



National Shattering Silence Coalition Our Social Impact

**Shattering the Silence & Inspiring Change for
22M with Serious Brain Disorders**

This report is dedicated to:

Terrell Alston, DOD Unknown
Farron Barksdale, 8/20/07
Bill Becker, 2/8/15
Paul Blair, 12/78
Sasha Bond, 8/16/20
Kelsey Rose Brouillette, 10/28/18
Gina "GG" G. Burns, 11/6/19
Casey Alan Campbell, 10/1/09
Paul Flannery, 5/1/08
Josh Francisco, 10/22/14
Vince Gieser, 8/27/13
Nolan Edward Harris, 6/18/17
Walter "Guy" Justus, 6/10/19
John "JT" Terrence Norton, 12/15/16
Christopher P. Pickering, 11/12/20
Zaccaria "Zac" William Pogliano, 1/18/15
Kevin Powers, 6/15/05
Dr. Robert Powitsky, PhD, 10/26/19
Patrick Ranahan, 7/23/14
Joseph Reinig, 10/6/21
Charles "Chuck" Winston Renz, 11/11/08
Ronald Micheal Robbibaro, 8/5/16
Evan Rumlow, 5/21
Jonathan Salcido, 5/4/17
Carl (Robby) Talbot, 3/21/19
Justin Wilkerson, 1/5/2021
Brian Wood, 3/28/18

And to all who have lived and died way too soon with serious brain disorders.

Special mention also to Laurie Mendoza, tireless and dedicated NSSC advocate, who passed away in May 2020, leaving behind a son with a serious brain disorder and anosognosia now lost to streets.

#RIP our fearless loved precious souls. You are not forgotten.



Since inception in October 2017, the National Shattering Silence Coalition has been speaking out and inspiring change on behalf of over 14.2 million adults and 8 million children with serious brain disorders, and their loved ones.

We are the voices for those living with and dying far too young from serious brain disorders (SBD).

Our nonpartisan alliance of family members, individuals suffering from serious brain disorders, professionals in the trenches, and caring people, united to ensure brain illness, health, and criminal justice systems count those with SBD and their families in all federal, state, and local policy reforms.

What started with three voices on October 5, 2017, has now grown exponentially by over 700% to 344 members strong. Our internal base of support has almost doubled each year, growing by an annual average of 178%.

Over the past five years, we've collectively shattered the silence about our humanitarian crisis, helping to ensure treatment before tragedy, and catalyzing a movement to build a more compassionate and just world through our collaborative advocacy.

This report shares a retrospective look back at our journey – our Coalition's social impact – a journey we are excited to now accelerate in 2022 as an official nonprofit organization with our new fiscal sponsor, Open Collective, with pro bono strategic advice from Accelerating Social Good.



A Mother's Prayer for Mental Illness

As I stumble from my bed this morning, help me to remember to be gentle and kind. My child's mind is shredding into a million pieces. He lives in a constant state of atrocious fear. I can see it in his eyes. Give him peace.

Guide me as I hold him in my arms. Help me to know what to say. What to do. Fill my heart with healing love, understanding, and empathy.

Give me the strength of a thousand angels to hold back my tears. My heart is broken and a tidal wave of grief is overwhelming me with the need to cry. Give me the strength to bear it long enough to keep it from disturbing my child. Help me find someone I can safely bring it to.

Help me answer my family's questions with the same amount of compassion I would want for myself. Help me remember they are hurting too. This is an unwelcome assault on an entire family. My heart is not the only heart that is broken. We all need time and each other to heal.

As my journey becomes more and more isolated and lonely, it reminds me that the lack of involvement on the part of family and friends is not always because of the stigma and the ignorance. For many, it is because they are hurting too. They have the privilege of turning to their own lives. This is my family's life now. I must deal with it whether I am hurting or not.

Send me your best physicians and healers. Give me presence of mind, as I walk through the exhaustion of my grief to not settle for just any one no matter how tiresome the journey becomes.

Help me adjust to the idea that although it appears my son is gone, there will be no goodbye. And that he is still inside somewhere waiting for us to find him.

Infuse the creative part of my mind with solution oriented thinking. Give me hope. Even if it is just a glimmer of hope. A mother can go for miles on just one tiny glimmer. Let me see just a flicker of the sparkle of joy in his eyes.

