

# **My Journey in Family Education; or, You Bet Knowledge is Strength!**

by Joyce Burland, Ph.D.,  
Author of NAMI's Family-to-Family Education Program

One of my first duties, as a brand new NAMI-VT board member, in 1990, was to accompany president Nancy Lanoue to a weekend NAMI training seminar on family education in Washington, D.C. There we assembled with NAMI members selected from 24 other states to become certified as family education specialists and to discuss plans for starting family education programs in our own home states.

By the end of the first session, I was pinching myself. Was it really possible that we had come this far? Could we, as stigmatized family members, actually seize the initiative and teach what we knew to be true about mental illness? Yes, indeed, we could! There was the venerable Dr. Agnes Hatfield from the University of Maryland, mother of a mentally ill person herself, teaching the seminar and giving us the tools for this bold mission.

Then I looked around the room at all the dedicated family members, eagerly taking notes. Yes indeed, I thought, every last one of us is uniquely qualified to take on this new role. We have earned our advanced degree of legitimacy through our own raw experience; we have all graduated, summa cum laude, from the school of hard knocks. At that moment I felt enormous pride for every NAMI family in the world!

The excitement and promise of that weekend started me thinking about my own journey over the past 30 years as a family member. Because this passage from ignorance to enlightenment is so large a part of my own education I want to tell you about it. I'm sure its twists and turns will be familiar to you.

My family has struggled with mental illness for two generations. My older sister became ill with paranoid schizophrenia in 1960, a time some of us recall, when the world of mental illness was thought to be flat and people who ventured too far were expected to fall off. My dear and extraordinary sister, the sturdy mother of five, was hustled off to psychoanalysis, a remedy which served only to intensify her psychosis and fortify her delusions. Determined to help her, my parents encountered immediate and degrading resistance. Blamed and reproached, they were summarily dismissed as pathogenic. They have never fully recovered from this assault upon their good will.

Twenty years later my own daughter, approaching the prime of her career as a dancer, was stricken with the same illness. Surely, I thought, things have changed. Certainly, as the person primarily responsible for her wellbeing, I will not be blamed and rejected as my parents were. But, it was as if the world had stood still. The treatment team viewed me with icy disdain, refusing to answer my questions. No one came forward to inform, to counsel, or to comfort me as I tried to cope with the catastrophe of psychotic illness.

I was instead remanded to a psychiatrist who explained, impassively, that my daughter's "infant psychosis" (due to maternal indifference), was breaking through again. I was also mandated to attend a family therapy session with my daughter and my ex-husband of 15 years. Here we were assured that she wasn't really sick at all. Once we stopped "using her symptoms" as a cover-up for our own marital failure, she would be fine!

I think that any family member who has ever watched the firestorm of mental illness consume the life of someone they love knows the utter irrelevancy of these professional responses. Our deliverance from this sort of badgering seems to occur in a flash of insight—when we at last rebel and throw out all this nonsense. You would think that the workouts with the psychiatrist and family therapist would have done it for me. But I was still dazed, still reeling from the impact this terrible illness was having, again, on our lives.

No, my moment came later, in a relatively minor collision with the system. I had returned home, at 2 a.m., from hospitalizing my child after a particularly harrowing psychotic break. Exhausted, I fell into bed. I was barely asleep when the phone rang. A man was calling from the hospital. He said he was very sorry to inform me that my daughter had eloped. "Eloped," I cried, struggling up from sleep, "What do you mean eloped? My daughter doesn't even have a boyfriend!" No, he explained, what he meant was that she had run away from the hospital. Snap! "Then why don't you say so!" I shouted, "Why in blazes are you using that idiotic word! Why don't you just admit that you let my daughter get out of your locked ward?"

What had finally set me off was my first close encounter with the bland, goofy euphemisms of the "mental health" profession. In that moment, I vowed I would never be stymied, bullied or blind-sided again. If it took the rest of my days, I was going to get to the bottom of this illness. I was going to learn everything I could get my hands on. In that instant of fierce determination, I remember feeling better, more in control of the total chaos around me. I rolled up my sleeves and went to work.

At first, I thought I might have a leg up on the task. A year before my daughter became ill, I had started a Ph.D. program in clinical psychology. I naively assumed that my courses and training would make my job easier. To my dismay I discovered that the psychoanalytic and family-system interpretation of mental illness still held sway, unchallenged. Nevertheless, I waded through the literature, from the classic monographs on schizophrenogenic mothers (mom's the culprit) to the modern psychology of tough-love (throw 'em out, let 'em hit bottom, they'll come to their senses). In the light of my own experience, none of this made a grain of sense.

So, I doubled back and took the same path every other exasperated family member has taken before me. I joined NAMI and a local support group. I talked to other families and poured out my heart. They told me their stories and I began to find many of the missing pieces to the puzzling illness in my own family. Together we unearthed the precious texts of the family movement and, like early Christians, passed them around and

proselytized. I found family member professionals that I could use as models for my own development as a clinician. I toiled with the complexities of brain biochemistry. Gradually I realized I was gaining ground. Glory be! I was getting a substantial, specialized education about mental illness.

But something else was happening that was even more rewarding. I was changing in ways that I could directly relate to this process of learning. I realized I had stopped blaming myself and feeling guilty. I began to express my grief and to gentle myself through the inevitable cycles of hope and disappointment. I started to educate my family and saw us come closer together. I found I could get angry and confront the system that had failed us so badly. I began to trust my own judgment and my own sense of direction. And once all this was happening, once I could no longer be shamed or intimidated, I was able at last to act and to become an advocate for people with brain disorders that cause mental illness.

You bet knowledge is strength! Educating ourselves about mental illness “our way” spells relief. It lightens our load and gives us the stamina to buck the system. It keeps us in touch with each other. This is fundamentally what family education is all about. Every single one of us has made a courageous journey and has something of value to teach. And, every one of us has something new to learn about the expanding frontiers of research, treatment and rehabilitation.

This is why NAMI wants to bring family education to every hamlet in America and why, each year, NAMI-VT will offer a family education course in every affiliate. We want you to be there! There is no better way to take care of yourself and to help the ones you love.