

# **U.S. Department of Health and Human Services**

## ***Minutes of the Interdepartmental Serious Mental Illness Coordinating Committee Fifth Full Committee Meeting***

July 2, 2019 9:00 a.m. to 2:30 p.m. (Eastern Time Zone)  
Substance Abuse and Mental Health Services Administration  
5600 Fishers Lane Room 5A02 Rockville, Maryland 20857

# Fifth Meeting of SAMHSA ISMICC July 2, 2019

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# Fifth Meeting of SAMHSA ISMICC July 2, 2019

## **Call to Order/Committee Roll Call**

*Pamela Foote, Designated Federal Official, Interdepartmental Serious Mental Illness Coordinating Committee (ISMICC)*

The meeting of the Interdepartmental Serious Mental Illness Coordinating Committee was called to order at 9:00 a.m. and quorum was established.

## **Federal ISMICC Members or Designees Present**

- Elinore F. McCance-Katz, M.D., Ph.D., Assistant Secretary for Mental Health and Substance Use, Substance Abuse and Mental Health Services Administration (SAMHSA)
- Tracy Trautman, Deputy Director for the Programs, Office of the Bureau of Justice Assistance (BJA) for the Attorney General, Department of Justice (DoJ)
- Sandy Resnick, Ph.D., Deputy Director, Northeast Program Evaluation Center (NEPEC), Office of Mental Health and Suicide Prevention, Virginia Central *Office* (VACO), for the Secretary of the Department of Veterans Affairs (VA)
- Jennifer Sheehy, M.B.A., Deputy Assistant Secretary of the Office of Disability Employment Policy (ODEP) for the Secretary of the Department of Labor (DOL)
- Deidre Gifford, M.D., Deputy Director, for the Administrator of the Centers for Medicare and Medicaid Services (CMS)
- Joyce Nicholas, Deputy Associate Commissioner, Office of Disability Policy, for the Commissioner, Social Security Administration (SSA)

## **Federal ISMICC Members Not Present**

- Alex M. Azar II, The Secretary of the Department of Health and Human Services (HHS)
- Ralph Gaines, M.B.A., Chief Operations Officer, for the Secretary of the Department of Housing and Urban Development (HUD)
- Kimberly Richey, Acting Assistant Secretary, Office of Special Education and Rehabilitative Services, for the Secretary of the Department of Education (ED)
- Terry Adirim, M.D., M.P.H., FAAP, Acting Principal Deputy Assistant Secretary of Defense for Health Affairs, for the Secretary of the Department of Defense (DoD)

## **Non-Federal ISMICC Members Present**

- Ron Bruno, Founding Board Member and Second Vice President, Crisis Intervention Team (CIT) International
- Clayton Chau, M.D., Ph.D., Regional Executive Medical Director, Institute for Mental
- Maryann Davis, Ph.D., Research Associate Professor, Department of Psychiatry, University of Massachusetts Medical Center
- Pete Earley, Author
- Mary Giliberti, J.D.
- Elena Kravitz, CPRP, Director, New York Association of Psychiatric Rehabilitation Services
- Kenneth Minkoff, M.D., Zia Partners
- Rhathelia Stroud, J.D., Presiding Judge, DeKalb County Magistrate Court

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- Elyn Saks, J.D., Ph.D., Orrin B. Evans Professor of Law, Psychology, and Psychiatry and
- Connie Wells, Owner/Manager, Axis Group, LLC

### **Non-Federal ISMICC Members Not Present**

- Linda S. Beeber, Ph.D., Distinguished Professor, University of North Carolina-Chapel Hill, School of Nursing
- David Covington, L.P.C., M.B.A., CEO/President, Recovery Innovations (RI) International

### **Opening Remarks**

*Arlin Hatch, CAPT, USPHS, Ph.D., ISMICC Coordinator, Office of the Assistant Secretary, and Senior Psychologist, Center for Substance Abuse Prevention (CSAP)*

Dr. Arlin Hatch greeted participants and explained that focus area workgroups met on June 20 and 26 and would report out to the full ISMICC.

### **Welcome**

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

Dr. Elinore McCance-Katz welcomed members and provided an overview of efforts and goals moving forward to improve coordination amongst federal agencies.

As mandated in the 21<sup>st</sup> Century Cures Act, the ISMICC submitted a report to Congress summarizing advances in SMI and SED research related to the prevention of, diagnosis of, intervention in and treatment in recovery of these conditions as well as advances in access to services and supports. The report also provided an evaluation of the effect of federal programs related to SMI on public health outcomes including suicidality and suicide, incidence in prevalence of serious mental illness and serious emotional disturbance, overdose and overdose deaths, emergency room utilization for serious mental illness, criminal justice interactions, homelessness and unemployment, increased rates of employment, vocational and educational supports aimed at increasing employment, and quality of mental health and substance use disorder treatment services.

Regarding Focus Area 1: Strengthen Federal Coordination to Improve Care, by sharing the approaches and activities of their agencies, workgroups are involved in an ongoing evaluation of the federal approach to SMI and SED and able to make recommendations for modifications that will improve coordination. Public members are now a part of these workgroups, which enriches the discussions. Workgroups have been tasked with developing and presenting their plans at the December 2019 ISMICC meeting.

Regarding Focus Area 2: Access and Engagement, SAMHSA recently convened an expert meeting on behavioral health crisis services for developing resources to address best practices in crisis services. Further, Congress increased SAMHSA's funding for Certified Community Behavioral Health Clinics in 2018, a program that requires 24/7 crisis services.

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Dr. McCance-Katz emphasized her belief that training and technical assistance to prepare the workforce (e.g., behavioral health providers, primary care providers, and other allied health providers); to screen, assess, and treat these illnesses is a means of positively impacting parity. To that end, she has completely changed SAMHSA's training and technical assistance programs to make such training readily available nationally and regionally. Additionally, she has implemented the National Privacy Training and Technical Assistance Center, offering education on Health Insurance Portability and Accountability Act (HIPAA), 42 CFR, and the various interfaces to practitioners and to the public.

SAMHSA was also able to fund bed registries, which let people know what local resources are available real-time, in the 23 states that expressed an interest. ISMICC members were encouraged to push their states to participate in such resource development. They are also working with the Drug Enforcement Administration on telehealth regulations, which SAMHSA agrees is key to care access, though they do not control this particular area. Lastly, civil commitment standards must be reviewed and modified to better assist those in need of care.

To the extent possible, SAMHSA is striving to make headway in Focus Area 3: Treatment and Recovery. However, due to SAMHSA's lack of statutory authority to compel states to implement, and lack of congressional funding, implementation is dependent on outside entities. One example is the December 2018 Federal Commission on School Safety Report wherein HHS recommends screening for mental health and substance use issues in schools. To that end, SAMHSA supports through its limited funding, the establishment of positive environments in schools and recommends the addition of counselors and peers to provide emotional supports to children in school-based settings. Further, SAMHSA has worked with Centers for Medicare and Medicaid Services to issue a joint advisory to states and school districts on resources for embedding mental health services in schools and how to be able to bill Medicaid for services. However, states make decisions about Medicaid funding streams. ISMICC members were encouraged to determine how they can help propel this process in their communities.

SAMHSA is also addressing Medication Assisted Treatment (MAT) for opioid use disorder with funding announcements explicitly stating that evidence-based practices, including Food and Drug Administration approved MAT that must be available for a facility to receive federal resources.

Lastly, SAMHSA is in the process of developing additional resources for addressing suicide prevention, albeit within the limitations imposed by statute and regulation. As many people die by suicide as by opioid overdose; therefore, Dr. McCance-Katz continues to advocate for the same level of resources for suicide prevention as has been given to the opioid crisis.

Focus Area 4: Increase Opportunities for Diversion and Improved Care for People with SMI and SED Involved in the Criminal and Juvenile Justice Systems has also made progress despite limitations around funding. For example, SAMHSA has diversion programs to help those with mental disorders to avoid arrest and to get the care and assistance they need to keep them out of jail. Further, SAMHSA supports a sizeable drug court system that provides services to adults, juveniles, and families and a reentry program that starts prior to release aimed at connecting people to ongoing care and services at the time of release. Working directly with the Department

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of Justice on these issues, SAMHSA recently published a guidance document for embedding MAT into jails and prisons, which is supported through technical assistance provided by the GAINS Center.

Dr. McCance-Katz re-emphasized the importance of SAMHSA's national and regional technical assistance and training programs, all resources available with the current funding that will help to improve care and increase access to services and allow practitioners or facilities to receive customized support. ISMICC members were again encouraged to educate their communities about these resources.

Focus Area 5: Develop Finance Strategies to Increase Availability and Affordability of Care, is an area that requires federal, public, and private payers to make changes in alignment with ISMICC recommendations. As previously mentioned, Congress increased funding for the recommended Certified Community Behavioral Health Clinics (CCBHCs) program. Further, SAMHSA worked with CMS on the 1115 waivers requiring states to institute levels of care and services in community-based settings and is another area that needs direct advocacy since, to date, few states have applied.

In closing, though the work of the ISMICC and the report are critical resources to improving outcomes for Americans living with SMI and SED and to their families, the Cures Act did not provide any funding or authority for ISMICC to compel change. However, change is possible through advocacy and working collaboratively and positively to engage those who, though unfamiliar with the issues, understand their importance.

### **Consideration of the ISMICC Meeting Minutes, December 11, 2018**

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

A motion to accept the December 11, 2018 meeting minutes was made by Ms. Jennifer Sheehy and seconded by Dr. Clayton Chau, followed by report outs from the focus groups.

### **REPORT OUTS BY FOCUS AREA**

#### **Focus Area 1: Data**

*Kirstin Painter, Ph.D., LCSW, Public Health Analyst, Center for Behavioral Health Statistics and Quality, Division of Evaluation*

The Data Workgroup has been sharing initiatives internally and externally about quality measures to reduce duplication and allow interagency collaboration since quality measurement is a primary driver in evaluating outcomes. The HHS Data Council, which meets monthly, coordinates data resources across HHS agencies and is principally an internal advisory body to the Secretary for Health and Human Services Data and Statistical Policy. Facilitating collaboration and coordination amongst various offices, the Council is leveraging HHS statistical and administrative data collections to support evidence building. The Council also develops recommendations regarding the collection analysis and dissemination of data to guide future decisions and enhance the health and well-being of Americans. The Data Inventory

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Subcommittee, formed in May 2018, is working on a descriptive inventory of data inventories across all federal agencies and includes financial data, grants data, research and project evaluation data, and survey data sets.