Guide my hands, calm my mind, as I fill out the multitude of forms for services. Then help me do it again over and over.

Provide me with the knowledge. Lead me to the books I need to read, the organizations I need to connect with. As you work through the people in my life, help me to recognize those that are here to help. Help me trust the right ones. Shine a light upon the right path.

Give me the courage to speak my truth; to know my son's truth. And to speak for him when he is unable to do it for himself. Show me when to do for him what he is not capable of doing for himself. Help me to recognize the difference.

Help me to stand tall in the face of the stigma; to battle the discrimination with the mighty sword of a spiritual warrior. And to deflect the sting of blame and fault finding from the ignorant and the cruel. Preserve my love for my family. Shield my marriage with the wisdom of the love that brought us together.

Protect him from homelessness, loneliness, poverty, hunger, hopelessness, relapse, drugs, alcohol, suicide, cruelty and obscurity. Lead us to the miracles of better medications, better funding, better services, safe and plentiful housing, meaningful employment, communities who care, enlightenment. Help us to find some way to replace all the greed with humanitarian work and intrinsic reward again.

Most of all, give me the strength to deliver whatever I can to the work of unmasking the man-made ugliness of this disease and revealing the human and all of its suffering beneath. Finally, when it is my time to leave my son behind, send a thousand angels to take my place.

~ Author Unknown

THE PROBLEM: Social INEQUITY for People with Serious Brain Disorders

Our discriminatory laws and practices have left those seriously ill homeless, incarcerated or dead far too soon. And, their loved ones are in a world of hurt.

#CostOfNotCaring



“Schizophrenia struck my brother in the prime of his life, robbing him of his mind, his future, and everything that mattered. Nothing could have prepared me for the cruelties of this disease, the social injustices he faced, and the trauma it inflicted on our entire family. Like so many others with serious brain disorders, my brother died far too soon. I advocate with NSSC in his honor in the hopes of creating a more compassionate, just world for people living with these devastating illnesses.”

~ Kristina Rolfes, Steering Committee Member & Blog Committee Co-Chair

THE PROBLEM (Continued)

For far too long, people with serious brain disorders have been marginalized, misunderstood, discriminated against, and treated with scorn and indifference. They have suffered injustices, such as being:

- incarcerated as a direct result of their untreated serious brain disorders,
- left to decompensate on the streets of America,
- denied medically necessary, lifesaving treatment
- and lost their lives even as their families begged for treatment.



“Over the course of the 13 years since our son became sick with a severe, treatment resistant Schizoaffective Disorder with Anosognosia, we have witnessed far too much unnecessary and unconscionable suffering. I know that we can do so much better, and we absolutely must, if we want to consider ourselves to be living in a civilized society.”

~ Leslie Carpenter, Head of Policy Action Committee

THE PROBLEM (Continued)

CRUEL AND UNJUST

Unless you have personal or professional experience with serious brain disorders, you may not realize the inequities these individuals face.

The mental healthcare system and the laws affecting treatment are more often than not cruel and unjust.

THOSE WHO LACK INSIGHT WILL NEVER ASK FOR HELP

Society expects the person with a serious brain disorder to ask for help, without understanding that the person's illness impairs the very organ that enables them to make decisions. Fifty percent of people with serious brain disorders lack insight into their illness, known as anosognosia. These individuals will never ask for help, because they don't know and cannot accept that they are ill.



THE PROBLEM (Continued)

WE ASK, WHY DO WE TREAT OUR ELDERLY BETTER THAN OUR YOUTH?

If a person with dementia were to wander the streets confused and vulnerable, we would demand that they receive proper care. Yet we allow individuals with serious brain disorders to deteriorate until the point of danger, or even death, without intervening.



RIGHT TO TREATMENT DENIED TO PROTECT CIVIL RIGHTS, AS THEIR LOVED ONES STAND HELPLESSLY BY

Families who desperately try to get their loved ones into treatment are shut out by privacy laws. Instead of offering compassionate, common-sense intervention, the person is effectively denied their right to medically necessary treatment. Their right to treatment is lost in the name of protecting their civil rights.

