



March 14, 2018

Interdepartmental Serious Mental Illness Coordinating Committee (ISMICC)
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Dear Assistant Secretary McCance-Katz & Members of the ISMICC Committee,

NSSC Position Statement in Response to the ISMICC 12/17/2017 Report Recommendations

The National Shattering Silence Coalition (NSSC) is grateful that Dr. McCance-Katz agreed to consider the points of view and experience of our members as she works to improve many of the federal systems that impact us. We read and reviewed the Interdepartmental Serious Mental Illness Coordinating Committee's (ISMICC) report and are in agreement with many of the recommendations. We have outlined the following additional recommendations pursuant to this report. Thank you for your consideration.

Focus 1: Strengthen Federal Coordination to Improve Care

- NSSC believes it is critical for the federal departments to demonstrate a committed role in all of the ISMICC activities. We support a broad outreach to all sub agencies that intersect with the SMI/SED population. We also encourage outreach to local and state leaders of system reform to introduce additional interested parties with new ideas and solutions. NSSC can aid the ISMICC by supporting crucial conversations with caregivers, family, and providers who are on the front lines.

- We are concerned about some of the language and terminology regarding mental illness and recommend that ISMICC establish a lexicon that promotes brain health and illnesses rather than ‘behavior’ issues. Behavioral health is often interpreted to be more volitional and less deserving of resources than other medical illnesses.
- We agree with the goal to align eligibility and benefits systems across federal departments to facilitate system navigation and continuity of care. We encourage ISMICC to specifically focus on this for DOJ/ criminal justice reforms. Linking inmates to benefits before release aids in continuity of care and prevents recidivism.
- NSSC supports a comprehensive system improvement process that will evaluate the current systems, create a baseline, and reimagine the future system through the lens of the SMI/SED patients, families and providers. Too often programs are evaluated through a system-focused perspective. NSSC encourages an authentic partnership approach that allows evaluations to occur collaboratively. Solutions and improvements must then be co-designed. NSSC encourages the ISMICC to consider creating a formal SMI/SED Family Advisory Council that can partner with SAMHSA and its stakeholders.
- NSSC supports a whole health, whole life, person-centered approach to serious mental illness that is grounded in science and promotes using quality measures that are equal to all chronic medical illnesses. We believe it’s time for federal policy and programs to meet the essential health standards established by the Institute of Medicine (Safe, Equitable, Timely, Efficient, Patient/Family Centered and Effective) for the SMI/SED population. This can only occur when we coordinate the medical model and the recovery model for SMI/SED based on a continuum of medically necessary treatment and other recovery supports. We need a both/and approach to health, not either/or. Further, we need to improve the capture of mortality data as those with SMI and SED are dying young.
- NSSC strongly supports the reclassification of SMI/SED as brain diseases or neurological illnesses so the affected can receive integrated psychiatric/primary care and coverage in the physical health system. Just like Parkinson's, Alzheimer's, and dementia.
- NSSC notes that duties of the ISMICC includes “(2) an evaluation of the effect federal programs related to serious mental illness have on public health,…”
<<https://www.samhsa.gov/node/176353>>. NSSC is concerned that under this duty, priority is given to PAIMI/P&A, which was not mentioned by the ISMICC report. PAIMI/P&A has drifted from its original purpose of advocating for effective humane treatment to actively opposing needed treatment interventions.