### **The Veterans Administration**

*Ira Katz, M.D., Ph.D., Deputy Chief Patient Care Services Officer for Mental Health, Department of Veterans Affairs*

Of approximately 20 million veterans in America, about 6 million receive care from the Veterans Health Administration (VHA) each year in the 140 to 150 medical centers, some with multiple campuses, and 1,000 additional clinics.

The VA is diligently working to implement measurement-based care in mental health services. Implementation will provide crucial information on patient-reported outcomes for outcome-based quality and performance measures. Though necessary, it is not sufficient; therefore, they are complementing it with a survey of about 10,000 mental health patients at the onset of care and at 90 days about whether they continue with treatment. Early analysis shows there is a difference in “intention to treat” versus “as treated” outcomes as well as problems with the application of the “intention to treat” concepts in the clinical context.

The most critical focus at the VA is implementing the VA Mission Act of 2018, Public Law 115-182, which increases the VA’s responsibilities for outsourced care. Therefore, the VA must learn more about the claims process and evaluating the quality of purchased care to ensure alignment. The Act includes a charge to establish quality metrics that allow comparison between care provided by the VA and purchased care, which will require significant help from partners.

As the Mission Act progresses, the VA is more interested in understanding the variability across the country of mental health issues for the entire veteran population. To that end, they are working with SAMHSA on evaluating the geo-files from the National Survey of Drug Use and Health (NSDUH). In collaboration with National Institutes of Health (NIH), National Institute of Mental Health (NIMH), and the Department of Energy, the VA is also continuing to pursue predictive modeling in ongoing projects related to suicide prevention, opioid overdoses, and missed appointments to allow proactive outreach. Further, the VA is using the framework of deaths of despair to consider suicide and overdoses.

Grappling with the fact that patients with SMI have a shorter lifespan, the VA has begun identifying site-by-site differences in excess mortality and is questioning the dependence on the surrounding community versus the internal processes of care.

Finally, the VA is modernizing the Electronic Medical Record (EMR). The new commercially purchased system will link the VA and Department of Defense (DOD) and improve interoperability and collaboration.

### **National Center for Health Statistics**

*Lillian M. Ingster, Ph.D., Director, National Death Index, Centers for Disease Control*

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As part of the Centers for Disease Control (CDC), the National Center for Health Statistics (NCHS) focuses solely on helping researchers by gathering data with no particular focus on any disease group, condition or health care delivery process.

The Long-Term Care Database has data on screening for alcohol or substance abuse, anxiety, depression, services used for activities of daily living, behavioral and mental health issues, medication management or administration of medications, social work, transportation, needs for medical or dental appointments, and physical and cognitive functioning.

The Long-Term Care Provider Survey provides data on health care use, such as emergency department visits, falls and injuries, hospitalizations, medications, antipsychotics, mental status changes as a reason for hospitalization.

The Hospital Care Survey uses all the International Classification of Diseases, Tenth Revision, Clinical Modification (ICD-10-CM) diagnostic codes, which can capture SMI, suicide attempts, or self-harm. The information comes from the hospitals as well as from inpatient stays, outpatient visits, and emergency department visits. The Survey captures associated variables whether demographic or considered risk factors, including procedures, payers, and clinical notes and medications from the Electronic Health Records (EHR) and can be tracked across hospital departments since the patients are assigned a unique code.

The Vital Statistics System is a statistical file of ICD 10 codes associated with mental illnesses and national patterns, while the surveys provide a national representative sample usually linked to the National Death Index (NDI). The NDI has every death certificate throughout the United States along with the DoD's out-of-country deaths and can provide mortality outcomes (e.g., date of death, state of death, and all causes of death).

The Health and Nutrition Examination Survey reaches 5,000 people every couple of years. Two particular models relevant to this committee is the collection of information on the PHQ-9, the Patient Health Questionnaire, and on prescription drug use.

Lastly, the National Health Interview Survey, split into two sections - adults and children - covers 50,000 to 100,000 households. The survey garners information on schizophrenia, bipolar, depression, and anxiety. They also look at the Washington Group on Disability questions dating back to 1997 on mental health care access and limitations to use. The section on children is similar to the adult section but is more limited since parents have to permit the asking of these questions.

In closing, Dr. Hatch challenged the Data Workgroup to consider and present at the December meeting on some of the overlapping data points and how the data positively affect outcomes for persons with SMI and SED.

### **Focus Area 2: Access**

*Richard McKeon, Ph.D., M.P.H., Chief, Suicide Prevention Branch, Center for Mental Health Services (CMHS), and Steven Dettwyler, Ph.D., Public Health Analyst, CMHS*

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The National Suicide Hotline Improvement Act was passed and signed into law August 2018. The Act requires SAMHSA, the Veterans Administration (VA) and the Federal Communications Commission (FCC) to work together regarding the feasibility and advisability of a national three-digit number for suicide prevention and crisis intervention, similar to 911 or other N11 numbers. To that end, SAMHSA, the VA, the FCC, and the HHS Office of General Counsel have been holding calls every two weeks. SAMHSA filed a report, as did the VA, in February 2019 that is now available as a public document on the FCC website. More recently, the North American Numbering Council, a federal advisory committee to the FCC, filed its report and the FCC will be making its recommendations to Congress in August.

President Trump signed an executive order called End a National Tragedy of Suicide (PREVENTS), which focuses on reducing suicide among all veterans. A multi-departmental taskforce has been established with SAMHSA as lead, with Dr. McKeon as co-lead on the state and local line of effort. There is also representation from other HHS departments, including the CDC, the Indian Health Service, HRSA, and the Administration on Aging. One of the deliverables will be a set of recommendations for a grant program targeted on reducing veteran suicide.

The Civil Rights Division of the Department of Justice is working with states to transform local systems and provide services to people with SMI and SED. Generally, the Division will either litigate or develop settlement agreements when there have been egregious state violations of the Olmstead such as segregating individuals in large institutions like psychiatric hospitals or group homes, some that house 150 to 200 people. Equally important, however, is the transformation of the system to allow de-institutionalization and to promote the development of community-based services to circumvent long-term institutionalization.

Directly related to ISMICC Recommendation 2.7, a 2018 study conducted by the Office of Assistant Secretary of Planning and Evaluation (ASPE) on telehealth focused on effective modalities, challenges to implementing telehealth in a variety of settings, (e.g., rural areas, low-density areas, urban areas), types of professionals involved, and financing, all of which impact access to and engagement in care. However promising, telehealth has not yet been implemented consistently throughout the country.

In 2014, Congress required SAMHSA to have a five percent set aside for early identification and evidence-based services for individuals with early-onset SMI and first episode psychosis (FEP), which increased to 10 percent in 2015. The significance to access and engagement is that individuals with psychosis historically have received services for years, greatly complicating both the illness and its prognosis. There are now over 280 of these programs nationwide serving over 10,000 individuals in 2018 alone, or about 10 percent of the total individuals that have FEP each year.

Lastly, in alignment with the recommendation to provide support to families of individuals at risk for suicide, SAMHSA is developing a toolkit for family members that will be completed by September, followed by the clearance process. Also, regarding screening in primary care settings for SMI and SED, a subject-matter expert panel was convened June 24 and 25 to address screening for suicide risk in pediatric settings.

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### **Focus Area 3: Treatment and Recovery**

*Justine Larson, M.D., M.P.H., M.H.S., Senior Medical Advisor, Center for Mental Health Services*

Due to the vast nature of the topic, the Treatment and Recovery Workgroup chose three primary areas of focus: suicide prevention, supported employment, and supported housing. Future workgroups meetings will focus on children and youth collaborative measures.

### **SUICIDE PREVENTION**

SAMHSA has an interagency agreement with the Department of Veterans Affairs (VA) to further suicide prevention efforts. One particular pathway is a nationwide effort to disseminate the CDC strategies via their toolkit on Suicide Prevention, which gives an overview of community suicide prevention efforts. To that end, SAMHSA partners with states through governor offices, mayor offices, and local county councils on a challenge to participate in suicide prevention efforts. To date, seven states, namely Arizona, Colorado, Kansas, Montana, New Hampshire, Texas, and Virginia, as well as 30 cities/counties, have joined the effort. While there are a several similar initiatives, communities need to create action plans that are inclusive of all issues, such as the key components of economic support (e.g., supported housing and supported employment).

Additionally, communities are taught to identify veterans at risk through screenings in community health care settings. Of the 20 veteran suicides per day, only six of those people are touching the VA system; the rest are in the community. Several executive orders strengthen the efforts, such as Order 13861 released in March 2019 that focuses on community partnerships to prevent suicide. Buy-in is strong in the community and with the DOD (i.e., National Guard Bureau), as well as state and local governments.

### **Centers for Disease Control (CDC)**

The CDC's National Violent Death Reporting System (NVDRS) is a unique surveillance system providing an opportunity for data analysis to enhance prevention efforts. This system includes violence by suicide, homicide or death of undetermined intent. This system is useful to people who want to understand how to direct their prevention efforts.

Regarding suicide, although the suicide rate in youth is rising, suicide screening for risk does not occur in the vast majority of pediatric primary care settings. Therefore, SAMHSA and its federal partners are working in collaboration with pediatricians, family medicine doctors, and nurse practitioners to help develop a guide for suicide screening in these settings.

The Federal Working Group on Suicide Prevention maintains close ties with the ISMICC Focus 3 Work Group because of objective 3.7: To increase national collaboration on suicide prevention and enhance the spread of Zero Suicide across the country. The Federal Workgroup emerged out of an HHS Working Group on Suicide Prevention that was part of the 2001 National Strategy for Suicide Prevention. Dr. McKeon leads the Federal Workgroup and hosts monthly conference calls to discuss suicide prevention activities of interest to federal agencies. Members include the DoD, Department of Education, the Department of Homeland Security, DOJ, the Department of Transportation, the VA, and HHS including the Administration for Community Living, CDC,

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HRSA, NIH, Administration for Children and Families, and SAMHSA. During the calls, the Federal Workgroup receives updates from fellow agencies that are also federally funding Zero Suicide to some degree, maximizing effectiveness, reducing duplication, and informing on how zero suicide is best implemented through federal agencies.

