NSSC

National Shattering Silence Coalition

Speaking Out • Inspiring Change

NSSC Position Statement

Protection and Advocacy for Individuals with Mental Illness (PAIMI) Act of 1986

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U.S. Government Accountability Office (GAO) Report, May 2018, Mental Health Federal Procedures to Oversee Protection and Advocacy Programs Could Be Further Improved

INTRODUCTION

The National Shattering Silence Coalition (NSSC) has developed this position paper after reviewing the May 2018 GAO Report, *Mental Health Federal Procedures to Oversee Protection and Advocacy Programs Could Be Further Improved*. NSSC's interest in the subject of the report stems from its founding positions regarding the failings of the mental health system to treat and protect the seriously mentally ill.

GAO's evaluation of SAMHSA's oversight of PAIMI grants and programs was produced in compliance with the 21st Century Cures Act of 2016. It focuses on the narrow issues of success in accomplishing stated numerical goals of the PAIMI organizations established in their annual grant applications as well as proper use and distribution of those federal funds. However, the GAO report steers away from evaluating whether the activities of the PAIMI organizations serve the federal mandate to eliminate abuse and neglect of the seriously mentally ill.

NSSC is a coalition of individuals and organizations from diverse political, economic, and cultural backgrounds that share values and principles of unity including the following:
Need for SAMHSA Reforms: Implement evidence-based programs and strong policies that will recognize mental illness as a medical disorder.
Need for PAIMI Reform: Focus on abuse and neglect, PAIMI's original mission, instead of lobbying to prevent medically needed inpatient and outpatient treatment and supports.

Need for HIPAA Reform: Clarify and improve HIPAA policies to include family/primary caregiver rights and prevent harm that occurs when family/primary caregivers who provide care are shut out of the process.

In 2016, there were an estimated 10.4 million adults (4.2% of the population) with serious mental illnesses. Those who receive care reside in a variety of settings including group homes, supportive housing, public and private hospitals, their families' homes, residential treatment facilities and increasingly, jails and prisons. However, those who are incarcerated, in many cases, do not receive adequate treatment. Those whose illness affects their reasoning to the point that they become violent are banned from group homes and supportive housing. If lucky, they may reside with family members; but often, they end up homeless and on the streets.

Looking back over 50 years ago, the reports of widespread abuse in institutional settings, as well as misinformed beliefs that adequate treatment could be obtained via a community-based treatment system, fueled by promising new medications led to the overreaction of wholesale shutting down of mental hospitals in the twentieth century that continues to this day. The promised community-based system was never developed to accommodate the number of patients nor successfully treat the severity of these patients' illnesses.

Instead of correcting the problems that existed, this mental health reform has led to utter disaster. The place and the ways in which seriously mentally ill are mistreated have changed over the past 50 years, but the gross neglect and exclusion of the seriously mentally ill remains the same.

In a further change to the mental health system, 1986 Congress passed the Protection and Advocacy for Individuals with Mental Illness Act which authorized SAMHSA to provide grant funding to the states to support the work of organizations (herein referred to as PAIMI organizations) that would investigate and defend cases of abuse and neglect in institutional settings. NSSC strongly supports efforts to eliminate abuse, neglect, inappropriate medication and coercion in any setting. Unfortunately, too often PAIMI organizations (PAIMIs) work actually results in neglect of appropriate treatment for the vulnerable mentally ill who lack awareness of their illness. This lack of awareness, called anosognosia, affects large numbers of people with severe schizophrenic and bipolar mental illness.

NSSC'S POSITION

- **The GAO report fails to take into account or communicate with organizations and individuals who have evidence of harm caused by PAIMIs, including consumers who were unable to receive vital treatment and family members of those too ill to advocate for themselves. This harm must be recognized and eliminated by taking these problems into consideration and acting to prevent harm in the future (endnote 2).**

The GAO report evaluates only 8 PAIMI program performance reports closely and the SAMHSA monitoring of 9 performance reports provided by PAIMIs. The GAO's process included interviews of PAIMI staff in 4 programs and 2 PAIMI State Advisory Councils. While the program staff and advisory councils may have been able to provide insights into their work, this does not provide the perspective of those actually affected by the work of the PAIMIs as to whether they have been ultimately harmed or benefited from the patient advocacy. This, we believe, is the ultimate measure of programs' effectiveness.

To obtain feedback for their evaluation, the GAO contacted two national organizations, the National Disability Rights Network (NDRN), which contracts with SAMHSA to provide technical assistance to PAIMIs, and the National Alliance for Mental Illness (NAMI). These are two well-established organizations, but neither currently formally recognizes and advocates for the special needs of those afflicted by the physical, medical illnesses that manifest as serious mental illnesses. In other words, the evaluation does not include the stories of those who, more often than not, end up homeless, incarcerated, repeatedly hospitalized and released before stabilized, or dead "with their rights on."