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

- We are concerned with the absence of any mention of anosognosia in this report. While patient-centered and patient-led care is often appropriate, many with serious mental illness are not capable of making the best decisions for their care and treatment. “Approximately 50% of individuals with schizophrenia and 40% of individuals with bipolar disorder are estimated to have co-occurring anosognosia. It is reported to be the most common reason why individuals with schizophrenia refuse to take medication.” (Treatment Advocacy Center, [Serious Mental Illness and Anosognosia](http://www.treatmentadvocacycenter.org/storage/documents/backgrounders/smi-and-an-osognosia.pdf). <<http://www.treatmentadvocacycenter.org/storage/documents/backgrounders/smi-and-an-osognosia.pdf>>). Involuntary treatment is vital for many of our loved ones/clients and continues to be a necessary method to bring them care.
- The shortage of inpatient beds and the discrimination by some inpatient units against the most challenging patients (e.g., the most violent, most likely to be stuck on inpatient units for months) results in long waits for beds and premature discharge at both emergency departments and hospitals. Emergency Departments specifically designed to treat those suffering from SMI/SED, crisis stabilization units, repeal of the IMD Exclusion, in addition to more psychiatric hospital beds and community-based alternatives to hospitalization, are needed to alleviate this problem.
- HIPAA is poorly understood both by providers and the public. We agree with ISMICC Focus 2.3 recommendation to create a program, perhaps through SAMHSA, whereby providers and the public can become educated as to what HIPAA laws actually mean in terms of the information that can be shared with others and when exceptions can be made. HIPAA laws are frequently cited as both a reason for excluding caregivers from patient care and for not notifying a family member/care provider of a patient’s discharge, thus abandoning the patient and resulting in families being unable to locate their SMI loved ones. Additionally, it would be very helpful if a HIPAA hotline could be created where family members and providers could call for clarification when in doubt about what the HIPAA laws mean in reference to a specific case they are attempting to navigate. Please note: HIPAA education programs and hotlines should be interim measures. NSSC believes HIPAA needs to be totally rewritten.
- Inpatient admission criteria need to be standardized. Wisconsin could be used as the model for all other states regarding inpatient admission criteria. This state considers need for treatment and a patient’s capacity to understand need for treatment in involuntary hold law. Many other states require imminent danger to self or others before allowing a patient to be admitted which results in the inability of caregivers and providers to obtain

treatment for those suffering from SMI and predictable violence. Many times, these patients are arrested due to their behaviors rather than hospitalized.

- The Level of Care Utilization System and Child and Adolescent Level of Care Utilization System used to assess needs, monitor progress, and treatment outcomes is not well known to front line clinicians. Top-down dissemination of educational tools should occur, down to the local level.
- In implementation of ISMICC Focus 2.2 and 3.5 recommendations, we support evidence-based programs that serve all transitioning youth (ages 16 through 25) with SMI or SED with medical, psychiatric, therapeutic, educational, community and vocational guidance into adult services. Currently, upon reaching age 18 or the completion of high school, the 504 and IEP accommodations abruptly halt, including transition planning post-high-school. Without supports in all of the domains, these young adults are falling into lack of treatment, denial of further education, and unemployment. The largest impact of such a program would be to integrate transition planning into the high school setting for students identified with SMI or SED regardless if they are included in special education (504/IEP) or the type of insurance they have. County health departments would be the logical continuation of the program to provide the service to individuals and their families.
- We support ISMICC Focus 2.7 recommendation to use telehealth and other technologies to increase access to care. While this is especially important for rural populations, it is also vital for emerging adults who leave home for college. College mental health clinics are rarely equipped to treat students with long term mental illness or emerging psychosis.
- Increase access to Clozaril/Clozapine clinics. Physicians who prescribe Clozaril/clozapine will also be needed. Patients who take lithium and other medications (including Haldol which is recommended for several different genetic psychosis conditions) that require lab monitoring need lab services to be more readily available, preferably in the same (primary care) setting. We believe this is consistent with the intent of the ISMICC Focus 2.8 recommendation.
- Adjust the licensing requirements for providers so they can continue to help their clients transition into local care when they relocate. Currently, providers have to be licensed in the state where the patient resides, which can force patients to end relationships with trusted providers just as they are going into a high risk time in their lives.
- Use Project ECHO (Extension for Community Healthcare Outcomes) more to improve the use of resources. Support research, testing, and dissemination of new technology.

