

# Families of Schizophrenics: A Movement in Jeopardy

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*The family self-help movement in schizophrenia is in danger of losing its effectiveness, the authors believe. Many in the movement seem overly concerned with being accepted by professionals and others, which means that they become less single-minded in their advocacy for their relatives and for their own needs. Family groups are having difficulty maintaining their separate and unique identity and are including others who tend to undermine their efforts. The family movement in schizophrenia would do well to follow the example of the parents of the developmentally disabled in their unswerving devotion to their cause, which appears to be the key to their success in achieving greatly increased services and funding.*

The family self-help movement is one of the most important developments in the mental health field

in recent decades. It has the potential to be a very powerful force for advocacy for treatment and services for schizophrenics. Families generally do not have ideological axes to grind and are usually not motivated by status and power needs or personal financial gain. Having carried a very heavy burden for many years, they only want adequate and effective help for their relatives and for the chronic mentally ill generally.

Families of schizophrenics have long been blamed for their relative's illness. The psychogenic theories of the causation of schizophrenia have been largely responsible, for it has long been held that mental illness of all types is the result of bad parenting and childhood trauma. Until recently mental health professionals have not questioned this causality, and they have treated families, and in particular parents, as persons who caused the illness (1). Thus families have been blamed, ignored, and treated with disrespect.

Now families have formed local and national self-help and advocacy organizations. They have devel-

oped a new self-concept and have become a force to be reckoned with (2,3). Moreover, families of persons with manic-depressive illness, another major mental disorder, have many of the same problems as families of schizophrenics and are an important part of the family advocacy movement. Many professionals have come to see families from a new perspective and have begun to treat both patients and families with a new sensitivity. It is the thesis of this paper that these gains are in danger of slipping away.

It should be emphasized that when we refer to relatives, professionals, patients, and former patients in the following discussion, we are by no means referring to all of them. But we are concerned about trends we have observed among many family groups, trends that work to the detriment of the mentally ill and their relatives.

## **The dangers of being accepted**

Parents of schizophrenics have felt disliked and disapproved of for so long that when they are shown some kindness and respect, many of them tend to lose their perspective. They become distracted from their main goals of improving treatment and services for the chronic mentally ill. Parents have been put on boards of directors or advisory boards of mental health organizations, have been asked to contribute chapters to books, and have been invited to speak at professional meetings. At last they feel some acceptance. It is all the more important to them since they have often felt very isolated from people for a long time, as happens

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when one has a mentally ill child. Under these circumstances it is understandable that many parents lose sight of the fact that some of the very persons and organizations that are embracing them have been, and continue to be, obstacles to the provision of adequate and appropriate services to their schizophrenic relatives.

If families are steadfast and militant in their advocacy, professionals and groups who have different agendas may not like their activities; families will be "liked" only if they lessen their advocacy for services for schizophrenics and follow the other agendas. Families are frequently given plaques and awards for their efforts on behalf of the mentally ill. In the glow of this seeming acceptance, their militancy frequently subsides, and they become less aware of when they are being manipulated. They would do well to refuse the plaques and demand better treatment for their schizophrenic relatives instead.

Families must be single-minded in their advocacy for their schizophrenic relatives. They should learn from the parents of the developmentally disabled, who are militant and unswerving—and very successful—in their efforts to improve the lot of the developmentally disabled. Parents of schizophrenics are often persuaded that they should champion other causes both in and out of mental health. "You must not be selfish by focusing only on schizophrenics," they are told. The parents of the developmentally disabled are not distracted from their goals. They advocate and work almost exclusively for their own objectives, and they cannot be dissuaded from this course. The result has been a proliferation of services and increased funding for the developmentally disabled.

Now that families of schizophrenics have gained some recognition and acceptance, many say, in effect, "We do not want to be adversaries to the system. We want to be liked. You catch more flies with honey than with vinegar."

Not so the families of the developmentally disabled. They may at times use honey, but those who stand in their way usually come to experience the force of their determination and dedication.

### **Reluctance to be steadfast**

Why are families of schizophrenics often reluctant to take such a firm approach? One can only speculate, but several factors seem to contribute. First of all, families feel guilty because they think they have caused the illness, which makes some hesitant to be assertive. Then there is the shame and stigma of schizophrenia; families may fear that as they become more visible in the community, the nature of their relative's illness will also become public knowledge, which will label and upset the mentally ill family member.

