National Shattering Silence Coalition (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.

Position Statement: NSSC Points of Unity #4: End Discrimination: Support the full repeal of the IMD exclusion and call for parity and a right to treatment under Medicaid/Medicare.

9/15/18

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I. INTRODUCTION: What is the IMD exclusion? What are its impacts?

In 1963, the U.S. Congress passed The Community Mental Health Centers Act. It was mistakenly believed then that treatment of persons with serious mental disorders in a community-based setting, using existing resources and the new psychotropic medications, would be in all cases superior to long-term residential treatment in a psychiatric hospital. Two years later, with the beginning of the Medicaid program, Medicaid funds were barred from use in the treatment of adults (persons between the ages of 21 and 64) in facilities having more than 16 beds for the specific treatment of mental disorders, a.k.a. institutions for mental disease (IMD). Although Congress included coverage for Alzheimer's disease and intellectual disabilities in Medicaid legislation, it determined that treatment of mental illness in adults was exclusively a state obligation.There was also the concern that if IMD's were included in the Medicaid program, the states would continue to warehouse people in hospitals instead of providing services in the community, which was their goal.

That reasoning has not lived up to the promise, however. Without funding, most IMD's have closed. Yet communities have failed to provide adequate comprehensive community-based services to take their place, leaving those with serious mental illnesses without adequate care. This failure occurred partly due to overly optimistic expectations as to the efficacy of the new psychotropic medications. Also, there existed a widespread lack of knowledge about severe mental illnesses, which did not anticipate that not everyone can be treated in a community-based setting. These, combined with other failures, including an unwillingness of communities to adequately fund a system of care which does not result in ready "cures," has resulted in no comprehensive support system which will permit those with serious mental illnesses to live successfully in the community. The IMD exclusion is an important factor in this failed system and is the focus of this paper.

Today, Medicaid is the most important safety net for health care, including mental health care. In 2015 it covered only 14% of the adult population, but it covered more than 25% of adults with SMI, and almost 20% of adults with substance use disorders (SUD).

II. THE ISSUE: Pending legislation H.R. 5797, also part of omnibus bill H.R. 6, is too limited and must be amended to repeal the IMD exclusion for all: people with serious mental disease (SMI) as well as those with all substance abuse disorders (SUD).

The Republican Policy Committee has provided this description of the problem with the IMD exclusion, which focuses solely on its applicability to the Opioid Crisis, and ignores how it also impacts the SMI population.

> Under the Medicaid statute, Federal funding cannot be used to finance care for Medicaid beneficiaries aged 21 to 64 receiving mental or substance use disorder care in a residential facility that has more than 16 beds. When a Medicaid-eligible individual is a

patient in an IMD, he or she cannot receive Medicaid coverage for services provided inside or outside the IMD. The Medicaid IMD exclusion is one of the few instances in the Medicaid program where federal financial participation cannot be used for medically necessary and otherwise covered services for a specific Medicaid enrollee population receiving treatment in a specific setting. According to the Medicaid and CHIP Payment and Access Commission (MACPAC), "The Medicaid IMD exclusion acts as a barrier for individuals with an opioid use disorder to receive residential treatment, which, depending on an individual's treatment plan, may be the most appropriate setting for care."

In response to this deficiency, in May, 2018, a bill was introduced to the House of Representatives (The IMD CARE ACT H.R.5797, now part of omnibus bill H.R.6), which would lift the IMD exclusion for people receiving care for substance abuse disorder (SUD). We (the National Shattering Silence Coalition) oppose H.R.5797 unless it is amended to completely repeal the Medicaid Institutions for Mental Diseases (IMD) exclusion not only for those with substance use disorders (SUD), but also for those who suffer from serious mental illness (SMI) and for those with both SMI and a co-occurring SUD. The full title appears below in a summary of the bill.

