

**CLINICAL BIAS TOWARD FAMILIES WITH SCHIZOPHRENIC RELATIVES :
IMPLICATIONS FOR THE LONG-TERM CARE OF
THE CHRONIC SCHIZOPHRENIC PATIENT**

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DANIEL J. BURBACH

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Abstract

The deinstitutionalization movement has necessitated that many families become the primary caretakers for their chronic schizophrenic relatives. These families are often not equipped to care for the needs of their chronic schizophrenic relatives and their own needs simultaneously. Consequently, the quality of life experienced by care-giving families and their chronic schizophrenic relatives is frequently diminished.

Rather than providing support and services to care-giving families, however, this study demonstrates that many mental health professionals instead, blame families (especially parents) for causing schizophrenia. Even more mental health professionals express negative or ambivalent attitudes toward families with schizophrenic relatives. Certain theoretical orientations, etiological assumptions, treatment strategies, and demographic factors are shown to be particularly associated with these negative and ambivalent attitudes.

Until scapegoating, criticizing, and character pegging of families with schizophrenic relatives ceases, it is unlikely that the mental health profession will be of any real benefit to the majority of care-giving families. It is proposed that an alliance between mental health professionals and care-giving families be immediately established and maximized—for the sake of both the care-giving family and the chronic schizophrenic patient.

Clinical Bias Toward Families with Schizophrenic Relatives: Implications for the Long-term Care of the Chronic Schizophrenic Patient

The Impact of Deinstitutionalization

Since the movement to deinstitutionalize chronic psychiatric patients was initiated almost three decades ago, families have found it increasingly necessary to assume the role of primary caretaker for their chronic schizophrenic relatives (American Psychiatric Association, 1979; Bassuk and Gerson, 1978; Klerman, 1977). It is estimated that between 54-70% of all deinstitutionalized chronic psychiatric patients—most of whom are chronic schizophrenic patients—return to the homes of their families for long-term primary care following hospital discharge (Bernheim, Lewine, and Beale, 1982; Hilton, 1979; Carpenter, 1978; Hatfield, 1978). Even when the discharged psychiatric patient lives outside the family home, it is not uncommon for the patient's family to still perform a major caretaking function in the daily life of their mentally ill relative (Bernheim, Lewine, and Beale, 1982).

While most mental health professionals report that they are indeed aware of the importance of care-giving families in the long-term care of the chronic schizophrenic patient (American Psychiatric Association, 1979; Serban, 1979), recent evidence suggests that a majority of these care-giving families believe they have not received the professional support or services necessary for effective primary caretaking for their schizophrenic kin (Holden and Lewine, 1979; Hatfield, 1978; Creer and Wing, 1975).

Recent evidence also indicates that most care-giving families believe that their own needs—especially those needs that arise as a direct

result of caring for a chronic schizophrenic relative—are often neglected by mental health professionals as well (Hatfield, 1979). Unfortunately, studies which have revealed the needs of care-giving families (Holden and Lewinc, 1979; Hatfield, 1978; Kraus, 1976; Creer and Wing, 1975; Grad and Sainsbury, 1968; Yarrow, Schwartz, Murphy, and Deasy, 1955) have had little impact upon the actual practices or current policy formation of mental health professionals (Kint, 1977).

Interestingly enough, mental health services have not appreciably lacked for families caring for relatives suffering from other types of chronic disorders (e.g., epilepsy, cancer, Down's Syndrome, etc.) (Cantoni, 1975). For example, numerous studies have depicted the impact of a Down's Syndrome relative upon the family unit (Robinson, 1974; Mandelbaum, 1967). As a result of these studies, families with Down's Syndrome relatives now enjoy a wide variety of mental health services (Cantoni, 1975).

But schizophrenia is different from most other chronic disorders in that it has not yet been confidently linked to an organic or genetic anomaly. When individuals suffer from what are considered to be "medical model disorders", adequate support and services almost always are provided to patients and their families (Siegler and Osmond, 1974).

In fact, it is the absence of an agreed upon organic or genetic anomaly in schizophrenia that has prompted some professionals to regard schizophrenic illness as a "myth" (Szasz, 1976) or merely a "label for socially unacceptable behavior" (Scheff, 1975). Polemics such as these do little to ease the burden of chronic schizophrenic patients and their families.

Family Theories

The absence of an identifiable organic or genetic anomaly in schizophrenia has furthermore, contributed to the rapid proliferation and acceptance of what is generically referred to as family or systems theory. All family theories share the common thesis that some condition of family life, especially certain forms of interaction among family members, can predispose an individual toward schizophrenic illness. Evolving out of this legacy of clinical theory has been the following diagnostic, character-pegging descriptions of families with schizophrenic relatives:

1. The schismatic family—"The schismatic family is characterized by continuing overt conflict between the spouses with each undercutting the worth of the other to the children . . . The mother not only has little self-esteem as a woman and is insecure as a mother, but her position as a wife is constantly undermined by her husband's contempt and derogation of her . . . Like Harlow's monkeys who had been raised by "wire mechanical mothers" (Harlow, 1958) and later rejected their babies when they became mothers, these women who had been deprived of maternal affection could not mother their babies" (Lidz, 1973, pgs. 43-44).
2. The skewed family—"In the skewed family, the attention is apt to fall upon the mother . . . who is imperious to the needs of other family members as separate individuals and is extremely intrusive into her child's life . . . The father in these families is apt to be a passive man who is unduly deferential to his wife's strange ways, behaving more as an adjunct to his seriously disturbed wife or as a son rather than a husband . . ." (Lidz, 1973, pgs. 31-32).
3. Symbiotic relationships—are characterized by pathologically strong attachments between parents and their child, which inhibits the child from differentiating a self-identity (Summers and Walsh, 1977).
4. Eroticized parent-child relationships—are relationships in which the parents fail to preserve appropriate age and sex boundaries between themselves and their child. In this situation, a parent turns to the child rather than the spouse to gratify emotional needs, or

the parent requires the child to perform a parenting role (Walsh, 1979).

5. The double-bind—is a condition produced by parents when they convey contradictory messages at different levels of communication to the child (Wynne and Singer, 1963; Wynne, Singer, Bartko, and Tookey, 1977).

When a child is placed in a "double-bind" predicament, it becomes impossible for the child to respond in a way the child believes will please the parents—so the child chooses to withdraw (Bateson, Jackson, Haley, and Weakland, 1956).

6. Failure to acknowledge—is the belief that parents cause schizophrenia in their children by not confirming their own or their child's psychological integrity (Lidz, Fleck, and Cornelison, 1965; Herman and Jones, 1976; Wild, Shapiro, and Deblin, 1977).

7. The schizophrenogenic mother—is a mother who is thought to cause schizophrenia in her child through her dominance, aloofness, emotional overinvolvement, and the pathological use of her child to fulfill frustrated desires (Fromm-Reichman, 1948).

8. The identified parent—refers to the schizophrenic child who developed the schizophrenic disorder because of attempts to save the parents' marriage by drawing off marital conflict (Lidz, Fleck, and Cornelison, 1965; Lidz, 1980).

The clinical lexicon used to describe families (especially parents) with schizophrenic relatives contains—as the previous characterizations of parents has illustrated—a number of extremely negative generalizations. But more importantly, these characterizations of parents imply that such familial variables as "symbiotic relationships", "double-binding", and "schizophrenogenic mothers" act as specific causes of schizophrenia.

Empirical Tests of Family Theories

Family theorists have traditionally focused upon four areas of family interaction: dominance, conflict, affect, and communication. A number of direct observational studies covering these four areas of family dynamics have been undertaken to determine if in fact, there is any etiological significance to "family pathology" theories. (For a more comprehensive description and review of family studies, see Liem, 1980; Goldstein and Rodnick, 1975; Jacob, 1975).

Dominance

The concept of "schizophrenogenic mother" articulated by Fromm Reichman (1948) and the identification of "schismatic" and "skewed" family structures by Lidz et al. (1957), interested some researchers in patterns of marital and/or parental dominance in families with schizophrenic relatives versus control families.

The basic hypothesis examined in dominance studies is that there may be either insufficient parental authority, or sex-role reversals among mothers and fathers in families with a schizophrenic child. Dominance in the family unit is most frequently measured by: 1) verbal activity counts (talking time, successful verbal interruptions, and statement length), or 2) observational judgments regarding the "yielding" or "accepting" frequency between members of a family.

The results of these dominance studies have been inconsistent at best. Some studies report that excessive maternal dominance characterizes families with schizophrenic offspring (Herman and Jones, 1976). Other studies report that excessive father dominance is typical of families with a schizophrenic child (Doane, 1978; Wild, Shapiro, and Goldenburg,

1975; Mishler and Waxler, 1968).

In conclusion, indices of dominance measurement have not allowed for any steadfast conclusions to be formulated regarding dominance hierarchies in families with a schizophrenic relative. The usefulness of the dominance concept in etiological theories therefore, should be seriously questioned at this point in time.

Conflict

Conflict is assessed with methods similar to those used to measure dominance. These are: 1) verbal activity ratings (interruptions and simultaneous speech), and 2) observational judgments of "agreement", "disagreement", and "overall conflict" between family members.

Most empirical studies concerned with conflict as an etiological factor were conducted prior to 1975. In these studies, no statistical differences in the amount of absolute conflict were convincingly found when families with schizophrenic offspring were compared to normal control families.

Friedman and Friedman (1970) for example, suggested that families with schizophrenic relatives exhibited more verbal rated conflict than normal control families. Studies done by Cheek (1964a, 1964b, and 1965) however, revealed that families with schizophrenic relatives produced less verbal rated conflict than normal control families.

Whether or not there is more conflict in families with schizophrenic relatives versus normal control families is unknown. The contribution of conflict to the etiology of schizophrenia also remains unclear.

Affect

Three dimensions of affect are usually measured during the course of an affect study. These are: 1) positive affect, 2) negative affect, and 3) affect intensity. Typically, raters judge family subjects along these three affect dimensions from recordings or transcripts made of the family unit interacting in a laboratory setting.

Mishler and Waxler's (1968) study of affect utilized one of the most sophisticated methodological designs of any affect study done to date. Their most interesting finding was that normal control families exhibited more tension release, laughter, and indirect positive affect than families with a schizophrenic relative.

In summary, the results of methodologically sound affect studies suggest that there may be some differences in affect expression between families with schizophrenic relatives versus normal control families. Yet there is no evidence to suggest that certain amounts or qualities of affect are in any way pathological or schizophrenia producing.

Communication

Research on family communication patterns is much more abundant than the research conducted in the other three spheres of family interaction. The research designs used in communication studies are also usually better suited to test the etiological assumptions professed by family theorists.

Communication theories have their historical origins in the work of Bateson, Jackson, Haley, and Weakland (1956). Bateson and his colleagues were the first to suggest that deviant parental communication styles could cause schizophrenia. These deviant communication styles

involve amorphous (meaning vague, indefinite, and loose) and fragmented (meaning easily disrupted, poorly integrated, and lacking closure) speech patterns.

While communication theories are frequently characterized as "transactional", (emphasizing the reciprocal nature of parent-child interaction), almost all communication studies selectively focus on the uni-directional effects of parental communication upon children.

Although measures, methodologies, and conditions differ across studies, most communication researchers report a poorer clarity of communication in families with a schizophrenic relative as opposed to normal control families (Wynne et al., 1977; Lieber, 1977; Glasser, 1976; Mishler and Waxler, 1968; Haley, 1968).

There have however, been a few communication studies which have failed to support this conclusion (Hirsh and Leff, 1975; Cheek, 1964a, 1964b, 1965). Yet most communication researchers tend to accept the notion that families with schizophrenic relatives engage in more deviant communication than normal control families. Furthermore, a majority of family theorists also consider deviant parental communication a prime causal factor in the ontogenesis of schizophrenia.

Family Theories: Facts or Artifacts?

Regardless of the often intuitive appeal of family theories, there are often countless methodological flaws in the design and implementation of family studies—the empirical foundation of family theories. An examination of these methodological flaws is therefore in order.

Reiss (1976), in his succinct articulation of the methodological requirements family theorists must satisfy before any causal relationships

can be established between family variables and the etiology of schizophrenia, has pointed out that:

"First, the hypothesized variables must be clearly defined and measured by reliable and objective methods. Second, the causal role of the variable must be assessed by demonstrating that it 1) is specifically linked with schizophrenia as opposed to other conditions and states, 2) has impact upon the individual before the onset of schizophrenia, and 3) is not confounded with a covarying or concomitant variable that is the "true" etiologic variable."
(Reiss, 1976, p. 181).

The criteria formulated by Reiss (1976, 1980) has not been satisfied by any family study done to date. For example, family studies are usually cross-sectional in design. The major problem with the cross-sectional design in this instance is that data regarding families with schizophrenic relatives is accumulated only after, rather than before a particular patient has been diagnosed schizophrenic. Any theories regarding the etiology of schizophrenia based upon cross-sectional studies are therefore, only inferred from retrospective data.

An "etiological assumption" (Fontana, 1966) inferred from retrospective data is obviously empirically suspect. Jenkins (1974) has demonstrated for example, that many people will report significant life events either very selectively or not at all as little as six months after the occurrence of that event. It has also been shown that a family's perception of "objective reality" can become distorted when one of the members of that family becomes mentally ill (Mednick and McNeil, 1968; Yarrow, 1955).

Family studies are also frequently correlational in design. The problem with correlational designs is that a cause cannot be inferred from a correlation. Even if more deviance is correlated with families

containing a schizophrenic relative, this does not prove that it was that specific deviance which caused the schizophrenia in the first place. In fact, it is just as plausible to assume that the familial deviance is manifested in reaction to, rather than the cause of the relative's schizophrenia.

Another flaw in the mechanics of family studies is that the sample size tends to be rather small. Some of the most respected and famous family studies have utilized 5 or fewer families (e.g., Goldstein, Gould, Alkire, Rodnick, and Judd, 1970; Morris and Wynne, 1965).

