guidance provided by the non-federal members to implement the 45 recommendations within the five focus areas identified in the 2017 ISMICC *The Way Forward* Report to Congress.

Together with non-federal members, they participated in meetings and workgroups, convened expert panel meetings, reviewed the state-of-the-art science, and critically assessed federal programming and policies. They heard from federal scientists and policy makers to determine the impact of current policies and programs, and to understand the federal levers for change. They

listened to the voices of adults with SMI, youth with SED, and their families and caregivers. They heard the pain, hopelessness, and successes experienced by people with SMI and SED who receive services affected by federal policies and programs.

The strength, dedication, and perseverance of ISMICC members has resulted in increases in federal coordination, reductions in duplication, and increased use of science-based decision-making to improve the availability and quality of care for people with SMI, children with SED, and their families and caregivers.

## Organization of Report

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The current Report builds off of the 2017 ISMICC *The Way Forward* Report to Congress, and is divided into the following sections:

- **Chapter 1** provides an overview of the advances in federal policy, programming, and collaboration in the past four years, as they relate to the areas of focus identified in the 2017 ISMICC *The Way Forward* Report to Congress (Appendix A).
- **Chapter 2** highlights changes since 2017 in the SMI and SED populations and their needs. Select federal initiatives that correspond to 2017 ISMICC recommendations are featured. The chapter also discusses the impact of COVID-19 and reinforces the urgency to address racial and ethnic disparities in behavioral health care.
- **Chapter 3** identifies opportunities for federal agencies to better align and coordinate their efforts to support people with SMI and SED, and their families and caregivers.

The Report highlights the value of interagency federal coordination for improving the availability of high-quality behavioral healthcare for people of all ages with SMI and SED. The ISMICC has demonstrated that there is much to be gained from convening federal and non-federal members to foster cross-sector learning. The ISMICC is a successful model that can continue to inform federal policies and promote behavioral health services that are easy to access and navigate, appropriate, and tailored to individual needs.

In 2022, the ISMICC members are planning to develop a supplemental report that will encompass all the work that was accomplished over the past four years related to the ISMICC focus areas and recommendations. This report will also highlight some of the ongoing needs of adults with SMI and children with SED, and their families and caregivers, and focus on high priority solutions to meet the needs.

# CHAPTER 1

## Advances in Federal Policy, Programming and Collaboration

Since the 2017 ISMICC Report to Congress, the field has advanced in ways that are likely to improve the lives of people with SMI and SED. Access to care improved through the use of synchronous telehealth (such as video and telephone appointments). Increases in the integration of mental health and substance use disorder (SUD) services within primary care clinics have helped ensure that attention is given to addressing metabolic side effects and chronic medical conditions.<sup>3</sup>

Although the ISMICC federal agencies were involved in these advances and more, this chapter provides a snapshot of the advances made by the federal partners within the five areas of focus identified in the 2017 ISMICC *The Way Forward* Report to Congress (see Appendix A). For each focus area, a dashboard summarizes the following:

### A SNAPSHOT OF ISMICC



**Federal Agencies Involved in Collaboration and/or Implementation.** Lists federal agencies that participated in workgroups and/or expert panel meetings and/or implemented a change in programs or policies (see Appendix C to view across areas of focus).



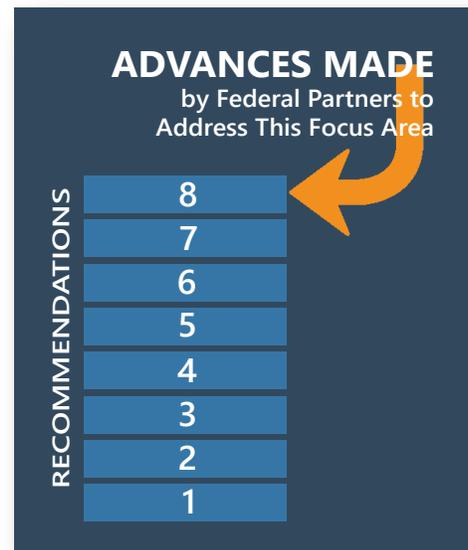
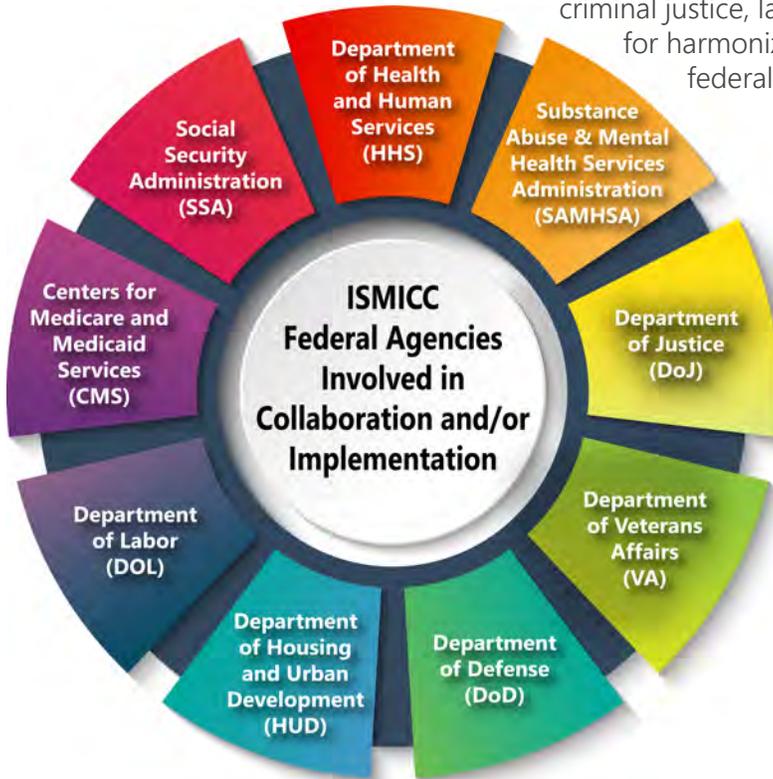
**Advances Made by Federal Partners to Address Focus Area.** The blue bar on each Focus Area page indicates the number of recommendations in that particular focus area and how many of those recommendations had advances made by at least one federal agency to address the recommendation. It is important to note that “advance” does not mean the recommendation was fully addressed or that all parts of the recommendation have been accomplished. The graphic indicates whether any of the federal agencies reported that they took steps towards addressing the recommendation.

The chapter also includes examples of federal programs, policies, and activities illustrating the influence of the ISMICC recommendations on federal agencies. These examples are illustrative, rather than exhaustive.

# FOCUS 1

## Strengthen Federal Coordination to Improve Care

The eight recommendations embedded in Focus Area 1 emphasize the need to understand the role, resources, and policies of the agencies represented on the ISMICC to identify opportunities and barriers to federal coordination. In particular, the recommendations urge improved linkages among federal and national data sets relevant to the lives of people with SMI and SED, including data sets on primary care, education, criminal justice, labor, military personnel, and veterans. They call for harmonization and the use of standard definitions across federal databases.