- Insurance companies often provide the largest obstacle for obtaining mental health treatment for those with serious mental illness. Treatments must “fail” at a lower level of care before clients are allowed a higher, more expensive level of care. Even when providers, patients and families all agree that a client will not benefit from a lower level of care, they still have to be referred and fail before insurance companies will allow a step up. These failures, in the best cases, result in demoralization and exhaustion by all involved. The worst cases result in incarcerations and fatalities. Health insurance is the only service provided where ‘pre-authorization is not a guarantee of payment.’ Pre-authorizing work on your home or car *is* a guarantee of payment; however, insurance companies require lengthy detailed pre-authorization processes for patients and clinicians and still deny claims. ISMICC needs to intercede with this incredibly dysfunctional part of the system.

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

- We support a federal plan to make Assisted Outpatient Treatment (AOT) and Outpatient Civil Commitment a national standard of care due to the vast evidence of its efficacy in improving health, decreasing arrests and homelessness.
- The use of peer and family support specialists as a matter of routine practice without empirical research proving their efficacy is concerning. Peer support is not proven to help people with SMI. <<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3933205/>> Unlike case management, supportive housing, hospitalization, involuntary interventions, and medications, there is no evidence it reduces homelessness, suicide, arrest, or incarceration of the SMI. In addition, one member of the NSSC observes the poor success in training peer specialist graduates in Orange County, California, where the position of Peer Specialist is up for consideration for licensure. A recent licensing class had 94 participants, and about a 50% pass rate. Only two peers have jobs in peer support. Further, of the graduating peers, many were concerned their workload jeopardized their own recovery path. Genuine oversight must happen, as people diagnosed with SMI are at a high risk of symptom return and reduced insight. It’s also possible that peer specialists might be unable to provide appropriate care, as codependent relationship dynamics tend to develop as peers struggle. Additionally, we have observed open positions for “peer support specialists” job descriptions state a central task of a peer specialist is to provide supportive counseling to patients and families. That is necessarily the job of the licensed social worker. We fear there will be attempts to replace social workers with cheaper “peer support specialists” who lack the skills and training of a licensed social worker.

Just as most inpatient psychiatric units have behavioral health techs and CNAs providing the largest share of direct patient contact, it is easy to see the temptation to use less costly peer support specialists to assume the responsibility of counseling patients and families while trained clinicians are delegated to clerical duties such as requesting insurance authorizations.

- *Gravely Disabled* should be a federally mandated disability category in relation to SMI/SED in all states. Recovery-oriented models of team-based care do not address those who cannot recover. The reality is that many with SMI will never reach a full “recovery” despite receiving the best treatments and care. Some will never be able to work or live without extreme support. Those with SMI/SED who are very severely disabled need to receive this determination more quickly. Since currently all mental illnesses are viewed as “recoverable,” many families have to reapply for services annually. For example, one NSSC member has a son who has a diagnosis of “severely disabled” with a prognosis of “Poor” via the Social Security evaluation and determination process. She reports that he has an autism spectrum diagnosis and also suffers psychosis. Her son is re-evaluated every 5 years, unlike those with a diagnosis of schizophrenia, despite very similar function and prognosis, who have to be re-evaluated every year. Her son receives full benefits and services, without the burden of constant re-evaluation. We recommend that the ISMICC align the way SMI is handled with the way autism spectrum and other neurological/brain based illnesses are addressed.
- Regarding ISMICC Focus 3.2 recommendation, we believe that school-based evaluations of all students who struggle socially and emotionally, not just academically, and subsequent funding and employment of necessary supports, would greatly help this problem. Many seriously ill children are not identified as ill in school and do not receive IEPs or 504 plans. One in 5 children shows signs and symptoms of a mental illness disorder, yet nearly 80% of those in need of services won’t receive them. Schools are too underfunded and understaffed to provide all necessary services and are therefore reluctant to refer all but the most profoundly disturbed for services. Schools all over the country are experiencing severe shortages of social workers, counselors, special education teachers, psychologists, and school nurses. Even in states such as California, where districts take on funding of IEP/504 supports, schools are undercutting the necessary supports. Often when children need higher levels of service, they go without until their families are left with a decision to either hospitalize or incarcerate them in juvenile facilities using their own finances. Often, families cannot find adequate services or do not know how to access services, are themselves ill, cannot navigate the systems, or do not believe that their child is ill, and thus, do not advocate for district-provided services for their kids. Children who are hospitalized frequently miss a great deal of school but

schools advance them to the next grade regardless. Enhance the Individuals with Disabilities Education Act to improve identification. Family history of SMI is our best predictor, currently, for development of SMI in youth. Coordination between the Department of Health and Department of Education to identify those at risk can help to identify and assist those most likely to develop SMI.