Sample bias is also prevalent in family studies. Researchers commonly opt for families with male schizophrenic patients, although some researchers such as Laing (1971) have based complete studies on female patients. Sample bias such as this will inevitably make important sex differences difficult or even impossible to detect—especially those sex differences that are of etiological significance.

Family theorists have also failed to prove that such pathological patterns of family interaction as "skewed family", "schismatic family", "double-bind", etc. are specifically associated with parents of schizophrenic children. Parents of children suffering from disorders other than schizophrenia have been shown to also match the character-pegging descriptions specifically applied to parents of schizophrenic patients (Goldstein and Rodnick, 1975).

A somewhat related criticism of family theories is that it has never been shown that parental/familial deviance is a necessary and sufficient etiological explanation. Basically, this means that there are many families with a schizophrenic relative who do not exhibit the aforementioned deviances; and there are even more families who do exhibit the

deviances described by family theorists, and yet these families contain no schizophrenic relatives.

Family theorists also commonly succumb to what can be regarded as a temporal temptation. Because a parental/familial deviance is noted to precede the onset of the relative's schizophrenia, family theorists often incorrectly conclude that this deviance was somehow instrumental in the etiology of the schizophrenia. Lidz (1980) states for example:

"A great deal of the family life had been distorted in each of these families from before the patient was born and persisted through the time the patient was hospitalized in adolescence or early adult life."
(Lidz, 1980, p. 47)

Despite Lidz's contention, the fact remains that most parents of schizophrenic children usually raise other children who exhibit no traces of schizophrenic disorder. Lidz's thesis fails to account for this fact.

It is also assumed by family theorists (as well as psychodynamic theorists) that certain early childhood experiences are tantamount to later psychological adjustment. There is however, no evidence to support this notion. In fact, numerous developmental psychologists (Clark, 1977) have begun to question the importance of early experience in the psychological health of later life.

And finally, despite the vast amount of clinical research devoted to family theory, these theories have not suggested a successful route of therapy for schizophrenic patients or their families (Beels, 1980; Massie and Beels, 1972). Therapists who do utilize family therapies based upon traditional family theories moreover, often have:

". . . an unavoidable tendency to identify with the patient, for him (the therapist) to find a

scapegoat for all the misery. In the psychotherapist's irrational emotions, the parents often become those scapegoats . . ."
(Bleuler, 1978, p. 135)

Needs and Problems of Care-giving Families

If the needs of care-giving families are to be met by the mental health profession rather than non-traditional mental health channels (Gartner and Riessman, 1980), this scapegoating of families must cease. Practical attempts to improve and maximize a relationship with care-giving families must also be initiated.

One way mental health professionals can begin to improve the relationship with care-giving families is to identify what it is about schizophrenia that makes life difficult for care-giving families on a daily basis. Griffin and Lewine (1980) have articulated three reasons for such an identification:

- 1) In targeting problems that are common across families, strategies that can be used in coping with problem behaviors may be developed,

- 2) Other researchers may be encouraged to investigate in more detail the impact of chronically mentally ill relatives upon their families,

- 3) In presenting the families' problems, mental health professionals might be encouraged to reevaluate their beliefs and attitudes about families who have a schizophrenic relative, and especially parents who have a schizophrenic child.

As was stated earlier, there have been several studies on the needs and problems of care-giving families. Seven of these studies will be examined here. Four of these studies utilized direct interview techniques, while the remaining three utilized survey methods.

Interviews

Yarrow, Schwartz, Murphy, and Desev (1955). Yarrow et al. interviewed 33 wives whose husbands were psychiatric patients. The purpose of the Yarrow et al. study was to analyze the cognitive and emotional problems encountered by wives while they attempted to cope with the mental illness of their husbands.

The results of the Yarrow team's study indicated that physical complaints/worries, behavioral deviations from routine, nervousness, irritability, strange or bizarre thoughts, delusions, hallucinations, and strange behavior manifested by the husbands were considered by the wives to be the most significant household problems.

Grad and Sainsbury (1968). Grad and Sainsbury compared the impact of hospital versus community care upon families with a mentally ill relative. One of the most significant findings was that over one-half of all respondents reported that their own mental health was effected by their relative's psychiatric disorder. Most of the care-giving families attributed the symptoms of their mental health disturbance to "worry about the patient". Many other families believed that their insomnia, headaches, excessive irritability, and depression were also due to concern over the relative's psychiatric condition.

Thirty-two percent of the care-giving families reported that their social and leisure activities were restricted by care-giving responsibilities. Domestic routine (e.g., housework, shopping, cleaning, etc.) disturbances were also noted by 29% of the care-giving families. Twenty-five percent of the care-giving families suffered an income reduction of 10%—while another 10% of the families endured a 50% reduction in income. The reduction in income was attributed to the loss of work hours—hours

which had to be spent with the mentally ill relative instead.

More specific problems of the mentally ill patient which made life difficult for the care-giving families included: aggression, delusions, hallucinations, confusion, and the inability of patients to care for their own needs. The least frequently cited problems were dangerous and embarrassing behavior, and behavior conspicuous enough to provoke comments from neighbors.

Pringle (1973). Pringle assembled an interview/personal experience study of the needs and problems of care-giving families. Pringle's work depicted the everyday lives of families who care for schizophrenic relatives. Erratic mood swings and unpredictable behavior were the problems described by Pringle as being most burdensome to care-giving families.

Creer and Wing (1975). The most recent interview study was conducted by Creer and Wing. The three-fold purpose of Creer and Wing's study was: 1) to describe the impact of schizophrenia upon the relatives of the patient, 2) to determine the problematic behaviors of the schizophrenic relative, and 3) to assess how families cope with those problems.

The results of Creer and Wing's study indicated that social withdrawal and closely related autistic type behaviors were most bothersome to family members. The most common problems confronted by care-giving families were the schizophrenic relative's lack of interaction, slowness/lethargy, lack of conversation, lack of leisure interests, and self-neglect. Care-giving families also found socially embarrassing behaviors of their mentally ill relative to be extremely discomforting. These behaviors included: restlessness, odd ideas, hallucinations, irrational fears, and laughing or talking to oneself.

A summary of the four previously described interview studies

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Insert Table 1 about here
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is presented in Table 1. In the next section, data obtained from the survey studies will be explored.

Surveys

Kraus (1976). A six item questionnaire was devised by Kraus and sent to 276 families who care for chronically mentally ill relatives. Forty-nine of the care-giving families responded. The majority of the respondents were parents or widowed mothers of a mentally ill child.

The most common complaints of these respondents regarded insufficient counseling from mental health professionals in the following areas: 1) their relative's psychiatric diagnosis, 2) their relative's prognosis, 3) their relative's progress, 4) their relative's therapy, and 5) the social implications of their relative's psychiatric illness. These families also charged that mental health professionals gave faulty diagnoses, were frequently ignorant of domestic conditions, and were callous in discharging or readmitting patients.

Less specific problems cited by care-giving families included various types of antisocial or asocial behavior of their mentally ill child and its effect upon their family's social relationships with friends and neighbors. Kraus suggested that a national organization dedicated to the support of families with chronically mentally ill relatives be created.

Hatfield (1978). In Hatfield's study, a questionnaire containing 250 questions was mailed to members of the Schizophrenia Association of Greater Washington. Eighty-nine of the 107 returned surveys were suitable for analysis. Eighty-five percent of the respondents were parents of a schizophrenic patient, while the remaining 15 percent were comprised of siblings, spouses, and other close relatives of a schizophrenic patient.

More than 50 percent of the respondents found the primary symptoms of schizophrenia the most difficult to bear. These symptoms included: hearing voices, nonsensical verbalizations, emotional lability, outbursts of anger, and unjustified suspicions.

Holden and Lewine (1979). Holden and Lewine's comprehensive survey of 203 families uncovered problems similar to those found by Hatfield. Aggression, irrational beliefs, unpredictability of behavior, and social inappropriateness were the problems described by care-giving families as being the most frequently occurring disturbances.

The results of these three surveys are summarized in Table 2.

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Insert Table 2 about here
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It is interesting to note that both interview and survey studies of care-giving families uncovered similar needs and problem areas. Two particularly good reviews of this literature presented by Griffin and Lewine (1980), and Kriesman and Joy (1974) also offer many interesting quotes from care-giving family members which provides even more insight into the plight of those who care for chronic schizophrenic relatives on a daily basis.

Care-giving Families Assess the
Mental Health Profession

Studies which have disclosed care-giving families' assessments of the mental health profession all reveal a mounting criticism of both mental health professionals and the services they offer (Holden and Lewine, 1979; Hatfield, 1979; Lamb and Oliphant, 1978; Kriesman and Joy, 1974). The care-giving families were especially critical of the theoretical orientations, therapeutic practices, and attitudes of mental health professionals toward schizophrenia and toward parents with schizophrenic children. These studies also reflect a general criticism of the awareness and response of mental health professionals to the needs of families caring for schizophrenic kin.

In order to gain a better understanding of how care-giving families assess mental health professionals, a survey study conducted by Holden and Lewine (1979) will be examined in detail. Holden and Lewine's effort is one of the best quantitative and qualitative research endeavors on care-giving families' assessments of mental health professionals done to date.

Although Holden and Lewine's survey was used mainly to investigate families' overall satisfaction with mental health professionals, there were questions on the survey pertaining to what families believed were the major shortcomings of the mental health profession, as well as what families believed mental health professionals should do to remedy those shortcomings. A final question on the survey requested that families comment on issues of specific interest to them that were not previously covered in the survey. All questions were of the forced-choice format (respondents chose the one response which best described their own

feelings), although there were numerous open-ended questions which allowed families to elaborate on their forced-choice responses.

Five hundred surveys were mailed out to the presidents of seven family support groups which represented five geographical areas: Community Mental Health Organizations Inc. (Englewood, N.J.), Friends and Family of the Chronically Mentally Disabled (Denver, Co.), Friends and Family of the Adult Mentally Ill (Boulder, Co.), Support Inc. (Lakewood, Co.), Alliance for the Mentally Ill (Madison, Wis.), Parents of Adult Schizophrenics (San Mateo, Cal.), and Families Unite for Mental Health Rights, Inc. (Oreland, Pen.).

Of these 500 surveys, 203 were returned. One hundred forty-five (66%) of the 203 responses came from mothers with a schizophrenic child.

Insert Table 3 about here

More detailed demographic features of the respondents are summarized in Table 3.

The general level of satisfaction with mental health professionals was quite low. Seventy-four percent of the responding care-giving families felt some degree of dissatisfaction with mental health professionals. Forty-two percent of the dissatisfied families rated themselves as "very dissatisfied" with mental health professionals. The remaining 32 percent of the dissatisfied families rated themselves as "generally dissatisfied." Two percent of the families felt "very satisfied" with mental health

Insert Table 4 about here

professionals. "General satisfaction" was expressed by the remaining 24 percent of the care-giving families. As Table 4 illustrates therefore, roughly 3 out of every 4 care-giving families in the sample were dissatisfied with mental health professionals.

Table 5 summarizes the primary response of care-giving families following contact with mental health professionals. More than a third of

Insert Table 5 about here

these families expressed frustration, and only 3 percent indicated that more insight into their child's psychiatric illness was gained by working with mental health professionals. In a separate but related question, 66 percent (N = 125) of the mothers expressed no confidence in the treatment provided by mental health professionals.

Families with schizophrenic relatives also had more specific complaints regarding the services rendered by mental health professionals. For example, 75 percent (N = 139) of the families believed that mental health professionals did not adequately explain their child's psychiatric diagnosis. Table 6 presents the reasons why care-giving families thought the professionals' explanation of the diagnosis was inadequate. As is evident in Table 6, most of the responding families

Insert Table 6 here

indicated that mental health professionals were either too vague about the psychiatric diagnosis, or avoided the issue of the diagnostic label

all together. In contrast to what one might expect, only 4 percent of the families regarded the explanation of the psychiatric diagnosis as too technical.

A more surprising finding of this study was that although 95 percent of these families cared for mentally ill relatives who used psychotropic medication, only 54 percent of the families were told why psychotropic medication was necessary for their relative. Even more surprising was the finding that only 20 percent of these same families were warned of the side-effects of the particular psychotropic medications used by their relative.

Responses to the open-ended questions further elucidated care-giving families' criticisms of the mental health profession. For example, care-giving families stated that:

"Family members are made to feel they have done something really wrong."

"Professionals treat parents as if they were the enemy."

"I was left out in the dark. Everything was frightening because it was unexplained."

Care-giving families also characterized mental health professionals as incompetent, motivated by money, and hostile.

Yet some might argue that care-giving families assess the mental health profession negatively because of unrealistic expectations, or because of frustration over the poor progress of their schizophrenic relative, or even because of some latent psychological problems within the family. Holden and Lewine however, disagree with this interpretation. These researchers argue that this conclusion would be inconsistent with

all the other data obtained from families. Families who Holden and Lewine believe repeatedly demonstrated a remarkable sophistication in knowledge regarding mental illness, and especially schizophrenia.

It appears that care-giving families are thus, seeking realistic and practical guidance from mental health professionals through their complaints. Examples of such complaints recorded by Holden and Lewine included:

"I need practical ways of dealing with day to day difficult behaviors."

"I would like professional advice on how to help my son live as normally as possible when not hospitalized."

"I would like consultations about what I could reasonably expect of my son."

"We need a clearer idea of the therapist's objectives and knowledge of how we could fit in with therapy."

"Professionals are reluctant or unable to communicate what they are about or how we can effectively aid in the process of recovery."

"We have received conflicting advice from professionals on what our role should be in treating the patient."

"Each doctor seemed to make a different decision and I was never helped to understand why. I'm not sure what to think."

Evidence obtained from care-giving families indicates however, that these legitimate requests for information and support are frequently interpreted by mental health professionals as a family's desire for simple reassurances and easy answers. This view of care-giving families has undoubtedly had a profound negative impact upon the working relationship between mental health professionals and families with schizophrenic

relatives (Christ and Wagner, 1966). And the end result is that neither the mental health professional nor the care-giving family understands what each other is all about.

