The Impact of Schizophrenia on Families: One Mother’s Point of View

by Mary Jean Willis

Abstract

The practical consequences of deinstitutionalization upon the families of the mentally ill are discussed. Not only is adequate care frequently lacking for the ill family member, but the families of the mentally ill often find themselves alone in their caretaking roles. The growing importance of consumer-advocacy groups may be a harbinger of increasing cooperation among all those concerned with the impact of schizophrenia on both affected individuals and their families.

When my mother-in-law’s youngest son became schizophrenic back in 1941, and was committed at age 18 to a mental institution where he still remains (that is the way it was done in those days), and my mother lost her only son in a training-mission plane collision 6 years later, I thought then (and still do) that of the two tragedies, my mother-in-law’s was the worst. At least my mother felt no guilt about what happened to her son; she could talk about him to her friends with pride, and she knew he was at peace and had died doing what he loved. My mother-in-law, on the other hand, never spoke of her “put-away” son, and in the beginning when friends and relatives asked about him, vague answers were given, and the subject quickly changed. In the end, he was forgotten by all but his closest family members, and became a sort of nonperson, one of the “living dead.” Never did I imagine then that 30 years later my husband and I would hear the same dread word “schizophrenia” applied to our own dearly beloved youngest son.

But things are different now than they were when my young brother-in-law was sent away to live out his days in the dreary confines of a state mental hospital. Now we have “deinstitutionalization,” release of the mentally ill from hospitals as soon as they are stabilized (and sometimes even sooner).

We think that our son was prematurely discharged from hospitals at least twice. At one time he was sent home on a weekend pass from a state hospital. When the family, including our older son, daughter-in-law, and their infant daughter, was gathered together to celebrate his homecoming, he suddenly disappeared into his room where he proceeded to smash a glass and slash at his throat. Another time, when he was hospitalized in San Francisco after throwing himself in front of a car, he refused medication and demanded to be released. The hospital would not keep him against his will, so he was discharged after a few days, whereupon he jumped in front of a truck and was severely injured.

Deinstitutionalization has meant not only early discharge, but also inaccessibility of hospitals. Because our son is suicidal, we have had no difficulty getting him into a hospital. However, I know of a mother who has not been able to gain hospital admission for her son, even though he is violent and a danger to society when he is in his manic phase.

In the 10 years that our son has been a diagnosed paranoid schizo-

Reprint requests should be sent to Ms. M.J. Willis at 980 6th St., Boulder, CO 80302.
schizophrenic, he has been in and out of hospitals, both private and state, in Colorado, Hawaii, and California. He has lived in halfway and three-quarter-way houses, and has been treated by private psychiatrists and mental health therapists. He has made many suicide attempts, and he chewed off part of his tongue in a frenzy when he was strapped down in both a private and a state hospital. He still retains a wry sense of humor and a consideration for others in spite of all the suffering he has gone through. We enjoy his company during the times when medication has stabilized his illness. But the stress we are under during the frequent periods when he is "decompensating" at times becomes almost unendurable.

It is very difficult to cope with our son's manic, irrational, paranoid behavior (with suicide attempts such as sticking a knife into his abdomen, cutting his throat, running in front of cars—all done in our presence). At such times we desperately need professional help in handling these crises—in getting him calmed down, persuading him to take more medication, or go to the hospital. We are fortunate now to be able to turn to his mental health center therapist for assistance, but in the past we did not always receive such help from his private psychiatrists.

When we are forced to manage by ourselves, we try to remain as calm and loving as possible. If our son is not completely out of control, we are sometimes able to persuade him to hike with us in the foothills around our home, or my husband might play pingpong with him, which often seems to have a calming effect. We find it best not to try to argue with him about his paranoid delusions, but to try to keep the conversation (such as it is) on a light and cheerful note. If hospitalization is necessary, we are sometimes able to get him to let us take him to the hospital. At other times, nothing we say has any effect, and then the only alternative is to call the police.

The deep sadness of such a blighted life (a former athlete, senior class president, Boy-of-the-Month, good student, and most important, a happy, loving person) doesn't bear thinking about. We must constantly fight with ourselves not to become bitter, guilt-ridden, and full of self-pity. In the last 2 years I have found a constructive activity which has helped me to deal with this tragedy. When I at last faced the fact that our son might not get better (unless there should be a miraculous breakthrough in attempts to find the cure of schizophrenia), I began to "come out of the closet" and to think about forming a mutual support/advocacy group. I felt that so much needed to be done for the chronic mentally ill that those of us who are the most deeply involved with them—their families—must band together to help them and to help ourselves. It so happened that two therapists from the Boulder County Mental Health Center, Boulder, Colorado, had also been thinking along these same lines. Eventually we got together and organized Families and Friends of the Adult Mentally Ill (FFAMI) for the purpose of helping families cope with mental illness by means of education and support.