The Federal Working Group on Suicide Prevention supports coordination of federal activities on suicide prevention to maximize effectiveness and impact and played a role in developing the 2012 Revised National Strategy for Suicide Prevention. In this role, it has monitored and summarized federal activities supporting the National Strategy for the National Action Alliance of Suicide Prevention's Implementation and Assessment Advisory Group.

### **SUPPORTED EMPLOYMENT**

#### **The Veterans Administration**

*Sandy Resnick, Ph.D, Deputy Director, Northeast Program Evaluation Center (NEPEC), Office of Mental Health and Suicide Prevention, Veterans Affairs Central Office*

In 2003, Congress passed legislation permitting the inclusion of supported employment as part of the broader array of rehabilitative services in the VA, which is now required by policy in all VA medical centers. Following the Independent Placement and Support (IPS) model of supported employment, the VA began implementation efforts in 2004 using gold standard fidelity monitoring, including onsite fidelity visits every six months over the course of almost six years. There has been continuous outcome monitoring as part of the Northeast Program Evaluation Center portfolio.

The VA uses performance metrics to ensure that veterans with psychotic disorders are prioritized for supported employment services. In fiscal year 2018, about 9,000 individual veterans nationwide met with a supported employment provider at least twice. Of approximately 2,300 veterans who completed supported employment, 41 percent had a competitive job.

In 2004, a query program funded a study of the initial implementation and dissemination of supported employment across the VA. More recently, they have funded multi-site studies showing the efficacy of supported employment for veterans with PTSD and spinal cord injuries, as well as developmental work to determine adaptations to supported employment for veterans with poly-trauma and traumatic brain injury. Through a partnership with the Department of Labor, a customized employment program, called Therapeutic Supported Employment Service, is currently in place to provide training and ongoing national webinars to VHA vocational rehabilitation providers around customized employment.

#### **Department of Labor**

*Richard Davis, MSW, Senior Policy Advisor, Office of Disability Employment Policy (ODEP)*

The Department of Labor (DOL) instituted a Supported Employment Workgroup that meets monthly with representation from 15 federal agencies. The Workgroup identified three target populations - youth, adults and veterans – and three areas of focus - best practices and strategies, addressing barriers and benefits, and any ongoing studies and outcomes.

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Specific to the ODEP, two initiatives, the Visionary Opportunities to Increase Competitive Integrated Employment (VOICE) and the Veterans Returning to Integrated Employment, target mental health and supported employment. In 2019, VOICE grants were awarded to 11 states, namely Alabama, Arkansas, Colorado, the District of Columbia, Iowa, Kentucky, Louisiana, Michigan, Missouri, Tennessee, and Utah. These states are working to increase the ability of providers to offer IPS supported employment and to build capacity through training, sustainable funding, and employer engagement. They are also working on Memorandums of Understanding to sustain IPS. For example, in Colorado, the governor's budget recently established an Office of Employment First, creating six positions, including one that is an IPS curriculum developer and trainer, to assist with statewide implementation. The other initiative, Veterans Returning to Integrated Employment, is a partnership with the VHA. Meetings in Orlando and Anaheim held in April introduced customized employment subject matter experts while June's convening in Chicago introduced mentor trainers. Six virtual webinars are in production that qualify for CEUs. Onsite visits are also being considered to provide additional training.

### **Substance Abuse and Mental Health Services Administration**

Transforming Lives through Supported Employment focuses on three populations: young adults ages 16-23 with SED, adults 18 and older with SMI, and adults 18 and over with co-occurring substance use disorder (SUD). The opportunity allows grantees to integrate other practices, like supported housing, and to help people gain competitive employment. An allowable activity is to collaborate with the Social Security Administration (SSA) to offer programs and practices that are relevant in their state as well as linkage and collaboration with the DOL's Employment Leadership program. Out of 124 applications, seven awards have been made to date.

### **SUPPORTED HOUSING**

#### **The U.S. Interagency Council on Homelessness (ICH)**

ICH coordinates efforts across 19 agencies to reduce redundancy and increase efficiency with the goal of ending homelessness. In 2018, the Home Together initiative, codifying the commitment of the federal government to end homelessness through a federal strategy, was approved by all 19 agencies and published.

#### **The Center for Substance Abuse Treatment (CSAT)**

CSAT's Co-occurring and Homeless Activities Branch has targeted programs around homelessness, mental health, and SUD. The new strategic plan also has an overarching component to reduce homelessness and unnecessary hospitalizations while improving community integration. One particular collaboration is with the Medicaid Innovation Accelerator Program (IAP), a program helping 16 states that are considering redesigning their community intervention and long-term services and support. The goal is to increase partnerships with non-traditional Medicaid partners to improve the lives of people with SMI.

Lastly, Dr. Hatch reminded participants from all focus areas to keep in mind the objectives of the 21<sup>st</sup> Century Cures Act to consider what to highlight in the 5-year ISMICC to report to Congress on advances, program effectiveness, and recommendations for better coordination of services for persons with SMI or serious emotional disturbance.

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## **DISCUSSION**

Regarding early death, three components that may contribute to a shortened lifespan for people with mental illness are healthy lifestyle issues, delivery of care, and the pathophysiology of mental health conditions.

The DOL's statistic of 41 percent of veterans having a competitive job at discharge from services means six out of ten people in the program did not find employment, which is fairly consistent with the randomized controlled trials in supportive employment. Despite limitations to the program, such as benefits, incarceration, and complicated lives of veterans, DOL is continuously trying to increase collaborations and to add customized employment skills to the job-seeking functions of the employment specialist.

There is noticeable progress of interdepartmental coordination and, though ISMICC members may not have a platform in their own state to compel change, many of the members have national platforms, such as the National Association of State Mental Health Program Directors (NASMHPD) and state Medicaid directors' organizations.

Similar to the joint commitment to end homelessness from the 19 agencies comprising the USICH, the federal departments on ISMICC could publish a statement regarding a collective commitment to end early death and incarceration for people with SMI and improve the outcome for people with SED transitioning into adulthood. Such a statement would then become a formal interagency activity that survives beyond ISMICC.

### **Focus Area 4: Justice**

*Larke Huang, Ph.D., Director, Office of Behavioral Health Equity Lead, Trauma and Justice Strategic Initiative Senior Advisor – Children, Youth and Families, Office of Intergovernmental and External Affairs (OIEA)*

### **Office of the Assistant Secretary for Planning and Evaluation**

The Office of the Assistant Secretary for Planning and Evaluation (ASPE) has been collaborating with CMS on implementing Section 5032 of the Support Act, which was signed into law on October 24, 2018. Section 5032, entitled Promoting State Innovations to Ease Transitions Integration to the Community for Certain Individuals requires ASPE to convene a stakeholder group on Medicaid Reentry and report back to Congress. The requirement on CMS is to develop and disseminate a Medicaid director letter, opening an 1115 demonstration opportunity to provide services for 30 days before release for inmates that incorporates the best practices from the stakeholder convening. Additionally, there is a reminder in the provision that rather than terminating eligibility, states can suspend eligibility for Medicaid while individuals are inmates in a public institution. This main change allows for the provision of Medicaid-covered services up to 30 days before discharge because of the inmate exception.

### **Bureau of Justice Assistance**

DOJ's Bureau of Justice Assistance (BJA) released the Police Mental Health Collaboration Framework in April 2019 guided by six questions and related scenarios to educate leadership on effective law enforcement responses to people with mental health needs. Secondly, the

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Police Mental Health Collaboration Toolkit is being updated to include the behavioral health perspective and lived experience perspective while providing an introduction to law enforcement regarding people with co-occurring intellectual and developmental disabilities (IDD). Characterized as a one-stop shop for law enforcement and behavioral health providers, the revised toolkit is expected to be online in October. Additionally, the Serving Safely initiative is focused on the delivery of expert training through a national center and provides products and services to support law enforcement responses to this population.

BJA will also launch the Strategy Lab, focused on reducing the number of people with SMI in jails, on the Council for State Governments Justice Center website. This interactive, searchable, online tool will provide best and promising practices in mental health collaboration regarding programs, policies, and practices with three live community-based examples.

BJA has a new partnership with the Interagency Autism Coordinating Committee Workgroup focusing on the intersection of people with autism and co-occurring mental illnesses and exploring gaps in law enforcement training. A focus group will convene in August 2019 as a follow up to their 2015 focus group. The 2015 convening included researchers, advocates, law enforcement, and behavioral health practitioners who identified the most challenging issues and gaps and set the vision for their portfolio over four years. BJA's Justice and Mental Health Collaboration Program provides nearly 122 million in grants for collaborative county approaches, strategic planning for law enforcement, mental health collaboration, and implementation and expansion.

### **Bureau of Prisons**

The Bureau of Prisons (BOP) also has initiatives directly related to reducing the use of restrictive housing. BOP's policy revision of 2014 shifted from merely managing people with SMI to treating inmates with SMI. They systematically defined what is meant by SMI, developed a screening process for restrictive housing, required BOP clinicians to use evidence-based intervention, and clarified the discipline process to ensure inmates are not punished for symptoms of mental illness. In 2016, another policy revision occurred around the use of restrictive housing, including enhancing the screening procedures and oversight.

A new unit, the Female Integrated Treatment Program, integrates trauma, substance use, and mental health treatment in one of their facilities. Another initiative, the Mental Health Companion Program, trains inmates to provide peer support to others within the facility and gives them an apprenticeship program so that upon release they qualify for reimbursable jobs in the community as peer specialists. Additionally, Secure Mental Health Treatment programs are available in several high-security facilities for inmates with mental illness and a history of violent behavior. They are beginning to increase their programming in secure settings and to provide opportunities for group and individual treatment as well as supervised recreation time. Further, a transitional care unit allows inmates who have completed treatment, but are still in high security, to have a safer, quieter preparation for beginning to live in recovery.

In facilities with a high SMI population, 24 hours of advanced training teaches staff how to best interact with this population. They are also adapting three programs to be dual-diagnosis

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drug treatment programs. Some facilities have specialized diagnostic units for depression and borderline personality disorder.

### **Social Security Administration**

Social Security benefits and supplemental income are suspended while in prison, although pre-release application processes are in place. A 2017 supported employment demonstration is evaluating whether offering evidence-based interventions of integrated vocational, medical, and behavioral health services to individuals with behavioral health challenges can significantly reduce the demand for disability benefits and help individuals remain in the labor force.

### **Department of Veteran Affairs**

The VA welcomes Sean Clark as the new director of the Veterans Justice Program and Matt Stimmel as the Training and Education Director. Workforce development is underway and required by the Veteran Treatment Court Improvement Act of 2018. They have been working with the field to prioritize hiring requests for 50 Veteran Justice Outreach Specialists.