Families may also wish to deny that their relative has a schizophrenic illness. Parents of the developmentally disabled know about their child's illness early in life, and they get angry and fight for their cause right from the beginning. Schizophrenia is usually not identified until adolescence, often after a seemingly normal childhood that was gratifying for the parents. Only then must the parents come to terms, over time, with the fact that their child has a lifelong disability. The parents of schizophrenics hope for change for the better; often when the patient goes into remission, the parents want to believe that the illness has been cured. They may at this point leave the family organization and return only when their child again becomes symptomatic.

Still another factor is that the course of schizophrenia can be highly unstable. Families may be too drained from attempting to cope with the illness, not to mention earning a living and taking care of the rest of the family, to mount a sustained, assertive advocacy effort. Developmental disabilities have a more stable course, and the lack of a "cure" motivates the parents to stand firm in their advocacy for services for their off-

spring. Moreover, the developmentally disabled probably will remain in the same day care centers or sheltered workshops or residential placements for many years, enabling the parents to come to know each other, organize, and become militant advocates from early on.

The parents of the developmentally disabled are highly organized. Organizations of the families of schizophrenics, after their initial enthusiasm, frequently question the need for structure. "People are listening to us. Why do we need to follow Robert's Rules of Order in our meetings, and why do we need bylaws and all this defining of who does what?" When this stage sets in, the effectiveness of the family movement is greatly diminished.

Families basking in the glow of their new status in the mental health establishment must not forget that a sizable proportion of mental health professionals have little interest in treating the chronic mentally ill and experience the treatment of schizophrenia as an unrewarding, frustrating experience that offers little hope for a positive outcome (4). Instead, many of these professionals may want to use public mental health funds to treat the healthy but unhappy, to do "insight" therapy with people who have neuroses and character disorders, to attempt to combat poverty and cure other ills of society, and to focus on problems in the schools. Families of schizophrenics, on the other hand, are the champions of the chronic mentally ill and are the leading advocates for making the treatment of chronic schizophrenia the foremost priority of public mental health.

Thus these families are an obstacle to funding for causes favored by many mental health professionals. Mental health professionals may accept families as partners in these causes, but the families often begin to feel that they are being narrow and selfish if they insist that services for schizophrenics be the primary public mental health task.

Families have gained a vast

amount of insight through their support organizations. They have learned a great deal from attending conferences. However, in many ways they have not made much progress in dealing with professionals. The highest priority of families of schizophrenics is to be listened to by professionals and by society and to have a significant impact in terms of changes in the system.

### **The need for a clear, separate identity**

People still tend to retreat from the use of the word schizophrenia just as they once were reluctant to use the word cancer. Organizations of families of schizophrenics need to say clearly who they are. The names of their organizations should contain the word schizophrenia, as in Families of Schizophrenics. (In Britain the families' organization is called the Schizophrenia Fellowship.) Families need to proclaim their identity, not hide it. Moreover, schizophrenia (and manic-depressive illness as well) must be recognized as a disease, not as problems in living or as an alternative life-style that people choose. Schizophrenia is a disease that needs to receive society's attention and resources.

An invaluable lesson can be learned from the history of an organization named the Research in Schizophrenia Endowment, or RISE, founded in 1958 (5). RISE's stated objectives were "to stimulate and support research, training, public education, interchange of knowledge, and funding for schizophrenia and to work in close ethical conjunction with the American Psychiatric Association and other involved organizations." The founders' rationale was enlightened: "The term 'mental illness' is a relatively disarming label which conceals some of the most vicious wreckers of human life. Of those scourges, the greatest is schizophrenia, seldom designated by name outside of scientific circles because it is too harsh for the ear, and too embarrassing for the mind."

RISE was extremely persuasive with Congress. In 1958 it succeeded in bringing about the first federal appropriation specifically for research in schizophrenia, in the amount of \$1,300,000 (5). In 1959 RISE was responsible for Congress' directing that half of the National Institute of Mental Health's total research funds be used for projects relating to schizophrenia.