INSTEAD OF BASING DECISION TO TREAT ON MEDICAL REASONS, IT IS BASED ON WOEFULLY INSUFFICIENT NUMBER OF BEDS

Our nation's discriminatory laws and practices deny medically necessary treatment primarily by limiting the availability of hospital beds. The decision to admit a patient for medical care is made based on laws and the availability of hospital beds rather than medical necessity. As a result, people with serious brain disorders end up homeless, incarcerated or dead far too soon.

THEY DESERVE A LIFE OF PURPOSE, NOT DESPAIR

Together, we are on a mission to raise awareness and create solutions for the humanitarian crisis faced by people with severe brain disorders, commonly referred to as severe mental illnesses, and those that love them.



THE SOLUTION: Social EQUITY for People with Serious Brain Disorders

We are harnessing the collective power of our voices to create a national movement too powerful to ignore. We are demanding equity for people with serious brain disorders.

[#ShatteringSilence](#)

CATALYSTS FOR CHANGE

One person or group alone can't change the world, but together our voices can be a powerful catalyst for change. The National Shattering Silence Coalition provides a platform for everyone who has been failed by the discriminatory, broken mental health system to turn their immense outrage and grief into action.



THE SOLUTION (Continued)

ENDING SUFFERING, ABANDONMENT AND CRIMINALIZATION

Our growing grassroots movement is speaking out and demanding an end to the suffering, abandonment and criminalization of those with serious brain disorders. We empower family members, those working in the trenches and people with lived experience to turn pain into purpose. And, we advocate for family members to ensure loved ones are not released from jails to streets but to a hospital bed instead.



"As a mobile emergency psychiatric social worker, I witness the tragic consequences of our broken system daily. The sickest patients with brain disorders (typically referred to as 'serious mental illnesses') are the ones most neglected by the system. I care about every one of these patients and will do all I can to help them access the treatment they deserve. When patients show positive treatment outcomes as a result of my interventions, I feel fulfilled and satisfied. And when I see the injustices they encounter, I get angry. This motivates me to advocate for the sickest of the sick with the National Shattering Silence Coalition."

~ Lynn Nanos, Member, Steering, Blogging & Policy Action Committees

THE SOLUTION (Continued)

ADVOCATE FOR EQUITABLE LAWS AND POLICIES ENSURING COMPASSIONATE AND COMPREHENSIVE CARE

Our members strive to change widespread misperceptions about SBD and advocate for equitable laws and policies to ensure policy makers understand problems and propose humane solutions. By doing so, people with serious brain disorders can receive more compassionate, comprehensive care to live their best lives.

From organized demonstrations to coordinated letters, phone calls, emails, testimonies and meetings with representatives or participation in state/local legislative workgroups, we leverage our collective voices for maximum impact.

Since 2017, NSSC has issued dozens of calls to action on issues ranging from:

- increasing the number of treatment beds,
- implementing the use of effective interventions such as Assisted Outpatient Treatment,
- revamping HIPAA privacy regulations blocking families from participating in the care of their loved ones,
- petitioning the President and Congress to introduce legislation to repeal the IMD Exclusion,
- rallying members to testify before policy makers to effect change, and much more.

THE SOLUTION (Continued)

EDUCATING PUBLIC TO CHANGE MISPERCEPTIONS AND RAISE AWARENESS ABOUT HUMANITARIAN CRISIS AND NEED FOR URGENT REFORM

We collect personal stories and videos to share on our website, blog and social media. By sharing our stories and collective knowledge with in our social channels, we inform the public about the reality of serious brain disorders, raising awareness about this humanitarian crisis and shattering the silence.

We have a very loyal and active following on Facebook, with over 2,000 followers, as well as over 500 on Twitter. And, we are now engaging in channels to reach younger generations on Instagram and building a stronger presence on LinkedIn.

"National Shattering Silence Coalition is a strong group of advocates who are working to remove barriers to care for the population of people with the most severe mental illnesses. The country has turned a corner because of their work and they have their finger on the pulse of serious mental illness policy reform. If you care about alternatives to incarceration, homelessness and death for seriously mentally ill people, you need to join this coalition!" ~ Facebook Testimonial



"I experienced first hand the torture of untreated schizo-affective disorder. When I finally accepted treatment the medication was ineffective and had brutal side effects. It took over ten years for a medication to be developed that would give me the ability to return to the workforce and live a fulfilling life. I want to help others get the help they need and advocate for research on new medications."