> Summary of Legislation: Last updated Jun 20, 2018.
> Source: Republican Policy Committee
> H.R. 5797 - Individuals in Medicaid Deserve Care That is Appropriate and Responsible in its Execution Act:
> H.R. 5797 allows state Medicaid programs to remove the Institutions for Mental Diseases (IMD) exclusion for Medicaid beneficiaries aged 21 to 64 with an opioid use disorder temporarily for fiscal years 2019 to 2023. By removing the exclusion, Medicaid would pay for up to 30 total days of care in an IMD during a 12-month period for eligible individuals. Opioid use disorder as defined in H.R. 5797 includes, but is not limited to: heroin, fentanyl, oxycodone, tramadol, and oxycodone. In addition, the legislation requires states to include in their state plan, amendment information on 1) How the State will improve access to outpatient care during the State plan amendment period. 2) The process for transitioning individuals to appropriate outpatient care. 3) A description of how individuals will receive appropriate screening and assessment.

As written, H.R. 5797 makes SMI adults (along with those suffering from a stimulant or hallucinogen use disorder) the only groups legally discriminated against in the provision of vital treatment for chronic conditions.

III DISCUSSION: Why the IMD exclusion for mental illness is discriminatory and wrong

A. The IMD exclusion misinterprets the U.S. Supreme Court's Olmstead Decision.

One argument against the reinvigoration of psychiatric hospitals is the perceived requirement, based on the Supreme Court's decision on *Olmstead v. L.C.*, 527 U.S. 581 (1999), that people with disabilities must be housed in the least restrictive setting possible, i.e. - not in a state mental hospital if at all possible. Also, the integration regulation mandate in title II of the Americans with Disabilities Act requires a "public entity [to] administer … programs … in the most integrated setting appropriate to the needs of qualified individuals with disabilities." Where a community setting is best for the individual Under Title II, the court concluded, unnecessary institutional segregation constitutes discrimination *per se*, which cannot be justified by a lack of funding.

NSSC believes that the ADA requirement that disabled people be cared for in the least restrictive environment possible is a laudable goal, but it is a spurious and false argument against maintaining psychiatric hospitals. Furthermore, just as not providing a community setting due to lack of funding cannot be justified, so, too, not providing a hospital setting when it is the appropriate course similarly cannot be justified by lack of funding. There are people for whom the least restrictive setting *is* a psychiatric hospital. To deny that care also constitutes discrimination *per se*.

In the majority opinion, Justice Ginsburg pointed out, "*The ADA is not reasonably read to impel States to phase out institutions, placing patients in need of close care at risk*." Further along in her summary she states, "*Some individuals, like L. C. and E. W. (the two women whose care was the concern of this Supreme Court decision) in prior years, may need institutional care from time to time to stabilize acute psychiatric symptoms. For others, no placement outside the institution may ever be appropriate*."

B. Successful trial waivers show the benefits of repealing the IMD exclusion.

The IMD exclusion has already been recognized as a barrier to treatment, and a few trial waiver programs already demonstrate that it would be effective to eliminate the exclusion. Under trial programs, states can direct federal funds to IMDs through the Medicaid Disproportionate Share Hospital (DHS) payments under a Section 1115 waiver. As of 2018, 6 states had approved programs and 21 have pending waiver requests for programs that include mental health waivers (currently 1115 waivers are demonstration programs that must be periodically renewed). It would be more efficient and beneficial to end this layer of bureaucracy and eliminate the IMD exclusion altogether.

C. The IMD exclusion violates existing law: the Mental Health Parity and Addiction Equity Act of 2008 (MHPAEA) or Parity Act.

The IMD exclusion discriminates against providing mental illness treatment to adults between the ages of 21 and 64, the time period where most serious mental illnesses become symptomatic. In addition to being unethical and unjust, this discrimination is a violation of the mental health parity requirement of the Mental Health Parity and Addiction Equity Act of 2008

(MHPAEA) or Parity Act, passed in 2008, and later its subsequent inclusion in provisions of the Affordable Care Act (ACA). There are over 10 million adults living with SMI in America. The IMD exclusion has been used to discriminate against this population for 53 years. These diseases are medical diseases of the brain and must be treated with the same care and attention any other medical disease of the brain, such as Alzheimer's or Parkinson's.