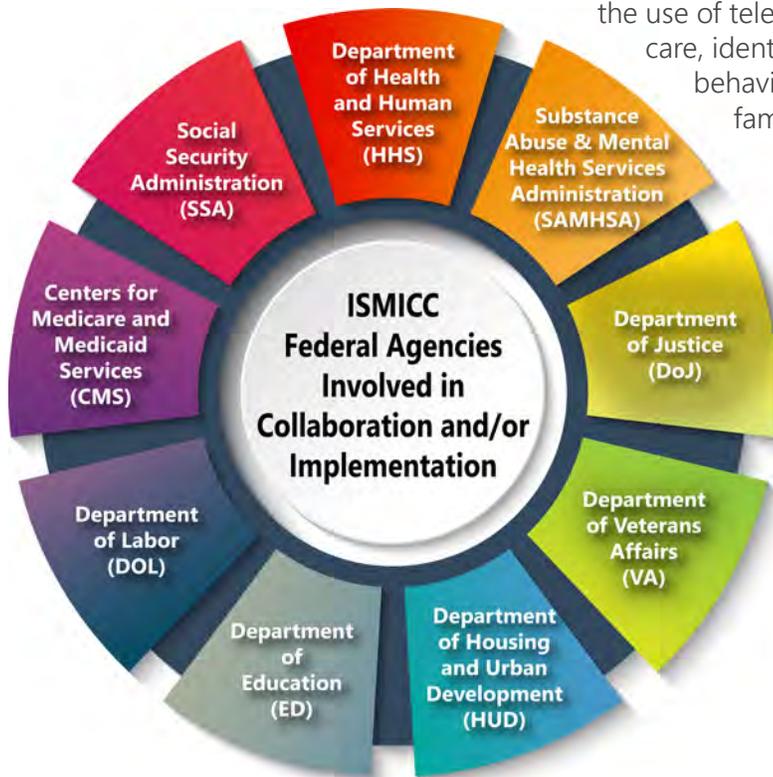
## Featured Programs or Policies

- As a direct response to the ISMICC recommendations, HHS, and specifically SAMHSA, are funding the Mental and Substance Use Disorders Prevalence Study to produce national estimates of the number of people experiencing SMI and SUD among U.S. adults. Obtaining this data will help federal agencies better target resources.
- The Social Security Administration (SSA) is collaborating with the Bureau of Labor Statistics (BLS) to develop a survey BLS will use to collect current, detailed, occupational data using the Occupational Requirements Survey (ORS). These data will contribute to the development of a new Occupational Information System to replace the Dictionary of Occupational Titles. The effort will provide current occupational information regarding the requirements of jobs that exist in the national economy and will better ensure an accurate disability determination process for people with SMI.
- The Agency for Healthcare Research and Quality (AHRQ), the Centers for Disease Control and Prevention (CDC), and SAMHSA, all within HHS, are collaborating to expand the content of several national surveys to include questions relevant to the lives of people experiencing SMI and SED. The surveys being updated include: The Medical Expenditure Panel Survey (MEPS), Health Care Cost and Utilization Project (HCUP), and the National Hospital Care Survey (NHCS).

## FOCUS 2

### *Access and Engagement: Make It Easier to Get Good Care*

The ten recommendations within this area of focus emphasize partnerships at the federal, state, and local levels to build the capacity of mental health systems to provide a comprehensive array of services in communities. They propose that people with SMI and SED receive care in the least-restrictive setting appropriate to the needs of the individual, that the use of standardized assessment tools be part of usual care, and that early identification and intervention for children, youth, and young adults become a federal priority. The recommendations call for the use of telehealth and other technologies to increase access to care, identification of ways to maximize the capacity of the behavioral health workforce, and continued support of family members and caregivers.



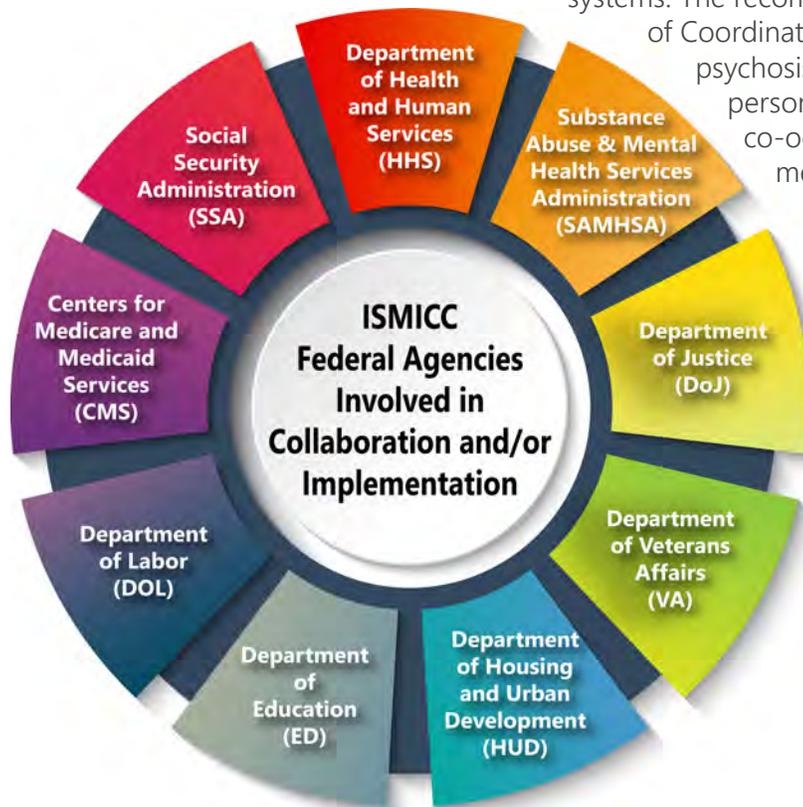
### Featured Programs or Policies

- By July 2022, HHS, SAMHSA, and the Veterans Administration (VA), in close collaboration with the Federal Communications Commission (FCC), will launch the “988” phone number to address suicide prevention and crisis intervention. Similar to when someone dials “911” for a medical emergency, the 988 number will connect people with a workforce trained in crisis response techniques to address behavioral health care needs of callers.
- The Office of Disability Employment Policy, within DOL, is leading a cross-agency Supported Employment Committee that is bringing together federal agencies and programs that fund employment services, to educate and advance implementation of proven employment strategies for people with SMI.
- SSA published the Youth Toolkit for caretakers and families of youth experiencing SED. The toolkit provides information on how to navigate services and supports to help youth become self-sufficient. Additionally, to strengthen the capacity of the workforce, the agency provided Continuing Medical Education training for more than 400 medical consultants on behavioral disorders in children.

## FOCUS 3

### *Treatment and Recovery: Close the Gap Between What Works and What Is Offered*

The ten recommendations within this area of focus call for the development of standards of care that include a full spectrum of integrated, complementary services known to be effective and to improve outcomes for people with SMI and SED. They note that standards should be appropriate to phases of development and aging, and that attention should be given to children and youth transitioning into adult systems. The recommendations also call for the broad availability of Coordinated Specialty Care (CSC) for first episode psychosis (FEP), trauma-informed services, whole-person health care, services for people with co-occurring substance use conditions, and medications for opioid use disorders.