Targeting the Clinical Bias

Toward Families with Schizophrenic Relatives

The attitudes of mental health professionals toward patients have been investigated (Wills, 1978). The effects these attitudes have upon the helping responses of mental health professionals have likewise been examined (Batson, 1975). Despite this fact however, little is actually known about the attitudes of practicing mental health professionals toward families with schizophrenic relatives. Consequently, nothing is known about the mediating effect these respective attitudes might have upon the willingness of mental health professionals to provide support and services to care-giving families and their schizophrenic relatives.

More research into the attitudes of practicing mental health professionals toward families with schizophrenic relatives is warranted for two basic reasons: 1) care-giving families and their schizophrenic relatives are consumers in need of the support and services that mental health professionals have been trained to provide, and 2) logic dictates that the effectiveness of care-giving families be maximized since traditional mental health services are often unavailable to the chronic schizophrenic patient placed into the community. The purpose of the following study is to determine how the theoretical orientations, therapeutic practices, and attitudes of mental health professionals toward schizophrenia and especially toward families with

schizophrenic relatives effect their willingness to offer support and services to care-giving families—the major primary caretakers of the deinstitutionalized chronic schizophrenic population.

Method

Subjects

One hundred and fifty-one mental health professionals throughout northern, central, and east central Illinois were contacted. These mental health professionals included: 1) psychiatrists, 2) psychologists, 3) psychotherapists, 4) psychiatric nurses, 5) social workers, 6) mental health technicians, and 7) crisis intervention/outreach workers. Eight University students currently enrolled in a mental health workers practicum program (for undergraduate psychology majors) also participated in the study.

The mental health professionals were recruited from a variety of psychiatric facilities, agencies, and clinics. These facilities, agencies, and clinics included: 3 private psychiatric out-patient clinics, 1 county run psychiatric out-patient agency, 1 community mental health center, 1 University affiliated psychiatric out-patient clinic, 1 psychiatric in-patient wing of a general hospital, 1 intermediate care psychiatric in-patient facility, and 2 state run psychiatric in-patient hospitals. Efforts were made to obtain equal population samples from each of the differing types of psychiatric settings.

Prior to contacting mental health professionals affiliated with any facility or agency, appropriate administrative authorization was first obtained. The administrations of every facility or agency contacted agreed to let their mental health staff members be recruited

for this study.

All mental health professionals recruited were assured that participation in the study was voluntary—and that refusal to participate and/or complete the study would not result in any on-the-job repercussions. Of the 151 mental health professionals originally recruited, 85 (56%) have completed the study thus far. A detailed description of the demographic characteristics of these respondents will be presented in a later section.

Follow-up contacts with many of the mental health professionals who failed to complete the study indicated that over 90% of the mortality rate was due to "lack of time". Other factors contributing to the mortality rate were: 1) disinterest in the study, 2) difficulty understanding purpose of the study, 3) difficulty understanding and responding to questions, 4) inability to characterize attitudes and therapeutic approaches in the format required by the study, and 5) lack of experience with schizophrenic patients and their families.

Apparatus

A survey entitled "Schizophrenia Survey for Mental Health Professionals" was devised (a copy of this survey can be found in Appendix A).

The survey was divided into six sub-sections:

General Information. The first section of the survey requested general information from the respondent such as their profession, sex, and age. Other questions included in the general information section concerned the economic resources of the schizophrenic patients treated by the respondent, as well as the percentage of schizophrenic patients in the respondent's caseload.

Theoretical Orientation and Therapeutic Approaches. The second section of the survey was used to target the theoretical orientations of respondents toward mental illness in general and schizophrenic illness in particular. In the remainder of this section respondents were questioned on the efficacy of various therapeutic approaches to the treatment of schizophrenia.

The Treatment and Cause of Schizophrenia. The third section of the survey requested the respondents to rank the importance of various factors to be considered in the treatment of schizophrenia. Other questions in this section required the respondents to indicate their beliefs regarding the etiology of schizophrenia. A final question in this section instructed the respondents to indicate the origin of their beliefs regarding the etiology of schizophrenia.

Practices of Mental Health Professionals. The fourth section of the survey sampled some of the specific practices of mental health professionals. For example, respondents were asked to indicate the types of questions received from families with schizophrenic relatives that they do and do not respond to. Respondents were also asked to identify the types of services they do and do not provide for families with schizophrenic relatives. The last question in this section instructed the respondents to indicate the percentage of families with schizophrenic relatives they believe are satisfied with the current mental health profession.

Families with Schizophrenic Relatives and Attitudes Toward Families with Schizophrenic Relatives. In sections five and six of the survey respondents were instructed to identify their perceptions of families with schizophrenic relatives. Specifically, respondents were

asked to characterize parents with a schizophrenic child and to disclose their feelings regarding these parents with a schizophrenic child. The respondents were also asked to provide opinions regarding the organization of self-support groups for families with schizophrenic relatives.

All the questions in the survey, except the last four questions, were of the forced-choice format. The final four questions were open-ended. A space for comments followed every question. These comment spaces allowed the respondents to expound on questions and issues of specific interest to them. The majority of mental health professionals fully completed the survey in approximately 10-15 minutes. The practicum students needed approximately 25-30 minutes to complete the survey.

Procedure

Selection of the psychiatric facilities, agencies, and clinics used in this study was based upon two factors: 1) type of psychiatric services offered by the particular establishment, and 2) geographic location of establishment. Attempts were made to obtain samples from mental health professionals affiliated with as many different types of psychiatric settings as possible. Efforts were also made to obtain samples from mental health professionals in as many different geographical locations as possible.

Once the particular psychiatric facilities, agencies, and clinics were selected, appointments were made with their administrators to discuss this study. As stated earlier, the administrations from every facility, agency, and clinic contacted allowed their mental health staff members to be recruited for this study.

Once administrative approval was obtained, announcements were

made to staff members that their participation in a research project concerning "the perspectives of mental health professionals on the cause, diagnosis and treatment of schizophrenia" was requested. Interested staff members were then summoned to a locale where the surveys were distributed.

Although the survey was self-explanatory (see Appendix A), any questions mental health professionals had concerning the questions or forced-choice responses were answered. Once the surveys were completed, respondents were individually asked if they had "any final comments or questions concerning this study". Responses made to this question were noted or tape recorded (Sony TCM-121) with the respondent's consent.

All cooperating facilities, agencies, and clinics were presented with the results of this study and a copy of this thesis for purposes of debriefing. The respondents were also presented with a phone number and an address where any final comments concerning the results of this study or this thesis could be directed.

Results

Demographic Characteristics of Respondents

Although attempts were made to obtain equal samples from each sub-specialty within the mental health profession hierarchy, several sub-specialties became disproportionately represented in the study nonetheless. For example, only 4 psychiatrists affiliated with the previously described agencies, facilities, and clinics completed and returned their surveys. At the other extreme, 22 social workers

Insert Table 7 about here

completed and returned their surveys. There was also an unfortunate under-representation of the crisis intervention/outreach worker sub-specialty. This can be attributed to the fact that only one agency contacted utilized this type of mental health professional. Table 7 contains a comprehensive description of the number of professionals from within each sub-specialty that participated in the study. The implications of this disproportionate representation will be discussed more fully later.

In terms of the gender of the respondents, 31.8% of the sample was male, while 55.3% of the sample was female. A remaining 12.9% of the sample chose not to report their gender.

The ages of the respondents ranged from 21 years to 73 years.

Insert Table 8 about here

The median age of the respondents was 29.8 years. A more detailed description of the ages of the respondents is contained in Table 8.

The respondents varied considerably regarding their years of experience in the mental health profession. While the majority (54.1%) of the respondents reported approximately 1-5 years experience in

Insert Table 9 about here

mental health services, there were respondents logging in between as many as 25-32 years experience in the mental health field. The mean and median years of experience for the respondents were 6.4 and 4.3 years respectively. An in-depth illustration of the respondents' years of experience in the mental health profession can be found in Table 9.

The percentage of schizophrenic patients in the caseloads of the respondents also varied considerably. 27% of the respondents indicated that 60-80% of their caseload consisted of schizophrenic patients. Caseloads comprised almost exclusively of schizophrenic patients were reported by 23% of the respondents. 20% of the respondents claimed that 0-20% of their caseload contained schizophrenic patients.¹ Another 17% of the respondents indicated that 20-40% of their caseload was comprised of schizophrenic patients. The remaining 13% of the respondents stated that 40-60% of their caseload was made up of schizophrenic patients.

The economic resources of the majority of patients treated by the respondents were characterized as less than adequate. Almost 50%

 Insert Table 10 about here

of the respondents indicated that a majority of their patients were totally dependent upon public aid and Social Security benefits for survival. 44% of the respondents claimed to primarily treat patients in the lower middle and lower income classes. The final 9% of the respondents reported that their patients were of the middle income status. As can be seen in Table 10, no respondents claimed to treat patients in the upper or upper middle income classes.

Theoretical Orientations and Therapeutic Approaches

The two most preferred theoretical orientations for understanding mental illness were psychodynamic (reported by 28.2% of the respondents)

¹This percentage figure was obtained primarily at a large state psychiatric hospital where a new psychiatrist had recently changed many of the chronic undifferentiated type schizophrenia diagnoses (295.92) to bipolar manic depression diagnoses (296.6X). The respondents reported the most recent of the two diagnoses. Otherwise, these respondents stated that they would have reported an 80-100% caseload of schizophrenic patients (see DSM III, 1981 for explanation of the diagnostic code numbers).

and social learning (reported by 24.7% of the respondents). The third most preferred theoretical orientation for understanding mental illness was described as genetic/biological (reported by 17.6% of the respondents). Other theoretical orientations such as phenomenological and

Insert Table 11 about here

diathesis/stress were about equally preferred by the remaining 16% of the respondents. Table 11 contains a description and summary of the preferred theoretical orientations of the respondents for understanding mental illness.

Interestingly enough, despite the fact that the psychodynamic orientation was the most preferred theoretical orientation for understanding mental illness, the psychodynamic approach was considered the least useful therapeutic approach for treating schizophrenia. Only three (3.5%) of the respondents considered the psychodynamic approach a viable treatment for schizophrenic illness. In fact, 70.5% of the respondents considered the psychodynamic approach the least useful of all possible treatments of schizophrenia.

Pharmacological (i.e. major tranquilizers) strategies were considered by 38.8% of the respondents to be the most useful treatment of schizophrenia. The next most useful strategy in the treatment of schizophrenia was considered to be an eclectic approach—consisting of both pharmacological and behavior/cognitive modification therapies. The eclectic approach was selected by 25.9% of the respondents. Behavior/cognitive modification therapies alone were regarded as the

Insert Table 12 about here

third most useful treatment of schizophrenia, being reported by 15.3% of the respondents. Table 12 illustrates how the respondents rated the usefulness of various types of therapeutic approaches to the treatment of schizophrenia.

The Treatment and Cause of Schizophrenia

A sizeable portion of the respondents (42.4%) reported that the most important factor to consider when developing a long-term treatment plan for the chronic schizophrenic patient was, "the degree of support the patient could obtain from family members". Respondents considered biological factors—such as medication efficacy—the second most important factor to consider in the development of the long-term treatment package. None of the respondents considered support from

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 Insert Table 13 about here

friends to be of primary importance in the construction of a long-term care plan. Table 13 illustrates the respective evaluations of respondents concerning the importance of these and other factors when devising a long-term treatment strategy for the chronic schizophrenic patient.

All of the respondents expressed definite beliefs concerning the cause of schizophrenia. Deviant familial influences were viewed by 35.7% of the respondents to be the one factor most contributing to the cause of schizophrenia. Biochemical malfunctions such as excess dopamine were regarded as the second most contributing factor to the cause of schizophrenia (chosen by 31.8% of the respondents). 24.7% of the respondents considered schizophrenia to be the result of a genetic predisposition. Other potential etiological factors such as diet/vitamin

Insert Table 14 about here

deficiency, social pressures, and labeling someone schizophrenic were not as implicated as deviant familial influences, biochemical malfunctions, or genetic inheritance in the etiology of schizophrenia. Table 14 depicts the evaluations of respondents concerning the importance of various potential etiological factors.

Almost 40% of the respondents attributed their beliefs regarding the cause of schizophrenia to "experience with schizophrenic patients and their families". Another 27.1% of the respondents attributed their beliefs regarding the etiology of schizophrenia to both "training and experience". 16.5% of the respondents thought that their training alone underlied their etiological assumptions. Less than 15% of the sample felt that their beliefs regarding the cause of schizophrenia were derived from reading current literature.

Practices of Mental Health Professionals

Contact with Families. Over 50% of the respondents reported that they have contact with at least 1-3 different families of schizophrenic patients per week. About 25% of the respondents claimed to meet with 4-10 different families per week. Only 3.5% of the respondents

Insert Table 15a about here

indicated that they interact with 11 or more different families per week. The frequency in which respondents meet with different families of schizophrenic patients on a weekly basis is contained in Table 15a.

As is shown in Table 15b, those mental health sub-specialties having the most frequent contact with families of schizophrenic patients were social workers and mental health technicians. Psychiatrists and

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 Insert Table 15b about here

psychologists were the sub-specialties having the least frequent contact with families.

Schizophrenia Information. A majority (78.8%) of the respondents reported that they regularly provide information about schizophrenia to families. Of the remaining 20% of the respondents who said that they did not regularly provide families with information regarding schizophrenia, most indicated that they did not do so because they felt families were not interested or would not understand the information anyway. A few respondents stated that they have never been asked about schizophrenia by any families.

Symptoms, Diagnosis, and Prognosis Information. About 20% of the respondents reported that they do not provide information regarding the prognosis of schizophrenia because of the uncertainty of the prediction.

Almost 6% of the respondents indicated that they do not discuss the diagnosis of schizophrenia. The reasons given for not discussing the diagnosis ranged from criticisms of the label itself, to not wanting to frighten the family or the patient.

None of the respondents claimed to avoid questions regarding the symptoms of schizophrenia.