As pointed out above, Congress itself, in the online summary of H.R.5797, admits that federal funds have been forbidden to pay for "medically necessary treatment" for specific populations; i.e. discriminating against certain people. According to the Medicaid and CHIP Payment and Access Commission (MACPAC), "The Medicaid IMD exclusion is a barrier for receiving residential treatment, …which, depending on an individual's treatment plan, may be the most appropriate setting for care." These statements are just as true, if not more so, for the population struggling with SMI.

The Intergovernmental Serious Mental Illness Coordinating Committee (ISMICC), in the report "The Way Forward," delivered to Congress in December, 2017, established recommendations that relate to the IMD exclusion and its effects:

> #5.4 Eliminate financing practices and policies that discriminate against behavioral health care.
>
> #2.2 Develop a continuum of care that includes adequate psychiatric bed capacity and community-based alternatives to hospitalization

D. The IMD exclusion for mental illness has unethical and unjust consequences: jail and death while incarcerated.

It is unethical to deny needed treatment. Those with a serious mental illness often act out their delusions in public and end up in the judicial system. Using our jails to house people suffering from SMI and preventing treatment for their illness is cruel and barbaric, and has sent our nation back to the practices typical in the 1800's.

In 2006, the US Department of Justice (DOJ) found that about ½ of state and federal prisoner and 2/3 of those held in local jails had mental health problems. These facilities are not equipped for and do not have professional staffing levels needed to provide humane and appropriate care for these prisoners. Documentation of violence and humiliation suffered at the hands of both prison staff and other prisoners abound. Solitary confinement is overused, cruel, and further compounds the destabilization of a person's psychotic state. This is cruel and unusual punishment for the crime of suffering from a brain disorder.

Gary A. Harki, writing for The Virginian-Pilot, August 23, 2018, after months of investigation of this problem nationwide, wrote one of the best descriptions of the problem to date in "Horrific deaths, brutal treatment: Mental illness in America's jails: A comprehensive Virginian-Pilot investigation". In the course of the investigation the team found that since 2010 there have been at least 404 deaths of jail inmates that were known to have mental illness prior to their

incarceration, but due to poor recordkeeping, there are likely many more. In Texas, which keeps better data than other states, the Virginian-Pilot study uncovered 36 deaths of mentally ill inmates in Texas jails, while the Texas Department of Corrections in their own compilation found 55 deaths. Only six of those appeared in both reports, indicating how likely even the best estimates of deaths of SMI inmates are grossly undercounted. The stories recounted in the article and elsewhere testify to the fact that lack of mental health medication, use of the wrong medication, or torture and neglect in solitary confinement directly result in these deaths.

The article notes that beginning in "*October 2019, the Bureau of Justice Assistance will start collecting more accurate data on deaths in police and jail custody. The collection, which has been long delayed, was prompted by the 2013 Death in Custody Reporting Act, sponsored by U.S. Rep. Bobby Scott, D-Newport News*." The required data is to include "*basic demographic information, as well as the date, time and location of death, the law enforcement agency involved and a brief description of the circumstances.*" But it still will not specifically collect data on whether the person was mentally ill.

Because of the IMD exclusion, jails have become the new mental asylums, and are just as horrific as the asylums that were closed back in the 1800's. The passing of the IMD exclusion in 1965 resulted in the closing of most state psychiatric hospitals and a great reduction in available crisis and long-term care beds. In 1955 there were more than 500,000 state hospital beds for mental illness, a rate of 337 per 100,000 population. In 2018 the rate has declined to less than 12 per 100,000 population. It has been determined that to meet the needs of the SMI population, there should be 50 beds available per 100,000 population. Psychiatric hospitals needed to be brought up to date and made more humane, not be closed. The mentally ill population has not just disappeared. People suffering from serious brain disorders, unable to care for themselves and without the services of a psychiatric hospital, have largely ended up in the judicial system.

