

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.

# Oppose the IMD CARE Act (H.R.5797)

June 26, 2017

## The Honorable Orrin G. Hatch

Chairman, Committee on Finance United States Senate 219 Dirksen Senate Office Building Washington, DC 20510

## The Honorable Ron Wyden

Ranking Member, Committee on Finance United States Senate 219 Dirksen Senate Office Building Washington, DC 20510

#### **The Honorable Mimi Walters**

215 Cannon Office House Building Washington, DC 20515

Dear Congressmen,

National Shattering Silence Coalition (NSSC) opposes the IMD CARE Act unless 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 illnesses (SMI) and co-occurring SUDs.

SMI and SUD are not mutually exclusive. There is a clear connection between SUD and mental illness. 21.5 million people (ages 12 and over) battled a SUD in 2014.<sup>1</sup> 7.9 million of those people had a mental illness and a co-occurring SUD, defined by the Substance Abuse and Mental Health Services Administration as co-occurring disorders (COD).<sup>2</sup> In 2015, SAMHSA determined that fewer than 7.54% of those with COD were receiving treatment for both

<sup>&</sup>lt;sup>1</sup> <u>https://americanaddictioncenters.org/rehab-guide/addiction-statistics/</u>

<sup>&</sup>lt;sup>2</sup> <u>https://www.samhsa.gov/disorders/co-occurring</u>

disorders and 55% received no treatment at all.<sup>3</sup> You will not be successful in your efforts to treat those with CODs if you don't treat *both* their SUD *and* their SMI.

Members of NSSC have found through experience and are in agreement with SAMSHA that there is about a 5-year window of opportunity, between onset of a mental disorder and co-occurring substance abuse.<sup>4</sup> Untreated SMI leads to more severe and treatment-resistant illnesses, and to the development of CODs. By far, the most common connection between untreated mental illness and substance abuse is self-medication.<sup>5</sup> 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.

There are over 10 million adults living with SMI<sup>6</sup> in America. The IMD Exclusion has been discriminating against this population for 53 years. These diseases are medical diseases and must be treated with the same care and attention any other medical disease would receive.

It's well documented that there is a much poorer prognosis for those with mental illnesses who do not receive prompt, early intervention and treatment.<sup>7</sup> Every episode causes further deterioration of the brain and other organs resulting in irreparable damage.<sup>8</sup> The IMD exclusion is the primary reason for the severe shortage of psychiatric inpatient beds.<sup>9</sup> Data collected by TAC reveals that from 1955 to 2016, the number of state hospital beds in the United States had plummeted almost 97%. By 2014,10 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.<sup>10</sup>

The few people with SMI lucky enough to be placed in a hospital who are only given 15 days for treatment, often quickly decompensate upon their release. Under the best of circumstances, when their illness is caught early, finding the right medication to treat SMI is a matter of trial and error. Every time a new medication is tried, it can take weeks or longer for the medication to take effect. If that medication proves to be ineffective, another medication must be tried until an effective medication is found. This process can evolve into months when a person has remained untreated for a long period of time. 30 days is simply not enough time to treat anyone suffering from a COD!

Failure to provide prompt inpatient psychiatric hospitalization when needed causes an inhumane and expensive, fiscally irresponsible pattern of cycling people in and out of the revolving doors of emergency rooms, hospitals, homelessness, jails and causes horrific suffering. Family members of the SMI are also the collateral damage inflicted by a government who has turned a blind eye on their loved ones suffering for decades.

<sup>&</sup>lt;sup>3</sup> <u>https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4695242/</u>

<sup>&</sup>lt;sup>4</sup> <u>http://www.cffutures.org/files/presentations/SAMHSAPerspectiveAndServiceInitiativesForChildren.pdf</u>

<sup>&</sup>lt;sup>5</sup> <u>https://www.drugabuse.gov/publications/common-comorbidities-substance-use-disorders/introduction</u>

<sup>&</sup>lt;sup>6</sup> <u>https://www.nimh.nih.gov/health/statistics/mental-illness.shtml</u>

<sup>&</sup>lt;sup>7</sup> <u>https://mentalillnesspolicy.org/consequences/prognosis.html</u>

<sup>&</sup>lt;sup>8</sup> <u>https://www.ncbi.nlm.nih.gov/books/NBK333029/</u>

<sup>&</sup>lt;sup>9</sup> <u>http://www.treatmentadvocacycenter.org/storage/documents/backgrounders/imd-exclusion-and-discrimination.pdf</u>

<sup>&</sup>lt;sup>10</sup> <u>http://www.treatmentadvocacycenter.org/key-issues/bed-shortages</u>

While the NSSC commends Representative Walters' efforts to aid those living with SUD in getting treatment by introducing the IMD CARE Act (H.R. 5797), we are deeply concerned that this bill does not go far enough. Without incentives for providers, much needed long-term care for adults suffering with SMI, with or without a SUD, will be excluded from accessing beds.