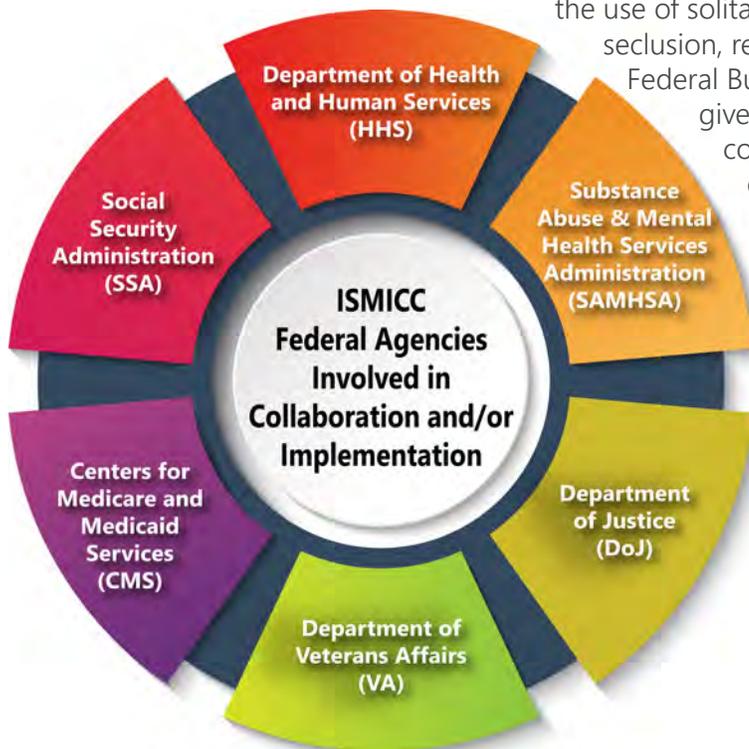
### Featured Programs or Policies

- Through the support of programs such as the Mental Health Block Grant Set-Aside for people with Early Serious Mental Illness, the Early Psychosis Intervention Network (EPINET), and the Early Psychosis Intervention Coordination (EPIC) program, the VA, SAMHSA, and the National Institute of Mental Health (NIMH), within HHS, are working to ensure the broad availability of CSC for people experiencing FEP.
- The Comprehensive Center Network funded by the Department of Education provides technical assistance to states, school districts, and schools to build the capacity of educational leadership in social-emotional, behavioral learning and mental health approaches to better support the well-being of students and families (<https://compcenternetwork.org/>).
- The VA and HHS, including SAMHSA and CMS, collaborated to expand the Certified Community Behavioral Health Clinics (CCBHC) program, which provides a robust array of services and addresses the comprehensive needs of people with behavioral health conditions, including 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*

The nine recommendations within this focus area call for the implementation of interventions to correspond to all stages of justice involvement for people with SMI and SED. They assert that there should be an adequate array of behavioral health services to divert people with SMI and SED from becoming involved in the justice system with a particular emphasis on avoiding initial arrest. Until that time, attention should be given to developing mechanisms for information sharing between crisis service providers and law enforcement personnel; implementing regular screening for SMI, SED, and suicide risk; and training first responders on how to work with people with SMI and SED. Through federal coordination, efforts should be made to implement a plan to reduce and eventually eliminate the use of solitary confinement and other forms of segregation, seclusion, restraint, and the isolation of people with SMI within Federal Bureau of Prisons facilities. Finally, attention should be given to establishing the use of best practices for competency restoration using community-based evaluation and services.



### Featured Programs or Policies

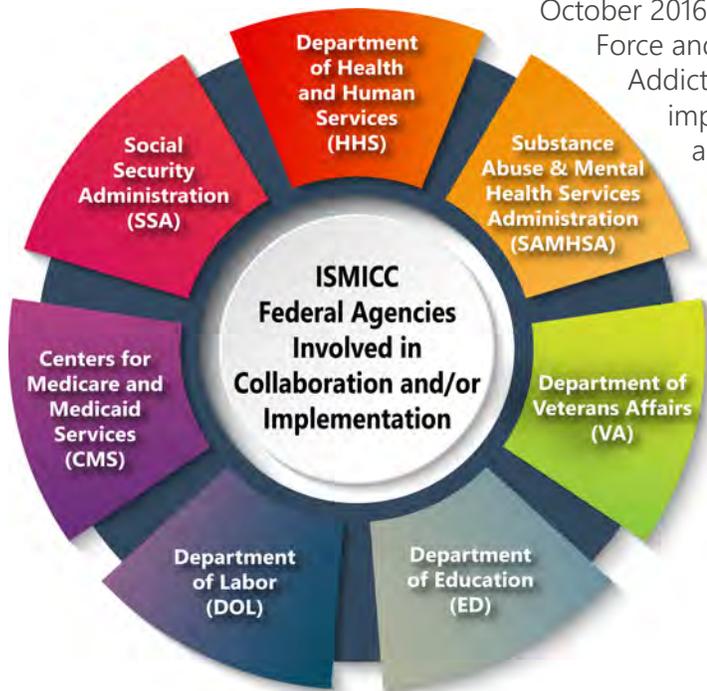
- The Bureau of Justice Assistance within DoJ, in collaboration with SAMHSA, supports a number of important initiatives. This includes the Stepping Up initiative to assist counties to use universal screening and assessment in jails; the Justice and Mental Health Collaboration Program which funds special court dockets and Mental Health Courts; and the Academic Training to Enhance Police Engagement with People with Behavioral Health Issues and Developmental Disabilities, which is designed to enhance, implement, and evaluate crisis intervention and disability response training for law enforcement and first responders.
- The VA expanded their Veterans Justice Outreach program by hiring a national coordinator and 51 Justice Outreach Specialists who are frontline workers working with Veterans Treatment Courts and jails. The Specialists connect veterans with SMI and SUD with VA-covered services.
- The Bureau of Prisons within DoJ is supporting the development of 10 Reintegration Units which provide an alternative to restrictive housing for up to 1,000 inmates who request protective custody. Additionally, the Bureau invested in three Secure Mental Health Units for inmates with SMI and histories of severe violence.