At first I was reluctant to come all the way "out of the closet" and have my name appear in the local papers in articles about our group because our son had indicated his displeasure at my being involved in such an activity (he usually will not admit that he is mentally ill). Other members also felt this way, but we finally decided that if FFAMI was going to succeed, it was necessary to publicize it. So we consented to giving interviews, and articles appeared in two newspapers which engendered much interest in our group, and were mainly responsible for a dramatic increase in our membership. No harm was done as far as our son was concerned, since he apparently did not read the articles.

FFAMI is almost 2 years old now and has begun to realize some of its goals. In cooperation with the Mental Health Center, a series of educational lectures is offered twice a year for the benefit of the families. In addition to the lecture series, educational and problem-sharing meetings are held each month. Members of FFAMI, through donations of money, furnishings, and rental houses, have made it possible for the Mental Health Center to set up two residential homes for the chronic mentally ill.

In our problem-sharing get-togethers we find that, although each person's situation is unique, there are many common problems, ranging from those which seem trivial (but which can be difficult to contend with), such as lack of personal care and poor grooming, sleeping and eating too much or not enough, to more serious problems, such as lack of motivation, inability to handle money (patient gives it all away or spends it all on street drugs), refusal to take medication, bizarre behavior, delusional thinking, paranoia, occasional...
violence, and suicide attempts. Another common problem for family members is the feeling of being tied down and not able to live one's own life. Families of a chronically mentally ill person find it difficult to travel or to maintain much of a social life.

Our own social life has become practically nonexistent, not necessarily because our friends have deserted us due to the stigma of mental illness, but because of the unpredictability of our son's illness, and because, after coping with the many problems it causes, we have little energy left over for entertaining.

The financial burden of mental illness is another big problem which families must face. When insurance (if there is any) runs out as it eventually does in most cases, not even well-to-do families can handle the frequent hospitalizations at exorbitant rates (about $200 a day in Boulder), and the many psychiatric sessions at $50 or $60 an hour. Many of the members of our group used private psychiatrists and hospitals in the beginning years of their family member's illness. As the years went on with no real improvement in their family member's condition, these families turned to the Boulder County Mental Health Center for help.

When all the above problems are considered, it can be seen that deinstitutionalization has in some ways made life for the families of the chronic mentally ill more difficult than it was for my mother-in-law back in the days when lifelong hospitalization was the fate of most of the mentally ill. But most of us, I'm sure, would rather that our schizophrenic relatives had a chance to be rehabilitated in their own communities than to be interned for a lifetime in a mental institution. We need, however, all the help we can get in coping with these problems, and the mental health professionals do not always cooperate with us. In fact, they often ignore or oppose us. Two incidents which happened to our family illustrate this uncooperative attitude: Our son was at one time under the care of a private psychiatrist in California who, after treating him for many months, decided that the best medication for him was lithium and fluphenazine. He was doing well on this medication, but suddenly decided to leave California and come home to Boulder. For 6 months he refused to have therapy or take any medication, and during all that time he was in remission. We began to think a miracle had happened, but suddenly, for reasons we do not know, he began to decompensate and was soon in very bad shape. We tried to persuade the doctors to give him the medication he had been doing well on 6 months previously, but they would not listen. It was not until he had spent long periods in three hospitals (private and state), and had mutilated his tongue and lips, that he was finally given lithium and fluphenazine, and gradually improved. The second upsetting incident occurred when I called our son at a halfway house where he had been living, and was told that he had been sent to the psychiatric hospital because he had jumped in front of a car. When I called the hospital, the staff member on duty denied that he was there. Most members of our family group have similar stories to tell.

One mother complains that her daughter's psychiatrist refused to communicate with her and did not even tell her what he thought was wrong with her daughter. Over and over, in our problem-sharing meetings, members reveal their resentment toward the professionals who ignore them, make them feel guilty, and neither give them practical advice on handling the patient nor information about the patient's illness.

Consumer-advocacy groups like FFAMI are spreading across the country. One of their goals is to become a potent force which can command the respect and attention of mental health professionals. All of us who are concerned with the mentally ill must work together to alleviate their great suffering and do what we can to help them "bear the unbearable." I think that the greatest problem I face with our son is not knowing what to say to him when he asks, "Mom, what am I going to do with the rest of my life?"

The Author

Mary Jean Willis is founder and president of Families and Friends of the Adult Mentally Ill, Boulder, Colorado.