The over 10 million suffering with SMI deserve the same opportunity to receive compassionate care which is covered by Medicare/Medicaid for all medical diseases. According to data from the Treatment Advocacy Center (TAC)<sup>11</sup>, 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. Currently, these same statistics report that 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.

By addressing the IMD Exclusion now and eliminating it altogether, you could potentially eliminate: 50% of mass killings, 29% of family homicides, 10% of all homicides, 20% of law enforcement fatalities, and over 40,000 suicides.<sup>12</sup> You could also eliminate the cost of providing a jail for nearly 400,000<sup>13</sup> SMI from the prison population, and take many of the estimated up to 325,000<sup>14</sup> people with SMI off the streets, greatly lessening the burden of caring for our homeless population. This would be a massive forward motion for our country. Using our jails to house the SMI and prevent treatment is cruel, barbaric and has sent our nation back to the practices typical in the 1800's. Treatment works and many societal problems will fade away if treatment is sufficient.

We proudly submit our request. Please abolish the outdated, discriminatory, and counterproductive IMD Exclusion which prevents over 10 million adults living with SMI and 7.9 million adults with co-occurring disorders from receiving the care they need. We look forward to hearing from those of you who are willing to work with us.

## Sincerely,

### National Shattering Silence Coalition Members:

Amazing Grace Advocacy, North Carolina Justice and Serious Mental Illness, Texas Sooner Than Tomorrow, California Parents For Care, Maryland P82 Project Restoration, Arizona A Path of Enlightenment Healing Arts, New York Due Justice Project/StandUP, Pennsylvania Advocates For Ethical Mental Health Treatment,NH Healthy Mind Ministry, West Virginia Leah Gutter, New York John Hallowitz, California Kari Hammond, Oregon Dianne Harris, Ohio Janet Hays, Louisiana Gloria Hill, Florida Susan Inman, Vancouver, BC Justtine Jackson, Illinois Brenda Jensen, Arizona

<sup>&</sup>lt;sup>11</sup> <u>http://www.treatmentadvocacycenter.org/evidence-and-research/fast-facts</u>

<sup>&</sup>lt;sup>12</sup> <u>http://www.treatmentadvocacycenter.org/key-issues/violence</u>

<sup>&</sup>lt;sup>13</sup> <u>http://www.treatmentadvocacycenter.org/storage/documents/emptying-new-asylums-exec-summary.pdf</u>

<sup>&</sup>lt;sup>14</sup> <u>http://www.treatmentadvocacycenter.org/storage/documents/backgrounders/smi-and-homelessness.pdf</u>

Healing Minds NOLA, Louisiana Pandora's Box Productions, California Cure Illinois, Illinois Jane Anderson, Illinois Terry Barker, Texas Gwen Bartley, North Carolina Tama Bell, New York Porsche Bellamy, Connecticut Gloria Bertrand, Michigan Jeannette Bjorklund, Maryland Kimberly Blaker, Michigan Sally Bricker, Ohio Jim Bricker, Ohio Gina Burns, Alabama Evelyn Burton, Maryland Diana Cardoni, Ontario Mary Sheldon, California Michael Sheldon, California Tamara Dalrymple, West Virginia Kathy Day, California Fawn Dessy, California Carmen Dilks, California Katharine Dougherty, Michigan Wanda Duryea, Michigan Gretchen Egeland, Illinois Courtney Michel Elwell, Oregon Pamela Field, New Mexico Anne Francisco, California Elizabeth Garrison, California Deborah Geesling, Arizona Jeanne Gore, Maine Heather Grimshaw-Lee, Hawaii Kimberlee West, Michigan Nadine Whalen, Florida Rev. Barbara Williams Brown, New York Cynthia Wolfe, Massachusetts Amanda Woodward, Virginia Sheila Ganz, California Madeleine Ward, Illinois Taylor Brown, Virginia Jeffery L. Hayden, Ph.D, BCBA-D, California

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