# FOCUS 5

## Develop Finance Strategies to Increase Availability and Affordability of Care

The eight recommendations that make up Focus Area 5 explore the need to eliminate financing practices and policies that discriminate against behavioral health care. Recommendations address the need for adequate funding for home- and community-based services for children and youth with SED and adults with SMI; for reimbursement for outreach and engagement services; and for payment rates for behavioral health services to be equivalent to other health care payments. They call for the expansion of the CCBHC program; and full implementation of the

October 2016 recommendations from the White House Parity Task Force and 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).<sup>4</sup>



## Featured Programs or Policies

- CMS provided states with flexibility to test comprehensive approaches to care for beneficiaries with SMI, SED, and/or SUD through an announcement of a Medicaid Section 1115 demonstration waiver published in November 2018. As of November 2021, CMS has approved 38 Section 1115 demonstration waivers related to behavioral health care.
- DOL, CMS, HHS, and the Department of Treasury developed a plan to enhance parity financing for mental health and SUD treatments and services. DOL also released finalized updates to its 2020 parity Self-Compliance Tool, which is published on the DOL website and intended to help health plan issuers evaluate their adherence to parity requirements, and vigorously enforce the requirements of MHPAEA with respect to improper limitations and financial requirements on mental health and SUD benefits as part of its national MHPAEA Health Enforcement project. CMS continues to work with state Medicaid agencies to enforce mental health parity in their Medicaid and Children’s Health Insurance Programs (CHIP).
- The Employee Benefits Security Administration within DOL is implementing a new enforcement program aimed at increasing equity and access to mental health and SUD benefits in plans covered by the Employee Retirement Income Security Act of 1974. Under the Consolidated Appropriations Act of 2020, the agency is pursuing more than 87 investigations into plans’ compliance with their statutory obligation not to impose different and more onerous hurdles on individuals in need of mental health and substance use benefits than the plans impose on individuals to medical and surgical benefits. These efforts have already resulted in the removal of unlawful barriers to treatment in plans covering tens of thousands of plan participants.

# CHAPTER 2

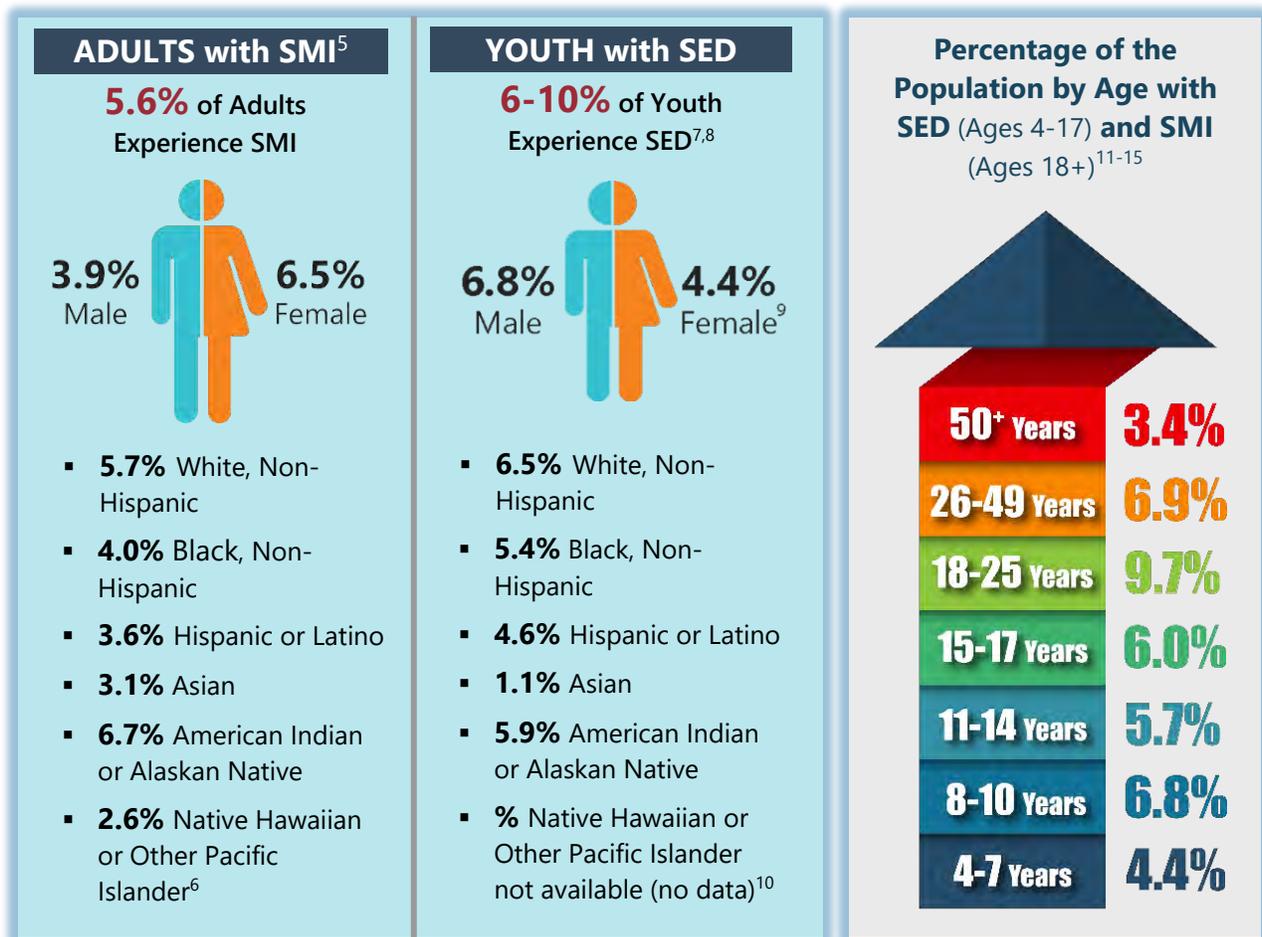
## National Data and Trends Related to SMI and SED

This chapter focuses on national data that are relevant to adults with SMI and youth with SED, and their families and caregivers. Attention is given to information identified in the 21<sup>st</sup> Century Cures Act (Public Law 114-255) as important indicators that can be influenced by federal coordination. Whenever possible, data trends are included to help identify change over time.

This chapter includes data related to the recommendations in the 2017 ISMICC *The Way Forward* Report to Congress. A select number of federal initiatives are showcased, as they relate to innovations and advances made through ISMICC federal partnerships and coordination.

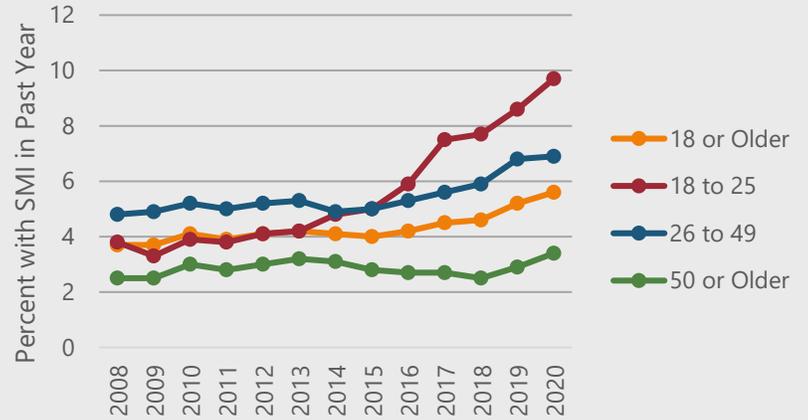
When viewing these data, it is important to acknowledge the global COVID-19 pandemic has disrupted all aspects of American life. All federal agencies that are members of the ISMICC have had to pivot to address crisis caused by COVID-19. Regardless, these agencies worked together to address the 2017 ISMICC recommendations and these efforts are reflected in the chapter.