By the end of 1959 it was clear that RISE was accomplishing its mission of focusing greater professional, federal, and public attention on the multiple problems of schizophrenia (5). The National Association for Mental Health (NAMH) was at that time the largest citizens' agency of its kind, and RISE was gradually persuaded to join forces with it to reduce competition and needless duplication of effort and present a more powerful united stand, with the proviso that schizophrenia would continue to receive special prominence. In 1960 RISE relinquished its corporate charter and became a support committee and an integral part of the Research Foundation of NAMH.

It is history that NAMH's emphasis on schizophrenia was soon diminished, displaced by other, more glamorous mental health causes. Clearly RISE should have retained its independence and its separate identity as an organization dedicated to promoting interest and research in schizophrenia. One can only speculate how much more we would know today about the causes and treatment of schizophrenia had RISE survived.

### **What families need**

It is important that families see that they must be advocates for themselves as well as for their schizophrenic relatives. What do families need, and have a right to receive, for themselves? They need to be part of the decision-making process, both about public policy issues affecting services for schizophrenics and about individual treatment plans for their own relatives. They need access to ade-

quate and appropriate help in crises. They need information about available resources and how to use them. They need access to respite care that allows them to take a vacation from the hard work of coping with a schizophrenic.

Families need to be seen as people who have valuable ideas and knowledge. Many mental health professionals give lip service to the importance of families and their organizations. However, often this attitude does not seem to have filtered down to their actual clinical work with schizophrenic patients. Clinicians often discount families' histories of the patient's illness and of what approaches and treatment have worked in the past.

Families need, and should expect, helpful advice from professionals on the practical management of schizophrenia. All too often families must learn by the painful process of trial and error what they should have been told early on by professionals. For example, professionals should tell families what is known about schizophrenia, making it clear that there are no scientific data to suggest that schizophrenia is caused by childhood upbringing or family interactions, and that almost certainly a biochemical imbalance is involved. Professionals must emphasize the importance of psychoactive medications and explain their side effects. Professionals need to help families have realistic goals. Professionals need to encourage families to set limits on inappropriate behaviors of their schizophrenic relatives.

Professionals also need to help families see that "independence" may not be a realistic goal for many schizophrenics and that it is appropriate to meet their relative's dependency needs, which may mean that the schizophrenic needs to live with family or in a protected residential setting. Professionals should help both patient and family see that the schizophrenic's need for distance relates to survival and does not necessarily constitute rejection of the family (6).

### **Who should belong to family organizations?**

Should membership in family groups be limited to parents, siblings, and spouses? Should others such as mental health professionals and former patients be excluded? (Obviously professionals and former patients who have schizophrenic relatives are not in question here.)

Family members share the same experiences and the same frustrations, and there is a bond between them that others do not share. We have already seen how some professionals may want to divert family members from their main goal of advocacy for services for schizophrenics. Even if professionals share the goals of families, they do not share their experiences, and we believe it is inappropriate to include them as members. Professionals can still, of course, be called on for consultation and assistance as needed.

The question of whether patients and former patients should join family organizations has been raised with increasing frequency and has engendered much controversy. Some say that it is undemocratic and untrue to the ideals of the family movement to exclude them. Most patients and former patients are not antipsychiatric and are not out to dismantle the mental health system. However, many of the more vocal patients and former patients who want to join family organizations have different goals than families.

For instance, a minority of militant patients and former patients often appear to wish to destroy the mental health system, not to improve it and make it more responsive to the needs of schizophrenics, as families typically do. This militant minority may often have different goals regarding "freedom" as well. Families want their relatives to have as much freedom as they can handle but, through hard experience, have learned that often the schizophrenic does not have the capacity to handle total freedom. Activist patients and former patients believe that no one's

freedom should be limited because of mental illness. Thus they try to neutralize parents' attempts to obtain more and better services and to reform the commitment laws. Moreover, many of these former patients are aggressive and guilt-provoking, and they attempt to dominate any meeting that they attend.

It is very difficult for family members to deal with the problems presented by former patients. Parents, in particular, tend to see former patients as extensions of their own children and thus hesitate to speak out; they do not want to hurt these young people who have suffered from mental illness. They find it very difficult to assert themselves with former patients who say that they also are only trying to better the lot of the mentally ill.

