

Letter to NAMI

I am writing this letter as a plea for reconciliation amongst those of us who have psychiatric diagnoses, those of us who issue them, those of us who have family members with them, and those of us who work toward related policies. As we are all aware, there are multiple tensions that exist amongst differing organizations within the mental health world, but I truly believe that if we can all begin to have a compassionate conversation, we will find a healthy common ground between our sometimes conflicting ideologies.

I specifically wish to address NAMI.

NAMI does good work throughout the country. They have power and use it to push for more awareness and treatment of psychiatric disorders. Indeed, NAMI has the constituency and funding to invoke a lot of positive change in our communities, providers, and legislators. I respect the work that they do, and see their passion as a measure of their enormous care of, frustration with, and optimism towards the mental health system in general.

So, it is with respect for their efforts that I wish to challenge some of the fundamental assumptions that they promote, specifically about what “mental illness” is, and how it is best treated. I hope that by speaking from my heart, my plea comes off as an invitation for more dialogue around these important issues that are sometimes taken for granted.

I want to start off by sharing something that I wrote the other night. I should state briefly that I am an individual who was diagnosed with severe and persistent mental illness, struggled for many years to emerge, and now am healed and work in the mental health world.

This is what I wrote when reflecting upon my relationship to diagnosis and the popular information floating around about “mental illness”:

When I believed that a chemical imbalance drove my everyday experience, I told myself, “I am Bipolar.” When I learned that the chemical imbalance was only a part of me, I told other people, “I have Bipolar.” When I discovered that a chemical imbalance has nothing to do with me, I realized, “I am Human.”

I share these words with you as an illustration of how insight shaped my own journey towards wholeness and healing. Being diagnosed had the residual effect of transforming how I relate to the world and my experiences.

In the beginning, I sorted through the various phases of my past and tossed them into clinical categories, and it all seemed to make sense. I also began to see my everyday emotions and thoughts as the product of a chemical imbalance in my brain. My sense of self became infused with a deep uncertainty, and because I was at a loss for why I did not seem to fit into the world, I absorbed all of the literature and psychiatric declarations that I *was* in fact Bipolar.

After a couple of years, I slowly graduated my thinking to: “I *have* Bipolar,” which was a product of learning about the principles of recovery and truly embracing the notion that my “mental illness” is a part of me, not the whole me. At that point, I learned about “managing my illness,” and as a result, came to believe that my chemical imbalance was in fact treatable – especially through medications – though highly volatile if left to its natural course.

Throughout this time, I was a voracious reader of mental health material, but I had never explored the *actual* scientific literature from which the material claimed to emanate, nor had I read many alternative perspectives on “mental illness.”

Then, one day, things changed. I met a man who had been diagnosed with schizophrenia, but no longer took medications. Moreover, he worked full time in a very challenging position, and was sharp, compassionate, and full of humanity. Certainly, he did not seem to be experiencing “symptoms,” and he didn’t seem to be “in remission” either. He seemed healed.

As things go, I began meeting more and more people who had experienced profound suffering in their lives – been traumatized, diagnosed, hospitalized repeatedly, stigmatized, and on and on. But these people were well now. And not just “stabilized.” But “well” in the sense of having emerged from a dark void with wisdom, clarity, and deep compassion; “well” in the sense of working long and hard hours altruistically. And again, they were not taking medications.

Slowly, I started to investigate some of my long-held assumptions, and slowly, I started to wake up to a different reality, one in which I started using terms like “experiences” instead of “symptoms”; “trauma” instead of “disease”; “problems” instead of “illness”; and “neuroplasticity” instead of “chemical imbalance”.

In my inquiry into the scientific literature, I was shocked to find that many of the messages that I had received about “mental illness” were in fact highly presumptuous, and in some cases, driven by economics. For example, the notion of a “chemical imbalance” is suspect and misleading, and certainly not supported by reliable science. In fact, in this month’s *Scientific American Mind* – a pop-culture psychology magazine – you can read, “The imbalance to which the SSRI ads refer is a deficit of the neurotransmitter serotonin at receptor sites in the brain. Such advertising is misleading, however, and does *not* reflect scientific findings. There is no clear scientific evidence that neurotransmitter deficits cause depression or that there is an optimal “balance” of neurotransmitter levels in the brain.”