### **Substance Abuse and Mental Health Services Administration**

In alignment with ISMICC recommendations, SAMHSA's goals are to divert people from arrest, jails, and emergency departments, while connecting them to treatment and support for successful community living. This effort has the most significant impact by fostering partnerships, and inspiring change through stellar programs in the field. A new five-year grant program for law enforcement partners has awarded 12 grants focused on diversion.

Product development evolves from expert panels, virtual training, and technical assistance via webinars and online office hours, virtual and in-person learning collaboratives, policy academies, and grant programs. Recently released documents include the Screening and Assessment of Co-Occurring Disorders in the Justice System, which is a compendium of annotated screening and assessment instruments available to the public. Another product is the Principles of Community-based Behavioral Health Services for Justice-Involved Individuals: A Research-based Guide, which includes charts of evidence-based and promising practices. Other products include Tailoring Crisis Response and Pre-arrest Diversion Models for Rural Communities, Forensic Assertive Community Treatment, and MAT inside Correctional Facilities.

Webinars have been especially successful. A virtual seven-hour symposium coordinated by SAMHSA GAINS (the model includes the following core strategies: Gather, Assess, Integrate, Network and Stimulate) Center with presentations from ISMICC members Mr. Ron Bruno and Mr. Pete Earley had over 700 participants. Another webinar looked at the criminal justice system role in reducing the duration in untreated psychosis, advancing innovation in crisis response models, and more. Additionally, Virtual Learning Collaboratives created around the products are successfully meeting the needs of the states. Virtual and onsite events are held to create coordinated local strategic plans and implementation strategies while increasing uptake.

In partnership with the GAINS Center, the Policy Lab provides a deeper dive. In April 2019, the Policy and Implementation Academy was held with decision makers from eight states and a diverse county representation. Participants left with action plans and training on priorities, such as expanding crisis services, and increasing diversion opportunities.

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### **Focus Area 5: Finance**

*Chris Carroll, M.Sc., Director, Health Care Financing and Systems Integration, Office of Intergovernmental and External Affairs, and David DeVoursney, Chief, Community Support Programs Branch, CMHS; Kristen Beronio, Senior Policy Advisor for Behavioral Health, Center for Medicaid Services*

The Center for Medicaid and CHIP (Children's Health Insurance Program) Services issued a state Medicaid director letter in November 2018 explaining various ways states could improve access to and quality of care for individuals with SMI and SED while using existing plan authority to support evidence-based models and best practices of care. The letter also offered states a new opportunity using the 1115 demonstration authority to cover mental health services traditionally excluded. Modeled after a demonstration for substance use disorders, this demonstration requires states to focus heavily on improving access to community-based care and subjects them to enhanced monitoring and evaluation during the demonstration. Technical guidance was provided for some components of the application, such as state appropriations and local funding levels for Medicaid beneficiaries, and funding for outpatient community-based services in the most recent year before the application. Other key issues addressed were the current availability of different levels of care throughout the state and the prevalence of SMI and SED. Advice on data sources was provided, including several sources from SAMHSA. The initial information feeds into the ongoing demonstration and is meant to be updated annually and reported quarterly.

Another key feature of these demonstrations is that states must provide a detailed implementation plan and a financing plan for the different action steps and milestones. Other assistance was provided to clarify terms and expectations around different topics. Currently, they are actively working with Washington, DC, and Vermont. While an additional ten states are expected to apply.

Regarding Mental Health Parity and Addiction Equity Act (MHPAEA) and parity, the Cures Act and the Opioid Commission are the two main drivers for the recent efforts. Section 13001 requires DOL, HHS, and the Department of Treasury to issue a compliance program guidance document, with examples of parity violations and how to comply and share findings with the state regulators. One of the recommendations of the opioid commission was for federal and state regulators to use a standardized tool to document and disclose their compliance strategies. As a result of the directives, an FAQ guidance product was issued about the requirements related to non-quantitative treatment limitations along with a self-compliance tool, which is available to state regulators on the website.

In addition to providing ongoing technical assistance and participating in the national meetings, a stakeholder meeting was held in January related to parity implementation and enforcement. DOL was interested in hearing ideas regarding parity implementation and the ongoing efforts to educate and provide technical assistance to state insurance departments. A kick-off meeting was held last fall with representatives from SAMHSA, DOL, and regional offices to explain their roles in parity enforcement regarding mental health treatment and substance abuse disorder. As a result, all representatives from the regional offices have participated in an opioid taskforce along with their SAMHSA counterparts. Further, coordination efforts concerning general enforcement have occurred. Additionally, it permits the agency to enter into common interest agreements to coordinate investigations.

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### **Certified Community Behavioral Health Clinics (CCBHCs)**

CCBHCs were tasked with developing guidance for prospective payment systems that reimburse participating clinics for their costs. CMS provided two choices to the demonstrations: 1) PPS1, which is the daily encounter rate; and 2) PPS2, which is the monthly encounter rate that also requires states to make quality bonus payments for achievement measures defined in the guidance issued by CMS. All CCBHC rates are matched by CMS. ASPE is currently working to contract an evaluation demonstration using qualitative data, state and clinic reporting quality measures, and claims data. The results are being shared through a series of reports to Congress with the final report available in 2021.

CMS has been working with the eight demonstration states to continue the payment and coverage model using Medicaid state plans and Waiver Authority. To date, one state amendment has been approved and other approvals are anticipated. Two state plans have not taken steps to ensure coverage after June 30, 2019, the end of the demonstration. CMS has been clear that the services provider on a demonstration will only receive the federal matching rate.

Additionally, SAMHSA was appropriated 100 million in the 2018 fiscal year to fund the CCBHC expansion grants and awarded 52 grants on September 30, 2018. CCBHC extension grantees are expected to implement the same model using SAMHSA grant funding of 2 million per year and include criteria such as staffing, availability and acceptability of services, care coordination, the scope of services, quality measure reporting, and organization authority in government. The expansion grants are also expected to provide crisis services, treatment planning, screening assessment, diagnosis and risk management, outpatient, mental health and substance use services, targeted case management, outpatient primary care screening and monitoring, community-based mental health care for veterans, peer family support, counselor services, and psychiatry rehabilitation services.

Lastly, behavioral health spending and use accounts are available on the SAMHSA website and provide a sense of federal funding trends for Medicaid and other grant programs.

### **DISCUSSION**

There is a tribal consultation requirement in the 1115 demonstrations that is taken very seriously. Various tribal advisory committees are also briefed on these initiatives, and their input is considered at the federal level. However, funding is not directly available to tribal nations as it is to states. Because of this, it is especially critical that tribes are engaged with Medicaid agencies and expressing their needs and willingness to partnership. Further, SAMHSA has specific grants and funding available for tribal programs separate from a waiver or a Medicaid plan.

Regarding the criteria or metrics used to decide whether there are parity violations, the DOL has issued guidance on their website. More information on this matter will be forthcoming.

### **Public Comments**

Public comments were provided, which can be found in Appendix C.

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### **Crisis Services Discussion**

*Richard McKeon, Ph.D., M.P.H., Chief, Suicide Prevention Branch, CMHS, and Steven Dettwyler, Ph.D., Public Health Analyst, Division of State and Community Systems Development, CMHS*

***Fact: In 2017, more than 47,100 Americans died by suicide, similar in number to the 47,700 who died from opioid overdoses.***

An expert panel convened during the summer of 2018, and discussed the reality of crisis services in America, including the following highlighted issues:

- Emergency room (ER) boarding is a critical issue across the nation. Adults and youth in psychiatric crisis may sometimes have to wait days in ERs.
- Too often people are getting the wrong care in the wrong place, compromising other medical urgent care.
- Law enforcement is often called upon as a substitute for clinical mobile outreach services.
- There is no real-time coordination of crisis services available and people sometimes may not get an immediate appointment or access to a bed when one is desperately needed.
- Mobile outreach teams and crisis stabilization facilities are essential services; however, there is great variability in availability across states.
- There are over 160 local crisis centers comprising the National Suicide Prevention Lifeline that are not federally funded. These centers network together to answer calls through the Lifeline, but capacity is currently strained. Many calls have to be answered outside of the caller's region or state through the backup centers.
- Police transport to distant hospitals is also a serious issue taking law enforcement away from their primary roles. These transports are often perceived as aversive, unpleasant, and stigmatizing for people in crisis. Further, people may experience a deepening of despair and isolation when encountering the crisis system.

At a time when inexpensive technology is changing nearly every other industry (e.g., a package can be tracked around the world), it is unacceptable to lose people within the cracks of the American crisis system. The 2018 expert panel discussed the Crisis Now model as a way of improving crisis services in America. Released by the National Action Alliance for Suicide Prevention, the model identifies three major components every community should have: a crisis stabilization unit, mobile outreach services, and a hotline or call center that has “air traffic control capabilities,” providing real-time information on available resources. SAMHSA recently awarded two Crisis Center Follow Up grants to crisis centers in DuPage County in Illinois and Onondaga County in New York to help them implement the Crisis Now model.

Numerous states, such as Georgia, Arizona, and Colorado, have engaged in innovative work. For example, the Georgia Crisis and Access Line allows people to get an appointment in the community mental health system 24/7. Other noteworthy developments include the VA’s implementation of the SPED program, Safety Planning in Emergency Departments, based on data from their Suicide Assessment and Follow-up Engagement: Veteran Emergency Treatment (SAFE VET) study. SAFE VET found that safety planning in the ER, combined with follow up phone calls, reduces suicidal behavior and increases linkage to mental health services.

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Additionally, due to DOJ's Olmstead efforts, crisis services are being implemented in other states, most recently in Louisiana and West Virginia. The collaboration of SAMHSA and CMS on CCBHCs has also shown a significant increase in crisis services that include 24-hour mobile teams, emergency crisis interventions, and crisis stabilization with protocols and care coordination with ERs, Integrated Practice Units and law enforcement. Currently, 66 behavioral health clinics are participating in the Medicaid demonstration in eight states and 64 are funded through the expansion grant program.

To help veterans in the crisis system, SAMHSA is also working closely with the VA on the Mayor's Challenges Site to ensure that when veterans are in the community emergency and crisis system, the veteran status is checked, access to lethal means is checked, and a plan is developed to deal with potential access to lethal means. The veterans are also linked with the veteran's crisis line and the local VA medical center. The objective is to improve the community crisis systems, strengthen partnerships between veteran and civilian community stakeholders, and develop an action plan to improve crisis services.