Psychotherapy and Medication Information. Three-fourths of the respondents were willing to provide information to families concerning specific psychotherapeutic techniques and the effects (both

wanted and unwanted) of medication. The respondents who indicated that they do not regularly discuss therapeutic techniques and medication effects with families gave the following types of reasons for not doing so: 1) feared the information would break the ethic of therapist-client confidentiality, 2) was prohibited from doing so by superiors, 3) felt it was not their responsibility to explain this information to families, and 4) did not have the knowledge necessary to discuss these issues.

Etiological Information. Nearly 45% of the respondents reported that they regularly inform families of their own beliefs regarding the cause of schizophrenia. A remaining 55% of the respondents stated that they do not provide information to families regarding the cause of schizophrenia because the information would be merely speculative.

Practical Suggestions. Over 80% of the respondents indicated that they regularly provide families with practical suggestions on how to deal with their schizophrenic relatives at home. Reasons given for not providing families with practical suggestions on home care ranged from beliefs that families would misinterpret or misunderstand such information, to the belief that families were not interested in receiving these types of suggestions.

Families with Schizophrenic Relatives

Guilt. Most (70%) of the respondents claimed that a majority of parents feel guilty about causing the schizophrenia of their child. 24.7% of the respondents reported that they have not sensed these guilt feelings in the parents of schizophrenic patients they have come into contact with.

Attention Given to Families. Almost three-fourths of the

respondents indicated that families with schizophrenic relatives do not receive adequate attention from mental health professionals. Several respondents who did report that families were indeed, receiving enough attention from mental health professionals commented that, "only so much can be done for families since the needs of many patients are not being met" and that "families are low priority when budgets are being cut."

Satisfaction of Families. About a third of the respondents believe that 40-60% of all families are satisfied with their contacts

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 Insert Table 16 about here

and experiences with mental health professionals. 22% of the respondents felt that 20-40% of the families were satisfied. Only one respondent thought that 80-100% of the families were satisfied with the mental health profession. Table 16 illustrates the comparative breakdown of respondents' beliefs regarding the satisfaction of families with the mental health profession.

Attitudes Toward Families

Characterizations of Parents. More than 50% of the respondents characterized parents with negatively charged descriptions. Some examples of these negative characterizations were as follows:

"Inadequate as parents, inconsistent with love and discipline."

"Superficial and evasive."

"Very ignorant . . . may have reasons for maintaining the patient's sick behavior."

"They look for miracle answers, and most quickly deny there is any other mental illness in the family."

"On the rigid side; problems with separation and individuation; often judgmental and critical."

"Overindulgent, preoccupied . . . give double-messages, detached emotionally . . ."

". . . often too invested."

"Aggressive, emotionally unbalanced, passive fathers, manipulative, rigid."

"Schizophrenic."

"Underlying marital problems. Readily allows child to refocus attention away from marital issue by his schizophrenic behavior. Significant communication problems (double-bind)."

"Though they often are not identified as the sick patient, they often exhibit many of the characteristics and behaviors found in the schizophrenic child."

". . . overprotective and controlling, often supporting the regressive behavior. . . . emotionally distant . . ."

"Rigid, anxious, overpermissive, give double messages."

"Concerned in a "matter of factly" way."

"I often see a lot of rejection, or the opposite of overinvolvement, and weak boundaries."

"They frequently demonstrate rigidity, ambivalence, ambiguity . . ."

"Most of the time one or both parents exhibit schizophrenic behavior."

Roughly 15% of the respondents characterized parents with schizophrenic children in an ambivalent fashion. Ambivalence was reflected in the following types of statements:

"Usually guilt ridden but also very over-protective."

"Overwhelmed and inadequate . . ."

"Stressed, confused, angry . . . generally
"weirder" than parents as a class in general."

"Suffering from stress. Inability to be ob-
jective regarding their son/daughter."

"Such parents are both witting and unwitting
contributors to their child's condition."

"Frustrated and impatient."

About one quarter of the respondents characterized parents in such a way as to indicate some insight into the plight of families with schizophrenic relatives. These characterizations took the following form:

"Guilt ridden, confused, frustrated, most feel abandoned by psychiatrists and other professionals."

"Discouraged, exhausted, guilt-ridden, desperate, burnt out parents."

"Frustrated, angry, guilty, embarrassed, concerned."

"From the parents I've met, they've been quite supportive."

"They have tried many solutions. They are burnt out on solutions and hopes. They feel extremely helpless."

The remaining 8% of the respondents reported that they did not have enough experience to characterize parents or they did not respond to the question.

Feelings Toward Parents. Although more than 50% of the respondents characterized parents of schizophrenic patients in a negative fashion—only 25% of the respondents expressed negative feelings toward these parents:

"I feel they are very much involved in the schizophrenic illness—as contributing factors and as victims themselves."

"I feel that they are so busy worrying about their own survival that they are too busy to do much in an emotional way for the patient. Some are detached and unable to love their children."

"They are merely continuing a pattern which spans at least three generations."

". . . parents have little concern about the schizophrenic resident."

"Often are a good part of the cause of schizophrenia, but not always."

"It is difficult to get them to be consistent and/or make changes that will benefit the patient."

"Unfortunately I often find them hard to work with because they are often dominating in interviews with their children."

Exactly 40% of the respondents expressed sympathy, empathy, and a willingness to work with more parents of schizophrenic patients. These respondents indicated that:

"There is a great need for programs of instruction and support for all families concerned."

"I find it very useful to involve parents in treatment."

"I am always pleased when parents ask for information and/or ways to help the patient and themselves."

Ambivalent feelings toward parents were expressed by 10% of the respondents. These comments took the following form:

"Sometimes I feel sympathy, sometimes angry."

"Understanding and sympathy . . . impatient when they are unwilling to have any insight or change behavior."

"In cases where I felt the parents were very much to blame, it would be hard to remain objective . . ."

Of the remaining 22% of the respondents, 10% were not able to, or chose not to describe their feelings. And the final 12% of the respondents reported that they either were not sure about their feelings toward these parents or that they did not have any feelings one way or the other concerning parents of schizophrenic patients.

Self-Support Groups for Parents. Only about 5% of the respondents expressed any reservations regarding the development of self-support groups for parents with schizophrenic children. The following statements are examples of those reservations:

"I feel the megavitamin thing got out of hand—making megavitamin treatment a cultish thing—and viewing orthodox psychiatry as a villain preventing the public from having a curative treatment."

". . . could result in a can you top this mentality because of the often bizarre behaviors and thought processes of schizophrenics."

". . . the majority of relatives I have dealt with have little or no interest in their ill family members."

". . . I would be wary of this as a panacea."

The overwhelming majority (83%) of the respondents expressed extremely positive reactions to the idea of self-support groups. Benefits to both the family and the schizophrenic patient were seen as resulting from the utilization of self-support groups.

Two (2.4%) of the respondents were not sure how they felt about self support groups, and six (7.1%) of the respondents did not report their feelings regarding this issue.

Factors Associated with the Attitudes of
Mental Health Professionals Toward
Families with Schizophrenic Relatives

Sub-specialty and Attitudes. Those respondents in the sub-specialties having the most contact with families of schizophrenic patients (i.e. social workers, mental health technicians, and psychiatric services), were the mental health professionals who most frequently characterized families with schizophrenic relatives in a negative fashion. Psychiatric nurses were the most likely mental health

Insert Table 17 about here

professionals to characterize families in a negative fashion. In fact, 91% of the psychiatric nursing respondents ($n = 11$) characterized families with negatively charged labels. Mental health technicians and social workers respectively, were the next most likely mental health professionals to characterize families in a negative manner. Interestingly enough, 66.7% of the practicum students ($n = 8$) characterized families in a negative fashion despite the fact that they have had limited to no contact with the families of schizophrenic patients. Table 17 summarizes the relationship between sub-specialties in the mental health profession and characterizations of families.

The characterizations showing the most insight into the dilemmas of families with schizophrenic relatives were received from the

²Using the chi-square analysis, the relationship between these three sub-specialties and negative characterizations of families was found to be significant ($p < .05$). The use of chi-square analysis with $n = 85$ is however, problematical. The chi-square statistical test of significance was nonetheless, reported for interested readers.

psychotherapist respondents. Almost 60% of these mental health professionals ($n = 12$) reported that families with schizophrenic relatives have needs in their own right—and deserve more support and services from mental health professionals. 50% of the psychiatrist respondents ($n = 4$) reported characterizations similar to those contributed by psychotherapists.

Experience and Attitudes. There is evidence to indicate that with increasing experience, mental health professionals begin to characterize families with schizophrenic relatives with more insight and empathy.³ As was indicated earlier however, those respondents with the most experience—were the least likely respondents to come into regular contact with families of schizophrenic patients.

Theoretical Orientations and Attitudes. Table 18 illustrates the relationship between the various theoretical orientations of respondents and their corresponding characterizations of families with schizophrenic relatives. About 72% of the respondents who described

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 Insert Table 18 about here

their preferred theoretical orientation for understanding mental illness as social learning ($n = 18$) also reported negative characterizations of families with schizophrenic relatives. Negative characterizations of families were also expressed by 71.4% of the respondents ($n = 7$) who claimed to prefer the diathesis/stress theoretical orientation. Roughly 65% of the respondents ($n = 9$) who described their preferred

³It should be pointed out that a chi-square analysis did reveal a significant ($p < .01$) relationship between experience and empathetic characterizations. However, the reader must be reminded that $n = 85$ in this study.

orientation as phenomenological also characterized families in a negative fashion.

Empathetic characterizations of families were primarily contributed by those respondents describing their theoretical orientations as basically genetic/biological ($n = 15$). Of this group, 53.5% indicated that ways to improve and maximize the alliance with families were warranted.

Treatment of Schizophrenia and Attitudes. The respondents who selected psychodynamic approaches ($n = 3$) and family therapy approaches ($n = 1$) as the most useful treatments of schizophrenic illness all characterized families extremely negatively. Negative characterizations of families were also obtained from 62.5% of the respondents who regarded phenomenological approaches as most efficacious in the treatment of schizophrenia ($n = 8$).

Those respondents favoring either a purely pharmacological approach ($n = 31$) or a purely behavior modification approach ($n = 12$) were particularly ambivalent in their characterizations of families. Over 33% of the respondents that viewed either one of the treatments alone as the treatment of choice for schizophrenic illness characterized families in an ambivalent fashion.

No one treatment or treatments were particularly associated with empathetic characterizations of families. All treatment approaches contributed about equally to the total number of empathetic characterizations of families.

Etiological Assumptions and Attitudes. Nearly 60% of the respondents who regarded deviant familial influences as the primary cause of schizophrenia characterized families in a negative fashion. About

60% of the respondents who espoused the genetic predisposition

Insert Table 19 about here

etiologiical theory also characterized families in a negative manner. A third of the respondents who considered schizophrenia to be the result of biochemical malfunctions described families with negatively charged labels. Table 19 illustrates that no other etiologiical group was substantially associated with negative characteristics of families.

Empathetic characterizations of families were about equally associated with each of the etiologiical factors considered to be primary causes of schizophrenia. It should again be pointed out that only 30% of the respondents expressed unconditional empathy or understanding of families with schizophrenic relatives.

Reactions of Mental Health Professionals to the Survey

There were many different types of reactions to the Survey. Several respondents stated that the survey contained obvious biases against families—while other respondents commented that they were pleased to see research contributing to the support of families with schizophrenic relatives.

Although some respondents were defensive about having to report their feelings and attitudes toward families, most respondents were quite receptive to the idea. The administrators from every cooperating agency, facility, and clinic requested copies of the results of this study so that the information could be disseminated to their mental health staffs.

Discussion

Representation in the Sample

The fact that several mental health profession sub-specialties were disproportionately represented in the sample might suggest that the results of this study are lacking in both internal and external validity. To accept this criticism of the results however, would be to implicitly imply that all mental health profession sub-specialties have approximately equal amounts of contact with families of schizophrenic patients.

As has been noted by Goffman (1961), not all mental health profession sub-specialties have equal amounts of contact with patients. In fact, Goffman has shown that the mental health profession sub-specialties engaging in the most contact with patients, are the mental health profession sub-specialties commanding the least amount of power within the mental health profession hierarchy. Consequently, it would not be unreasonable to assume that those mental health professionals having the most contact with patients, are the same mental health professionals having the most contact with families.

The results of this study indicated that indeed, the mental health professionals commanding the least amount of power within the mental health profession hierarchy (i.e. mental health technicians, social workers, and psychiatric nurses) reported the most overall contact with families and were the most represented mental health professionals in the entire sample. Conversely, those mental health professionals enjoying the most authority within the mental health profession hierarchy (i.e. psychiatrists and clinical psychologists)

reported the least amount of overall contact with families and were the most under-represented mental health professionals in the sample. This occurred in spite of the fact that equal numbers of mental health professionals from each sub-specialty were asked to participate in the study.⁶

In conclusion, it is likely that a representative sample of mental health professionals having regular contact with families of schizophrenic patients was in fact, achieved. Unfortunately, this type of representation did not permit equal representation of all mental health profession sub-specialties—since not all mental health profession sub-specialties have regular contact with families of schizophrenic patients.

Implications of the Experience Factor

Attitudes toward families with schizophrenic relatives were found to be most negative among mental health professionals with the least amount of experience working in psychiatric settings. As years of experience increased however, the attitudes of mental health professionals toward families correspondingly tended to reflect both more insight and empathy.

Yet with tenure comes promotions within the mental health profession hierarchy. And as was pointed out earlier, mental health professionals usually engage in less and less contact with families as they scale the mental health profession hierarchy. The end result of this spiraling process is that those mental health professionals

⁶The sole exception was the number of crisis intervention/out-reach workers contacted. Only two could be contacted because only one cooperating agency utilized this type of mental health professional.

possessing the greatest degree of insight and empathy into the lives of families with schizophrenic relatives, are the mental health professionals having the least amount of contact with patients and their families.

In order to solve this dilemma, it might be profitable to enlist the assistance of experienced mental health professionals to: 1) train new staff members to the needs of families, 2) model therapeutic and supportive staff interactions with families, and 3) insure that the appropriate services and support are offered and made available to families in need.