There may be a million people saying that mental illness is caused by a chemical imbalance in the brain, but that doesn’t make it true. The truth is, in the scientific research, there has never actually been a chemical imbalance observed or measured. It is all inferred, and the inference is based upon a dangerous line of reasoning: “there is a form of circular reasoning that goes: if SSRIs are helpful in alleviating depression, and if they do change the “chemical imbalance,” then depression must be caused by that imbalance. Inferring causality from the success of a treatment is frequently a flawed endeavor: aspirin is effective for headaches, but no one would seriously claim that headaches are caused by a deficiency of aspirin.”

As my awareness expanded, I started rethinking the notion of “mental illness” as “chronic” and “persistent”. Certainly, what is called bipolar disorder and schizophrenia can show up for many years, but if you look at the research, you will find that a *majority* of individuals in longitudinal studies are shown to significantly improve or recover entirely, and many without medications. How can “schizophrenia” be “chronic” and “persistent” when there are so many people out there who have *emerged* from it entirely? In fact, doesn’t the evidence suggest just the opposite, that the chances are, you’ll recover (and not just “recover” in the sense of “illness management,” but in the sense of having a satisfying life without psychiatric experiences)?

The link to trauma in the development of “mental illness” is even more shocking, with some studies indicating that over 90% of people diagnosed with SPMI having had experienced

trauma. If this is the case, can we really say that “mental illness” is “just like diabetes,” as if it were all a physical flaw, and a permanent one at that? If trauma in fact triggers “mental illness” in the brain, wouldn’t it be more appropriate to say that the illness and the disease are trauma, and that the symptoms of the disease are the plastic brain changes that we see? My point here is that popular messages about “mental illness” have stripped it of its context, thereby making it a brain error, when in fact, the brain is highly malleable, and could be thought of as reflecting experience as much as creating it.

What’s most surprising in the scientific literature is that which surrounds the use of medication. Let me be clear in saying that medication can be helpful to individuals, and that some individuals attribute medication to saving their lives. But, there is plenty of evidence suggesting that medication should not be used by all people, and that with some people, it may actually hinder recovery. Thus, if we are to make any statement about medication, we should say that it is a tool that some people find useful, and that some people don’t. In an ideal world, the scientific literature would inform psychiatric practice, meaning that just because someone shows up on the sofa with “symptoms” of a “severe and persistent mental illness” doesn’t mean that s/he will be given medicine. But have you ever heard of a psychiatrist choosing not to administer medication to someone diagnosed with schizophrenia?

I no longer identify myself with Bipolar, though others still do, as I was recently rejected to a Meditation Retreat based upon my past psychiatric history and the “risk” that they assumed I pose. I am not in denial; nor am I in remission. Like all people, I cannot say where I will be emotionally in a year, but I do believe that I will be able to handle whatever happens, for I am now learning how to be fully human, not just the manager of my brain chemicals.

In terms of NAMI, I am concerned with some of their positions on “mental illness”, which seem to be highly medical and follow a line of reasoning that medication is fundamental. As a brief example of such material, here are some statements from their handout on Bipolar Disorder that I find troubling (I have offered my counterpoint to each):

1. “The greatest risk in bipolar disorder is not getting treatment, or refusing treatment because of lack of insight into, or inability to resist, the lure of mania.”