- We disagree with ISMICC Focus 3.4 recommendation and are concerned with the increased focus on trauma-focused care. Many people with SMI and SED do not have trauma histories. The focus on trauma as a cause for SMI/SED has resulted in invalidation of symptoms and shame and blame of patients and families who have SMI/SED. Many people with SMI are misled by the myth that somehow trauma causes SMI. They feel that they do not need treatment for symptoms because they were not traumatized and therefore must not really be sick. Many providers, teachers and the general public treat families with suspicion when a child becomes ill, assuming that families caused the symptoms through abuse or neglect. Psychiatry and psychology share a long history of blaming parents for mental illness in their children. While sometimes this is accurate, most often it is not. The perception that mental illness is a result of abuse increases misdiagnosis, poor treatment, poor compliance, and rejection of care by those who need it most.
- Related to ISMICC Focus 3.5 recommendation, special attention needs to be given to college campuses as early adulthood is the age of onset for many psychiatric illnesses, yet there is little to no treatment available on campuses. Most campus mental health clinics are set up for minor adjustment disorders, not first break psychosis. Several have 6 session limits and long wait lists to get basic MH services. Additionally, campus mental health clinics are set up to help the college, so when students come in stating that they are having thoughts of killing themselves in their dorm rooms, they can lose their housing and/or schooling over risk management concerns. Commonly, students in first-episode psychosis, when seeking help, often state a desire to drop out. Some colleges tend to encourage such decisions as the student is then no longer their burden.
- Improving access to supportive housing and independent living options for those able to live on their own is vital for those living with SMI and their families. People with SMI often wind up, at best, living with their families who are ill-equipped and lacking resources to care for them. At worst, they become homeless or cycle between nursing facilities, hospitals, and incarceration, or death. Many studies have shown that supportive housing breaks this cycle. The cost of providing supportive housing can be offset by the associated reduction in costs of homeless shelters, prisons, jails, emergency room visits and hospitalization. Group homes and board and cares that do not include supports for the

residents are commonly no more than a room and board. With little to no oversight, the conditions vary from adequate to dismal. Those with SMI/SED who are in desperate need of supportive housing require medication management by licensed staff. While guidelines for group homes/board and cares operations are helpful, requirements for minimum standards and consistent monitoring to insure compliance and accountability are also needed to ensure that people are consistently receiving their medication and being provided with decent, safe, and appropriate housing.

- Align funding to prioritize care for SMI and eliminate gaps in offered treatments. Those with SMI are estimated to be 4% of the US adult population and 10% of the US child population (SED). This minority regularly consumes significantly more dollars than larger populations of people with other mental health diagnoses. Will funding be first divided by prevalence rates and then by costs and burden or will this be divided based on the total number of prevalence plus costs/burden? The 4% are the least prevalent and the most costly. This has worked against providing adequate funding for SMI/SED historically and the ISMICC should work to remedy this disparity.
- The IMD exclusion criterion needs to be removed for SMI/SED as it has been for substance abuse disorders to allow for much needed treatment and beds.
- Illinois has a program called SASS (Screening Assessment and Support Services) that uses masters-level social workers and therapists to evaluate children and teens in the community who are either uninsured or in Department of Children & Family Services care who are thought to be in psychiatric crisis. They are granted admitting rights to hospitals and then they monitor the children in the hospital and ensure that they get appropriate care and follow up. Perhaps SASS could be a model for other states to develop similar programs to help children, teens and adults access treatment.

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

- All discussion, planning, and program implementation concerning reducing the number of persons with SMI or SED who become involved in the adult and juvenile justice systems should begin with the acknowledgement that the most effective strategy is to provide needed treatment prior to crisis and arrest. First episode psychosis must receive quick treatment rather than incarceration. Studies have shown that it's common for a person to have psychotic symptoms for more than a year before receiving any treatment, despite the fact that we know earlier treatment increases a person's chance for recovery.