Even before entering the mental health professions however, students have definite attitudes—mostly negative—toward families with schizophrenic relatives. This was illustrated by the fact that almost every undergraduate psychology practicum student represented in the sample not only expressed negative attitudes toward families (especially parents) with schizophrenic relatives, but also thought that deviant familial influences were the primary cause of schizophrenia. Surprisingly, only one of these practicum students had ever even spoken with or observed a family of a schizophrenic patient.

This fact raises some important questions regarding the ways in which students are taught about things like mental illness, etiology, and treatment strategies. Are tentative hypotheses and theories presented to students as though they were proven fact? In the case of schizophrenia, evidence seems to indicate so.

It is also possible that a more basic intrapsychic force underlies the attitudes of mental health professionals toward families with schizophrenic relatives. As Goffman (1963) has illustrated, parents

have long been implicated in the physical and emotional disabilities of their children—even when there is no evidence to support the allegations. A child's disability frequently comes to be viewed by people (including the parents themselves) as a form of punishment or just retribution for some supposed wrongdoing of the parents. The worse the child's disability, the worse the supposed wrongdoing of the parents is usually considered to be.

It has been hypothesized by Lerner (1965) that attributional processes such as these result from a motivational need of people to view their world as though it were a just, orderly, and predictable place where everyone gets what they deserve. This hypothesis is referred to as the "just world hypothesis", and it may underlie many of the attitudes expressed toward schizophrenic patients and their families (Burbach, 1981).

The Effect of Theoretical Orientations upon Attitudes

Theoretical orientations utilized to understand mental illness have been shown to have important impact upon the ways in which mental health professionals conduct assessment and treatment functions. Bernstein and Nietzel (1980, pgs. 82-91) presented the same case history of Mr. A., a 42 year old Caucasian male agoraphobic to a psychoanalytic, social learning, and phenomenological therapist. Each different type of therapist reported quite unique (1) initial reactions, (2) assessment strategies, (3) hypotheses regarding etiology, (4) influences of additional assessment data, and (5) outlines of treatment strategies.

In Bernstein and Nietzel's study, as was the case in this study, different theoretical orientations were associated with different types

of reactions and attitudes toward the patient and the patient's family. The differences in attitudes observed in the present study were, however, more obvious than the differences obtained by Bernstein and Nietzel. For example, the social learning orientation was particularly associated with negative attitudes toward families with schizophrenic relatives. Of the mental health professionals identifying their theoretical orientation as social learning, 72% expressed negative attitudes toward families with schizophrenic relatives.

The social learning orientation postulates that behavior (including deviant behavior) is primarily influenced by learning in a social context. Given the fact that the social context for most children is confined to the home, and that children are dependent upon parents for information, rewards and punishments, it is not difficult to understand how parents and other family members often become implicated in the etiological assumptions of mental health professionals who abide by the tenets of social learning theory.

Theoretical orientations which put more emphasis on the genetic/biological substrates which may potentially mediate schizophrenic illness, tend to characterize families of schizophrenic patients less negatively. About 50% of the respondents who described their theoretical orientations as genetic/biological indicated that steps to improve and maximize the alliance with families of schizophrenic patients were needed.

Attitudes as a Function of Treatment Strategies

Contrary to the results of Bernstein and Nietzel's study, preferred treatments of schizophrenia were found to be independent of theoretical orientations. Despite the fact that 24 respondents identified

their theoretical orientation as psychodynamic, only 3 respondents regarded psychodynamic therapies as the treatment of choice for schizophrenia. In fact, psychodynamic therapies were regarded by about 70% of the respondents to be the worst possible approach to the treatment of schizophrenia.

Pharmacological therapy alone was considered to be the most useful treatment of schizophrenia. Nearly 40% of the respondents thought that pharmacological approaches provided the most help to the schizophrenic patient.

The next most efficacious strategy was regarded as eclectic—specified as combined pharmacology and behavior modification therapy. Over a quarter of the respondents preferred the eclectic approach.

Behavior/cognitive modification schemes alone were noted as being the third most productive treatments of schizophrenia. Slightly more than 15% of the respondents identified their treatment of choice as behavior/cognitive modification therapy.

All therapeutic approaches were about equally associated with negative attitudes toward families. Two exceptions were the psychodynamic and family therapy approaches. Every respondent who selected psychodynamic therapy or family therapy as the most useful approach to the treatment of schizophrenia, described families with schizophrenic relatives quite negatively.

While ambivalent attitudes toward families were particularly associated with pharmacological treatments of schizophrenia, empathetic characterizations of families were not particularly associated with any therapeutic approach. No treatment strategy appeared to facilitate insight into the needs of families with schizophrenic relatives.

Attitudes as a Function of Etiological Assumptions

Deviant familial influences were considered to be the factor most contributing to the cause of schizophrenia. Genetic inheritance and biochemical malfunctioning followed respectively as the second and third most contributing factors in the cause of schizophrenia.

The results of this study revealed that the more familial based (and that includes genetic) the mental health professionals considered schizophrenia to be—the more likely the mental health professionals were to describe families negatively. Families are thus, not only implicated in the etiology of schizophrenia through supposed deed but also through genetic endowment. In any case, the blame rests upon the heads of the parents. As one respondent phrased it

"I believe schizophrenia is familial based (or at least genetic)."

And this, it appears, is reason enough to blame and derogate families with schizophrenic relatives.

Discrepancies Between Self and Other Evaluation

The study conducted by Holden and Lewine (1979) demonstrated that about 3 out of every 4 families were dissatisfied with the mental health profession. Reasons given for this dissatisfaction included the lack of information provided to families concerning (1) schizophrenia, (2) symptoms of schizophrenia, (3) diagnosis of schizophrenia, (4) prognosis, (5) therapy, (6) medication, and (7) practical suggestions on how to manage the schizophrenic relative at home.

In contrast with the results of Holden and Lewine's study, about 70% of the mental health professionals recruited for this study

claimed that they do regularly provide information to families concerning the above issues. It is indeed hard to reconcile such a large discrepancy. Perhaps social desirability influenced the responses of the mental health professionals. One way to resolve this issue would be to conduct observational or field studies in psychiatric settings. Only then could better insight be gained into professional-family interaction.

In terms of families' satisfaction with the mental health profession, mental health professionals significantly overestimate their value to families. As noted earlier, 75% of the families in Holden and Lewine's study expressed dissatisfaction with the mental health profession. The majority of mental health professionals contacted in this study believed however, that 40-80% of all families are satisfied with the current mental health profession.

Time for a Change

Some mental health professionals have begun to sense the dissatisfaction of families and have attempted to develop and implement services specifically suited for families with schizophrenic relatives (Anderson, Hogarty, and Reiss, 1980; Hiner and Kindie, 1979; Atwood and Williams, 1978; Dincin, Selleck, and Streicker, 1978). Two of these programs will be examined here.

Anderson, Hogarty, and Reiss, 1980. The goal of this psycho-educational program was to "increase the predictability and stability of the family environment by decreasing family members' anxiety about the patient and increasing their self-confidence, knowledge about the illness, and ability to react constructively to the patient". In order

to accomplish this goal, the Anderson team derived a four-phase treatment program.

In Phase I, the team "connected" with families and enlisted their participation in the program. At the time of this connection they attempted to decrease family guilt, emotionality, negative reactions to the illness, and also tried to reduce overall family stress.

In Phase II of the program, families were taught about schizophrenia, and the needs of the schizophrenic patient. Continued emphasis was on reduction of family stress. Attempts to de-isolate the families by enhancing their social network were also initiated.

Phase III of the program was marked by efforts to strengthen the marital/parental coalition and to increase family tolerance for low level dysfunctional behaviors. The families were also encouraged to allow the schizophrenic relative to gradually resume more and more responsibility in their lives during this phase.

Phase IV was utilized to reintegrate families into the "normal roles of their social system." And finally, families were encouraged to maintain their levels of progress.

Hiner and Kindler, 1979. Hiner and Kindler organized an educational group for families of the mentally ill. The objectives of the educational group were articulated by the families themselves. These were:

1. To gain a better understanding of severe mental illness including probable causes, treatment, prognosis, management, and new research development.

2. To create a source of support and self-help.

3. To create a group of consumer advocates for the severely mentally disabled, including lobbying in the legislature for priority for funds for mental health programs and mobilizing community resources to increase available housing and jobs for the mentally ill.

Members of the local mental health community were invited to speak to the educational group concerning the above issues. After enough speakers were recruited, a 12 week program was developed. Each week a different topic was covered. Topics included: 1) psychosis, 2) etiology of schizophrenia, 3) manic depressive illness, 4) medication, 5) epidemiology and culture, 6) treatment modalities, 7) activity therapy, 8) how to deal with treatment facilities, 9) legal issues, 10) available services for jobs, housing, and financial assistance, 11) current research, and 12) prognosis.

Hiner and Kindle reported that their program was quite successful. They also indicated that the families in the local community have continued to engage in similar types of programs.

The Clinical Lexicon

The development of psycho-educational groups are but one of the many things mental health professionals can do to ease the burden of families with schizophrenic relatives. Another thing mental health professionals can do, as Lewine (1979) has pointed out, is to re-evaluate the clinical lexicon used to describe families with schizophrenic relatives. Even mental health professionals who claim to be interested in the needs of families use this clinical lexicon, which frequently contains highly moralistic evaluations of families.

"Clearly, the language used in describing parental attitudes is highly negatively charged; it suggests that parents are willfully working against their children and unable to change. Note, for example, the use of the words such as denial, resist, inability, demand and refuse."
(Lewine, 1979, pg. 433)

Lewine later goes on to state:

"As one possibility, consider the following words . . . rather than denial, unbelief; for blaming, in terms of; for resist, count r; for inability, difficulty in; for unrealistically, impractically; for confront, face; for working against, hindering; for demand, require; and for refuse, are unwilling."
(Lewine, 1979, pg. 434)

Lewine's main point is that the clinical lexicon used to describe parents/families of schizophrenic patients often implies ambivalent or negative thoughts and attitudes, even if they were not intended as such by the mental health professional. The solution to this problem, as Lewine sees it, is to develop a clinical lexicon that does not place blame upon anyone.

Justice at Last

E. Fuller Torrey (1977), aware of the blame imposed upon parents of schizophrenic patients by mental health professionals, was moved to write "A Fantasy Trial About a Real Issue" several years ago. In his article, Torrey set the stage for a trial at JFK Stadium. This trial was the result of a class action suit filed by over 12 million parents of schizophrenic and autistic children. These parents were charging "family theorists and therapists" with iatrogenic anguish (anguish caused by treatment).

"Over a period of more than two decades, the accused did willfully and with forethought but no scientific evidence blame the parents of patients with schizophrenia and autism for their child's condition, thereby causing great anguish, guilt, pain, and suffering by the parents. As healers you broke the cardinal rule; you caused suffering when you should have been relieving suffering."

(Torrey, 1977, p. 24)

Clinicians such as Bettelheim, Laing, Lidz, Sullivan, Fromm-Reichman, Bateson, and Halley took the stand. Those family theorists and therapists who had died were tried in absentia. The prosecutor asked the defendants why theories were extrapolated from such few case studies and experimental designs, and why there were very few or no controls, and why biased samples were used. The prosecutor also asked the defendants why they ignored genetic, biological, and neurophysiological factors, and why they were not reading current literature in the clinical journals. Lastly, the family theorists were asked if they thought the prestige gained by the propagation of these theories was worth the cost paid by families (see Appendix B). The case was indeed devastating.

"Finally the sentence was read. The convicted, for a period of ten years, shall be forced to read and reread continuously their own writings. Everyone was stunned. Relatives wept openly. Nobody had expected that harsh a sentence."

(Torrey, 1977, p. 24)

Families with Schizophrenic Relatives: A New Perspective

The deinstitutionalization movement has had a tremendous impact upon families with chronic schizophrenic relatives. Released to community psychiatric networks that often exist only in theory, chronic

schizophrenic patients have had to return to the homes of their families. Unfortunately, families are not usually equipped to handle the awesome responsibility of caring for a chronic schizophrenic relative on a daily basis. Consequently, the quality of life experienced by these care-giving families—as well as the chronic schizophrenic patients themselves—is often diminished.

Care-giving families have found themselves in a unique position, as this study has shown. More than half of the mental health professionals surveyed expressed negative attitudes toward families with schizophrenic relatives. Another 17% of the mental health professionals characterized these families in an ambivalent fashion. All things considered, about 70% of the mental health professionals interviewed expressed negative attitudes toward families with schizophrenic relatives.

These negative attitudes might stem from the fact that almost half of the mental health professionals contacted reported that deviant familial influences were the primary causes of schizophrenia. Many other respondents thought deviant familial influences provided the necessary and specific stresses which combine with a diathesis to cause schizophrenia.

At the same time families are being criticized and blamed for causing schizophrenia, they are being asked to assume the primary care of their schizophrenic relatives. In fact, more than 50% of the responding mental health professionals thought that support from family members was the most important treatment factor in the long-term care of the chronic schizophrenic patient.

Criticism and blame from the mental health profession has forced care-giving families to seek out support and services from non-traditional mental health channels (see Cockerham, 1980, pgs. 309-339, for some examples of non-traditional mental health channels); support and services that mental health professionals have been trained to provide.

Scapegoating, criticizing, and viewing the family of the schizophrenic patient as an enemy has not served the needs of either the schizophrenic patient or the care-giving family. Perhaps it is time to re-evaluate the stance of the mental health profession concerning families with schizophrenic relatives. Only then will an alliance between the mental health profession and care-giving families be possible.