In the 2017 book *Insane Consequences,* D.J. Jaffe points out that nationwide there are now more than 390,000 persons with SMI incarcerated in our jails and prisons. This figure is the result of an almost a direct transfer, over recent decades, of the mentally ill from hospitals to jails and prisons where there is little to no appropriate treatment of their illness. Another 755,000 seriously mentally ill are on probation or parole. The National Council for Behavioral Health projects that another 84,000 people are chronically homeless due to untreated mental illness, addiction, or other disability. We are aware of the abuse and neglect that occurred in the asylums of the last century. But transferring the mentally ill to jail or to the streets is even greater abuse and neglect. What is needed is funding, including Medicaid payments, for modern, community-based hospitals, a continuum of care, and long-term supportive housing for this neglected population.

E. Lack of psychiatric beds results in poor care.

The IMD exclusion limits facilities to 16 beds for express treatment of psychiatric illness. This limitation does not allow for the economies of scale needed to stay in business or provide effective care. Those in crisis who manage to get to an emergency room are often left

“boarding” in the ER, waiting for a psychiatric bed to become available, or simply tranquilized and released without follow-up care. Unless facility providers are paid, they cannot provide much-needed long-term care for adults suffering from serious mental illnesses, with or without opioid addiction. Thus adults with SMI experience long delays in getting care and are denied beds.

It is well documented that there is a much poorer prognosis for those with mental illnesses who do not receive prompt, early intervention and treatment. Every episode causes further deterioration of the brain and other organs resulting in irreparable damage. Making the seriously mentally ill wait for beds hurts their prognosis as well as their health and safety.

The IMD exclusion is the primary reason for the severe shortage of psychiatric inpatient beds. Data collected by the Treatment Advocacy Center (TAC) reveals that from 1955 to 2016, the number of state hospital beds in the United States had plummeted almost 97%. By 2014, ten times more people with SMI were in prisons and jails than in state mental hospitals, a circumstance widely attributed to the shortage of beds to provide timely treatment.

In 2016, a new “managed care rule” from the Centers for Medicare and Medicaid Services (CMS) allowed states to receive “capitation” payments to managed care plans to cover IMD care for up to 15 days. Fifteen days, however, may not be not long enough to provide lasting improvement for SMI, even to those lucky enough to live in a state using this rule and to have prompt access to a hospital bed. They are likely to decompensate quickly upon their release, because even when the illness is caught early finding the right medication to treat SMI is a matter of trial and error. It may take weeks or longer for a new medication to show its effectiveness, and if it is not effective, the doctor must try another medication until an effective medication is found. This process can evolve into months when a person has remained untreated for a long period of time. Even Medicare's current hospitalization limit of 30 days is often not enough time to treat people suffering from chronic SMI or co-occurring disorders (COD)!

Currently, according to data from the Treatment Advocacy Center (TAC), in any given year 3.9 million people with SMI are untreated. In other words, nearly half are unable to secure proper treatment in this country. That statistic is appalling and unacceptable and can only be defined as grossly negligent.
Failure to provide prompt inpatient psychiatric hospitalization when needed causes an excruciatingly inhumane and expensive, fiscally irresponsible pattern of cycling people in and out of the revolving doors of emergency rooms, hospitals, homelessness, and jails. Family members of the SMI also experience collateral damage inflicted by a government who has turned a blind eye to the suffering of their loved ones for decades.

F. Legislation like H.R. 5797 is too limited a solution to the IMD exclusion: It ignores SMI that often co-occurs with SUD.

