

**BRIEF HISTORY OF NAMI 2**  
**(National Alliance on Mental Illness)**

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November 1, 2007

In the fall of 1979 some 250 families, consumers (persons with a diagnosis of mental illness) and a few professionals gathered at the University of Wisconsin to form NAMI and the transforming events of that weekend resulted in NAMI of today, nearly 1000 times larger and clearly the Nation's Voice on Mental Illness. That astonishing growth was the product of the labor of tens of thousands of dedicated volunteers as well as the parallel growth of understanding in the scientific community. Here is one version of the story starting with what happened to research:

1. Explosion of public funding for research. Early in the decade of the 80s, NAMI declared a war of research on mental illness. We declared that it was our intention to double the NIMH research budget (whence nearly all research money came) by the end of the decade. We did not quite make that goal, but we did fight the battle of the budget so vigorously that by the end of the century it had multiplied more than six fold, from about \$150 million to more than \$1 billion. One anecdote illustrates our effort: I remember in the 1980's NAMI collected thousands of letters from its members supporting funding for research, loaded them into a wheelbarrow and wheeled them into a congressional budget hearing on funding for mental illness research. Patty Duke was testifying for a budget increase and the entrance of the load of thousands of testimonials made quite an impression on the members of that Congressional committee.
2. The NAMI role in creating NARSAD. In the early 1980s, the idea of creating a private foundation to solicit funds for research on mental illness began to motivate us. That idea has prospered and on April 4, 1985, NARSAD was born, the product of an agreement between NAMI and a small Kentucky non profit foundation which had received approval from IRS for this activity to be tax exempt. Later, in order to invite other participants to join, NAMI decided to separate NARSAD from NAMI. Now NARSAD provides about \$20 million a year to high quality research on brain disorders.
3. Sharpening the NIMH focus on real mental illnesses. In the late 80s we began to examine what NIMH was doing with the money that was appropriated each year. NAMI formed a Science Research Committee which examined a large fraction of the research grants made each year by NIMH, identified the ones we thought had little to do with mental illness and referred them to a volunteer committee made up of some of the best brain scientists in the country. After these distinguished but anonymous persons reviewed our work we took the final results of this examination to the management of the NIMH. We like to believe that this is resulting in an NIMH grant portfolio that is more focused on major mental illnesses.
4. The move of NIMH to NIH. Also in our quest to prompt NIMH to focus more intently on mental illness as distinct from poor mental health, we initiated a campaign to move NIMH to NIH. NIH is by common consent the best health

research institution in the world. Our hope in making that move was to press NIMH to focus its research on major mental illness and to underline that the brain is a part of the body. After about two years of effort, the Congress agreed and NIMH is now a part of this world renowned team of scientists in NIH.

5. Science: from confusion to consensus: mental illnesses are treatable brain disorders. Some time in the mid to late 80s, NAMI sought to get a consensus statement from two dozen of the leading mental illness researchers in the country. Even that late it was not possible to get a unanimous decision that these were brain disorders but we did get all but two of them to agree that mental illnesses are "a physiological disorder involving the brain". Since that time thanks in part to NAMI's efforts and, of course to the march of science, it is now the conventional wisdom that mental illnesses are, indeed, treatable brain disorders. That may sound unspectacular to those of you who come late to this struggle, but, I assure you it is a giant victory to those of us who lived through the days when a common explanation offered by psychiatry was a theory that mothers caused mental illness. One theory referred to such persons as "schizophrenogenic mothers."
6. Relations with providers: during the time when some providers considered families (especially mothers) as the cause of the problem, NAMI members responded as you would expect: with anger both from the unfair accusation and because providers held us at arms length claiming "confidentiality" if we sought to find out the basic facts about our loved one or to offer suggestions. Those dark days are largely gone. We now even dare to conduct classes to teach professionals how to work with us (our "Provider Education Program") and, so far, they like it.
7. Kids do get mentally ill. In the early days of NAMI, we focused largely, although not exclusively, on adult mental illnesses. The wisdom among many professionals held that mental illness could not occur in persons under 18 years of age. Our Executive Director at the time came from a background of concern for children, having adopted seven children to round out her family at an even dozen, one of whom became mentally ill. It was inevitable that she would steer NAMI in the direction of early intervention and of recognition that kids do get ill and that NAMI could serve them by devoting a portion of its considerable clout on advocating for early intervention. The results of this re-direction are clear: NAMI and indeed the psychiatric field as a whole are now emphasizing that kids do get ill and that early treatment is a high priority. In fact there is a theory among some researchers that leaving mental illness untreated may cause brain damage.
8. Growth. Starting in 1979 with some 250 eager volunteers at the founding meeting in the University of Wisconsin, we now have one thousand times that number of members. Today we have over 1,100 affiliates covering every state in America.
9. Consumers: There was a day when many consumers were on the outside looking in the window at NAMI and debating whether to join NAMI. I remember one day when NAMI was meeting in Louisiana and we had on the ballot a change which would create what we called the Client Council (composed of consumers). We needed a two thirds majority of the votes to win. Over scattered opposition, we won easily, and from that day, participation by consumers has grown to the point

where NAMI has more members recovering from mental illness than any organization in the world. And today, consumers rightfully take their growing place at the NAMI tables of governance. At least three of our national presidents (and many Board members) have been recovering consumers.