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Tables

TABLE 1

Summary of Studies Assessing Problem Behaviors
Faced by Families of the Chronically
Mentally Ill

Interview		
Study	Respondents	Problem
Yarrow, Schwartz, Murphy, Deasy (1955)	Wives (N = 33)	Physical Problems, Complaints, Worries Deviations from Routines Expressions of Inadequacy or Hopelessness Nervous, Irritable, Worried Withdrawal (verbal, physical) Changes or Accentuations in Personality "Traits" (slovenly, deceptive, forgetful) Aggressive or Assaultive and Suicidal Behavior Strange or Bizarre Thoughts, Delusions, Hallucinations and Strange Behavior Excessive Drinking Violation of Codes of "Decency"
Grad and Sainsbury (1968)	Relatives (N = 410)	Uncooperative and Contrary Restless Odd, Unreasonable, Peculiar Harmful to Self Disturbed at Night Suicidal Violent Unpleasant, Objectionable Speech or Behavior
Pringle (1973)	Families	Unpredictable Behavior Ups and Downs of Moods
Creer and Wing (1975)	Relatives	Social Withdrawal Underactivity Lack of Conversation Few Leisure Interests Slowness Overactivity Odd Ideas Depression Odd Behavior Neglect of Appearance Odd Postures and Movements Threats or Violence Poor Mealtime Behavior Socially Embarrassing Behavior Sexually Unusual Behavior Suicide Attempts Incontinence

TABLE 2

Summary of Studies Assessing Problem Behaviors
Faced by Families of the Chronically
Mentally Ill

Survey		
Study	Respondents	Problem
Krauss (1976)	Parents (N = 49)	Antisocial behavior Asocial behavior Effects of above on neighbors and friends
Hatfield (1978)	Parents (N = 89)	<u>Poor Task Functioning</u> Poor grooming and personal care Lacks motivation Handles money poorly Forgets to do things Shows poor concentration Fails to consider future Refuses medication <u>Bizarre and Abnormal Behavior</u> Thinks people talk about him or her Hears voices Tries to commit suicide Talks without making sense <u>Intrusive and Disturbing Behavior</u> Argues too much Has unusual eating and sleeping patterns Breaks and damages things Tries to hit or hurt others Drinks too much Uses harmful drugs Upsets the neighbors Steals from the family "Mooches" from others
Holden and Lewine (1979)	Family Members (N = 203)	Aggression Withdrawal Social Inappropriateness Unpredictability Irrational Beliefs Talking to Self Poor Hygiene Not Contributing to Household Tasks Other

TABLE 3

Demographic Characteristics of Respondents

Characteristic	N	%
<u>Age</u>		
Less than 25	1	—
25-35	13	7
35-45	12	6
45-54	60	31
55-64	78	40
65-74	29	15
Greater than 74	1	—
<u>Sex</u>		
Male	50	26
Female	146	74
<u>Race</u>		
White	194	99
Black	1	—
Asian	1	—
<u>Marital Status</u>		
Single	6	3
Married	156	80
Divorced	18	9
Widowed	16	8
<u>Education</u>		
7-11 years	9	5
High School	49	26
Some College	39	21
College Graduate	93	48
<u>Employment</u>		
Professional/Business	40	24
Semiprofessional/Lesser Whitecollar	78	46
Skilled/Semiskilled Laborer	15	9
Homemaker	37	21
<u>Relationship</u>		
Mother	137	71
Father	32	16
Spouse	6	3
Sibling	17	9
Child	1	—

Source: Holden and Lewine, 1979.

TABLE 4
Family Member's Satisfaction
With Mental Health Professionals

Degree of Satisfaction	N	%
Very Dissatisfied	79	42
Generally Dissatisfied	61	32
Generally Satisfied	46	24
Very Satisfied	4	2
Total	190	100

Source: Holden and Lewine, 1979.

TABLE 5
 Family Member's Primary Response After Working With
 Mental Health Professionals

Response	N	%
Frustrated	60	38
Contact with Professionals not helpful	34	22
Powerless	21	13
Learning of coping strategy	15	9
Confident	13	8
Anger	6	4
Understanding of Schizophrenia	4	3
Guilt	4	2
Total	158	99

Source: Holden and Lewine, 1979.

TABLE 6
Reasons for Inadequacy of Explanation
of Diagnosis

Reason	N	%
Too vague	51	35
Not thorough enough	45	31
Completely avoided	35	24
Too technical	6	4
Other	9	6
Total	146	100

Source: Holden and Lewine, 1979.

TABLE 7
Professions of Respondents

Profession	<u>n</u>	Relative frequency (Percent)
Psychiatrists	4	4.7
Psychologists	9	10.6
Psychotherapists	12	14.1
Psychiatric Nurses	13	15.3
Social Workers	22	25.9
Mental Health Technicians	14	16.5
Crisis Intervention/Outreach Workers	2	2.4
Students in Practicum Program	8	9.4
No Response	1	1.2
Total	85	100

Note: Results are based on n = 85.

TABLE 8
Ages of Respondents

Age	<u>n</u>	Relative Frequency (Percent)	Cumulative Frequency (Percent)
21-29	38	44.7	48.1
30-39	21	24.7	74.7
40-49	11	12.9	88.6
50-59	6	7.0	96.2
60-69	2	2.3	98.7
70-79	1	1.1	100.0
No Response	6	7.1	—
Total	85	100	—

Note: Results are based on n = 85.

Minimum = 21.0

Range = 52.0

Median = 29.8

Maximum = 73.0

Mean = 33.6

Mode = 21.0

TABLE 9

**Experience of Respondents
in the Mental Health Profession**

Years Experience in the Mental Health Profession	n	Relative Frequency (Percent)	Cumulative Frequency (Percent)
1-5	46	54.1	56.8
6-10	19	22.4	80.2
11-15	11	12.9	93.8
16-20	1	1.2	95.1
21-25	1	1.2	96.3
26-30	2	2.4	98.8
31-35	1	1.2	100.0
No Response	4	4.7	—
Total	85	100	—

Note: Results are based on n = 85.

Minimum = 1.0

Range = 31.0

Median = 4.3

Maximum = 32.0

Mean = 6.4

Mode = 1.0

TABLE 10

**How Respondents Characterize the Economic Resources
Available to the Patients with Whom They Work**

Economic Resources	n	Relative Frequency (Percent)
Upper Class	0	0
Upper Middle Class	0	0
Middle Class	9	10.6
Lower Middle Class	19	22.4
Lower Class	18	21.2
Public Aid Recipients	38	44.7
No Response	1	1.2
Total	85	100

Note: Results are based on n = 85.

TABLE 11

**Preferred Theoretical Orientations of Respondents
for Understanding Mental Illness**

Theoretical Orientation	n	Relative Frequency (Percent)
Social Learning	21	24.7
Psychodynamic	24	28.2
Genetic/Biological	15	17.6
Phenomenological	9	10.6
Diathesis/Stress	7	8.2
Other	7	8.2
No Response	2	2.4
Total	85	100

Note: Results are based on n = 85.

TABLE 12

What Respondents Find to be the Most and Least Useful Therapeutic Approaches to the Treatment of Schizophrenia

Therapeutic Approach	most useful		least useful	
	<u>n</u>	relative frequency (percent)	<u>n</u>	relative frequency (percent)
Behavior/Cognitive Modification	13	15.3	4	4.7
Psychoanalysis (dynamic therapy, uncovering therapy, etc.)	3	3.5	60	70.6
Pharmacological (drug)	33	38.8	5	5.9
Phenomenological (client-centered; humanistic; gestalt, etc.)	8	9.4	3	3.5
Family Therapy	1	1.2	9	10.6
Eclectic Approach (combination of above)	22	25.9	2	2.4
Other	3	3.5	0	0
No Response	2	2.4	2	2.4
Total	85	100	85	100

Note: Results are based on n = 85.

TABLE 13

What Respondents Think are the Most to Least Important Factors
to Consider when Developing a Long-Term Treatment Plan
for the Chronic Schizophrenic Patient

Factor	Degree of Importance					Row Total
	(most) 1	2	3	4	(least) 5	
Biological Factors (e.g. drug maintenance)	<u>n</u> = 34	24	10	10	3	= 81 (4) ^a
Family of Patient (support from family)	<u>n</u> = 36	34	14	0	0	= 81 (4)
Friends of Patient (support from friends)	<u>n</u> = 0	5	15	51	7	= 78 (7)
Social/Economic Status of Patient	<u>n</u> = 7	20	35	14	3	= 79 (6)
Other	<u>n</u> = 8	0	5	1	2	= 16 (69)
Column Total =	85	83	79	76	16	

Note: Maximum total for any column or row total = 85 (n = 85).

^aNumbers in parentheses indicate the number of respondents who did not rank the importance of each particular factor.

TABLE 14

What Respondents Think are the Most to Least Important Factors Contributing to the Cause of Schizophrenia

Factor	Degree of Importance							Row Total	
	(most)	1	2	3	4	5	6		(least)
Genetic Inheritance	<u>n</u> =	21	18	11	18	7	5	5	= 80 (5) ^a
Biochemical Malfunctions	<u>n</u> =	27	21	18	8	6	0	0	= 80 (5)
Improper Diet; Vitamin Deficiency	<u>n</u> =	0	0	3	15	22	27	1	= 68 (17)
Family Influences (e.g. deviant parents)	<u>n</u> =	30	23	25	2	3	1	0	= 84 (1)
Social Pressures	<u>n</u> =	5	18	21	28	6	2	0	= 80 (5)
Labeling Someone "Schizophrenic"	<u>n</u> =	2	2	4	11	25	29	1	= 74 (11)
Other	<u>n</u> =	0	2	1	0	0	1	0	= 4 (81)
Column Total =		85	84	83	82	69	65	7	

Note: Maximum total for any column or row total = 85 (n = 85).

^aNumbers in parentheses indicate the number of respondents who did not rank the importance of each particular factor.

TABLE 15a

Amount of Contact Respondents Have with
Families of Schizophrenic Patients on
a Weekly Basis

Number of Contacts with Families Per Week	<u>n</u>	Relative Frequency (Percent)
No Regular Weekly Contact	16	18.9
1-3 Different Families	47	55.3
4-10 Different Families	19	22.4
11- or more Different Families	3	3.5
Total	85	100

TABLE 15b

**Relationship Between Respondent's Profession
and Amount of Contact with Families
on a Weekly Basis**

Profession	Amount of Regular Contacts Per Week				Total of Row
	None	1-3	4-10	11-above	
Psychiatrists	0	4	0	0	= 4
Psychologists	1	7	1	0	= 9
Psychotherapists	1	8	2	1	= 12
Psychiatric Nurses	3	7	3	0	= 13
Social Workers	2	11	8	1	= 22
Mental Health Technicians	2	7	4	1	= 14
Crisis Intervention/Outreach	0	1	1	0	= 2
Students in Practicum	7	1	0	0	= 8
Total	16	47	19	3	= 84

Note: Results are based on n = 85.

TABLE 16

Percentage of Families with Schizophrenic
 Relatives Respondents Believe are
 Satisfied with the Mental Health Profession

Percentage of Satisfied Families	n	Relative Frequency (Percentage)
0-20	16	18.9
20-40	22	25.9
40-60	27	31.8
60-80	17	20.0
80-100	1	1.2
No Response	2	2.4
Total	85	100

Note: Results are based on n = 85.

TABLE 17

Relationship Between the Sub-specialty of the Respondent and Characterizations
of Families with Schizophrenic Relatives

Profession	Characterizations				Row Total
	Negative	Positive	Ambivalent	Indifferent	
Psychiatrists (4) ^a	0	2	1	1	= 4
Psychologists (9)	3	4	1	1	= 9
Psychotherapists (12)	3	7	2	0	= 12
Psychiatric Nurses (13)	10	0	1	0	= 11
Social Workers (22)	13	4	4	0	= 21
Mental Health Technicians (14)	9	3	2	0	= 14
Crisis Intervention/Outreach Workers (2)	1	0	1	0	= 2
Students in Practicum Program (8)	4	1	1	0	= 6
	Column Total = 43	21	13	2	79

Note: Results based on $n = 79$; 6 respondents provided incomplete information.

^aNumbers in parentheses indicate the number of respondents from each sub-specialty that participated in the study.

TABLE 18

Relationship Between the Theoretical Orientations of Respondents and Characterizations of Families with Schizophrenic Relatives

Theoretical Orientation	Characterizations				Row Total ^a
	Negative	Positive	Ambivalent	Indifferent	
Social Learning	13	4	1	0	= 18
Psychodynamic	12	4	7	1	= 24
Genetic/Biological	3	8	3	1	= 15
Phenomenological	6	3	0	0	= 9
Diathesis/Stress	5	1	1	0	= 7
Other	3	2	1	0	= 6
Column Total ^b =	42	22	13	2	79

Note: Results based on n = 79; 6 respondents provided incomplete information.

^aThese totals indicate the number of respondents who preferred each orientation.

^bThese totals indicate the number of respondents who characterized families in the noted manners.

TABLE 19

Relationship Between the Etiological Assumptions of Mental Health Professionals
and Their Attitudes Toward Families with Schizophrenic Relatives

Primary Causal Factor	Attitude of Mental Health Professional				Row Total ^a
	Negative	Positive	Ambivalent	Indifferent	
Deviant Familial Influences	16	6	5	0	= 27
Biochemical Malfunctions (e.g. excess dopamine)	8	10	5	2	= 25
Genetic Inheritance	13	6	2	0	= 21
Social Pressures	1	2	0	2	= 5
Labeling Someone Schizophrenic	1	1	0	0	= 2
Diet/Vitamin Deficiency	0	0	0	0	= 0
Other	0	0	0	0	= 0
Column Total ^b =	39	25	12	4	= 80

Note: Results are based on $n = 80$; 5 respondents provided incomplete information.

^aThese totals indicate the number of respondents who regarded each factor as the primary cause of schizophrenia.

^bThese totals indicate the number of respondents who characterized families in the noted manners.

Appendix A

Schizophrenia Survey for Mental Health Professionals

On the following pages you will be asked various questions regarding your perspectives on the cause, diagnosis, and treatment of schizophrenia. Please note that there are no correct or incorrect answers. Rather, we are interested in your views. After the data from this survey have been recorded, these pages will be destroyed. Your responses will thus, remain completely anonymous. Thank you for your cooperation.

Section 1

General Information

1. Profession: _____ Sex: M/F Age: _____

2. Years of experience in the mental health profession: _____

3. How would you characterize the economic resources available to most of the patients with whom you work?

 _____ Upper class

 _____ Upper middle class

 _____ Middle class

 _____ Lower middle class

 _____ Lower class

 _____ The majority of patients are on public aid.

4. What is the approximate percentage of schizophrenic patients in your case load?

 _____ 0-20%

 _____ 20-40%

 _____ 40-60%

 _____ 60-80%

 _____ 80-100%

Section II

Theoretical Orientation and Therapeutic Approaches

Please mark only one response for each of the following questions. Each question will be followed by a space for you to make any comments if you wish to do so.