SMI and SUD are not mutually exclusive. There is a clear connection between SUD and mental illness. The proposed legislation does not provide for treatment of serious mental illness for individuals that have become addicted. It is estimated that 21.5 million people (ages 12 and over) battled a SUD in 2014. 7.9%—almost eight million—of those had a mental illness and a co-occurring SUD. In 2015, SAMHSA determined that fewer than 7.54% of those with COD, were receiving treatment for both disorders *but more than half, 55%, received no treatment at all*. Successful treatment of their CODs requires treating *both* their SUD *and* their SMI. The proposed legislation will not improve these numbers and in fact appears limited to only opioid dependency, not all SUDs.

SAMHSA has identified that there is only about a 5-year window of opportunity for prevention of co-occurring substance abuse after the onset of a mental disorder. Untreated SMI leads to more severe and treatment-resistant mental illnesses, and to the development of CODs. By far, the most common connection between untreated mental illness and substance abuse is self-medication. In many cases the SUD is a symptom of the SMI and would not have developed had the patient received prompt, consistent care for their mental illness.

G. The IMD exclusion for mental illness imposes financial costs.

We hear, in debates at the state level about expanding Medicaid and eliminating the IMD exclusion, that paying for hospital treatment for the SMI is cost prohibitive. But we argue that the costs of not paying for treatment are likely much greater. Many authors have attempted to quantify the potential costs of treatment and to compare them to the current costs to society of not using Medicaid/ Medicare funds for treatment of SMI/SUD. The data available is not comprehensive. The ISMICC report to Congress pointed out that programs and policies need to be guided by more comprehensive data to improve quality of care and outcomes. Congress should authorize SAMHSA to undertake a comprehensive study of costs of care vs. costs of failure to provide timely and appropriate treatment, or as NSSC coins it, “the cost of not caring,” as well as the efficacy of treatment protocols. Using good data would facilitate efficiencies by narrowing payments to evidence-based practices. Repealing the IMD exclusion would immediately improve access to care for the SMI.

Eliminating the IMD exclusion and allowing appropriate treatment in the most appropriate setting eliminates the cost of providing a jail for nearly 400,000 SMI currently in the prison population, and takes many of the estimated up to 325,000 people with SMI off the streets, greatly reducing the burden to local, county, and state governments of caring for our homeless population.

Many costs are invisible. Because access to appropriate treatment is so limited, many families choose to shelter their mentally ill loved ones while attempting to get help for them. They do this rather than abandon their loved ones to the streets, or risk the abuses that await their loved ones in jail or prison. But caring for their loved ones at home not only exposes them to potential grave violence, but too often also results in financial hardships. Family caregivers lose work and may lose their jobs if they are absent too often dealing with emergencies or court appearances.

They resign their jobs when it is clear the mentally ill family member cannot be left unattended and no respite can be found. They may have to pay for repairs to their property from violent outbursts, or they may pay for bail bonds or legal defense for their loved ones. Because of danger to others in the home, some parents will pay for private apartments or private treatment, both inpatient and outpatient, until their money runs out. These caregivers experience unmeasurable grief and stress while battling the dysfunctional mental health system in vain attempts to get effective care and shelter for their loved ones.

Many of those who suffer from serious mental illnesses do not qualify for SSDI (Social Security Disability Insurance) because their illness struck when they were too young to have worked enough time in the system to be entitled to SSDI. They are forced to accept the lower-paying SSI (Supplemental Security Income) or a combination of SSI and SSDI. If so, their benefits are limited to a range between $750 per month (if only SSI), and the minimum for SSDI which averages $1,197 a month (for 2018). These amounts—even with a rent subsidy and even with food stamp benefits of $192 a month—are not enough to cover rent and living expenses, even for a mentally ill person who is well enough to live in their own space. Families end up supplementing their children's income with food, gas, automobiles, clothing, and so on in order to keep their children housed and out of jail.

Because the untreated SMI are at high risk for other chronic diseases such as diabetes, heart disease, lung disease, and infections, leaving mental illness untreated increases costs for Medicaid and other public health systems that deliver non-IMD services.