~ Eric Dias, Surviving & Contributing with Schizoaffective Disorder for 23 Years; Member, Steering, Blogging & Communications Committees

HEAR FROM OUR FACEBOOK FOLLOWERS

"Love NSSC for the work they do so well, and we need many more members to combat the advocacy for anosognosia, the no fault neurological brain disease and recognize it for what it is, so we can properly speak for the voiceless."

"Sign me up! I have lost two adult children to suicide. I am so sick of bad mental health services and the ignorance about mental illness. Even among so-called professionals. Had my children had proper treatment, they would still be here."

"Here is cutting edge advocacy from some of the most experienced mental illness advocates on the web. Lots of members are strong family caregivers who have been forced by circumstance to take up mental illness advocacy."

"This cause is so important. Families facing member's serious mental illness deserve better help for their loved ones. People with brain diseases - men and women (and children!) - suffer misunderstandings with others in a world that does not understand and can easily be misread by police officers or others who perceive them as a threat. And too many young lives are shattered because mental illness is regarded somehow as a lesser cause than someone with a physical illness. We've got to break the shame and silence... We need open discussion NOW. We have lost too many."

"This a very much-needed coalition for the unfortunate people who suffer from psychological issues in the criminal justice system and other areas."

"The most honest, tell it like it is organization ever!"

OUR NORTH STAR:

A COMPASSIONATE AND JUST WORLD



#justiceforSBD #righttotreatment
#HIPAAhandcuffs #lifelongcare4SBD
#parityforsbd #fundingequity #abedinstead
#treatmentbeforetragedy

IMAGINE THE POSSIBILITIES ... #JUSTICEFORSBD

What if discrimination based on serious brain disorders were no longer socially acceptable or tolerated and the world was as outraged about the injustices faced by people with serious brain disorders as they are about racism, LGBTQ+ discrimination and xenophobia?

The U.S. is outraged about discrimination against people of color, the LGBTQ+ population and other marginalized groups, and rightly so. The COVID-19 pandemic shed light on widespread racial inequities, and with the death of George Floyd, the country came together to support Black Americans.

Conversely, when scientists discovered that people with severe brain disorders were disproportionately dying from COVID-19, our country did not have a similar reckoning.

People with serious brain disorders are 16 times more likely to be killed during a police encounter.

They are disproportionately incarcerated, living in poverty, homeless, living with co-morbidities and have shorter lifespans.

They suffer horrific abuses and neglect, and yet Americans have shown no widespread outrage—there have been no marches on Washington, no protests or national conversations about these injustices. It's time for that to change.

The National Shattering Silence Coalition is giving a voice to all those who have suffered injustices. It is time for us to shatter the silence and finally bring these inequities to light, so that our loved ones will suffer no more.

IMAGINE THE POSSIBILITIES ... #RIGHTTOTREATMENT

What if people understood the true nature of serious brain disorders?

The National Shattering Silence Coalition provides information to the public to correct the misperceptions about brain illness. We speak out so people can fully understand that illnesses currently labeled as serious mental illnesses in adults and serious emotional disturbances in children, such as schizophrenia, schizoaffective disorder, bipolar disorder, and major depressive disorder, are biologically based, no-fault brain disorders.

They are not a failure to control one's behavior, a character weakness or the result of a traumatic childhood.

What if we created a world where it was universally recognized that disorders originating in the brain were not "behavioral" but medical disorders?

Imagine if everyone understood that when the organ that allows a person to think, behave and reason is impaired, the ability to make informed, rational decisions is also impaired.

We advocate for laws and policies reflecting the truth that as many as half of those with serious brain disorders lack insight into their illnesses, known as anosognosia. They should not be expected to ask for help.

Providing the right to medically necessary treatment is the only humane response. It would eliminate needless suffering, prevent incarceration, homelessness and death, and offer the best chance of recovery.