5. Your theoretical orientation toward mental illness can best be characterized as:

_____ Social learning

_____ Psychodynamic

_____ Genetic/Biological

_____ Phenomenological

_____ Diathesis/Stress

_____ Other (Specify): _____

Comments: _____

6. The single therapeutic approach you find most useful in the treatment of schizophrenia is:

_____ Behavior/Cognitive modification

_____ Psychoanalysis (dynamic therapy, uncovering therapy, etc.)

_____ Pharmacological (drug)

_____ Phenomenological (client-centered; humanistic; gestalt; etc.)

_____ Family Therapy (specify): _____

_____ Eclectic approach (specify): _____

_____ Other (specify): _____

Comments: _____

7. The single therapeutic approach you find least useful in the treatment of schizophrenia is:

- Behavior/Cognitive modification
- Psychoanalysis
- Pharmacological (drug)
- Phenomenological (client-centered; humanistic; Gestalt; etc.)
- Family Therapy (specify): _____
- Eclectic approach (specify): _____
- Other (specify): _____

Comments: _____

Section III

The Treatment and Cause of Schizophrenia

Please respond to the following questions as completely as possible. Again, space is available for you to make any comments.

8. Which of the following factors must be considered in the treatment of schizophrenia? (mark as many factors as necessary to make your response complete)

- Biological factors
- Family of patient (parents, sibs, spouse)
- Friends of patient
- Social and economic status of patient
- other (specify): _____

Comments: _____

9. Please rank in order the following factors from most to least important when considering the long term treatment of a patient's schizophrenia. (Number 1 equals most important, number 2 equals next important, etc.)

- _____ Biological factors
- _____ Family of patient (parents, sibs, spouse)
- _____ Friends of patient
- _____ Social and economic status of patient
- _____ Other (specify): _____

Comments: _____

10. Which of the following factors most contribute to the cause of schizophrenia? (Mark as many factors as necessary to make your response complete)

- _____ Genetic inheritance
- _____ Biochemical malfunction (e.g., enzyme deficiency)
- _____ Isoper diet; vitamin deficiency
- _____ Early influences (deviant parent)
- _____ Social pressures (crowding, noise, etc.)
- _____ Labeling (e.g., "schizophrenic," "deviant," "low level")
- _____ Other (specify): _____

Comments: _____

11. Please rank in order the following factors according to what you believe to be the most to least important factor contributing to the cause of schizophrenia? (Number 1 equals most important, number 2 equals next important, etc.)

- _____ Genetic inheritance
- _____ Biochemical malfunctions (e.g., excess dopamine)
- _____ Improper diet; vitamin deficiency
- _____ Family influences (e.g., deviant parents)
- _____ Social pressures (job, economy, etc.)
- _____ Labeling someone "schizophrenic"
- _____ Other (specify): _____

Comments: _____

12. Please indicate the primary reason why you selected the above factor in question 11 as the factor most contributing to the cause of schizophrenia:

- _____ Reading current literature
- _____ Experience
- _____ Training
- _____ Other (specify): _____

*If you selected "reading current literature", please list the names of several journals you had read that most contributed to understanding schizophrenia: _____

Comments: _____

Section IV

Practices of Mental Health Professionals

Please provide complete answers to the following questions.

Circle Yes or No for questions that require such a response. Space to make any comments is available following each question.

13. How much contact do you have with the families of schizophrenic patients?

- *No contact
- Seldom (1-3 different family contacts per week)
- Regular (4-10 different family contacts per week)
- Frequent (11- and above)

*If you marked this response, please replace the underlined "do you" portions of the following questions (14-21), with the words "would you".

Comments: _____

14. Yes/No During your interactions with families who have a schizophrenic relative, do you regularly provide information about schizophrenia to them?

Comments: _____

15. Yes/No? Do you regularly provide answers to any and all questions from the families of schizophrenic patients who have asked you their family member's schizophrenia symptoms and/or side effects which you are capable of answering?

*If you answered No to this question, indicate the type of questions you prefer not to respond to:

- Questions about symptoms
- Questions about the disease "schizophrenia"
- Questions about outcome
- Other (specify): _____

Comments: _____

16. Yes/No* Do you regularly provide information and answers to any and all questions the families of schizophrenic relatives may have about their family member's therapy and medication (questions which you are capable of answering)?

*If you answered No to this question, please indicate the types of questions you prefer not to respond to:

_____ Questions about specific therapeutic techniques

_____ Questions about the effects of medication

_____ Other (specify): _____

Comments: _____

17. Yes/No Do you regularly provide families of schizophrenic patients with information regarding your beliefs about the cause of their relative's schizophrenia?

Comments: _____

18. Yes/No Do you regularly provide families of schizophrenic patients with practical suggestions on how to manage their schizophrenic relative at home?

Comments: _____

19. What percentage of families with schizophrenic relatives do you believe are satisfied with their contact and experiences with mental health professionals?

0-20%

20-40%

40-60%

60-80%

80-100%

Comments: _____

Section V

Families with Schizophrenic Relatives

Please answer Yes or No to the following questions, and then elaborate upon your answer as much as possible.

20. Yes/No Have you found that many parents feel guilty about causing their child's schizophrenic condition?

Comments: _____

21. Yes/No Do you think that the needs of families with schizophrenic relatives are given adequate attention by mental health professionals?

Comments: _____

Section VI

Attitudes

Please provide brief answers to the following questions.

22. How would you characterize most parents who have a schizophrenic child?

23. How do you personally feel about parents who have schizophrenic children?

24. How do you feel about families with schizophrenic relatives organizing self-support groups to discuss issues and participate in activities of interest to them?

25. Any final comments?

Thank you for your participation.

Appendix B

views

At last, my tormented son is at peace

William York Newman
New York Newman

THE NOTICE OF my son Fred's death has appeared in this paper. The official cause of death was a ruptured aneurysm, but the real cause was a crippling disease of the brain known as chronic paranoid schizophrenia.

This devastating, cancer-like, biochemical imbalance of the brain is generally brought to the public's attention only in terms of sensational headlines when it is described as the illness that haunted "Son of Sam" or John Hinckley or John Lennon's murderer.

IN ACTUAL FACT, there are over a million schizophrenics in this country who have never killed or harmed anyone, and who are themselves horrendously victimized—for they are the ones who constitute the vast bulk of our mental patients, who cannot be cured, and who in an agony of loneliness have not been meaningfully deinstitutionalized when referred to a community setting.

Although I have spent the last three years and more working full time as a professional volunteer in the field of mental health, it is as a grieving parent that I now write.

As a parent whose grief is now acceptable and understood because a physical death has occurred, and who thus no longer has to grieve year after year in private or with a few understanding friends

As a parent who has watched a handsome, gentle, intelligent, maturing child lose all contact with reality and ultimately live like a hunted animal in dark, cold crawl spaces and attics, unable to care for himself in any way, unable to speak coherently, unaware of who he was or even that I was his mother

As a parent who sought help around the country and who, after expending all reasonable private financial resources and after exhausting all the best professional expertise, had to depend on state facilities for care

As a parent who watched her son go through 14 hospitalizations in less than five years and who often had to suffer with her son the



FRED YORK

'There are over a million schizophrenics in this country who have never killed or harmed anyone, and who are themselves horrendously victimized.'

indignities of the commitment process

As a parent who had to listen to well-meaning friends and family offer suggestions and ideas that were incorrect and only served to increase the feeling of helplessness and aloneness

As a parent who has known unfair moments of hope when a medication seemed to work for a little while or when her son was coherent enough to be released to a community that did not want him and did not understand him

As a parent who has seen her son raped, physically beaten, repeatedly robbed and victimized when out in the community and not under 24-hour surveillance

As a parent who has known great fear and slept with a knife under her pillow when the raging and hallucinatory angers of her son turned violent and she feared he might harm himself or others

And as a parent who has suffered overwhelming guilt and who has watched a family torn apart in despair and accusations.

But now my son is dead. He died in his sleep in a mental hospital.

Now all those who loved him can grieve and remember the days of his youth and gentleness.

No more will he beat his head bloody in an attempt to drive out the demons, no more will he have to suffer the terrible inadequacies of our care and knowledge, for he is finally at peace.

IF SOME OF YOU who read this will try to understand and will try to see that energy and funds are directed toward research that will someday eliminate this terrible disease, and if you will understand in the meantime that there is a great need now for humane, decent living conditions and care on many different levels for those who must suffer until a cure has been found, then all those parents who grieve for years in silence and those who suffer the fires in their mind will not endure a continuing despair.

We ask for compassion and for understanding, for only then can there be hope.

Gwyl York Newman lives in Chicago and is a trustee of the Brain Research Foundation at the University of Chicago.

MY BROTHER JOHN



Many families have a relative who is "different." My brother John is like that. When I was young, he protected me, but now it's my turn to help him. This is the story of our battle with his mental illness—a struggle few talk about but millions share.

My brother John is tall and skinny, with thick wavy brown hair, handsome features at the top and big feet at the bottom. Somewhere in John there exists a gentle spirit; you can read it in his large brown eyes. But sometimes just the sight of him makes me feel pain.

One such time I recall was Christ-

mas Eve, 1975. I had flown from New York to Georgia that day to spend the holiday with my family, and had just driven the 40 miles to a state mental hospital to pick up John. He suffers from chronic schizophrenia, a mental disorder characterized by separation of emotion and thought, by hallucinations, delusions and bizarre behavior.

John had already spent more than a decade at the hospital, and during visits I had noted the physical and spiritual erosion caused by both illness and institutionalization. Looking at him that afternoon, I had to fight back tears.

John was underweight to the point of appearing emaci-

ated. Torn and mismatched clothes hung from his stooped shoulders, and too-short pants barely covered his shins. Something black and odious was encrusted on an ankle. John smelled as though he hadn't had a bath in days. His bare feet were crammed into shoes that were too small, causing him to walk stiff-legged, and there was a haunted look in his eyes.

John slept all of Christmas Eve and Christmas Day. "Got to sleep," he pleaded when we asked if he wanted to help decorate the tree. He ate only a little of the food we took him on a tray, and his presents remained in a neglected pile under the tree. Perhaps John had received too much medication. Perhaps he was exhausted from sleeplessness. Or perhaps he had no spirit for merrymaking.

Today John is 41. His condition is chronic. Periodically he regresses, often the case with schizophrenic cyclical syndrome of regression and remission. When my brother is at his worst, he hallucinates, speaks incoherently, is ambiguous about his needs, and has a total lack of motivation.

Although today John is an inmate in a state mental hospital, his sister visits him often so they can play softball, walk, talk, be together and dream of the day when he'll be able to live in the community once again.

MY BROTHER JOHN

continued

such as cigarettes and soap, loses control of his bladder, vomits when he is upset, and distrusts people.

If you had told me when I was growing up that my brother was going to end up in a mental hospital, I would have thought that you were crazy. As children, John and I relied on each other for companionship. John, the older by four years, was expected to take care of me—see that I wasn't kidnapped or make sure that I didn't drown at the pool.

Although he rarely applied himself in school, he managed to get by with little studying. One of his teachers even told our parents that John had a very high I.Q.

Then, when John was 17, the police brought him home late one night. He and some fraternity brothers were caught stealing hubcaps as a prank, but it was a prank that misfired. They endured an emotionally grueling trial and were put on probation for a year. John never talked to me about this, but I knew how guilty he felt about "having let the family down" and "having marred [his] reputation."

John's withdrawal was so gradual that no one noticed at first. Quiet by nature, he became even more so. School became difficult, and he barely made it to graduation. After a semester of college, he dropped out. Back home, John became a health food freak and a religious fanatic. He became weird before it was a popular thing to be. John fought with Mother and Dad. He told the minister to go to hell. Trying to talk to him was like talking to a brick wall. He felt no one loved him and that he loved no one. Life was pointless. John was angry—angry over the rejection, the failures, the emotional hardships.

He disappeared into the woods for days at a time, and, like a frightened animal, avoided everyone. Then one evening, he came to the dining room window and begged, "Please, Daddy, help me. I'm so sick."

I was terrified. I didn't know what was happening to John. The older brother whom I had tagged behind for years was ill, but I didn't understand his sickness, or how to help him.

A psychiatrist was consulted. He advised putting John in the state hospital. "It's going to take a long time and a lot of money to get your son well." And that's where John's chances for getting well may possibly have ended.

At first, John came out of the hospital for months at a time; then he'd have to go back. Sometimes he'd go willingly; sometimes he'd have to be taken by the police.

Early in his illness, he biked to Al-

aska and homesteaded there for nine months before having another breakdown and returning to Georgia, where he entered the hospital. The shock treatments frightened him, and the drugs made him so groggy that he could barely talk. Over the years, as his condition worsened and he failed to respond to a long list of psychotropic drugs, hopelessness set in, and John was shunted to the back ward.

There, John was physically abused, raped and put in isolation when he rebelled. He was provided with shabby clothing (his own was stolen), was allowed to develop nicotine poisoning (caused by eating cigarette butts), and developed a heart condition, which we were never informed of. At one point both his arms were broken—we were never able to find out how.

Instead of being cared for, John's body was horribly abused, and his spirit broken. John is six feet two inches tall, but his weight dropped to only 130 pounds. Many of his teeth decayed, and his arm shook from the side effects of medication. I was afraid John was dying. He told me, "I'm already dead."

I remember our weekend visits to John, the feelings of shame, the re-annihilation over whose fault it was that John had become mentally ill—a paranoid schizophrenic. John had threatened our parents and they were afraid of him. They asked me not to mention his illness and I didn't, even when my sociology class took a field trip to the hospital, and I was terrified we would bump into John on one of the wards.