A study published by Valenstein, et al., found that discharge does not signal the end of a crisis, but rather is a time of heightened risk. Therefore, the VA developed a significant follow-up system. The ED SAFE study, similar in many ways to the SAFE ED study, also showed reductions in suicide-related outcomes with telephonic follow-up after discharge from ERs when combined with screening and collaborative safety planning.

The expert panel also recommended a national mental health emergency system similar to the 9-1-1 based emergency medical system. As mandated in the National Suicide Hotline Improvement Act, SAMHSA provided a report to Congress in February 2019 on the effectiveness of an N11 number. Though SAMHSA did not recommend a specific N11 number, the North American Numbering Council recommended that 211 be extended to include suicide prevention and crisis intervention. FCC will make their own recommendations in their report to Congress in August 2019.

Currently, the Lifeline, (1-800-273-TALK), links over 160 crisis centers, routing calls from anywhere in the United States to the closest certified local crisis center. Veterans are directed to press one, which routes their calls to the three crisis centers directly run by VA. There is also a sub-network with 24/7 Spanish language capacity, when pressing two. Trained counselors assess calls for suicide risk, provide crisis counseling, crisis intervention, and engage emergency services when necessary (e.g., dispatching ambulance or police if somebody is in the midst of a suicide attempt).

To aid their assessment, SAMHSA funded evaluation studies that revealed reductions in hopelessness and self-reported intent to die as a result of the Lifeline. The study also found that callers at imminent risk could be de-escalated, police intervention avoided, and a proportion of follow up calls helped callers not kill themselves. These evaluation studies resulted in the development of Standards for Assessing Suicide Risk and Guidelines for Responding to Callers at Imminent Risk, which were accepted by all the crisis centers in the network and led to widespread adoption of follow-up across the network.

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The greatest challenge to the Lifeline is its capacity to respond rapidly to the steadily increasing call volume of about 15 percent per year, (e.g., 2.2 million answered calls in 2018). Back-up centers for local communities ensure that every call is answered, though it takes longer.

Therefore, the best solution is to increase capacity to answer locally as it reduces the average answer time from 116 seconds to 44 seconds.

SAMHSA's conclusion follows:

“Based on SAMHSA's experience with national and state crisis intervention efforts over the past 18 years, and informed by a meeting of experts and stakeholders in mental health, crisis intervention, emergency services and suicide prevention that SAMHSA convened November 29 to 30, 2018, our judgment is that an N11 national suicide prevention number **has the potential to play a key role in improving national crisis intervention and suicide prevention efforts**; if the launch of a new number is accompanied by efforts to develop a more coordinated crisis system with greater capacity and access to sophisticated data and technology systems, and an ongoing commitment to data driven quality improvement.”

Lastly, there is no specific number regarding the number of hospital beds needed in a community because the answer is completely dependent on the community in question. For example, fewer beds are needed in more responsive and effective multi-modal crisis systems because at each intercept stage, people are diverted to other effective levels of care, such as a crisis hotline or crisis stabilization unit.

### **Schizophrenia and Related Disorders Alliance of America**

*Raymond Cho, M.D., M.Sc., Board of Directors Chairman, Schizophrenia and Related Disorders Alliance of America*

The vision of the Schizophrenia and Related Disorders Alliance of America (SARDAA) is to promote hope and recovery through support programs, education, collaboration and advocacy. SARDAA's vision is that every person living with schizophrenia receives respect, proper evaluation, treatment, and support rather than incarceration and other dire consequences such as homelessness. While their scope is national, their reach is international with programs like peer-led support groups now available on almost every continent.

With a collective commitment to help improve the lives of individuals living with schizophrenia, there is a wealth of scientific information to help the field understand and conceptualize schizophrenia properly. This information provides a tremendous opportunity to implement a proper assessment of its nature and impact at a societal level in the form of a neurological survey. Further, the FY2020 House Labor HHS Appropriations Committee and H.R. 2740 states:

*“**Neurological Diseases Surveillance System.** The Committee is pleased that CDC initiated developmental and implementation work for the National Neurological Conditions Surveillance System (NNCSS). The NNCSS will provide a foundation for the evaluation and understanding of neurological conditions by collecting information on incidence and prevalence, geographic clusters of conditions, demographic variability, outcome measures and health care practices and*

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*utilization. The Committee provides \$5,000,000 within the total for Surveillance, Epidemiology, and Informatics to add at least one severe neuropsychiatric disorder, such as schizophrenia, to NNCSS implementation.”*

Dr. Cho urged everyone to express support for this measure to get it passed in the Senate.

SARDAA’s key strategic priorities are to: 1) lead a coalition to reclassify schizophrenia spectrum disorders as a neurological brain illness; 2) drive data-driven description and analysis of schizophrenia spectrum disorders in the most comprehensive way as possible, including accounting for patients who are ending up homeless or in the criminal justice system; and 3) engage in advocacy that seeks to reduce the tragic and unjust personal and social consequences of the illness.

Schizophrenia is a severe, chronic, disabling brain disorder marked by delusions, hallucinations, disorganization, problems with motivation and expression of emotions. It is unclear what percentage of the population and what regional differences in this incidence and prevalence are across the country. Approximately 10 percent of recipients of permanent disability in the US have schizophrenia with direct and indirect costs estimated of at least \$156 billion. Further, according to the Treatment Advocacy Center Research Weekly, schizophrenia and other psychotic disorders are the number two reason for hospitalization in the 18 to 44-age range.

Understanding schizophrenia as a brain-based disorder affects evaluation and treatment. Additionally, understanding the illness as a neurodevelopmental disorder with a high degree of heritability is an impetus for research and clinical strategies to address early diagnosis and intervention. Myriad brain image studies provide solid evidence that cortical matter decreases in the prefrontal cortex and temporal cortex, which are important areas for abstract thinking, working memory, attention, and perception. These changes in brain matter are even more striking when you look at childhood-onset schizophrenia.

When comparing schizophrenia to more traditional neurological disorders like Alzheimer's and Parkinson's, the cognitive, affective, social, and sensory motor disturbances are linked to well-replicated findings. These disorders have more structural and functional changes, a high degree of heritability, and are typically diagnosed on a clinical basis. There is no specific lab tests for these diagnoses, and all are managed with an array of psychotropic medications. The similarity ends, however, in the way people are treated. For example, there is a negligible rate of having poor access to care, homelessness, and incarceration for those with Alzheimer’s or Parkinson’s.

The Epidemiologic Catchment Area studies from data gathered in the '80s as well as the National Comorbidity Survey characterized the scope of the problem and provided useful information. Further, the National Neurologic Survey aims to have an accurate, current, and more comprehensive accounting of incidence and prevalence, improve the overall surveillance, strengthen stakeholder collaboration and shared resources, improve awareness and support, and encourage research into the causes and treatment. The goals of this survey are aligned with the data-driven, compassionate approach needed, and including schizophrenia could have a positive cascading effect.

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### **National Institute of Mental Health Strategic Plan**

*Meredith A. Fox, Ph.D., Director, Office of Science Policy, Planning, and Communications, National Institute of Mental Health*

The mission of NIMH is to transform the understanding and treatment of mental illnesses through basic and clinical research, paving the way for recovery, prevention, and cure. This is accomplished through an overall strategic plan, objectives, and research priorities over a five-year period while a separate document, the Strategic Research Priorities, is updated annually. Other reports from special workgroups are used in the strategic planning.

Currently, the strategic plan includes a director's message focused on the state of the science and goals for the next five years. The introduction includes separate sections on initiatives, major projects, and research themes. The new draft plan, SP2020, will resemble the framework in the current plan. The four strategic objectives (SO) will be retained with a few minor language changes. SO1 is for longer-term research into transformational treatments while SO3 and SO4 are near-term investments and more relevant to the ISMICC and to SMI. The biggest change is that the Strategic Research Priorities are being included in the plan.

Opportunities and challenges will be addressed in the plan in sections on the burden of mental illness and suicide, neural circuits, the next steps for RAISE, the promise for the future, recovery after an initial schizophrenia episode, and more. Crosscutting research themes that do not belong in any particular section will be retained and cover mental health equity both domestically and globally, computational psychiatry and big data, and workforce development to sustain the future.

By comparing the strategic objectives to the first four ISMICC focus areas, NIMH was able to map across to current funding opportunity announcements (FOAs). The first highlight is leveraging electronic medical records for psychiatric genetic research, which maps to ISMICC Recommendation 1.6. The goal of this effort is to elucidate the interplay of genetic and environmental influences in large populations and leverage existing electronic medical records from large cohorts. This will build an ongoing data repository and allow for more low-cost, large-scale studies moving forward.

The Aurora Study, a longitudinal assessment of post-traumatic syndrome, has higher variability in its presentation and frequent comorbidity with other conditions. The goal of the Aurora Study is to identify discrete intermediate phenotypes of post-traumatic stress and then to look at the course and trajectory of this over time in other longitudinal associations. This highlight maps to ISMICC Recommendation 3.4 and is an interagency effort since PTSD cuts across the VA and the DoD.

The Early Psychosis Intervention Network (EPINET) is another cross-agency effort currently underway, all taking place in SAMHSA clinics, with two FOAs available: 1) practice-based research to improve treatment outcomes by linking evidence-based specialty care for persons with early psychosis and improve early identification, diagnosis, and intervention efficacy; 2) establishing a data coordinating center.

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SO4 highlights Zero Suicide Healthcare Systems, which aligns with SAMHSA to prevent suicide attempts and deaths within the health care system. In 2017, NIMH published a Notice of Interest to specifically encourage applications to leverage time-sensitive opportunities in clinical infrastructure. This includes collaborations with organizations supported through SAMHSA's recently announced Cooperative Agreement Initiative to implement Zero Suicide in the health care systems. There is also a small business mechanism aimed at incorporating novel and perhaps commercially viable health IT products to improve health care settings.

The final highlight is Advanced Laboratories for Accelerating the Reach and Impact of Treatments for Youth and Adults with Mental Illness (ALACRITY), aligned with ISMICC recommendation 3.10. ALACRITY aims to support centers of interdisciplinary teams of researchers and mental health stakeholders in projects normally unviable through individual grants. This effort will support rapid development, testing, and refinement of innovative approaches for interventions in mental health services.