IMAGINE THE POSSIBILITIES ... #HIPAAHANDCUFFS

What if family members who know their loved ones best were welcomed as part of a person's treatment team, just as we do for family members of those with dementia, brain injuries and other brain disorders?

Family members have vital insight and information about their loved ones' health history and must not be shut out of communication with medical professionals due to overly restrictive or misinterpreted HIPAA privacy laws.

Participation of family members, especially when a person lacks insight due to their brain illness, is critically important to ensure the best care.

Just as doctors share health information with family members of those with dementia, brain injuries, and stroke, we envision a world where doctors actively seek out input from family members of those with serious brain disorders and communicate openly with them.

Doctors and families who desperately want to help their loved ones would collaborate to ensure the best possible outcome for the person with brain illness.

IMAGINE THE POSSIBILITIES ... #LIFELONGCARE4SBD

What if people with serious brain disorders received a full continuum of care at every stage of their illness?

Serious brain disorders are chronic, life-long illnesses that require differing levels of treatment depending on the severity and stage of illness. These individuals need a full range of services—including long-term inpatient care, step-down units, intensive outpatient services, community programs, supportive and independent housing options and supportive services—instead of a revolving door of short-term stays with inadequate treatment and no follow up services in between.

We must provide enough treatment beds and centers to serve all who need them, just as we do for every other type of illness.

People with serious brain disorders need and deserve comprehensive wrap-around services in the community, including counseling, social supports, education, job training and opportunities, connection to resources, and assistance with legal issues (e.g., applying for SSI/SSDI, creating mental health advance directives, filing tax forms).

Their family members/caregivers also need and deserve education, social and financial support, and assistance with legal issues such as applying for guardianship and setting up trust funds on behalf of their loved ones.

IMAGINE THE POSSIBILITIES ... #PARITYFORSBD

What if the determination of whether to receive medical care were based on a doctor's expertise rather than a judge or the law, or just because there are not enough beds?

If we treated serious brain disorders like we do every other medical illness, doctors would decide the appropriate medical intervention instead of laws that are designed to thwart the right to treatment.

Instead of waiting until a person has deteriorated to the point of danger, we would ensure medically necessary treatment. The inhumanity of withholding treatment can no longer be justified in the name of civil liberties.

With the success of many Assisted Outpatient Treatment (AOT) programs and what we now know about early intervention, those with serious brain disorders would be freed as victims of their illness, no longer prisoners of their own minds. Psychosis, delusions and hallucinations would no longer be a right to protect—instead we would focus on the right to treatment that would restore one's sanity, dignity, free will, and the ability to exercise their liberties.

We envision a country where a person with a chronic serious brain disorder would not be denied treatment because of an arbitrary limit on the number of treatment days or lifetime caps. They would be cared for as compassionately and humanely as a person with Alzheimer's or Parkinson's.

IMAGINE THE POSSIBILITIES ... #FUNDINGEQUITY

What if we spent as much on serious brain disorder research as we do on mental health or on other serious illnesses?

Our society's lack of caring has seeped into our government's research priorities. We spend far less on research into serious brain disorders than we do for mental health or for other serious illnesses such as Alzheimer's.

For example, the National Institutes of Health, our leading government agency for public health, spent \$519 million on serious mental illness research with a 14.2M prevalence in adult population compared to \$3.5 billion on mental health research or \$2.9 billion on Alzheimer's with a 6M prevalence.

If you do the math, there is a glaring mismatch: \$36.55 spent on adults with SBD compared to \$478 on those with Alzheimer's, which is 13x or 1,327% more per person.

If the U.S. invested more in research, people with serious brain disorders would have better treatment options than medications that come with terrible side effects such as obesity, permanent movement disorders and lethargy, to name just a few.

Research may finally reveal the causes of these disorders, paving the way for new treatments and therapies that would reduce suffering and lead to a better quality of life. We would learn why people with schizophrenia and bipolar disorder die 25 years earlier than the average life span and, in time, eliminate this disparity.

IMAGINE THE POSSIBILITIES ... #ABEDINSTEAD

What if we no longer criminalized serious brain disorders and instead offered compassionate treatment?