One difficulty, when identifying and quantifying the savings from repealing the IMD exclusion, is that the costs and savings are borne by so many different agencies. Diverting a person from the criminal justice system, or helping him avoid it in the first place, saves money, but that money does not flow back to Medicaid or state or county mental health systems where it could be used to provide appropriate treatment and supportive housing to more people. Costs now borne by families and businesses due to lost productivity aren't counted anywhere. The costs of dealing with homelessness are borne by local governments and businesses who have no easy way of being compensated. Our lawmakers must take all of these costs into account when considering the costs and benefits of eliminating the IMD exclusion.

H. The IMD exclusion for mental illness imposes social costs: public and family tragedies.

Tragic incidents that arise from untreated mental illness are increasing. Psychiatrist E. Fuller Torrey estimates that up to 10% of all US homicides are probably due to untreated serious mental illness. Between 1982 and 2012, 63% of mass shooters had a mental illness, according to *Mother Jones.* This dynamic continues to play out in the national news all too frequently now. For example, the young man responsible for the Parkland shootings fell through the cracks in the system after his mother's death. We need a more structured way to care for someone with an emerging mental illness so that they receive adequate care before they act out.

In addition, according to data from the Treatment Advocacy Center (TAC), half of those living with schizophrenia or bipolar disorder will attempt suicide at some point in their life. Many go homeless and/or wind up incarcerated. Yet suicide awareness campaigns ignore this.

In 2008 one study showed that more than 26,000 persons with mental illness were incarcerated for murder. Parents and other family members are the most likely victims. 29% of family homicides were perpetrated by a family member with a SMI. In 2013 alone, over 1,100 people were killed by a family member with mental illness, usually when medication was stopped for various reasons. Police and other public servants are also at greater risk of injury and death at the hands of a person with untreated mental illness. The Treatment Advocacy Center (TAC) and the National Sheriffs' Association (NSA) conducted a joint study in 2013 finding that at least half of all attacks on law enforcement officers and 20% of officer fatalities were by people with mental illness, many of whom had ceased taking medication. This preventable violence destroys not only the life of the victim, but also the life of the ill person, and causes emotional and financial devastation of both of their families who are left to deal with the fall-out.

By eliminating the IMD exclusion altogether, the Treatment Advocacy Center estimates that the country would eliminate:

- 50% of mass killings
- 29% of family homicides
- 10% of all homicides
- 20% of law enforcement fatalities
- and over 40,000 suicides.

These tragedies and emotional and financial stress on families and communities would be largely preventable by simply providing needed treatment, which may require inpatient care for many weeks. Ending the IMD exclusion is a crucial first step in preventing this collateral suffering.

III. CONCLUSION

Modern investigation techniques show that serious mental illnesses are biological diseases of the brain. The over 10 million people suffering with SMI deserve the same opportunity to receive the compassionate care provided by Medicare/Medicaid for all other medical diseases. Using our jails to warehouse the SMI while preventing treatment repeats the cruel and barbaric practices typical in the 1800's.

There is a dire need for more treatment beds for the Seriously Mentally Ill. Denial and delay of care worsens the condition and leads to adverse changes in the brain. Denying care for the SMI is not a cost savings, as in the absence of care, costs will be even higher, including costs to the health care system, to the criminal justice systems to which patients are diverted in lieu of

treatment, and to a range of local and state governments who deal with the homeless mentally ill.

By eliminating the IMD exclusion, the US and individual states can achieve immeasurable alleviation of human suffering and do so in a very cost-effective manner. If we give it a chance, treatment can work, though sometimes it takes time and experimentation, and it will prevent many societal problems that result from untreated SMI.

REPEAT: Current legislation including H.R. 5797 must be amended to repeal the IMD exclusion for all people with serious mental disease (SMI) as well as those with substance abuse disorder (SUD). SUD and Mental Illness disorders cannot be separated and both need to be treated concurrently,

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