- With regard to ISMICC Focus 4.1 and 4.2 recommendations, we believe the mental health system must take responsibility for preventing justice system involvement as well as diversion of those who become involved. Every arrest of a person with SMI/SED should be counted as a failure of the mental health care delivery system. A parent should never hear from a provider that their only recourse when insurance runs out or is inadequate, or when the 16 allowed beds are full, is to place their SED child/SMI adult child in juvenile detention or jail. Yet, this is commonplace.
- The federal government must take the lead in developing a standardized paradigm of accountability measures. Accountability should include management performance data (including number of SMI inmates, number of special housing beds, number of psychotropic medication prescriptions, etc.) and outcome measures (including number of suicide attempts and completions, restraints, self-injuries, incident reports, etc.). NSSC recommends that subject experts and designated staff from the National Institute of Corrections (Jail and Prison Divisions) be tasked with developing a current baseline and outcome measures that would provide standardized accountability for mental health care delivery systems and increase protections and accountability for mistreatment for mentally ill inmates. Another recommended resource is the National Association of Correctional Mental Health Administrators. NSSC offers their help in this important task. Several of our members have experience in this area and have made local efforts which will help in this important area.
- In addition to training for first responders, NSSC recommends development and implementation of effective training for judges, prosecutors and defense attorneys. Currently, there appears to be a belief that mental health courts are “a hall pass” rather than necessary diversion programs to focus on treatments rather than punishments.

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

- NSSC recommends that all SAMHSA funds currently directed to anti-psychiatry groups who refuse to acknowledge the existence of serious mental illness, and to those who discourage the use of empirical science to evaluate programs, be redirected to treat those with serious mental illness and fund proven evidence-based programs for the SMI/SED population.
- The NSSC agrees that federal departments should employ outcome and quality measures at the individual and population levels; however, we are concerned that frequently these models focus on preventing SMI. Preventing SMI is not currently possible. The unintended consequence of tying funding to readmission and relapse rates has resulted in

those with the most severe SMI being refused admission or discouraged from seeking needed treatment. Again, the target of recovery is not achievable for everyone, and penalizing those who continue to require services discourages providers from treating those most affected. Hospitals end up setting limits, for example, where they will not admit eating disorder patients with too low a BMI, or schizophrenia patients who have been admitted elsewhere in the prior 72 hours. When patients are refused readmission to the last place they were admitted, that disrupts continuity of care. Locking the “revolving door” to keep SMI/SED on the outside saves money and makes the numbers look better on paper, but it risks the lives and health of SMI/SED clients.

- The NSSC recommends that ISMICC acts to end the clear violation of parity laws in authorization of and access to mental illness treatment for those who have health insurance. The Milliman group recently published an article showing widespread disparity in the funding of mental health care.
<<http://www.milliman.com/uploadedFiles/insight/2017/NQTLDisparityAnalysis.pdf>>
This article shows how even those who have health insurance must frequently use their out-of-network benefits to pay for treatment of their mental illness. They use these out-of-network benefits at a rate far exceeding the use of such benefits for other medical illnesses. Furthermore, the deductibles for mental illness are significantly higher than those for physical illness. Accessibility and affordability of treatment for mental illness must be on the same level as other brain illnesses that also affect behavior such as autism, dementia, or Parkinson's disease.

Thank you for your consideration of our views. If we can be of any assistance as the ISMICC works to address the needs of adults with SMI and children and youth with SED and their families, please don't hesitate to contact us at coordinator@nationalshatteringsilencecoalition.org.

Sincerely,

National Shattering Silence Coalition (NSSC)

NSSC is an alliance of diverse individuals and organizations who are uniting to ensure that mental illness, health, and criminal justice systems count those with SMI, SED, and their families in all federal, state, and local policy reforms. We are voices for the 10 million adults and 7 million children living with and dying too young from serious mental illness.