

MENTAL ILLNESS POLICY ORG.

UNBIASED INFORMATION FOR POLICYMAKERS + MEDIA
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Mr. Steve Pittman
President
National Alliance on Mental Illness
3803 N Fairfax Dr., Suite 100
Arlington, VA 22203
June 3, 2017

Dear Steve:

Hope all is well. Someone was kind enough to share with me, the letter you sent to all affiliates, concerning the upcoming NAMI Board elections. In your letter, you essentially argued that the National Alliance on **Mental Illness** should not focus its efforts on helping the seriously mentally ill because that would kick others out and create a smaller tent. That is not what we are arguing. We are arguing that by broadening NAMI's mission beyond the seriously mentally ill to encompass mental-everything, it is the seriously mentally ill who have been kicked out.

Candidates for the NAMI board, like me, were told not to campaign, and yet we find the NAMI President campaigning to influence the election, with NAMI resources, and couching issues in a way we would not. Your materials were distributed to NAMI voter mailing lists that we don't have access to. Surely there is something wrong with that. Surely the election should be fair.

While sixteen candidates are running for five open board seats on various platforms, your letter specifically targeted the four (advocate Lauren Rettagliata, mental illness attorney Mary Zdanowicz, Dr. Rob Laitman, and I) because we are running on a "Focus on Serious Mental Illness" ticket that encourages NAMI to make the seriously mentally ill a more important priority. I am hoping you will share this response as soon as possible with the same affiliates and state organizations you sent your original letter to. As someone who like you, loves NAMI, I thank you for considering this. It is appreciated.

The moms and dads who sat around the dinner tables in Wisconsin, California, Maryland, Washington and elsewhere founded the National Alliance on **Mental Illness** because they had loved ones with schizophrenia, bipolar disorder and other serious and often devastating mental illnesses. But they were alone. Mental **Health** America existed, but its "big tent" approach ignored the needs of the most seriously ill. No organization was providing parents of the seriously mentally ill with support or advocating for treatments, research and services for the seriously ill, hence a NAMI was needed. Dr. Torrey came out with books on serious mental illness and did media interviews that turbo-charged the initial efforts of the NAMI founders. NAMI grew and became the leading organization representing the seriously mentally ill, while MHA continues to represent all others. I was proud to serve two terms on the NAMI National Board in the 1990s when we unapologetically prioritized the seriously ill.

Unfortunately (at least to many) NAMI National has strayed and it is the seriously ill who are paying the price. Many of us believe mission-creep is causing NAMI to ignore, marginalize and shun the seriously ill. We would like to help NAMI National do a better job on focusing on the most seriously mentally ill which is exactly what the moms, dads, siblings, children, local affiliates and some states still focus on.

Over the last fifteen years, to appease and make room for all the others in your big tent approach, NAMI National essentially kicked the seriously ill out. Following are a few examples of how:

- NAMI replaced the phrase “mental illness” with the more palatable normalizing phrases “mental health conditions” or “behavioral health” favored by the higher functioning. The seriously mentally ill simply disappeared from the NAMI narrative.
- NAMI created formal media guidance urging the media not to use the word ‘suffering’ when talking about mental illness. Again, the seriously ill who do suffer were erased from the NAMI narrative.
- NAMI signed on to full page ad in the *Washington Post* against importing meds from Canada thereby making meds more expensive for the seriously mentally ill who often rely on medicine rather than talk therapies.
- NAMI robustly embraced replacing the scientific medical model with the recovery model parts of which lack a scientific basis and put every consumer in charge of their own recovery no matter how psychotic. For some of the seriously mentally ill, that does not work out well.
- NAMI National went from an organization that acknowledged and worked to reduce incidents of violence--for example by creating reports on rates of violence against family members by mentally ill relatives--to one that now refuses to recognize increased rates of violence in the untreated seriously ill. NAMI now hides behind the PC platitude that the mentally ill are no more violent than others. But that statement is not true for the untreated seriously ill, so NAMI simply ignores them. We believe it is violence by the untreated seriously ill minority that stigmatizes the non-violent majority, so it is particularly important for NAMI to play a role in reducing it. NAMI won’t even admit to the problem.
- NAMI has invited anti-psychiatry, Bazelon, Protection and Advocacy Programs, and the most radical consumer groups into the tent, in spite of their belief that psychosis is a civil right to be protected rather than an illness to be treated.
- NAMI decided that one of the important issues it should dedicate resources to was to proactively lobby to make it easier for the most seriously mentally ill to buy guns.
- After a direct vote by the entire NAMI membership calling on the NAMI board to expand access to Assisted Outpatient Treatment (AOT) to reduce homelessness, arrest, incarceration and hospitalization of the seriously mentally ill, NAMI sided with the ‘big tent’ advocates and simply refused to incorporate AOT in its advocacy. As a result, more individuals with serious mental illness are homeless and incarcerated.
- NAMI routinely diverts advocates who used to fight for more housing and programs, and against the prejudicial laws policies and politics that deny our seriously mentally ill loved ones care-- to fighting an amorphous concept of stigma. Stigma has become the black hole of advocacy diverting tens of thousands of advocates away from working for real legislative reform.
- NAMI’s big-tent approach causes NAMI to turn a blind eye as SAMHSA and other groups in the tent divert funds that should help the seriously mentally ill to programs to eliminate bad grades, poverty, hunger, bad parenting, angst about sexual identity, prostitution, sex trafficking, crime, unemployment, divorce, and truancy, by wrapping them in a mental health narrative.
- There are many other examples in my book, “Insane Consequences: How the Mental Health Industry Fails the Mentally Ill” of how the mental health industry, including NAMI National have largely abandoned the seriously ill.

Your letter correctly claimed that “The 2017 candidates ... will influence the direction of NAMI for the next three years.” But I don’t think having four or five of the fifteen being concerned about the most seriously mentally ill influences it in a bad way. I think it is a good thing. Your majority can still outvote us if it wants, but at least the voices of the seriously ill will be heard.

It is not as if NAMI doesn’t have a priority already. The 2015-2019 NAMI strategic plan is to “Focus on Youth.” We believe it should be, “Focus on the Seriously Mentally Ill” whatever age they are. When kids age out, we want NAMI to be there for them. You are not really against ‘focusing’, which we advocate for, you just don’t want the focus to be on the seriously ill. Let the members decide.

I respectfully disagree when you say members have embraced the recent years of mission-creep. I believe most members, affiliates, and many state organizations still focus on the seriously ill and would like NAMI National to do so too.

I know you, as I, love NAMI. With that in mind, I hope you will refrain from trying to prevent a fair vote, and to mitigate the damage your campaigning did by sharing this letter with the same e-mail list as quickly as possible. Thank you very much for all you do. I look forward to hearing from you.

Sincerely,

DJ Jaffe

2017 Candidate for the NAMI Board on the “Focus on Serious Mental Illness” Ticket

Two-term former NAMI National Board Member (1992-1998)

Co-founder and former board member of Treatment Advocacy Center

Executive Director, Mental Illness Policy Org.

Author, “Insane Consequences: How the Mental Health Industry Fails the Mentally Ill”