



## **NSSC Membership Packet**

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## **ABOUT NSSC**

The National Shattering Silence Coalition brings attention to the silent epidemic of untreated or inadequately treated serious mental illnesses (SMI) in adults and serious emotional disturbances in children (SED)<sup>1</sup>. NSSC speaks up for the 14 million - the 4% who suffer from SMI and the 6% who suffer from serious emotional disturbances - and their shattered families.

NSSC is an alliance of diverse individuals and organizations who are combining energies, logos, and mission statements 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.

## **HISTORY OF NSSC**

Following the Newtown Tragedy in 2012, and Liza Long's essay, "I am Adam Lanza's Mom," mothers across the country formed alliances and built secret national networks of activism, advocacy, and support. They joined Treatment Advocacy Center, Mental Illness Policy.org, law enforcement and other key stakeholders to tell their stories. They helped build a lobby as the families and advocates of the 4% to support the Helping Families in Mental Health Crisis Act. They started a movement focused on the subset of the mental illness system that too many national organizations and coalitions ignore. They focused on people and families living with SMI and SED. At the same time, they realized they had to stop hiding in the sub-nation they'd constructed out of fear. This realization led to the formation of NSSC.

NSSC calls out injustice, inequity, inhumanity, and discrimination. Too many are dying too soon due to comorbidities, suicide, solitary cells, and shame while everyone watches with their eyes wide open and mouths shut. It's time to get real, get radical and get results.

## **MISSION STATEMENT**

**The National Shattering Silence Coalition** speaks out about federal, state and local policies that impact adults living with SMI and children and youth living with SED.

## **VISION STATEMENT**

**The National Shattering Silence Coalition (NSSC), a voice for SMI adults and SED children and youth, will change the perception of SMI and SED in public attitudes, words, and laws.**

NSSC's vision is for a medically based system of non-discriminatory, comprehensive, and coordinated mental illness care that includes long-term inpatient psychiatric beds, appropriate housing, prioritized funding for mental illness and neurological research (including medications without challenging and discouraging side effects), pre-incarceration diversionary programs, mental illness courts, a robust mental illness

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<sup>1</sup> <https://www.samhsa.gov/sites/default/files/federal-register-notice-58-96-definitions.pdf>

workforce trained and willing to help those with SMI and SED, policies that reduce redundancies and wasteful spending, and proper oversight of mental illness agencies, community clinics, psychiatric hospitals and hospital psychiatric units.

### **POINTS OF UNITY**

As a coalition of individuals and organizations from diverse political, economic, and cultural backgrounds, we agree to the following shared values and principles of unity:

1. SAMHSA Reforms: Implement evidence-based programs and strong policies that will recognize mental illness as a medical disorder, not a behavioral problem.
2. PAIMI Reform: Focus on abuse and neglect, its original mission, instead of lobbying to prevent medically needed inpatient and outpatient treatment and supports.
3. HIPAA Reform: Clarify and improve HIPAA policies to include family rights and prevent harm that occurs when parents who provide care are shut out of the process.
4. End Discrimination: Support the full repeal of the IMD Exclusion and call for parity and a right to treatment under Medicaid/Medicare.
5. End the Incarceration of those suffering from SMI and SED
  - Promote, strengthen and fund Assisted Outpatient Treatment, mental illness courts, crisis intervention teams, FACT and any other evidence-based pre-incarceration alternatives that permit treatment and care for seriously mentally ill people based on treatment standards that focus on the need for treatment and grave disability, not on danger to selves and others.
  - Dramatically increase the number of psychiatric hospital beds, providing a hospital bed instead of a jail cell.
  - Support evidence-based post-incarceration diversion solutions. Invest in re-entry programs for SMI and SED.
  - End the hospital practice of criminalizing the symptomatic behavior of mentally ill patients while under treatment or medical management. Patients must not be prosecuted and punished for the consequences of poor ward management, deficient facility dynamics and infrastructure, poor staff training, and other critical factors. People who work with this patient population, including security staff must be provided comprehensive education to impart knowledge and comprehension of psychotic disorders and the behavioral aspects of the disorders.
  - End solitary confinement for those suffering from SMI and SED.

6. Support the funding of programs designed to grow the mental illness workforce.
7. Support both long-term to permanent dignified institutional housing for those who are too ill to live in the community and supportive and independent housing for those who are able to safely live in the community.
8. Seek to identify other points in federal law that need reform.