### Current Prevalence of SMI and SED at a Glance



## Increasing Rates of SMI

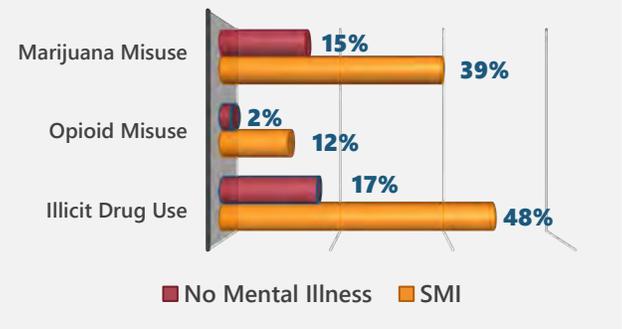
The rates of SMI have continued to increase for all age groups among adults.<sup>16</sup>



## SMI, SED, and Co-occurring Substance Use

Of the 14.2 million adults with SMI, 5.7 million, or 40 percent, also have SUD. Further, over 60 percent of adolescents in community-based SUD treatment programs also meet diagnostic criteria for mental illness.<sup>18</sup>

### Adults with SMI Misuse Drugs at Higher Rates<sup>17</sup>



## Consequences of Unmet Needs



**17-34%** of criminal justice involved individuals have an SMI.<sup>19</sup>



**25%** of the homeless population have an SMI.<sup>20</sup>



**76-90%** of adults with SMI do not have jobs.<sup>21</sup>



**62%** of youth involved with the juvenile justice system has at least one mental health diagnosis.<sup>22</sup>

## Access to Care

Unfortunately, 35% of adults with SMI do not receive mental health treatment. This rate is even higher, at 42%, among young adults aged 18-24.<sup>23</sup> The consequences of unmet needs include criminal justice involvement, homelessness, and unemployment, making access to quality care essential.

Seventeen percent of youth, 12-17 years old, access mental health services in mental health settings.<sup>24</sup> Schools often serve as significant support to children and adolescents with SED and their families and frequently provide or refer those in need to mental health treatment. The majority, 85% of youth who receive mental health services from outside of the mental health specialty system, receive their care in schools.<sup>25</sup>

# Data Trends Advanced by ISMICC

## Fostering a National Consensus on Crisis Care

The 2017 ISMICC *The Way Forward* Report to Congress noted that the lack of a comprehensive coordinated crisis response system for youth and adults has resulted in inconsistent care, repeated emergency department visits, hospitalization, and avoidable involvement with the criminal justice system. In most communities, when a person experiences a behavioral health crisis, such as suicidality, they are transported to the nearest hospital emergency department (ED) for evaluation and may be admitted to an inpatient unit. This approach is frequently inadequate and expensive.<sup>26</sup>

In 2018, SAMHSA and its ISMICC partners convened a panel of federal and state agency leaders, providers, consumers, and their families to outline standards for an array of crisis care. The culmination of the meeting is the publication titled, *National Guidelines for Behavioral Health Crisis Care Best Practice Toolkit*,<sup>27</sup> which builds on knowledge and data from other reports.<sup>28,29,30</sup>

States are finding ways to fund three core service elements identified in the toolkit.<sup>31</sup>

- **96%** of states fund 24-hour call centers/hotlines
- **94%** of states fund mobile crisis services
- **92%** of states fund crisis receiving and stabilization programs

### SUICIDE AMONG PEOPLE WITH SMI AND SED

Among youth, 15-24 years old who are diagnosed with schizophrenia, suicide is the leading cause of premature death.<sup>32</sup>

It is the second leading cause of death for adolescents and young adults aged 10 to 24 in the United States.<sup>33</sup>



Rate of suicide among people with SMI is **20-25 times higher** compared to the general population.<sup>34</sup>

*While suicide attempts have not decreased in the past decade, in 2019 suicide rates, declined for the first time in 13 years, after over a decade of consecutive years of rate increases.*

### Decline in Rates of Suicide Between 2018 and 2019<sup>35</sup>



**2.1%** decline in the overall suicide rate

**3.2%** decline among females

**1.8%** decline among males

**2.9%** decline in the lethal use of firearms

## COMING IN JULY 2022!



On July 16, 2020, the Federal Communications Commission, in coordination with HHS, VA, and other ISMICC federal partners adopted 9-8-8 as the new, nationwide, easy-to-remember 3-digit phone number for Americans in crisis to connect with suicide prevention and mental health crisis counselors. The rules require phone service providers to direct all 988 calls to the existing National Suicide Prevention Lifeline by July 16, 2022.

During the transition to 988, Americans who need help should continue to contact the National Suicide Prevention Lifeline by calling 1-800-273-8255 (1-800-273-TALK) and through online chats. Veterans and Service members may reach the Veterans Crisis Line by pressing 1 after dialing, chatting online at [www.veteranscrisisline.net](http://www.veteranscrisisline.net), or texting 838255.

## Implementing a Model for Whole Health Care

In 2014, Congress authorized the establishment of CCBHCs. Eight states were selected to implement a two-year Medicaid-funded demonstration program. In 2020, two more states were added to the demonstration. CCBHCs are expected to coordinate comprehensive behavioral health care and services, including crisis care services, with social services, hospitals, health clinics, law enforcement, justice systems, veterans' services, and schools in the community. Individuals seeking care cannot be refused based on their inability to pay or lack of a fixed address. Further, CCBHC boards must include people with the lived experience of SMI or caregiving to a loved one with SED.

By 2017, 67 CCBHCs began providing person/family-centered, trauma-informed, and recovery-oriented care, serving the "whole-person" rather than simply one disconnected aspect of the individual. Between 2018 and 2021, SAMHSA awarded 466 CCBHC Expansion grants to existing and new CCBHCs in 40 states, plus Washington, D.C., and Guam.

### Select Accomplishments within the CCBHC Program

 **31%** increase across CCBHCs in the number of peer specialist/recovery coaches.<sup>36</sup>

 **46%** increase in the number of 24-hour mobile crisis teams in the first year.<sup>37</sup>

 **54%** decrease in the number of CCBHC clients using behavioral health inpatient care in New York.<sup>38</sup>

 **70%** of clients who had some prior law enforcement involvement had no contact with law enforcement within 6 months of engaging with a Missouri CCBHC.<sup>39</sup>

## Preventing Criminal Justice Involvement for Individuals with SMI and SED

The Sequential Intercept Model is widely accepted and used by communities to map the progression of people through the criminal justice system and to identify opportunities to reduce the number of adults with SMI and youth with SED in jails and prisons.<sup>40</sup> In 2017, an additional intercept, Intercept 0, was formally incorporated into the model.<sup>41</sup>

Intercept 0 recognizes that intervention, through mental health services, crisis care, and community supports, can help people with SMI and SED before they have contact with the criminal justice system. These interventions are needed to prevent justice involvement.