- In 2013, Joe Bruce provided a statement to the House Committee on Energy and Commerce Subcommittee on Oversight and Investigations. Bruce's statement describes the tragedy of the "advocacy" provided by the Disability Rights Center of Maine (DRCM, Maine's PAIMI organization), and condemns the irresponsible actions that NSSC objects to. The DRCM advocate encouraged and worked aggressively to see that Joe's son, Willie, was prematurely released from inpatient mental health hospital care *without any follow-up:* without any plan for continued treatment in the community, without prescriptions for necessary medications, and without consulting his family. Once home without his medication, Willie decompensated and in a severe psychotic state, murdered his mother. The DRCM is directly responsible for her death; but it was Willie Bruce who was arrested and was committed back to the inpatient psychiatric hospital by the criminal court.

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> *"Will was advised that without his consent, his parents had no right to participate in his treatment, or have access to his medical records. Will believed there was nothing wrong with him, that he was not mentally ill, a condition characteristic of many persons with severe bipolar disorder or paranoid schizophrenia, particularly of younger ages such as Will's. He would not consent to our involvement with his treatment…." Joe Bruce* (**endnote 3**)

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Then, the DRCM attempted to further interfere with Willie's best interests by attempting to foil Joe's petition for guardianship of his son. Guardianship would have allowed Joe to

be included in any treatment decisions and to be able to insure Willie received any necessary treatments. The patient advocate told Willie that guardianship was a bad idea and convinced the attending physician to refuse to provide the evaluation required for the guardianship hearing. Only after Joe finally succeeded in getting guardianship and getting Willie appropriate treatment, was Willie able to begin to recover. (Note that there are no cures for psychotic conditions like schizophrenia or bipolar disorder; therefore, recovery means only that with continued medication and supports, the individual may be able to resume some aspects of "normal" function and life. Those normal functions will be lost if treatment is disrupted.)

- **State and territorial governors as well as SAMHSA are responsible for and have failed to closely supervise the actions of PAIMIs and the ill effects that have too often resulted. It is critical that these governors and SAMHSA be vigilant and act responsibly to appoint only PAIMI organizations that are not anti-treatment and/or anti-psychiatry and stop supporting those organizations that are anti-treatment and/or anti-psychiatry.**

  The GAO report describes a cursory review of self-generated performance reports, which describe only numbers of cases and whether they were resolved. A successful resolution by PAIMIs' standard is whether the consumer is happy with the service. PAIMIs usually receive on-site monitor visits from SAMHSA only once every 10 years. Even then, the PAIMIs are not answerable to anyone for the impact of their "advocacy" on the consumers, their families and the community at large. The functions of the state PAIMIs should be of critical importance not only to mental illness advocates; but also, to all state and territorial governors and to SAMHSA. It is the governors, by statute, who appoint the PAIMIs that are expected to serve in the prevention of abuse and neglect of individuals with mental illnesses and those with developmental disabilities.

- **We hold our legislators accountable in their budget-making capacity responsible for directing mental health funds to research and treatment of the seriously mentally ill. Problems with the program were observed by SAMHSA in 2011; yet in 2018, the misdirection of funds continues.**

  In 2016, SAMHSA awarded $36 million of federal grant funds to the PAIMIs; based on a formula, the awards ranged from $229,300 to over $3 million. Various other state and organizational funds contribute to the PAIMI operations as well; but, SAMHSA's 2011 evaluation of PAIMI revealed that as much as 30% of the funds were used for activities not permitted by statute, such as "reducing stigma." **(endnote 4)** Stigma is not the most common barrier to obtaining treatment. Both federal and state legislators have a

responsibility to insure that taxpayer dollars are spent, not only according to federal statute and regulations; but also, according to the purpose and mission of federal laws. Taxpayer dollars should not to be diverted to purposes that work against the judicially recognized responsibility to provide adequate and appropriate treatment to those with serious mental illnesses.

- **NSSC calls for an end to PAIMIs' actions that flagrantly interfere with vitally needed reforms that would provide the seriously mentally ill with the treatment and supports they require to live safely in the least restrictive environment that is appropriate to their needs.**

  Close examination of the 2011 evaluation by SAMHSA showed that PAIMIs have actively worked to block the implementation of Assisted Outpatient Treatment (AOT) programs. AOT and other outpatient commitment programs are evidenced-based programs supported and promoted by SAMHSA**.** Thus, a SAMHSA funded program is actively engaged in undermining the evidenced-based programs promoted by SAMHSA. **(endnotes 1 and 3)**

- **PAIMIs must be held accountable for lobbying for legislation which is clearly a violation of statutory provisions of the PAIMI Act.**

  In Joe Bruce's statement, he shows that DCRM actively lobbied (in violation of statutory provisions of the PAIMI Act) *against* Joe's push to amend state laws in Maine to provide for AOT as a third optional result of a commitment hearing. This is a common activity of PAIMIs across the nation.