There are approximately 383,000 inmates with serious brain disorders in jails and prisons. Individuals with schizophrenia and bipolar disorder are 10 times more likely to be in a jail or prison than a hospital bed. In addition, people with untreated serious brain disorders are 16 times more likely to be killed during a law enforcement encounter than other civilians. These individuals need treatment, not handcuffs.

Serious brain disorder should be treated as a public health issue, not a criminal issue that is addressed with punitive and restrictive environments that lack the appropriate resources, supportive housing and adequate treatment supports.

In a just world, we would provide treatment to those with serious brain disorders rather than sending them to jail to decompensate further. Compassionate care delivered through Assisted Outpatient Treatment programs when needed and appropriate would help end criminalization of serious brain disorders by connecting those in crisis to treatment and a continuum of care.

These services are vital to helping individuals maintain stability and safety. Timely intervention would help avoid a criminal record, which becomes a significant barrier to many essential aspects of healthy living, including employment, income and housing.

A collaborative program that involved interdisciplinary health care teams providing intensive treatment services designed to promote stability and achieve recovery in the community would replace incarceration and hospitalizations. Instead of the criminal justice system deciding the fate of those with serious brain disorders, a collaborative medical team would determine the appropriate medical care needed.

Having a brain illness is not a crime – we must continue to work on decriminalization by offering comprehensive treatment as an alternative to jail.

IMAGINE THE POSSIBILITIES ... #TREATMENTBEFORETRAGEDY

What if we provided treatment at the earliest symptom of disease instead of waiting until after a tragedy to intervene?

Research has shown that allowing brain illnesses to go untreated—to grow progressively worse—causes irreparable damage to the brain and reduces the likelihood of recovery.

Withholding treatment for a neurodegenerative disease is cruel and causes immense suffering to both the individual and their family. In addition, allowing an individual to deteriorate can lead to tragic consequences.

While perpetrating violence is relatively uncommon among those with serious mental illness, it is more prevalent when untreated psychosis with paranoia or command hallucinations are present.

Roughly 3% of the population with serious brain disorders are estimated to account for approximately 50% of mass killings, 20% of law enforcement fatalities, 10% of all homicides and 29% of family homicides.

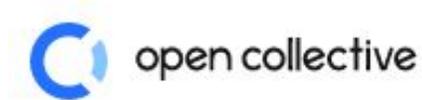
The tragic and costly consequences of untreated serious brain disorders are preventable. The best outcomes occur with early identification and intervention focusing on a full continuum of care with comprehensive services.

It is possible for those with serious brain disorders to overcome challenges and lead meaningful, productive lives.

THE HOPEFUL ROAD AHEAD

We have partnered with Accelerating Social Good for pro bono strategic advice on accelerating our social impact and secured a fiscal sponsor, Open Collective Foundation. Now, as a nonprofit organization, we are able to solicit tax-deductible donations and secure grants and sponsorships.

With our experienced helping hands and our new financial foundation, we will be able to further amplify our voices and our reach, with the goal to continue to form strategic partnerships with like-minded advocacy organizations and corporate partners to further our cause and accelerate our impact.



“It took 13 years of pushing bureaucratic boulders up mountains only to have them come crashing back down on us to finally gain treatment for my son. During that time, he went missing, I rescued him from a religious cult, he was jailed twice, homeless, beaten up by 7 police officers in Burlington VT to within inches of his life, hospitalized 43 times, before I could finally get AOT for him.

This unfathomably painful experience, and the knowledge that so many of our children never made it, is what drives me like a dog with a bone to see that our grandchildren and future generations never have to go through this.

I will not rest until we have treatment with dignity and compassion or I stop breathing, whichever happens first.

These are treatable illnesses, if only we could gain access to treatment.”

*~ Jeanne Gore, Coordinator and Co-Chair, Steering Committee,
National Shattering Silence Coalition*



HELP US TO SHATTER THE SILENCE
& INSPIRE CHANGE AT:
NATIONALSHATTERINGSILENCECOALITION.ORG



Social Impact Report by Kerry Martin, Pro Bono Strategic Advisor, Accelerating Social Good, with contributions by Kristina Rolfes, Ann Corcoran, Jeanne Gore, Lynn Nanos and others from the dedicated team at National Shattering Silence Coalition.



**ACCELERATING
SOCIAL GOOD**

CAUSE COLLABORATION