Lastly, the first presentation of the strategic plan draft was given during the NIMH council meeting in May 2019 and will be shared again over the summer and again in the fall of 2019 in open meetings followed by a request for information in the fall or winter. The plan is to then integrate feedback and present a near-final draft at the council meeting in fall 2019 or on February 4, 2020 and publish by spring 2020.

### **DISCUSSION**

One suggestion is for NIMH to “crosswalk” their efforts with the SAMHSA strategic plan, which also references the ISMICC. Because the ISMICC recommendation on trauma-informed care is focused on system improvement activity, it was suggested that NIMH connect biomarker efforts to recommendations on screening or identification.

An observation was made that NIMH seems to be taking a systematic implementation science approach. Specifically, SO4 is focused on Zero Suicide research within systems of care, finding failure points within the system, and experimenting with quality improvement strategies that could then be broadly implemented. One example is SAMHSA’s work with the VA on the Early Psychosis Intervention Network. The network is a model strategy for embracing a learning health care framework, systematic data collection, improving quality of services and driving further scientific endeavors. Other strategic approaches recommended for NIMH to consider are crisis system implementation, recovery interventions, and rehabilitation.

The issue of perceived discriminatory laws under Medicaid was raised. For instance, it was opined that schizophrenia should not have to be classified as a neurological disorder to have it treated properly through Medicaid; a number of participants agreed that any progress made on behalf of schizophrenia would be a leverage point for all mental illnesses and that schizophrenia might be the easiest case to make because there are clear cognitive brain changes resulting in debilitation. Other concerns raised included the following : 1) desire for increased accountability for errors in diagnosis and medication treatment; 2) a call for experimentation and administering low-cost unhelpful medications to end; 3) desire for more consumers to be at the table to enrich the dialogue; 4) statement that public comments from callers were hard to hear; 5) desire for

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increased acknowledgement of peer support specialists given they represent a huge population of workers; and 6) hoping for policy changes to decriminalize mental illness and allow better and more effective communication with family members.

### **Discussion with the Assistant Secretary on Key Topics**

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

Access to and engagement in services for people living with SMI is vital. Therefore, Dr. McCance-Katz and her staff have worked collaboratively with CMS to give states the option to obtain an 1115 waiver IMD exclusion. States that apply and obtain the waiver demonstrate the ability to provide levels of care and thus divert people from hospitalization while opening more beds for acute cases.

Yet, because many people living with SMI are unaware that they need services, the issue of civil commitment is included in the ISMICC's initial report to Congress. States need to review their laws, modify them when necessary, and consider implementation while keeping the autonomy of the individual intact. Because the laws should never be used against an individual or their family, there has been a focus on psychiatric advance directives (PADs). Interestingly, though CMS asked psychiatric institutions to work with individuals on crafting a PAD prior to discharge, it was not consistently implemented. However, the Joint Commission has agreed to make it an area of opportunity and psychiatric facilities should be surveyed on their efforts. Further, SAMHSA's mental health technology transfer center educates providers on PADs, which have been shown to reduce civil commitment.

The report from an expert panel on civil commitment was given to ISMICC members. In summary, the panel highlighted the need for levels of care that currently do not exist in most communities to divert people from hospitalization when appropriate.

Dr. McCance-Katz asked for input on why states are not applying for the 1115 waiver to lift the IMD exclusion, even though many states applied for an 1115 IMD exclusion waiver for SUD treatment. It was suggested that states might fear institutionalization. If states are not applying due to an inability to provide levels of care, leadership needs to identify ways of helping states to do that. For example, states could focus on care and treatment rather than criminal justice.

It might be helpful for ISMICC to engage representatives of NASMHPD and the National Association of Medicaid Directors on how to promote more universal implementation across the states. Secondly, there is a recommendation to the Level of Care Utilization System (LOCUS), created by the American Association of Community Psychiatrists (AACCP), as a standard level of care instrument. The National Council is beginning to work with AACCP to create broad LOCUS dissemination and a LOCUS manual. Notably, LOCUS is referenced in the IMD waiver. If states identify the levels of care within their continuum currently paid for within their standard Medicaid plans, they may see that it is not such a big leap to apply.

A concern was raised about the lack of focus on children under the age of 16 even though all but one ISMICC recommendation is related. Therefore, it was suggested that the December

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ISMICC meeting focus on children's issues, models, services, and needs. Members were directed to the Federal Commission on School Safety report, containing recommendations all related to children. Further, ODEP has some initiatives specifically around youth with mental health needs, such as Guideposts for Success that are forthcoming. They are also in the process of doing Requests for Applications (RFA) for a new youth policy development TA center that incorporated some of the ISMICC recommendations around the needs of youth. Lastly, the Employer Assistance and Resource Network (EARN) released a Mental Health Accommodations and Accessible Workplace Toolkit that is fitting regardless of age.

Regarding PADs, though SAMHSA does not have a model law, they are contemplating discussing PADs at the state level. Technology development is also being considered to help store and access a PAD instead of having to carry a bulky document. Additionally, the ISMICC could advocate for health care providers to initiate conversations about PADs since they are potentially a very powerful clinical and legal tool. This dialogue could balance some of the ethical issues of protecting the patient while honoring their autonomy and independence. Further, PADs lay a foundation for reminding people of their wishes, increase the continuity of care across multiple providers, and help family members to potentially gain guardianship or decision-making authority in these situations.

One non-federal member expressed appreciation for being included in ISMICC workgroups. The Cures Act does not require workgroups; yet, if they are put in place, all ISMICC should be included in the meetings. It was also suggested that presentations be sent in advance to allow members to prepare for deeper conversations during the meetings.

Further, the ISMICC has no authority to compel departments to engage in an interdepartmental strategic plan process and have their own meetings that do not include the ISMICC. However, representatives from these agencies attend the meetings and report back to leadership, which is a way to progress. For instance, as a result of the ISMICC meetings and recommendations, the ODEP created a supported employment workgroup that meets without a mandate to do so.

Dr. McCance-Katz asked for input on addressing civil commitment more publicly and anticipated pushback. There is a bit of a misapprehension among many mental health providers regarding the reality of commitment laws. Almost every state has updated their civil commitment laws and have moved toward being medically based.

Many states are confused about the IMD exclusion and CMS could do a better job providing materials and guidance to them. Many states have also been concerned that the Department of Justice is resistant to providing needed hospital beds, which denies people of treatment and makes them vulnerable to incarceration.

Another issue about civil commitment is educating the public. Many people with SMI have been warned by well-meaning friends and family to avoid commitment. Adding language that says civil commitment is a less restrictive alternative than incarceration is a very powerful argument. In addition, a model of civil commitment could emphasize situations when people would deteriorate with a high risk of severe consequences (e.g., incarceration), were it not for the

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intervention. However, it is also important to allow people to have access to services voluntarily without having to be committed, which is not possible in some states.

In looking at the continuum of services, it is helpful to consider access to psychiatric rehabilitation services in residential settings along with the acute front-end crisis continuum. The same standard medical benefit allowing one to be treated in a residential rehabilitative setting after a stroke or head injury, for instance, is rarely available for people who are suffering acute psychiatric episodes. Home health or assertive outreach are also standard for medical rehabilitation but not mental health. This should be approached from a parity and funding continuum level.

The lack of patient education is another issue that must be addressed. A UK charity known as SANE, released a report revealing that people with psychosis and mania relapse because of stressful events in their life and when they stop their medication precipitously. Yet, there is a lack of education about these outcomes even though there is a major effort to educate people on other conditions, like HIV.

Lastly, Dr. Hatch acknowledged a request for participants to receive information on what states are implementing or applying for, to help non-federal partners discern where to focus their advocacy efforts.

### **CLOSING**

Drs. McCance-Katz and Hatch expressed gratitude for the input of all attendees and seeing no further comments or questions, Ms. Pamela Foote adjourned the ISMICC meeting at 2:32 p.m.

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## Appendix A: Meeting Agenda

### U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES INTERDEPARTMENTAL SERIOUS MENTAL ILLNESS COORDINATING COMMITTEE FULL COMMITTEE MEETING

July 2, 2019

9:00 a.m. to 2:30 p.m. (Eastern Time Zone)

Substance Abuse and Mental Health Services Administration  
5600 Fishers Lane, Room 5A02  
Rockville, Maryland 20857

Toll Free Number: 888-928-9713; Passcode: 1858202

WebEx Link: <https://protect2.fireeye.com/url?k=a21c7e81-fe4857aa-a21c4fbe-0cc47a6d17cc-ad7b9f7b669ad5be&u=https://www.mymeetings.com/nc/join.php?i=PWXW9134696&p=1858202&t=c>

#### AGENDA

##### OPEN SESSION

- 9:00 a.m. Call to Order/Committee Roll Call**  
Pamela Foote, Designated Federal Official, Interdepartmental Serious Mental Illness Coordinating Committee (ISMICC)
- 9:05 a.m. Opening Remarks**  
*Arlin Hatch, CDR, USPHS, Ph.D., ISMICC Coordinator, Office of the Assistant Secretary, and Senior Psychologist, Center for Substance Abuse Prevention (CSAP)*
- 9:10 a.m. Welcome**  
*Elinore F. McCance-Katz, M.D., Ph.D., ISMICC Chair, Assistant Secretary for Mental Health and Substance Use*
- 9:15 a.m. Consideration of the Minutes for the December 11, 2018 ISMICC Meeting**  
*Elinore F. McCance-Katz, M.D., Ph.D., ISMICC Chair, Assistant Secretary for Mental Health and Substance Use*
- Report Outs by Focus Area – 20 Minute Sessions**
- 9:20 a.m. Focus Area 1: Data - Kirstin Painter, Ph.D., LCSW, Public Health Analyst, Center for Behavioral Health Statistics and Quality, Division of Evaluation**