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  "Their campaign included proffering 20 or so consumer witnesses in opposition to the law, but these consumers were completely aware of their mental illness, stable on medication and successfully living in the community - the very goals that the proposed law was designed to achieve for our loved ones… This cynical opposition to the AOT law shocked me and the families. The incident illustrates the national policy of the PAIMI program to oppose any form of involuntary treatment." Joe Bruce **(endnote 3)**

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- **SAMHSA must curtail both PAIMIs' efforts to close psychiatric hospitals exacerbating a shortage of 93,000 beds nationwide and PAIMIs' refusal to work to insure appropriate care in existing hospitals. PAIMIs should be forced to abide by their statutory mission: providing advocacy to individuals with psychiatric disability who are abused and neglected, especially those residing in nursing homes and in**

criminal justice settings where these individuals are particularly vulnerable and isolated.

SAMHSA's 2011 evaluation of PAIMI determined: "*As public psychiatric institutions close, more individuals with psychiatric disability are found in nursing homes and jails."... "In the evaluation team's opinion, such settings constitute the new institutions."* SAMHSA evaluators found that PAIMI fails to focus on people in those institutions (jails, prisons and nursing homes). "*Given that the Federal regulations still emphasize institution-based over community advocacy, more PAIMI attention should be directed to eliminating abuse and neglect in jails and nursing homes*." Yet, in one state, a PAIMI worked with stakeholders to ensure what advocates described as the "responsible closings of state hospitals." In another state, PAIMI efforts were found to be a major factor in "the closure of a state hospital." The [State MH] directors cited the significant influence of PAIMI advocacy on their agencies' activities, including… "*planning for closure* of state hospitals and large personal care homes." **(endnote 4)**

SUMMARY

On page 19 of the GAO report, there are two examples of systemic activity cases requiring extended effort to resolve that we would agree with. In Indiana, a lawsuit countering restrictive housing of prisoners with mental illnesses took 4 years to resolve. In Vermont, the PAIMI reported working to reduce force and isolation. These actions are urgently needed; and as in the two cases above, are found to need frequent revisiting to insure that mistreatment does not again seep into institutional operations.

However, the abuses of the patient advocacy program by PAIMIs observed in 2011 have continued unabated. As summarized by Mental Illness Policy Org., "An analysis of the SAMHSA 2011 Evaluation of PAIMI reveals PAIMI ignores the institutionalized, minorities, and people with SMI. Rather than focus on abuse and neglect they use the rubric of 'civil rights concerns' to allow them to focus on whatever they find ideologically palatable. They engage in activities harmful to the seriously ill (threatening states that implement AOT and working to close hospitals). SAMHSA has looked the other way and implemented little oversight." **(endnote 4)** NSSC agrees with Mental Illness Policy Org., and urges SAMHSA and the states to act immediately to correct the misuse of the PAIMI grant funds and return PAIMI to its original mission - to protect mental health patients from abuse, neglect, and civil rights violations.

ENDNOTES:

1. D.J. Jaffe, *Insane Consequences, How the Mental Health Industry Fails the Mentally Ill,* 2017, Note #20, page 317: The following quotes from the 2011 SAMHSA evaluation of PAIMI proves

that SAMHSA is aware the PAIMI programs are working to block implementation of AOT. "A number of PAIMIs worked to prevent the enactment of state laws creating outpatient commitment systems." PAIMI may "collaborate with…a consumer advocacy organization to block passage of a proposed expansion of an outpatient commitment law," (p.30), "PAIMIs reported joining other advocates in activities such as: Ad hoc partnerships focused on specific issues (e.g., opposing outpatient commitment)," (p.66). "At the state level, PAIMIs have been involved in systemic issues including outpatient civil commitment," (p.79). "A number of PAIMIs worked to prevent the enactment of state laws creating outpatient commitment systems," (p.94). SAMHSA, *Evaluation of the PAIMI Program, HHS Pub. No. PEP12-EVALPAIMI.*

2. Table 1 of the GAO report outlines the requirements for a PAIMI program, including the makeup of the advisory councils and requirement to consult with the public and the advisory council on program design and goals.
3. HOUSE COMMITTEE ON ENERGY AND COMMERCE SUBCOMMITTEE ON OVERSIGHT AND INVESTIGATIONS Examining SAMHSA's Role in Delivering Services to the Severely Mentally Ill Statement of Robert "Joe" Bruce and Exhibits, May 22, 2013, accessed at https://mentalillnesspolicy.org/wp-content/uploads/joe-bruce-5.22.13.samhsa-testimony.pdf
4. "PAIMI Problems", Mental Illness Policy Org., accessed June 2018, from https://mentalillnesspolicy.org/wp-content/uploads/paimifails2011samhsaevaluation.pdf