Growing attention to social justice and health equity has further propelled law enforcement and mental health agencies to develop a more effective and coordinated response to 911 calls involving mental health crises. To promote better collaboration, the Justice Department's Bureau

of Justice Assistance's Justice and Mental Health Collaboration Program promotes innovative cross-system collaboration to improve responses to people with mental illnesses who are involved in criminal justice processing. Funding for this DoJ program requires collaboration with mental health agencies.<sup>42</sup>

### REASONS TO INTERVENE EARLY

 **15%** of all 911 calls involve individuals with mental illness.<sup>43</sup>

Approximately **10%-25%** of U.S. prisoners experience SMI.<sup>44</sup>

## Preventing SMI by Intervening with Youth

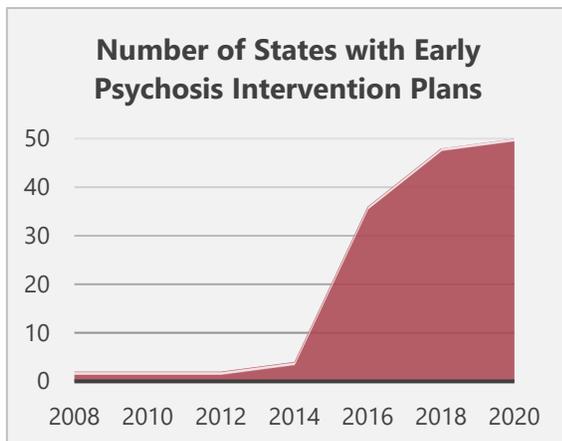
The transition to adulthood begins in the late teenage years and continues through the mid- to late-20s. The challenges of this transition can be much more difficult to navigate in the context of an emerging SMI, such as FEP. During 2020, the proportion of mental health-related ED visits among adolescents aged 12-17 years increased 31% compared with 2019. In May 2020, during the COVID-19 pandemic, ED visits for suspected suicide attempts began to increase among adolescents aged 12-17 years, especially girls.<sup>46</sup>

Over the past decade, there has been a national effort to increase the availability of Coordinated Specialty Care (CSC).<sup>47</sup> CSC is a team-based approach that includes a set of evidence-based outpatient services designed to address the needs of individuals experiencing early, or first episode, psychosis. CSC seeks to prevent the onset of SMI and improve quality of life.<sup>48,49</sup>

### Continued Investment in Research to Inform Practice

Initiated in 2019 and sponsored by the NIMH, the EPINET initiative includes eight regional hubs, 101 CSC programs across 17 states, and the EPINET National Data Coordinating Center (ENDCC).<sup>45</sup>

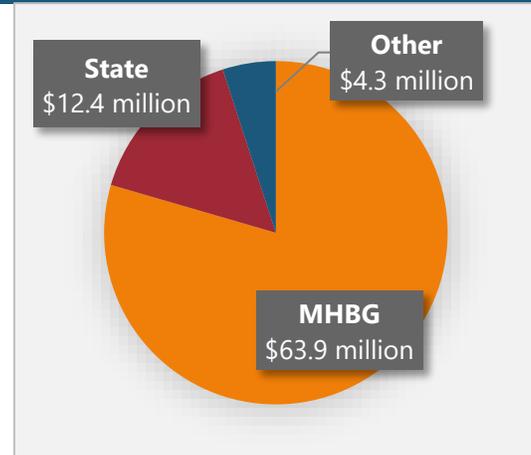
EPINET, a national learning health care system, links CSC clinics through standard clinical measures, uniform data collection methods, and integration of client-level data across service users and clinics. Through collaboration and coordination, EPINET seeks to improve treatment and effect the course of SMI.



Jointly, SAMHSA, CMS, NIMH, and the Assistant Secretary for Planning and Evaluation (ASPE), have helped grow the number of CSC programs in the U.S. In 2008, two states reported funding CSC programs using federal funds.<sup>50</sup> Today, there are over 375 CSC programs, including at least one in every state and four U.S. territories. The number of programs in the U.S. has grown with federal funding allocated to states to support their efforts to incorporate CSC into their communities.<sup>51</sup>

## 2020 Spending on CSC Programs

Since 2014, states have been required to use mental health block grant (MHBG) set-aside funds to support early intervention and prevention services for individuals experiencing the first symptoms of psychosis or SMI. The set-aside funds were doubled in December 2016 through the 21st Century Cures Act. The funding was increased again in 2020 and 2021 when states received additional federal funds: \$82.5 million through the MHBG COVID-19 Supplement and \$150 million through the American Rescue Plan (ARP) Act. States have two years to expend the COVID-19 supplement and until September 2025 to expend the ARP funds.<sup>52</sup>



# Challenges and Opportunities Ahead

## The Impact of a Pandemic

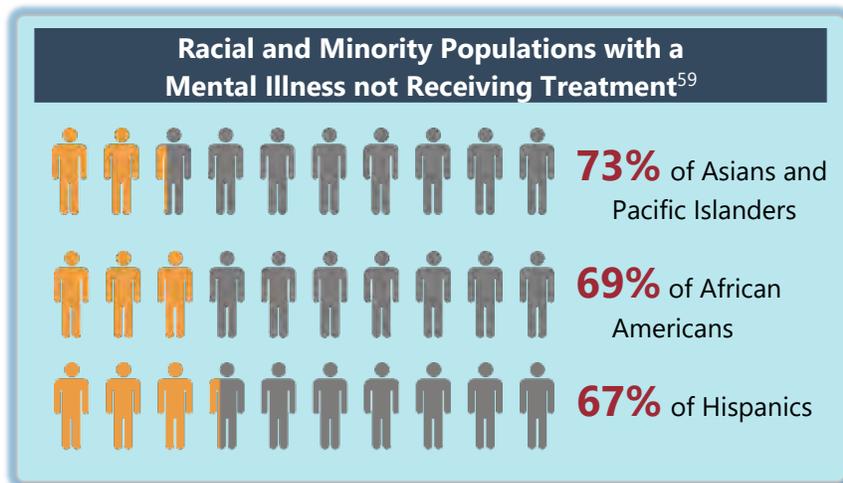
The COVID-19 pandemic has affected all aspects of life. Adults with SMI are particularly vulnerable to the pandemic. They are at increased risk of COVID-19 infection and death.<sup>53-55</sup> While children have not experienced increased mortality rates directly associated with COVID-19, changes in their environment (such as virtual schooling, lack of interaction with peers, and parental stress) have affected their well-being.<sup>56</sup>

The long-term effects of COVID-19 on people with SMI and SED are unknown. However, during June 2020, U.S. adults reported considerably elevated mental health conditions associated with COVID-19.<sup>57</sup> Younger adults, racial/ethnic minorities, essential workers, and unpaid adult caregivers reported having experienced disproportionately worse mental health outcomes, increased substance use, and elevated suicidal ideation. The emerging needs of these populations must continue to be addressed.

## Health Inequities Among People of Color

Disparities can occur at multiple points along the healthcare continuum and include accurate diagnosis; access to care; provision of community services; receipt of appropriate standard-of-care treatment; and inadequate monitoring and follow-up.<sup>58</sup> There are marked racial and ethnic differences in measures of health status, access, and affordability with evidence of improvement in some subgroups but persistence overall. In 2018, Black individuals with low income had the highest estimated prevalence of poor or fair health (24.9%), while White individuals with middle

or high income had the lowest (6.3%). Considering how to effectively reduce these disparities at each step is crucial for optimizing care for patients with SMI and SED, who often have complex and chronic treatment needs. Barriers to equity must be identified and investments must be made to address the needs of all people.