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- 9:40 a.m.**     **Focus Area 2: Access** - *Richard McKeon, Ph.D., M.P.H., Chief, Suicide Prevention Branch, Center for Mental Health Services (CMHS), and Steven Dettwyler, Ph.D., Public Health Analyst, CMHS*
- 10:00 a.m.**     **Focus Area 3: Treatment and Recovery** - *Justine Larson, M.D., M.P.H., M.H.S., Senior Medical Advisor, OCMO and CMHS*
- 10:20 a.m.**     **BREAK**
- 10:35 a.m.**     **Focus Area 4: Justice** - *Larke Huang, Ph.D., Director, Office of Behavioral Health Equity Lead, Trauma and Justice Strategic Initiative Senior Advisor – Children, Youth and Families, Office of Intergovernmental and External Affairs (OIEA)*
- 10:55 a.m.**     **Focus Area 5: Finance** - *Chris Carroll, M.Sc., Director, Health Care Financing and Systems Integration, OIEA, and David DeVoursney, Chief, Community Support Programs Branch, CMHS*
- 11:15 a.m.**     **Public Comments**  
Pamela Foote, Designated Federal Official, ISMICC
- 11:30 a.m.**     **LUNCH (on your own)**
- 12:30 p.m.**     **Crisis Services Discussion**  
**Richard McKeon, Ph.D., M.P.H., Chief, Suicide Prevention Branch, CMHS, and Steven Dettwyler, Ph.D., Public Health Analyst, Division of State and Community Systems Development, CMHS**
- 1:00 p.m.**     **Schizophrenia and Related Disorders Alliance of America**  
*Raymond Cho, M.D., M.Sc., Board of Directors Chairman, Schizophrenia and Related Disorders Alliance of America*
- 1:20 p.m.**     **National Institute of Mental Health Strategic Plan**  
*Meredith A. Fox, Ph.D., Director, Office of Science Policy, Planning, and Communications, National Institute of Mental Health*
- 1:50 p.m.**     **Discussion with the Assistant Secretary on Key Topics**  
*Elinore F. McCance-Katz, M.D., Ph.D., ISMICC Chair, Assistant Secretary for Mental Health and Substance Use*
- 2:25 p.m.**     **Final Comments**  
*Elinore F. McCance-Katz, M.D., Ph.D., ISMICC Chair, Assistant Secretary for Mental Health and Substance Use*
- 2:30 p.m.**     **Adjourn**  
Pamela Foote, Designated Federal Official, ISMICC

## Appendix B: Official List of Meeting Participants

### PARTICIPANTS LIST

**Erin Bagalman, MSW**, Director, Office of the Assistant Secretary for Planning and Evaluation, ASPE, Department of Health and Human Services, HHS

**Kirsten Beronio**, Senior Policy Advisor for Behavioral Health at The Center for Medicaid and CHIP Services, Centers for Medicare and Medicaid Services (CMS)

**David Barry, PsyD**, Clinical Communications Advisor, SAMHSA

**Ron Bruno**, 2nd Vice President, CIT International

**Chris Carroll, MSc**, Director, Health Care Financing and Systems Integration, SAMHSA

**Carlos Castillo**, Committee Management Officer, SAMHSA

**Clayton Chau, MD, PhD**, Regional Executive Medical Director, Providence St Joseph Health

**Raymond Cho, MD, MSc**, Board of Directors Chairman, Schizophrenia and Related Disorders Alliance of America

**Richard Davis, MSW**, Senior Policy Advisor, Office of Disability Employment Policy

**Maryann Davis, PhD**, Professor and Director, UMass Medical School

**David De Voursney, MPP**, Branch Chief, SAMHSA

**Steven Dettwyler, PhD**, Public Health Analyst, SAMHSA

**Elmer Pete Earley**, Author, Pete Earley, Inc.

**Paul Emrich, PhD**, Under Secretary, Chickasaw Nation

**Pamela Foote**, Designated Federal Official, SAMHSA

**Meredith A. Fox, PhD**, Director, Office of Science and Policy Planning and Communications National Institute of Mental Health

**Mary Giliberti**, ISMICC Member

**Arlin Hatch, CAPT, USPHS, PhD**, ISMICC Coordinator & Senior Psychologist, Office of the Chief Medical Office, SAMHSA

**Larke Huang, PhD**, Director, Office of Behavioral Health Equity Lead, Trauma and Justice Strategic Initiative Senior Advisor – Children, Youth and Families, SAMHSA

**Lillian M. Ingster, PhD**, Director, National Death Index, National Center for Health Statistics Centers for Disease Control & Prevention

**Ira Katz, MD, PhD**, Senior Consultant, Department of Veterans Affairs

**Elena Kravitz, CPRP**, Senior Staff Advocate, Disability Rights New Jersey

**Justine Larson, MD, MPH, MHS**, Senior Medical Advisor, SAMHSA

**Elinore F. McCance-Katz, MD, PhD**, Assistant Secretary for Mental Health and Substance Use, SAMHSA

**Richard McKeon, PhD**, Chief, Suicide Prevention Branch, SAMHSA

**Kenneth Minkoff, MD**, Senior Consultant, ZiaPartners

**Joyce Nicholas**, Social Science Research Analyst, Social Security Administration

**Arne Owens**, Deputy Assistant Secretary for Planning and Evaluation, Department of Health and Human Services, HHS

**Kris Painter, PhD, LCSW**, Public Health Analyst, SAMHSA

**Tracie Pogue, MDIV, MSW, LCSW**, Public Health Analyst, OCMO, SAMHSA

**Sandy Resnick, PhD**, Deputy Director, NEPEC, Office of Mental Health and Suicide Prevention VACO

**Elyn Saks, PhD, JD**, Professor, University of Southern California

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**Michael Schoenbaum, PhD**, Senior Advisor, National Institute of Mental Health

**Jennifer Sheehy, MBA**, Deputy Assistant Secretary, Department of Labor

**John Snook**, Executive Director, Treatment Advocacy Center

**Rhathelia Stroud**, Judge, DeKalb County Misdemeanor, Mental Health Court

**Tracey Trautman**, Deputy Director, Department of Labor

**Conni Wells**, Manager, Axis Group I, LLC

## Appendix C: Official List of Public Comments

### 1. *Sherri McGimsey, Morgnaton, N.C.*

I would really like to ask why a Veteran Psychiatric Dr. has to beg a State Psychiatric Dr. to take a few Veterans for some long term treatment that they need? Serious Mental Illness schizophrenia, schizoaffective needs a level of care to have any hope of keeping our loved ones alive! We love our son we hate his disease! Jails or prisons are not the answer! SOS from a Mom of a Veteran Marine.

### 2. *Jeanne Gore, Coordinator, National Shattering Silence Coalition*

"My name is Jeanne Gore and I'm the coordinator for the National Shattering Silence Coalition or NSSC. We are voices for the 11.2 million adults and roughly 7 million children living with and dying too young from serious mental illness.

Please, when looking at finances, request that there be a full accounting of what NSSC refers to as "the cost of not caring." Things like, the cost of physical illnesses - 75% of persons with SMI have at least one chronic illness, 50% have 2, and 33% have 3 or more. The cost of homelessness and not allowing for AOT to treat those with anosognosia, including the costs to courts, police, crisis, prisons, judicial systems, and the medical system. The cost for patients who go through revolving doors, in and out of hospitals, jails, and emergency rooms because they are not treated early enough and/or not kept long enough to stabilize them. The cost of criminal justice with and without treatment. The cost of disability payments, lost income, loss of productivity, loss of life, and the cost to family members who bear much of the emotional and financial burden of these illnesses.

Please recommend that the IMD Exclusion be repealed and fully staffed, comforting, safe facilities be created where people can receive the medical treatment they deserve early on in the course of their illness instead of waiting for them to become a "danger to themselves or others" and throwing them in jail where they often are thrown into solitary confinement untreated and languish there for years and years.

Federal budget for research into Alzheimer's Disease in 2019 is \$2.3 billion dollars. For 2020, it's \$2 billion dollars. Federal budget for research into SMI is \$443 million in 2019 and \$383 million in 2020 yet there are 11.2 million suffering from SMI and 8 million with Alzheimer's Disease. Saving our youth needs to be just as important as saving our elderly.

HIPAA handcuffs must be removed. We are fighting for our loved one's lives and cannot even know what their medication is, where they are, etc...

Please support efforts to see that schizophrenia spectrum disorders are reclassified as neurological brain illness so they will be recognized as a physiological illness like any other illness treated medically.

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I don't think I need to tell anyone in this room that we have a silent epidemic in this country of untreated serious mental illness that's been going on literally for decades.

Let's be the generation that finally fixes this problem and brings treatment with dignity, respect, and love. Thank you."

### **3. Tama Bell, Mother of Masai Stewart**

My son has been mentally ill since the age of 7. He has had numerous diagnoses including Bipolar and has had over 10 Hospitalizations. He went off all medications at the age of 18, he is now 27. He became homeless, and committed his first felony at the age of 18 and went to prison for the first time. My sons illness has gotten much worse since his first prison stay for 3 years-he now has delusions where he believes things that are not real or true.

I begged the County Department of Mental Health for help (I asked for help for 9 years, with various horrible situations happening with my son, to no avail) with an AOT (Assisted Outpatient Treatment-Kendra's Law in New York-which is a Civil Commitment Law) and every time they evaluated whether or not my son was a candidate for AOT or even ACT they determined that he did not meet criteria. Every time he did something, the County and State Mental Health would tell me allow him to go to jail or prison where he would get better treatment than he would in the community!!!! He then endangered others and himself, and each time, went on about his own until now:

He is now in Jail again and facing another prison term possibly for puncturing tires on a car He has had delusions where he believes things that are not real that he thinks are happening to him, such as, he believed that the victim whose car tires he punctured owed him money (the young man claims he did not know my son), he believes currently that Jail Staff are contaminating his food (the Jail is using hermetically sealed food to prevent contamination of my son's food because he stopped eating due to his delusions).

Currently the Dutchess County Jail tells me that they can barely house him he is so sick. They feel he needs a mental health facility not a prison or jail.

But yet, the prosecutor is looking to put him back in state prison for puncturing tires.

I wonder what can be done for my son. He needs the Rockland Psych Center near us where he can get back on Medications and treat his condition.

Is there anything that can be done?

### **4. Janet Hays, President - Healing Minds NOLA**

For the July 2, 2019 ISMICC virtual public meeting, I would like to make the following comment pertaining to the lack of appropriate housing modalities in Louisiana for seriously mentally ill adults.

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This is a huge gap in continuity of care and is fueling the revolving doors of ERs, jails and unnecessary institutionalization. In New Orleans, we have a fairly robust Permanent Supportive Housing program but we have no state run or contracted licensed and accredited group homes in LA outside of forensic residential facilities. Consequently, seriously mentally ill people have become prey to derelict landlords who are happy to take SSI/SSDI checks without offering any services in return. Efforts have been made to require licensing, however that poses a risk of derelict landlords simply selling off properties and returning tenants back to homelessness. Unless the state steps up to fill this need, we will continue to be at a standstill.