- a. This is untrue for many of us. Many of us have actually been hurt by treatment, or experience great benefits from what is labeled “mania.” I once made a 14-song album in a month and played every instrument on it during a period of “mania.” The “lack of insight” declaration is arrogant and assumes that doctors know best, as opposed to allowing for people who actually have these experiences to define whether or not they value them. Also, many people “refuse treatment” because they find the treatment harmful, not because of “lack of insight” or the “inability to resist, the lure of mania”.
2. “Bipolar disorder is a complex medical illness of the brain.”
 - a. This statement strips “Bipolar disorder” from its context. Nothing happens in a vacuum, especially human experiences. The brain responds to the environment by literally changing shape, so that trauma actually physically alters the brain. If this is so, how can we call “Bipolar disorder” a “complex medical illness of the brain” as opposed to a reaction to trauma? Personally, I have found “Bipolar disorder” to be a “Spiritual Journey” more than anything else, and I know of many, many other individuals who share the same opinion. We would like our voices to be included in this ongoing dialogue, not to be told what we have or are, especially given the lack of scientific evidence.
3. “While no one knows the exact cause of bipolar disorder, most scientists believe that bipolar disorder is likely caused by multiple factors that interact with each other to produce a chemical imbalance affecting certain parts of the brain.”
 - a. Again, the “chemical imbalance” theory is highly manipulative of the science we do have. Furthermore, much of the research into such theories is actually paid for and sponsored by the pharmaceutical companies, creating an obvious conflict of interest. It should be noted that an actual chemical imbalance has *never* been observed.

4. “Bipolar disorder is a chronic condition, much like diabetes. Because periods of remission are sometimes complete, but are often complicated by persistent symptoms, bipolar illness requires preventive maintenance treatment as well as acute treatment, ongoing medication management, and close monitoring during periods of remission.”
 - a. “Bipolar disorder” is nothing like diabetes. For one, “Bipolar disorder” is often not chronic or “everyday”, as scientific studies show again and again. Second, “Bipolar disorder” is a highly subjective experience that is culturally defined, whereas diabetes is pretty much agreed upon around the world as a disease and as unwanted. Third, “Bipolar disorder” does not require ongoing medication management, as many of us do not take medications and are clear and well.

5. “Your management plan should include attention to lifestyle, stress management, supports, and also medication options.”
 - a. This statement says that my management plan “should” include medication options. No, it *may* include medication options. This statement should be followed with information about the number of people who do not respond to medications or who prefer not to take them to allow for the reader to understand that he or she does not *have to* take medications to be well.

6. “While medication is one key element in successful treatment of bipolar disorder, psychotherapy, support groups, and education about the illness are also essential components of the treatment process.”
 - a. The first part of this statement, that medication is “one key element” in successful treatment, is again presumptuous and declarative that medications are essential.

7. “The most useful psychotherapies generally focus on understanding the illness, learning how to cope with it, and changing ineffective patterns of thinking or interacting.”
 - a. This is untrue for many of us. I went through 9 months of therapy with a man who intentionally did not use the term “Bipolar,” and with whom I learned to successfully

re-transcribe my experiences into meaningful ones as opposed to chemical ones. In fact, I just heard a recent study presented during a SAMHSA teleconference that “Illness Insight” may actually be detrimental to recovery, in that it often leads to self-stigmatization, which was certainly the case for me.

8. “The ideal course of research is to identify medication that, used alone or in combination, effectively prevents episodes and offers maximum periods of symptom-free maintenance coverage during periods of remission.”
 - a. Where does this information come from? I think that the “ideal course of research” should be to find treatments that work, not just medication treatments. Unfortunately, so much money is given by pharmaceutical companies to research that there is little in the way of “alternative treatments,” which many of us claim have been the most helpful.

9. “People living with bipolar disorder should remember, however, that the recovery they attain usually depends in large part on the medications they are taking and their other health and wellness strategies.”
 - a. This is a presumptuous statement and does not reflect the majority of interactions I have with “recovered” individuals. Most of us would attribute the “recovery we attain” to things like meaning, spirituality/faith, employment, human connection, peer support, personal responsibility, and so on, the same mechanisms that bring all human beings peace and joy. In our recovery, medication may or may not be helpful, but many of us would not say that our recovery has depended in large part on it. I see that the second half of this statement says “other health and wellness strategies,” but again, the wording indicates that medication belongs in a class by itself, as a fundamental cornerstone to healing.