### People with SMI and SED Can Benefit from Telehealth by Accessing Services through Technology<sup>60,61</sup>

Telehealth offers the same benefits as in-person care for individuals with SMI. Use of telehealth does not make psychotic symptoms worse.



**70-80%** of adults with SMI own smartphones.



**75%+** of adults with SMI report satisfaction with their smartphone or tablet.



**50%** report that they download apps on their smartphone.

## Promoting Telehealth for Treatment of SMI and SED

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In response to the COVID-19 pandemic, the CDC and CMS issued guidance encouraging the use of telehealth for the delivery of many clinical services. Further, CMS developed the Medicaid & CHIP Telehealth toolkit to help states accelerate adoption of broader telehealth coverage policies during the COVID-19 emergency. Since 2020, the use of telehealth has increased to 154% in some healthcare sectors, especially for non-COVID-19 healthcare visits.<sup>62</sup>

## Embracing Measurement-Based Care

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There is growing support for the regular use of measurement-based care (MBC).<sup>63</sup> MBC involves the systematic collection of data and the use of the results to drive clinical decision making. Overall, MBC has been shown to improve clinical outcomes, inform collaborative care efforts, enhance treatment

decision-making processes, and increase client engagement in therapy.<sup>64</sup> Validated symptom measures<sup>65</sup> for individuals with SMI can be used as a part of MBC to provide insight into treatment progress, highlight ongoing treatment targets, reduce symptom deterioration, and improve client outcomes.<sup>66</sup>

As Fortney and colleagues summarized in their notable “tipping point” paper concerning the use of MBC in mental health and substance use care, patients receiving usual care have far worse outcomes than patients who received MBC. Successful recovery rates are much higher when MBC is utilized. Fortney, et al. cited studies that found up to nearly a 75% improvement in remission rates between patients receiving MBC for mental health and substance use and those who received usual care.<sup>67</sup>

CMS supports the development of outcome measures in mental health and substance use care and awarded funds to the American Psychiatric Association to develop a number of quality measures<sup>68</sup> that will be used in quality measurement programs. Most of these measures are focused on the delivery of MBC, covering a number of mental health and substance use conditions, as well as expanding measurement of outcomes to additional conditions beyond depression.

# CHAPTER 3

## Specific Recommendations for Actions

The second ISMICC Report to Congress highlights some of the advances made by the federal agencies represented on the ISMICC. Significant progress has occurred since 2017, when the first ISMICC Report to Congress, *The Way Forward: Federal Action for a System That Works for All People Living with SMI and SED and Their Families and Caregivers*, was submitted. The advances have been fostered and strengthened through coordination and collaboration among federal agencies represented on the ISMICC and with the input of non-federal members. For example:

- The crisis care continuum continues to be strengthened with the inclusion of a new 988 crisis phone number, as well as continued growth of mobile crisis services, 24-hour call centers, and stabilization programs.
- Early psychosis programs are now available in nearly every state and territory.
- National data collection efforts, such as the HCUP, MEPS, NCHS, and the ORS, now include survey items that will inform policy-making and programmatic decisions that can improve the lives of people with SMI and SED, and their families and caregivers.

On October 27, 2021, Miriam E. Delphin-Rittmon, the Assistant Secretary for Mental Health and Substance Use, designated as the ISMICC chair by the Secretary of Health and Human Services, convened ISMICC members and public stakeholders to invite comments on the second ISMICC Report to Congress. ISMICC members and the public were asked to provide input on specific recommendations for action, as well as ISMICC's continuation and future areas of focus.

The value of regularly convening federal and non-federal representatives to focus on treatment and needs of people with SMI and SED was broadly acknowledged by ISMICC members as unique and important. The members of ISMICC unanimously endorsed a recommendation at their October 27, 2021, meeting to continue ISMICC beyond the end of the current authorizing legislation, which is March 2023. The Secretary of the U.S. Health and Human Services recommends that Congress reauthorize the ISMICC for another six years.

The remainder of the chapter highlights the comments provided by ISMICC members and public stakeholders.

### **Recommendations by ISMICC Members and Public Stakeholders for Strengthening ISMICC**

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- 1) Non-Federal ISMICC members should receive orientation materials to help them better understand opportunities for enhancing federal program and policy coordination.
- 2) The roles of federal and non-federal members within ISMICC should be made clearer. One person acknowledged a learning curve in terms of the role of non-federal members to

advise on the work of ISMICC, and the role of federal members to work within their agencies to implement change. Clarification of the roles will help further solidify the partnership among members.

- 3) Federal agencies should provide regular updates to the ISMICC and the public regarding advances they have made on ISMICC areas of focus. Reporting should include advances made by agency and areas of coordination among multiple agencies.
- 4) An ongoing inventory of federal programs and policies changed or implemented due to the 2017 ISMICC *The Way Forward* Report to Congress should be created to more completely document the advances made by federal agencies over the past four years. A document like this could help ISMICC draft future recommendations.
- 5) Non-federal members of ISMICC should continue to take the lead in advising on the existing ISMICC areas of and recommendations. This was a model used in the preparation of the 2017 ISMICC *The Way Forward* Report to Congress. Federal leadership should also be available to provide guidance regarding the feasibility of recommendations based on the role, authority, resources, and structure of the federal government.
- 6) In advising on and developing future ISMICC recommendations, each recommendation should include reasonable metrics that establish a baseline and determine measures for progress.
- 7) Once metrics are determined, data visualization should be used to create a “dashboard” that displays progress made by federal partners in addressing each recommendation.
- 8) Create opportunities to feature ISMICC advances. Make prominent the role of ISMICC in shaping treatment and care for people with SMI and SED. For example, areas of focus and recommendations should be widely marketed and disseminated so that states, communities, and service providers can all work toward the same goals. Progress made by federal agencies should be broadly acknowledged so that Congress and others understand the impact of the ISMICC.
- 9) Strengthen the non-federal membership group by including additional adults with SMI and youth with SED.
- 10) Consider more frequent reporting of progress to Congress to provide more structure to ISMICC proceedings and track progress.
- 11) While the full ISMICC meetings should continue to be subject to Federal Advisory Committee Act (FACA)<sup>69</sup> rules, working groups that do not include the entire ISMICC should not be subject to FACA. For example, smaller meetings (such as workgroups), that do not include all ISMICC members and are meant to clarify ideas or direction, should be allowed to occur as needed. These workgroups would still be official ISMICC workgroups and would report to the parent ISMICC body for review and deliberation.

- 12) Recommend the ISMICC continue to focus on ongoing federal coordination and collaboration with state and local partners, with an emphasis on decreasing institutionalization, homelessness, and criminal justice involvement for people with SMI and SED.