The need is everywhere. For instance, we are ramping up efforts on AOT programs but we have difficulty assisting program participants with treatment adherence without the availability of an array of housing options that meet them where they are.

In addition to case management, many SMI people need on-sight professional support along with positive group activities in order to stay motivated. Housing models should range from transitional locked and/or unlocked intensive stabilization and support housing, to medium intensive, to peer run, to permanent supportive housing. Levels of housing should be elastic so that people can be moved up or down the scale as needed.

I also want to comment briefly on the need for HIPAA reform. I have received many tragic stories since the passage of the 21st Century Cures ACT that are directly attributable to the withholding of information from family caregivers, and even refusing to receive information from family caregivers, due to misperceived HIPAA rules. Clarification of HIPAA rules need to be legislated and covered entities need to be mandated to learn the rules.

### **5. Lynne Gibbs, California**

#### Critical IMD Bed Shortage in California, and the Need to Repeal the IMD Medicaid Exclusion

I write as the mother of a young woman living with a serious mental illness. I serve on our county's Stepping Up Committee dedicated to diverting persons with mental illness from the jail to treatment.

In CA, we have a severe shortage of secured treatment beds resulting in a situation in which persons in our jails deemed incompetent-to-stand-trial (IST) on felonies and needing a state hospital bed wait anywhere from months to more than a year to be moved for restoration. For many of these persons, their only real crime is having a mental illness. Many spend months essentially in isolation for their own protection while in jail waiting, growing more ill without treatment. This is an unacceptable situation, and a national problem. It has been described as a perfect storm in California, because of the growing number of ISTs statewide. Over the years, the number of state beds nationally has declined from approximately 550,000 to 38,000, while the need for such beds has grown.

Our county, with a population of 4.5 hundred thousand, has a single psychiatric hospital with only 16 beds for persons needing the most intensive level of care for crisis stabilization; whereas 40 beds per 100,000 population is the recommended standard. As a result, persons in mental

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health crisis are more likely to be arrested than placed in involuntary care in a treatment facility. Then, persons with mental illness deemed IST on misdemeanors wait months in the jail for one of these 16 beds, when they need an IST bed in the county for restoration. We have NO secured IMD beds in our county for persons who need longer stays for treatment in a secured setting – ZERO beds. This means we pay a premium for out-of-county IMD beds for persons under conservatorship, with increasing competition among counties for these beds, and the cost rising as the need increases.

Our county has set the goal of establishing a Mental Health Rehabilitation Center (MHRC), a category of IMD, but the cost of treating patients in such a facility is prohibitive, as would be the cost of expanding the number of hospital beds beyond 16 for crisis stabilization, due to the federal IMD Medicaid Exclusion that blocks Medicaid funding for psychiatric facilities exceeding 16 beds.

I urge the ISMICC to give priority to repeal of the IMD Medicaid Exclusion.

### **6. Kathleen M. Pike, Ph.D., Professor, Departments of Psychiatry and Epidemiology**

To: Interdepartmental Serious Mental Illness Coordinating Committee (ISMICC)

From: International Leadership of the *Asylums: Reframing the Narrative* Session of the Healthier Longer Lives Conference hosted by the World Health Organization, Fountain House, The Global Mental Health Programs at Columbia University, Grand Challenges Canada, and Cities Rise.

Re: Public Comment for the ISMICC Meeting July 2, 2019

*Asylum(s): Reframing the Narrative* took place on November 7, 2018 at Fountain House in New York City. The event consisted of an international panel of speakers and discussants – including ISMICC members Elyn Saks, Pete Earley and John Snook.

The asylum movement was a progressive – even enlightened - movement in its day. That was over 150 years ago. Today, in the US, prisons, jails, homeless shelters and the streets have become de facto warehouses for people with serious mental illness. The time has come to reframe the narrative on where individuals with serious mental illness can find a place to belong and a life purpose.

It is widely agreed that the US health system is failing to ensure that the least restrictive, appropriate care is available to individuals with SMI and SED throughout the course of their lives. For an unacceptably high number of individuals with SMI and SED, community-based care is not available, and the health care system is marred by failure to provide continuity of services.

With this background, the international *Asylums* panel participants provide the following recommendations to ISMICC:

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1. Community Mental Health Centers provide essential services to a broad segment of the American population; however, to serve the particular needs of individuals with SMI and SED, federal and state policy must prioritize funding for places in the community that deliver care designed specifically to serve individuals with serious mental illness.
2. Federal and state policy and funding must be available for community-based treatment that combines primary and psychiatric care with social interventions in the areas of employment, education and housing.
3. Community-based care must be part of a network of coordinated, comprehensive services so continuity of care is provided across treatment settings when individuals with SMI and SED experience exacerbation of symptoms that require enhanced levels of care.
4. Appropriate inpatient care must be available in communities to support individuals with SMI and SED. Institutionalization and inpatient hospitalization should be utilized only when necessary and such care can largely be minimized when comprehensive community-based care is available and coordinated.
5. The criminalization of individuals with SMI and SED must stop. The high rates of contact with the criminal justice system of individuals with SMI and SED is largely a function of federal and state policies that make it impossible to intervene early and effectively. Comprehensive, community-based programs enhance quality of life, social connection, purposeful work and reduce cost. Such strategies must become the backbone of services for individuals with SMI and SED.

These recommendations represent the consensus views of panelist, discussants, advisors:

- Jeff Aron, Fountain House
- Gary Belkin, Executive Deputy Commissioner of Health-Mental Hygiene, NYC Department of Health and Mental Hygiene
- Sudipto Chatterjee, National Institute of Advanced Studies, India
- Joel Corcoran, Executive Director, Clubhouse International
- Lisa Dixon, Professor of Psychiatry, Columbia University Irving Medical Center
- Pete Earley, Family Member & Author
- Stephen Eide, Senior Fellow, Manhattan Institute for Policy Research
- Elizabeth Ford, Chief of Psychiatry for Correctional Health Services, New York City Health & Hospitals
- Michael Franczak, Director of Population Health, Partners in Recovery
- Tad Gary, Chief Operating Officer, Mercy Care
- Gary Harki, Investigative Reporter, The Virginian Pilot
- Donald Mays Jr. Community Wellness Center
- Bharti Patel, National Executive Director, South Africa Federation for Mental Health
- Kathleen M. Pike, Professor of Psychology, Columbia University Irving Medical Center
- Cheryl Roberts, Executive Director, Greenburger Center
- Stefan Robinson, Certified Recovery Practitioner and Director of Collaborative Support Programs,

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- Elyn Saks, Director, Saks Institute for Mental Health Law, Policy, and Ethics; Associate Dean and Orrin B. Evans Professor of Law, Psychology, and Psychiatry and the Behavioral Sciences, University of Southern California Gould Law School
- Shekhar Saxena, Professor, Global Health & Population Harvard T H Chan School of Public Health
- Steve Sharfstein, Clinical Professor of Psychiatry, University of Maryland
- Jody Silver, Executive Director, Collaborative Support Programs, CSPNJ
- Elizabeth Sinclair, Director of Research, Treatment Advocacy Center
- John Snook, Executive Director, Treatment Advocacy Center

### 7. ***Martie Rhoden Bessler***

Thank you Dr. Elinore McCance-Katz and ISMICC!

There are absolutely NO words to describe what it is like for me and my son who is suffering from Serious Mental Illness, living day-in and day-out. I am caregiver and now guardian of my son afflicted with Schizoaffective Disorder going on 19 years. I am a nurse; and at 56 yrs. of age, I recently had to quit working as my son and my own health continues to deteriorate. The collateral damage to caregivers and loved ones is immeasurable as well.

There are people like my son who are UNABLE and may NEVER be able to be part of the "recovery" model; and they continue to live under our bridges, rot in our jails, or suffer and die.

Regardless to what is written on paper, or what my state of Kentucky policy-makers are telling me, Our Community ACT teams are Not working, and I have no doubt this is the same in other states as well. I am at ground level every single day and see the truth for myself!

I understand and appreciate you recognizing benefits for our SMI loved ones that must actively be pursued by each of the states; However, I pray that you develop a much more specific way to educate and guide the states to take advantage of these opportunities so these positive changes can ACTUALLY happen for our SMI loved ones.

Given the track record of my state of Kentucky with the SMI, I am fairly confident that KY will Not actively pursue any of this on their own for the SMI. Our SMI loved ones Must have access to Long-Term Adequate Housing With 24 hr. supervision WITH licensed medication staff on the medication cart.

Adherence to accurate medication administration is one of THE best ways to avoid re-hospitalization and further deterioration.

Long-term Supervised housing opportunities are paramount to providing stability for our SMI loved ones. Sadly, I do Not hear much about this topic. I pray that you will work hard to make that happen!

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As more and more focus is placed on substance abuse and all the myriad categories under behavioral health increases, the More our SMI loved ones continue to get squeezed out from the very limited resources available out in the community to provide treatment, So those afflicted with SMI ALONE, continue to deteriorate and continue to live a miserable existence or die!!

An individual with an undiagnosed and untreated mental illness, will most likely, self-medicate within 5 years. So what we have is the tail wagging the dog! I pray you will change this!

IT SEEMS IT JUST ISN'T ENOUGH that my son is tortured by hearing persecutory voices Every. Waking. Moment. Of. Every. Single. Day!

Or that my son has a chronic diabetic foot wound in which he nearly lost his foot 2 yrs. ago. and experiences pain with Each. And. Every. Step. He. Takes!

My son was afflicted with a neurological brain disease; and at the age of 16 yrs. old, and this illness took away his bright future.

My mother-in-law has a neurological brain disorder called Alzheimer's, and became afflicted After a Long and Joy Filled Life.

Access to adequate treatment and care for my son VS. treatment and care my mother-in-law is ABSOLUTELY ASTOUNDING; As well as the HIPAA barrier to help care for my son VS. the freedom to be involved with my mother-in-law's treatment plan and care!

I pray that you will continue to work hard to change that!

PAIMI has been given WAY TOO much power AND INAPPROPRIATE power at that!

Our SMI loved ones should NOT be allowed to have a "Right to choose" when they do NOT even realize that they are choosing their "Right to Die!!"

I pray that you will be that voice that is needed to change that!

In closing, I leave you with Matthew 25, verse 40:

40 "The King will reply, 'Truly I tell you, whatever you did for one of the least of these brothers and sisters of mine, you did for me.'

God, Please Help Us All!