Too often the rhetoric of passionate debates skips over solutions, thus, I have listed them here in an attempt to be proactive as opposed to just long-winded 😊

Here are some of my proposed solutions:

1. NAMI consider changing some of its language.
 - a. I am specifically concerned about the use of medical language. No one has a perfect solution to getting the language surrounding mental health “just right.” We must all be creative in this process. I have found a great way to start challenging my own medically- induced worldview is by refusing myself to use the word “symptoms.” Being a worker in the mental health world, I have to communicate with others, so I have consequently started talking about thoughts, emotions, and behaviors just as they are – thoughts, emotions, and behaviors, as opposed to a detached and bland reductionism of human experiences to “symptoms” of an “illness.” I find that by doing this, I am doing myself, whomever I’m speaking to, and certainly anyone I am describing, a huge service. Indeed, by describing specifics, I am more clearly communicating. I am also re-humanizing some of the experiences that people with psychiatric diagnoses have. By saying something like, “Dave says he is feeling scared” instead of “Dave is symptomatic” or “Dave is paranoid,” I am changing the way in which my colleagues and I perceive and communicate about other peoples’ life experiences. Some other great solutions that I have heard: people using the term “big emotions” and “huge feelings” to describe what are traditionally thought of as “symptoms.” I myself say things like “really hyper” or “full of energy” instead of “manic,” and “I am with sadness” or “I am feeling vulnerable” as opposed to “I am depressed.”
 - b. Additionally, the term “mental illness” may want to be revisited. This is, of course, tricky and new territory, but there are many alternatives that people are using to compensate for “mental illness.” I say “psychiatric experiences” – I feel that term is ambiguous enough to encapsulate the people who feel harmed by psychiatry itself – and talk about “individuals with psychiatric diagnoses” as opposed to “adults with mental illness.” By saying “individuals with psychiatric diagnoses,” I feel that I am not claiming that the individual “accepts” or is burdened by an “illness,” but simply that s/he has been given a diagnosis, whatever s/he feels about it. In that sense, I

think it differentiates the individual from the diagnosis and somewhat severs the assumed relationship. Other people say “adults with psychiatric disabilities” or “people diagnosed with psychiatric disorders” and so on. As for “mental illness” itself, there are some people who refer to it as “spiritual emergency” or “spiritual emergence,” or terms as clear as “mental health issues” or “mental health problems.”

- i. Please consider revamping the repeated and emphatic use of “illness” to describe crises.
 - ii. Also, Shery Mead has written some excellent work on Worldview and Language: www.mentalhealthpeers.com
 - c. On a whole, NAMI may want to emphasize less on the brain and more on environmental and existential conditions that lead to psychiatric experiences. Of course, there could certainly be more material on the impact of trauma.
 - d. I personally feel that the comparisons between “mental illness” and “diabetes” or other physical diseases are flawed and not supported by science.
 2. NAMI add conflicting opinions to its existing literature and Provider Education program.
 - a. I may be going out on a limb here, but wouldn't it be wonderful to read something like this (currently in the existing NAMI literature):

“While no one knows the exact cause of bipolar disorder, most scientists believe that bipolar disorder is likely caused by multiple factors that interact with each other to produce a chemical imbalance affecting certain parts of the brain.”
 - Followed by this (not currently in the existing NAMI literature)

“However, there are many other people, including individuals who have been diagnosed with bipolar disorder, who would claim otherwise, instead defining the cause as related to life experiences, spiritual crises, past trauma, or various cultural expectations.”
- In fact, my challenge to NAMI is to include as many “consumer” voices and opinions

as those of scientists. That would allow for people who are reading the materials or taking the Provider Education course to be introduced to an array of models for understanding human experience, which in fact would be empowering to those many individuals who currently feel marginalized by the “brain disease” theories that they find disagreeable.