Thus former patients who are members of family organizations weaken and at times immobilize these organizations. Further, we believe it is even more inappropriate for patients and former patients to be placed on the boards of family organizations (unless they are also relatives of schizophrenics), and particularly inappropriate for board positions to be specifically designated for them. Organizations of former patients understand this principle well; they will not allow parents on their boards.

### **Involuntary treatment**

Through hard and painful experience families have learned that the commitment laws as they stand today are too narrow. They make it very difficult for acutely ill schizophrenics in crisis to receive emergency treatment if they will not accept treatment voluntarily. Fully as important as the laws governing emergency involuntary commitment is the need for and therapeutic potential of ongoing involuntary treatment, such as conservatorship and outpatient commitment (7,8). Frequently schizophrenics, because of their illness, are not competent to make a decision about treatment. In the states of Alaska and Washington, parents

have taken the lead in changing the laws to make involuntary treatment easier to obtain (9).

The issue of involuntary treatment, both emergency and ongoing, illustrates the pressures on families to *not* do what they know to be necessary for their schizophrenic relatives. These pressures come from patients' rights groups, from former-patient groups, and from some mental health professionals. Members of these groups ask, "How can you take away an individual's freedom just because someone has labeled him schizophrenic?" "Are you against civil rights?" "Are you reactionaries?" Not only do these accusations make families feel guilty, but the families also may fear that they will lose the acceptance they believe they have finally achieved.

### **In conclusion**

Is the family movement in danger of losing its effectiveness? It seems to us that it is, and that the following questions need to be posed. Can family organizations be single-minded in their advocacy for their schizophrenic relatives and for their own needs even if it means relinquishing some of the "acceptance" from professionals and others that they have yearned for so long? Can they maintain their separate identities and not let themselves be co-opted by groups, such as professionals and former patients with other agendas? Can they say who they are? For instance, can they use the word schizophrenia when referring to their organization and their concerns?

Can family organizations be advocates for themselves and their own needs as well as for their schizophrenic relatives? Can they limit their organizations to family members and exclude those who would become a fifth column in their midst? The future of the family self-help movement depends on the answers to these questions.

We have learned that schizophrenia tends to become lost in the competition for public funding unless there is organized and assertive advocacy by a large, active

constituency devoted solely to schizophrenia. Who can and will fulfill this role if not the families of schizophrenics and their organizations? Who else will fight for adequate funding of research on schizophrenia, and for funds to provide what is grossly lacking nationwide in our mental health service system for schizophrenics?

To quote a strong advocate for schizophrenics, "The mad will be liberated only when those fortunate enough to have escaped the illness become mad as well" (10). If family organizations become indistinguishable from mental health associations, with their multiplicity of causes, then not only has the family movement lost its way, but,

of even greater concern, the families' mentally ill relatives have been put in jeopardy.

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## Psychotropic Prescribing Patterns of Nonpsychiatric Residents in a General Hospital in 1973 and 1982

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*The findings of a study of the frequency and type of psychotropic drugs that nonpsychiatric residents prescribed for nonpsychiatric patients in a teaching hospital in 1982 were compared with the findings of a similar study in the same hospital nine years earlier. The overall per-*

*centage of patients receiving psychotropic drugs remained almost the same, at less than 10 percent. However, in 1982 residents prescribed antidepressants almost four times as often as in 1973, and the use of antianxiety agents decreased. Deficiencies in chart documentation of psychotropic prescribing and the tendency to use conservative dosages remained unchanged from the earlier study.*

Psychiatric morbidity, which may be as high as 15 percent to 23 percent in the general population

(1,2), is estimated to be even more prevalent in general medical settings. Surveys have found up to 83 percent of patients in such settings to be impaired (3-7). As a result, the ability to use psychotropic medication has come to be an important skill for all physicians regardless of specialty. While these drugs are generally associated with the practice of psychiatry, the fact that the majority of psychotropic prescriptions are actually written by nonpsychiatrists (8-10) indicates that the latter group's prescribing practices may have the more important public health implications.

The purpose of the study reported here was to examine how these practices have changed with time. We repeated after an interval of nine years a survey of psychotropic drug use for nonpsychiatric inpatients that was initially conducted by Davidson and associates (11) at our teaching hospital in 1973. To

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