10. Stigma is on the run. It was not always so. I remember that a large toy manufacturer came out with a toy that they called "Zartan the Schizophrenic". They made the toy change colors, hence he was schizophrenic; (remember that schizophrenia originally meant "split mind") and made this particular toy the enemy of their hero toy. NAMI challenged them for marketing a toy that fixes stigma against persons with Schizophrenia in the susceptible minds of children. They invited some of us to come talk with them. Such was the strength of our case that this large company not only took the toy off of the market but, for several years became one of our largest financial supporters. This is only one case in hundreds where today across America, our NAMI stigma busters are challenging stigma wherever it raises its head.
11. Discrimination. This force was rampant in all aspects of the lives of people with mental illnesses. NAMI played a key role in getting laws passed affording consumers some protection against discrimination in employment, housing, and other aspects of life in the community.
12. Finding a focus. There was a time when NAMI was in some danger of being considered limited to just one diagnosis: schizophrenia which was a position advocated by some of our members. Over time it became evident that persons with other diagnoses needed our support. Today we are a movement that encompasses all major mental illnesses. That was a wise decision.
13. Hospital versus community. There was a time when some of our members sought to have NAMI focus on hospitalization to the exclusion of community support. Some sought the opposite. Clearly we need both and we found our way from contention to the consensus that good community support is paramount but hospitals are occasionally needed too.
14. Phone support. We became aware that there were thousands of consumers and families who needed support. Our esteemed Executive Director found a donor who saw the need for NAMI to be able to respond directly to such people across America. With this support, NAMI established the NAMI Helpline. Volunteers who have lived through the battles with mental illness answer the phones and bring support and practical advice to countless families and consumers across our nation.
15. Ethics in research: NAMI was a pioneer in articulating the need for meaningful protections for individuals with mental illnesses who participate as human subjects in research. NAMI also developed the first training program for consumers and family members who participate on institutional review boards at research facilities.
16. Education: NAMI emerged as the nation's voice on mental illness through educational vehicles such as the NAMI Conventions, the Advocate, the Decade of the Brain, NAMI E-News, the periodical "Because Kids Grow Up" and other means for telling the truth about mental illnesses to the public.

17. Jobs for Consumers. NAMI played a prominent part in getting rules changed to create meaningful (albeit partial) incentives for SSI and SSDI recipients to work without risking loss of medical and other benefits.
18. Criminalization of people with mental illnesses. NAMI brought this tragedy to public attention and played a key role in achieving some potential solutions to this national tragedy, including CIT programs (Crisis Intervention Teams which train police forces how to stabilize crises in a non threatening way which avoids violence), Mental Health Courts and other jail diversion strategies. The crowding of our jails and prisons with no fault victims of mental illnesses still remains a shameful fact.
19. Abuse of Restraints. NAMI led a national effort to impose limitations on the use of physical and mechanical restraints in Medicaid or Medicare funded programs and to create standards governing the use of such restraints.
20. Education. Finally, NAMI has become a major national educational institution creating and nourishing the Family to Family Education Program, the Provider Education Program, NAMI CARE, Peer to Peer, Living with Schizophrenia and Other Mental Illnesses and training for our support group facilitators. It is an amazing transformation.

So there in 20 short paragraphs, you have at least a piece of the story of the amazing transformation of America's response to mental illness. It is a story of historic proportions. Throughout the millennia of human history, countless people have been subjected to unimaginable torture because their fellow species deemed them "bad" rather than "ill" due to their different behavior. Then, only recently, in our lifetime, all of this has begun to change dramatically. This is because science (with support from NAMI) has revealed that these illnesses are physical diseases of the brain. What an incomparable breakthrough! Generations to come will owe a deep debt of gratitude to what science (with encouragement from NAMI) has done to free the human family from this ancient scourge.

Finally, nobody will ever be able to appreciate the story of NAMI without including note of our profound respect and admiration for persons who have traveled the lonely journey of mental illness with such strength, courage and determination.