3. NAMI change their overall emphasis of medication in treatment.

- a. First and foremost, NAMI could introduce statements such as “Medications do not work for everyone” and “Some people find recovery without medications” into the existing literature and dialogues. They could even back the statements up with current scientific research.
- b. Also, please consider removing statements like “People living with bipolar disorder should remember, however, that the recovery they attain usually depends in large part on the medications they are taking and their other health and wellness strategies” that feel – to me – paternalistic, and that in my experience are not entirely true.
- c. NAMI could consider some of the shifts of consciousness in medication use promoted by people like Pat Deegan (www.patdeegan.com). I cannot justly speak for her, but she has basically introduced the concept of “using medication” as opposed to “taking medication.” In this way, a person who is prescribed medication uses it as a tool as opposed to simply taking it passively. The emphasis for medication use is that it should be the person’s choice, and that the person should feel empowered with it to help in his or her recovery, not ashamed or passive.
- d. NAMI may want to revisit the use of literature from pharmaceutical companies that emphasizes the necessity of medication use. While much of this literature is seemingly helpful and useful, if the literature proclaims that medicine is a necessary component to recovery, then it is promoting a one-sided belief system that many of us see as damaging.

4. NAMI mention in its literature and at its meetings the scientific studies that demonstrate that a majority of individuals diagnosed with schizophrenia significantly improve or recover entirely, many without medications. I was very pleased with the two speakers at the recent NAMI-VT annual conference who cited Courtney Harding's work! These studies are powerful, scientific, and dramatically challenge our presumptions about the course and outcome of diagnoses such as schizophrenia. Here is a great place to start for some research and perspectives into the many faces of recovery: <http://www.bu.edu/cpr/repository/> or check out this quick review of studies: <http://www.power2u.org/evidence.html>

5. NAMI consider promoting alternative treatments at conferences.
 - a. At the recent NAMI-VT conference, a representative for Abilify had a booth and handed out materials. I do not see the point in having a drug rep at an annual conference, but if NAMI wishes to have drug reps in the future, they would be doing a great service to the term "fair and balanced" by having reps from health clubs, alternative therapeutic communities (which, to NAMI VT's credit, there were some reps from Spring Lake Ranch, which I presume is "alternative," though I am not too familiar with them), naturopathic facilities, consumer/survivor/ex-patient organizations, local community interests, spiritual communities /organizations/facilities, and so on. It would be too idealistic to suggest having all of these types of peoples represented at every conference, but I think NAMI could at least consider having some other options available.

6. NAMI keep away from highly political and moral/ethical controversies such as involuntary treatment. I am writing this proposed solution strictly from my heart, though I can point to some rational reasons why NAMI would benefit from staying out of advocacy on involuntary treatment. The most obvious reason is that these issues are highly emotional and dear to many people who have in fact experienced things such as involuntary treatment. Thus, when NAMI gets involved, or promotes people who advocate for one side only, NAMI

isolates a lot of people, and quite frankly, a lot of anger and resentment results. NAMI has a large constituency that makes it very powerful, and I ask that it please be mindful of this power when working on legislative levels. NAMI did not begin from people with psychiatric diagnoses, and while many of us are connected nowadays to NAMI, the organization still doesn't fully represent our many voices. Thus, while advocates at NAMI may see their work on issues such as involuntary treatment as kind and compassionate, they may find that the people for whom they are advocating actually strongly disagree with their positions and stances. It is so important to many of us who have experienced some of the uglier sides of mental health treatment that our voices are heard and respected, and that we are not unfairly represented by large organizations who may be making skewed though well-meaning presumptions.

I would like to end my list by saying that I am not by any means "the voice" for those of us who may have concerns with some of NAMI's messages/practices, nor do I feel hardly able to represent the many brilliant and beautiful solutions that people are offering as alternatives. In my proposed solutions here, I am simply offering the best list that I can think of on a given night, so I want to attest to the fact that is just my opinion! The best that we can all do is continue to research, ask questions, and listen to one another. I hope that others who have differing solutions will also either speak up or be engaged to be included in any process of reform.

Thank you for your time and consideration,

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