The pain we both felt

I know the pain that I felt—that I still feel—and can only imagine John's to be a hundredfold: the bewilderment, the neglect, the ostracism by society, the rejection by friends and family members. The loss of personal freedom, of self-esteem. And to top it off, the incredible shock of finding that your mind doesn't work properly, that thoughts no longer connect, that you see rabbits on top of someone's head, and from somewhere in your past, you know that's not supposed to happen.

In the mid-70s, with my parents both elderly and my father's health failing, I felt John had become my responsibility. I began researching Dad's insurance policy, and looking for private hospitals in New York, where I was working as a free-lance writer. After more than a year of negotiating, New York Hospital in White Plains agreed to accept my brother to determine whether a newly formed program for chronic schizophrenics would be an effective one for him. John was put through weeks of testing and treatment, only for us to be told in the

end that our insurance company had changed its coverage and now had a \$20,000 limit, which would soon be used up at the \$250-a-day hospital.

No one agreed on where John should go when his insurance ran out. New York Hospital said, "Back to Georgia." I said, "No." New York Hospital suggested a nearby state hospital. I said, "No, they're all alike." I suggested, "Home with me. I'll take him." New York Hospital said, "No!"

Bringing John home

I applied for guardianship, but I knew that bringing John home would be excruciating. Everyone had said so—my lawyer, psychiatrists, social workers, friends. I remembered the warning of John's psychiatrist, Dr. Herbert Saltzman: "You can't keep your brother at home. There's no way you can help him get better. I've seen it fail even with wealthy families who could afford round-the-clock attendants. You'll make your life miserable; you won't be able to work, and you and your brother will end up on welfare."

Everyone seemed to be thinking of me, no one was thinking of John and the poor chances he'd have of ever getting well in a state hospital. And at the court hearing, the judge ruled in favor of New York Hospital's request—that John be transferred to Rockland Psychiatric Center, a state facility.

Ten days after his transfer, John told me, "You shouldn't leave me here." I applied for a second hearing and five months later became John's guardian.

John's first week home, in July 1978, turned out to be a nightmare for me and an extended anxiety attack for him. Every bar of soap in the house contained his teeth marks; he drank water until he threw up, and his hyperactivity took him all over the house, with me dogging his heels. I even timed my trips to the bathroom to coincide with his so he wouldn't wander away. John laughed incessantly, talked incoherently and wet the bed endlessly. One morning I awoke at one-thirty to discover the back door ajar and John striding away into the dark. "Where are you going?" I called in my loudest whisper so I wouldn't wake the neighbors. "Taking a walk, taking a walk," he replied. "Come on," I urged. "I'll fix you some warm milk." Warm milk proved a remedy for John's insomnia; however, it didn't cure mine.

John was enrolled in the Rockland Community Mental Health Clinic in nearby Yonkers, an out-patient treatment center funded by the state, which offered a day rehabilitation program for people trying to make the transition from hospital to community. After his first day there, John came

(continued on page 120)

MY BROTHER JOHN

continued from page 38

home so high from eating cigarette butts that he ran out onto the roof of our house nude from the waist down (Thank God it was a foggy day!) The second day when I arrived to pick him up, I was told, "Your brother disappeared an hour ago." It took three harrowing hours to find him—in another village, ten miles away.

By the third day, John was threatened with expulsion from the program if he didn't settle down, stop eating cigarettes and start acting better.

At home, I was unrelenting, talking long and hard to John about his behavior. "They're warning you to either shape up or ship out," I yelled. "Shape up or ship out," John echoed vaguely and stared off into space. Lonely and frightened by the new pressures of living outside a hospital, John felt rejection because of his craziness. For 17 years it had been the norm. Now he had to relearn all the modes of social behavior. John thought that getting out of the hospital meant that he was well. He hadn't realized that he was going to have to work at getting well, and that it would be so difficult.

John's behavior caused me embarrassment. In grocery and bank lines people stared as he compulsively rocked to and fro or knocked impatiently on the counter. I cringed inwardly at their disgusted looks when John snatched cigarette butts off the floor and popped them in his mouth. At the same time, my behavior caused John anxiety. Once when I was yelling about his eating cigarettes, he turned to me, his eyes large with concern, patted my shoulder and said, "Calm yourself, calm yourself."

At times I adopted the attitude of an army sergeant with a new recruit; at times I mothered John, tucking him in at night and holding his hand when we crossed the street or walked in crowds, which made him nervous. After their initial threat, the staff at the center leaned over backwards to help John fit into the program. He was the most childlike member of the group, and everyone took part in making him feel welcome, keeping him out of subways and seeing that he didn't wander away from the center.

Gradually John shed some of his antisocial behavior; he moved from the center of the floor in group therapy to a chair in the circle, and later he even commented occasionally. He danced at the Friday afternoon socials and learned how to be a dinner guest. He learned to use the laundry machines, wash the floor, make his bed and

a repertoire of jumping jacks, sit-ups, push-ups and sometimes jogging. We read aloud the poetry of Robert Frost, Emily Dickinson and Samuel Taylor Coleridge. We occasionally cooked together, took photographs, worked on simple math and spelling, painted with water colors, or drove to Manhattan to have a look around. John was unprepared for this rigorous routine, and at one point he asked, "Don't you ever give up?" He was used to people giving up on him, frustrating them until they just left him to be crazy.

We sold our house and moved to an apartment in Yonkers, near the center. Even though John received Supplemental Security Income and Social Security, it was not enough to pay for his therapy, medication, rent and food, or to keep him in clothes, haircuts, movies and magazine subscriptions. I figured it out once, and it came to about \$800 a month. John's federal aid amounted to \$268 a month.

Part of the profit from the sale of the house went for expenses and part went to buy a small plot of land located on the Croton River, half an hour north of us. Clearing the land and planting gardens became John's work therapy. He'd always wanted a farm—this was the best we could afford.

John was also enrolled in a number of other therapies: orthomolecular (megavitamin) therapy, art therapy and swimming therapy at the Yonkers Y.M.C.A. Together, we took a course in organic gardening, attended movies, museums and outdoor festivals.

Trying—and succeeding

By now, John had lost his institutional stoop. The pelvic rock was gone and so was the inappropriate laughter. He was trying to make more sense—and succeeding. He was off heavy medication, except for a small dose of Lithium, which he began taking 14 months after coming home. John had long ago stopped wetting his bed and throwing up. He no longer told me he was dead. Sometimes he even said, "I'm alive," flexing his muscles a bit.

Along with progress there was regression any time John experienced a lot of stress. There was the time I was sick in bed with the flu for a couple of days, and although John was fed, he had to take care of his other needs. When I finally crawled out of bed, he was highly indignant at having been ignored, so much so that he defecated in the shower, took off his bathing suit during swimming therapy, was uncooperative with everyone and by the end of the week was jumping up and down on the living room floor.

I explained to John that no one can

take on more responsibility for yourself," I urged. "If you got sick and stayed in bed, I wouldn't take off my bathing suit in the middle of the pool, would I?"

"No, I guess you wouldn't," replied the contrite John.

There also were times when John's awareness shocked everyone. Like the time our canoe turned over in the middle of a lake, and when John resurfaced, he yelled to me, "Grab the life jackets!" Just like my older brother of years ago, ordering me around. I was so startled by his coherence that I couldn't grab anything.

Ready for change

For more than a year now it had been evident that John was ready for a change. He was bored with the Yonkers program. He needed more contact with peers, and the supervision of a man—someone he could emulate and be a pal with. He needed more activity than I could give, and I could see he was frustrated.

During the last half of 1980, John's frustration became unbearable for him and everyone else. By mid-summer he had wandered off into the crowd twice at Jones Beach, disappeared in New York City and struck out at me a number of times. By summer's end he was stomping determinedly into the ladies' room at the center despite the warnings of the staff, and was incontinent again. By mid-autumn I had a couple of black eyes, and by the end of the year I had stitches in my upper lip.

Friends asked me, "What keeps you going?" What kept me going were John's successes. There was his first train ride in five years, his ability to sit through the movies, his renewed strength, his courage to yell back in anger. Faith was another source of strength; I was constantly asking God, "Please, just get me through this one." I guess I believed that miracles can happen. They just take a lot of work.

John's condition continued to plummet. Then one Sunday in March of last year, as we were getting ready to drive out to the beach, John, who had been acting agitated all morning but couldn't say why, struck out at me again. Finally, I realized that I was no longer helping him, that I could no longer protect his safety when he wandered off, or mine when he hit me. We had reached a dead end: Either I had failed to connect with sources of help, or else they just didn't exist.

Dr. Dennis Gorotaky, a New York psychiatrist, told me, "Psychiatry is in a period of decline; there's not much dedication anymore. Funds are being cut, and doctors must now care for

With John back on the ward at Rockland Psychiatric Center it was the same old story. "He always wants to hug me," said the social worker. "He likes to be hugged," I told her. "He doesn't participate," said the doctor. "He needs to be encouraged to take part—he's never wanted to participate; he's afraid he'll fail," I told him.

I wonder how long it will take for us to understand that a great deal of caring and common sense must be infused into the mental-health care system before it will work. Why do we treat the disease instead of the patient. Or forget that the mentally ill need love as much as normal people? They need to have decent clothes and

normal hairstyles to raise their self-esteem. They need an enormous amount of encouragement to overcome the fear of failure and rejection.

What does the future hold for John? Once, when I asked him that, he replied, "The future holds possibilities for every opportunity I can think upon." I haven't asked John lately, and I don't know the answer right now. I do know that John has a goal—to own a little farm. And I have encouraged him to hold fast to this dream because it will give him something to focus on, a reason to get well.

At the same time, I have my own dream—of starting a residential farm for John and others like him, and of

insuring that he doesn't spend the rest of his life in an institution. I keep thinking that a fluke of the genes could have reversed our situations . . . that I could have been the one in the institution waiting to get out. If that were the case, I'd want John out there looking for some answers for me.

I remember saying to John not long after he returned to Rockland, "Please try to get better. It makes me sad for you to live here." He waited quietly for me to dry my eyes then we continued hiking around the grounds. When I left John at the ward door, he put his hand on my shoulder and said, "I'll always love you." It was the only coherent thing he said all afternoon.

THE MENTALLY ILL: The Sad Facts, The New Hopes

Mental illness is the number one cause of hospital admissions in this country, and schizophrenia alone fills one-fourth of all hospital beds—more than cancer, heart disease, diabetes and arthritis combined.

According to the National Institute of Mental Health, some 32 million Americans suffer from some form of mental illness, which costs the country \$20 billion in care and treatment annually and another \$20 billion in lost productivity. And each year, more than a million and a half people—young and old, rich and poor, well educated and illiterate—become patients in psychiatric facilities. In women, one in five is affected by depression, the most common of mental diseases. Of men, one in ten.

In recent years, tremendous advances have been made in using drugs to minimize the symptoms of mental illness, but in place of symptoms have come the drugs' serious side effects, such as erratic movements, polay-like shaking, or a kind of stupor.

Other factors in the mental health system seem to work against a patient's progress as well. Perhaps the major difficulty is money. Even the wealthy find that cash runs out when private hospitals charge an average of \$167 to \$247 per day. "In the mental health system, everyone is indigent," says Shirley Starr, president of the National Alliance for the Mentally Ill. And you can't count on insurance or even Medicare to pay the bills. The latter, for example, pays for only 180 days of hospitalization out of the many years that the chronically ill may spend in psychiatric hospitals.

Then there's the dilemma of de-institutionalization. Theoretically, the movement to get patients out of the hospitals is a good one. With community services, a former patient can be cared for at about half the in-

patient hospital cost. And a patient has a much greater chance of improving when out in the "real world" as opposed to a hospital ward.

That's the theory, but it falls far short of the reality. Many communities haven't been able to support the exodus from hospitals. Although some former patients have found excellent mental health programs, many more have suffered—and continue to suffer—in slum-like halfway houses, where they are the victims of criminals and of their own inability to care for themselves or to regulate their medication. Community programs have never been adequately funded, have served only a fraction of the people who need them and seem headed for budget cuts in 1982.

There are, however, some signs of hope. A handful of communities do have programs that work. At New York City's Fountain House, former mental patients learn a variety of skills and are then placed in jobs with corporations like Chase Manhattan Bank, Sears Roebuck or Macy's. Today, the former patients can boast of combined annual earnings of \$62,000.

At the Jackson County Mental Health Alternative Support Program in Oregon, community volunteers are matched with clients, then encouraged to find activities of mutual interest to forge emotional bonds.

The Montana Community Support Project discovered that it could attract students, business executives and retired people to volunteer up to ten hours a week to teach clients bike riding, penmanship, basic housekeeping techniques and other useful skills.

Perhaps the best hope for the future lies in the area of scientific research, which continues to uncover new and exciting information about the mind and how it works. In addition to developing new drugs that can

help the mentally ill without side effects, scientists are trying to determine whether there is a genetic link in illnesses like schizophrenia and depression, and are exploring ways to repair the malfunctioning brain through biochemistry and tissue transplants.

This is only some of the work that should give hope to the mentally ill and their families if funding isn't slashed too severely. But these are solutions that are still in the future. In the meantime, the mentally ill must rely on their advocates . . . and more and more frequently their families and themselves.

"We're encouraging patients to join together to give support to each other," says Judi Chamberlin, a spokesperson for the Patients' Liberation Movement, who spent a number of years in mental hospitals. She and others believe that patients and their families do have rights. Here are some sources:

- The National Alliance for the Mentally Ill, 1234 Massachusetts Avenue, N.W., Washington, D.C. 20005, telephone (202) 783-6393, has begun a number of projects to help link families to services and to educate the public about the chronically ill. Bi-monthly newsletters are available: \$10 for individuals, \$15 for families.
- Project Release, Box 9, Bayside, N.Y. 11361, is a consumer group that has compiled a free resource guide to patient-controlled alternatives to the mental health system. To receive a copy of *Alternatives*, send a stamped, self-addressed envelope. For a copy of the group's *Consumer's Guide to Psychiatric Medication*, which details side effects of commonly prescribed drugs, send \$2.50 to the above address.
- The American Civil Liberties Union, 132 W. 43rd St., New York, N.Y. 10036, offers a paperback handbook, *Rights of Mental Patients* (\$1.75).