### **MEMBERSHIP RIGHTS AND RESPONSIBILITIES**

Coalition membership is inclusive of both individuals and organizational representatives. Below are the responsibilities and rights of membership:

#### **Responsibilities of Membership**

1. Sign on to the Coalition's Points Of Unity.
2. Should an individual or organization member agree to attend regular meetings (to be held via teleconference or Facebook group), they are agreeing to support the work of NSSC through all of the NSSC activities they have committed themselves to participating in. **It is the responsibility of members to notify the NSSC coordinator of a meeting absence.** Organizations may elect who from their organization will be represented at NSSC, and are encouraged to have continuous representation.
3. Publicly lend name to the Coalition. **It is the responsibility of the member to notify the coalition if they do not endorse a particular effort.**

#### **Rights of Membership**

1. Participate in decision-making
2. Participate in a secure membership list serve.
3. May be asked to speak on behalf of the Coalition.
4. Opportunity to enlist the support of the Coalition for individual or organizational efforts that are aligned with coalition's work.
5. Publicly claim membership in the NSSC.

### **DECISION MAKING & ACCOUNTABILITY**

Decisions are made through a cooperative decision-making process; basic strategy is discussed in general meetings and a decision about how to proceed is reached. When there is a significant decision that the coalition must make, NSSC will operate based on a *consensus* model. 75% of members present constitute a quorum to reach consensus. Notice should be given within reasonable time to all members when a consensus decision will be made.

Under a consensus process, people can also *stand aside*, which means that they might disagree but will not block consensus. If there is strong disagreement, an individual can choose to *block* consensus, at which point discussion continues until consensus can be reached.

## **STAFF, COMMITTEES, OTHER ROLES & EFFORTS**

### **Staff**

#### **Coordinator**

A Volunteer position under the direction of NSSC, the NSSC Coordinator is the point of contact and liaison between NSSC's members. The role of the coordinator is to ensure the work of NSSC is carried out, followed through, and sustained, and to coordinate all efforts such as meetings, events, and actions. This position can be shared and may be rotated among members on a monthly or quarterly basis.

### **Committees**

#### **Steering Committee**

The purpose of the steering committee is to guide the coalition, ensure implementation of the strategic plan, provide oversight and direction to staff and members, and ensure the longevity of NSSC.

#### **Ad-Hoc & Standing Committees**

Some work will continue to occur at the committee level. Ad-hoc committees can be formed to deal with specific tasks. These committees are limited in task, purpose and timeline, and empowered to make decisions regarding specific issues at hand in order to implement the work of the coalition. All members of NSSC are encouraged to participate in committee work.

#### **Other Roles & Efforts**

NSSC members are encouraged to take on the following roles on a rotating basis:

#### **Note Taker**

Steering Committee meetings via teleconference will be recorded and then transcribed into notes to be kept by the Coordinator and shared with steering committee members via Google Drive.

#### **Meeting Facilitator**

Facilitates NSSC meetings

#### **Communications**

Regularly update and post relevant articles and statements to social media (Facebook, Twitter, etc.).

#### **Fundraising**

NSSC members will be encouraged to contribute to the financial sustainability of NSSC. NSSC is currently in the process of investigating the use of a fiscal sponsor to enable the coalition to seek grants and solicit donations under a sponsor's exempt status.

Fundraising efforts and methods must be approved by the Steering Committee.

#### **Media Spokespeople**

Media requests will be handled on a case-by-case basis. Efforts will be made to circulate requests to appropriate members in order to draw on relevant experience and expertise. Active members, and particularly people who are directly impacted by the issues NSSC addresses, are especially encouraged to be spokespeople.

## **CONFIDENTIALITY**

NSSC is a coalition composed of individual and organizational members. Everyone, who becomes a member of NSSC, agrees to the organizational points of unity before being added formally as a member of the group. Because meetings are public, people who are

not members occasionally participate in meetings. The confidentiality expectations stated below apply to NSSC members and to non-member participants of NSSC meetings.

NSSC meetings involve discussions of strategy that may need to be kept confidential. Occasionally, NSSC strategy may impact the strategy or work of a meeting participant or member of the coalition. NSSC requires every member or meeting participant to agree to maintain confidentiality when confidentiality is requested during the course of a meeting.

If a meeting participant is unclear about sharing something discussed in an NSSC meeting—E.g., if sharing will impact the success of the strategy or action discussed—the member must check with NSSC members before sharing with other parties.