### **Future Topics/Areas/Recommendations for ISMICC**

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- 1) As the COVID-19 pandemic continues, ISMICC should consider how it has impacted the lives of adults with SMI and youth with SED. For example, we know that it has impacted mental health, physical health, and health care delivery. The lessons learned from the pandemic, and its ongoing impact, should inform federal policies and programs.
- 2) As the 2017 ISMICC *The Way Forward* Report to Congress did, the next group of recommendations from the ISMICC should reflect the current themes and issues of the times. Topics should include the continued development of coordinated crisis response systems, the elimination of racial disparities, and addressing behavioral health equity, the effects of trauma, and the impact of COVID-19 on children, adolescents, and youth with SED.
- 3) Recommendations should emphasize the foundational importance of person-centered thinking, planning, and practice. For example, person-centered planning should be emphasized within the MHBGs and the CCBHC program.
- 4) Many of the members of ISMICC and public stakeholders echoed the need to focus on overcoming racial and ethnic disparities and to look at ways to achieve behavioral health equity for all Americans.
- 5) Future recommendations should continue to include attention to the criminalization of mental illness and its traumatic effects, especially for black youth.
- 6) Federal initiatives to advance misdemeanor mental health courts would significantly impact the quality of life for individuals with SMI and SED who are thrust into the criminal justice system. A proposed initiative would look much like the work of the National Association of Drug Court Professional and its National Drug Court Institute, which provides standardized evidence-based training and technical assistance to their courts. These courts safeguard individuals from criminalization, which is happening aggressively on the local level.
- 7) The crisis care system should be expanded beyond phone and chat helplines. Attention should be given to innovative ideas, such as virtual face-to-face crisis response and expanded community resources.
- 8) ISMICC could consider which national databases are able to measure advances within the various areas of focus or specifically for certain recommendations.

- 9) ISMICC members should continue to work on Focus 2: Access and Engagement and incorporate the impact of social determinants of health within this area of focus.
- 10) ISMICC members should consider classifying eating disorders as an SMI and create recommendations to address the needs of individuals who are struggling with this disorder. Ensure the coverage of eating disorders treatment within federal disability and insurance programs. Create and centralize federal resources for people with eating disorders. Finally, reevaluate the use of Body Mass Index in medical and non-medical settings.
- 11) A recommendation around eliminating psychiatric boarding should be considered.
- 12) ISMICC members should think about how to engage law enforcement so that there are non-violent encounters with people with SMI and SED.
- 13) ISMICC members should focus on the roles of schools in providing behavioral health care to children, adolescents, and youth. Consider how to strengthen the partnership between behavioral health care and schools. Provide adequate resources to foster the partnership.
- 14) ISMICC members should continue to think about how to support transitional aged youth with SED/SMI and the unique and turbulent journey they face as they move from the children's behavioral health system to the adult one.
- 15) The use of evidence-based telehealth should be promoted and explicit guidelines for service delivery and reimbursements should be articulated.

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# APPENDIX A

## Summary of the 2017 Recommendations from the Non-Federal ISMICC Members\*

The non-federal members of the ISMICC created a set of recommendations aimed at coordinating the efforts of federal departments to develop a comprehensive array of care focused on improving outcomes for people of all ages with SMI and SED and promoting evidence-based practices and a strong community-based system of care. These recommendations were developed based on input from the non-federal members of the ISMICC and do not represent federal policy. These recommendations should not be interpreted as the formal position of the Administration.

Organized within five main areas of focus, the recommendations aim to realize the ISMICC vision. Realizing this vision will require changes at the state, tribal, and local levels, with assistance from federal policies and programs, and support from Congress. It is anticipated that the recommendations will be refined and amended as the work of the ISMICC moves forward.

### **Focus 1: Strengthen Federal Coordination to Improve Care**

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- 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.

*\*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 is 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.*

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

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

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- 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-aged 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**

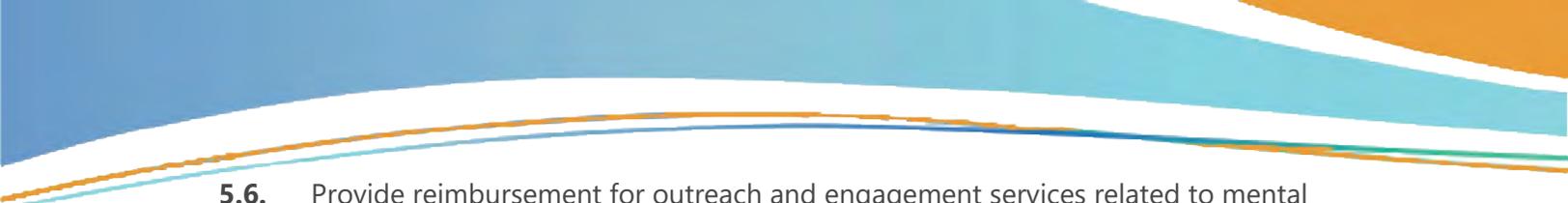
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- 4.1. Support interventions to correspond to all stages of justice involvement. Consider all points included in the sequential intercept model.
- 4.2. Develop an integrated crisis response system to divert people with SMI and SED from the justice 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 21<sup>st</sup> 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**

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- 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.

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- 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.

# APPENDIX B

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

### Federal Department and Agency Representation on the ISMICC

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Secretary of Health & Human Services

Assistant Secretary for Mental Health & Substance Use, U.S. Department of Health & Human Services

Attorney General, Department of Justice

Secretary of Veterans Affairs

Secretary of Defense

Secretary of Housing & Urban Development

Secretary of Education

Secretary of Labor

Administrator of the Centers for Medicare & Medicaid Services, U.S. Department of Health & Human Services

Commissioner of the Social Security Administration

### Current List of Non-Federal Members

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# APPENDIX C

## Federal Agencies Involved in the Collaboration and/or Implementation of the Areas of Focus Identified in the 2017 ISMICC Report to Congress – The Way Forward

|   | <b>Focus 1: Federal Coordination &amp; Data</b> | <b>Focus 2: Access &amp; Engage</b> | <b>Focus 3: Treatment and Recovery</b> | <b>Focus 4: Criminal Justice</b> | <b>Focus 5: Finance</b> |
|---|---|-------------------------------------|--|----------------------------------|-------------------------|
| <b>Department of Health and Human Services</b> (Includes ASPE, CDC, NIMH, AHRQ) | ●   | ●                                   | ●                                      | ●                                | ●                       |
| <b>Substance Abuse and Mental Health Services Administration</b>                | ●   | ●                                   | ●                                      | ●                                | ●                       |
| <b>Department of Justice</b>  | ●   | ●                                   | ●                                      | ●                                |                         |
| <b>Department of Veterans Affairs</b>   | ●   | ●                                   | ●                                      | ●                                | ●                       |
| <b>Department of Defense</b>  | ●   |                                     |  |                                  |                         |
| <b>Department of Housing and Urban Development</b>                              | ●   | ●                                   | ●                                      |                                  |                         |
| <b>Department of Education</b>  |   | ●                                   | ●                                      |                                  | ●                       |
| <b>Department of Labor</b>  | ●   | ●                                   | ●                                      | ●                                | ●                       |
| <b>Centers for Medicare &amp; Medicaid Services</b>                             | ●   | ●                                   | ●                                      | ●                                | ●                       |
| <b>Social Security Administration</b>   | ●   | ●                                   | ●                                      | ●                                | ●                       |