If there is a conflict of interest between an individual or member organization and a strategy or action being considered by NSSC, individuals or representatives of the group will be asked to either leave the discussion or commit to strict confidentiality until the group decides it is appropriate to share. If a member or participant also has ties through employment or community work to an organization or individual potentially impacted by an action or strategy of NSSC, the member or meeting participant may not share confidential information with that organization or individual or any other parties without explicit permission from the group.

### **EVIDENCE OF NEED**

**The consequences of ignoring untreated serious mental illness and serious emotional disturbance cannot be overstated.**

The withering away of mental illness facilities and services over the last few decades has left gaps in the mental illness care system resulting in enormous economical and societal costs. The epidemic of those left untreated is creating chaos, and families who constantly struggle to find help for their loved ones are emotionally and physically exhausted. Below are some statistics to illustrate these points.

- Approximately one out of five adolescents has a diagnosable mental illness disorder, and nearly one third show symptoms of depression. Psychiatric disorders affect 12 percent of children. Children are 3 to 4 times more likely to be abused if they are mentally ill.<sup>2</sup>
- “For the past 20 years, studies have consistently estimated that between 40 and 50 percent of all individuals with schizophrenia or bipolar disorder are receiving no treatment for their mental illness at any given time. According to disease prevalence estimates of NIMH, this means that approximately 3.0-3.5 million such individuals are receiving no treatment.”<sup>3</sup>
- A report released by the Treatment Advocacy Center and the National Sheriffs’

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<sup>2</sup> <http://www.hhs.gov/ash/oah/adolescent-health-topics/mental-health/home.html>

<sup>3</sup> [http://www.treatmentadvocacycenter.org/storage/documents/what\\_percentage\\_of\\_individuals\\_with\\_serious\\_mental\\_illnesses\\_are\\_receiving\\_no\\_treatment\\_final.pdf](http://www.treatmentadvocacycenter.org/storage/documents/what_percentage_of_individuals_with_serious_mental_illnesses_are_receiving_no_treatment_final.pdf)

Association in 2010 showed that Americans with severe mental illnesses are three times more likely to be in jail or prison than in a psychiatric hospital.<sup>4</sup>

- “According to the Department of Justice (1996 Source Book: Criminal Justice Statistics), it costs American taxpayers a staggering \$15 billion per year to house individuals with psychiatric disorders in jails and prisons (\$50,000 per person annually; 300,000 incarcerated individuals with mental illness).”<sup>5</sup>
- 30% of the chronically homeless population is estimated to have SMI.<sup>6</sup>
- People in mental illness crisis wait for days — even weeks — in ERs because of psychiatric bed shortages.<sup>7</sup>
- More than 1.8 million people with SMI are booked into jails every year.<sup>8</sup>
- 20% of jail and prison inmates are estimated to have SMI.<sup>9</sup>
- 25% of individuals with mental illness are victimized in some way each year.<sup>10</sup>
- Up to 50% of those with schizophrenia or bipolar disorder attempt suicide, and far more kill themselves than people without these disorders.<sup>11</sup>
- 29% of family homicides are committed by someone with SMI.<sup>12</sup>
- 7% of all homicides, 20% of all law enforcement officer fatalities and up to 50% of mass homicides are associated with SMI.<sup>13</sup>
- 5.8% or 4 million children, ages 4-17 suffer from a SED.<sup>14</sup>

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<sup>4</sup>[http://www.treatmentadvocacycenter.org/storage/documents/final\\_jails\\_v\\_hospitals\\_study.pdf](http://www.treatmentadvocacycenter.org/storage/documents/final_jails_v_hospitals_study.pdf)

<sup>5</sup> <https://mentalillnesspolicy.org/consequences/criminalization.html>

<sup>6</sup> <http://www.treatmentadvocacycenter.org/key-issues/consequences-of-non-treatment>

<sup>7</sup> *ibid*

<sup>8</sup> *ibid*

<sup>9</sup> *ibid*

<sup>10</sup> *ibid*

<sup>11</sup> *ibid*

<sup>12</sup> *ibid*

<sup>13</sup> *ibid*

<sup>14</sup> [https://www.childstats.gov/americaschildren/health\\_fig.asp](https://www.childstats.gov/americaschildren/health_fig.asp)

**Please click here to pledge your support and fill out the NSSC's membership application:**

**[Pledge of Support & Membership Application](#)**