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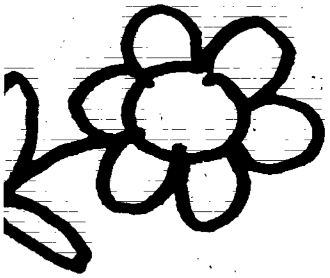
ABSTRACT

Science Monographs, published by the National Institute of Mental Health, are book-length, integrative state-of-the-art reviews, critical evaluations of findings, or program assessments of current research on topics related to the NIMH mandate. This set of articles concentrate on mental illness in the family. "Depression and Low-Income, Female-Headed Families" describes an intensive project involving low-income single-parent and married mothers of young children. "The Mentally Ill at Home: A Family Matter" explores the practical, humanitarian and theoretical issues of mental illness and the consequences of mental illness for patients' families. "Heredity and Mental Illness" investigates research confirmations of an important hereditary element in schizophrenia and depression. "Poor Family Communication and Schizophrenia" stresses the importance of family relationships as factors in schizophrenia and its prevention. "Detection and Prevention of Childhood Depression" describes ways investigators detect masked depression, acute, and chronic depressive illnesses in children and presents methods of treatment. "New Light on Autism and other Puzzling Disorders of Childhood" discusses research findings in autism and other developmental disabilities. "Basic Training for Parents of Psychotic Children" describes the Training and Education of Autistic, Psychotic and Related Communications Handicapped Children (TEACCH) program for parents. (NRB)

families today

a research sampler on families and children

Eunice Corfman, Editor, NIMH



mental illness in the family

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Families Today

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- *Science Monographs* are typically book-length integrative state-of-the-art reviews, critical evaluations of findings, or program assessments of current research on a selected topic related to the NIMH mandate.
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DEPRESSION AND LOW-INCOME, FEMALE-HEADED FAMILIES

Principal Investigator: Deborah Belle, Ed.D., et al.

Author: Eunice Corfman, NIMH

Not often, but on occasion, a research project is undertaken on the cutting edge of an urgent social issue where "something must be done," even though the knowledge base is not yet secure enough to show clearly what that "something" should be. The Stress and Families Project is such an undertaking. Initially under the direction of the late Dr. Marcia Guttentag, this cross-disciplinary team of women researchers is now under the direction of Dr. Deborah Belle at Harvard's Graduate School of Education.

The Stress and Families Project deals with several urgent social issues that have kindled passion and reaction over the last decade. One is the role of women, an issue formulated, explored, and developed mostly by white middle-class women, but here extended to both white and black low-income women. A second is the cultural phenomenon of depression characterized as "the 70s illness," as anxiety was said to belong to the 60s. Related to both is the common but debated finding that far more women suffer from depression than do men. Still a fourth issue is the specialized but tantalizing one that, like oil and water, research and activism do not mix. And last is the social reality of increasing numbers of low-income female parents who are rearing their children alone and the social issues of what this bodes for them, their children, and society.

To approach this knot of social issues required a broadly conceived research scheme and a broadly scaled research program spaced over several years. Much of the original scheme was conceived under the tutelage and with the driving spirit of Dr. Guttentag. With her sudden and unexpected death, her colleagues' task was the conversion of grief to an abiding commitment to carry the work to its conclusion.

A somewhat special spirit has marked development of the research design and also the relation of the colleagues to each other and to their respondents. The term "sisterhood" is a wan and still awkward expression for the close and interdependent collaboration of the extended team of researchers specializing in different aspects of the project. One outcome of the women's movement has been to question the necessity of a hierarchy or pecking order for the efficient execution of a large and complicated enterprise. The team does not have one. Moreover, in the second phase of the research scheme, a series of intensive interviews with a selected number of low-income families, the team has consistently invited their respondents to share in the collaboration. In part this may be women's movement sisterhood, but it is also a deliberate function of the research objective and design: In human research, gaining the intimacy and trust of subjects may be a precondition for authentic, true responses. In intervention research, trusting the subject's capacity to know what's needed can be an important guide in the research design of interventions.

The research scheme may be divided into three phases. In the first phase a study was undertaken to investigate the validity of the common understanding that many more women suffer from depression than do men and to see why this might be so. One outcome of this investigation was the finding that disproportionately large numbers of low-income, single-parent mother and low-income married mothers of young children were depressed. This led to a second phase of the research scheme, an intensive investigation of a small sample of these mothers, using a combination of recently developed questionnaires, observations, and open-ended interviews. These were designed to elicit what could be learned about the primary causes of such depression and what intervention strategies might be likely to succeed.

Toward the close of this second phase, a conference was held at the Aspen Institute for Humanistic Studies in Aspen, Colo. The activist commitment of the project became explicit as the team described the project in careful detail to invited participants from the worlds of journalism and the mass media, the Federal bureaucracy, national and State legislatures, and the academic community. The participants were asked in turn to publicize the problem, critique what had been done, and realistically appraise the political, legislative, and program difficulties in actually bringing about effective interventions. The third phase of the research scheme is still ahead. It has two parts. The first will be a follow-up to the second phase intensive study, to confirm many of its leads. The second will be to test a selected number of interventions in the light of the advice from Aspen and of findings from the follow-up study.

It is a long and sustained march the team has undertaken, ambitious in its variety of goals and challenging in requiring control of the tensions introduced by trying to satisfy all of them—the rigor of practicing science, the commitment of finding ways to mitigate a painful social condition, the bonding to women who need help.

THE FIRST PHASE

In the early 70s, one consequence of the rising consciousness and sense of outrage of militant feminism was a claim by Phyllis Chesler in a book for the general reader, *Women and Madness*, that in the area of mental health women are blatantly misdiagnosed and mistreated (1971). Much of the evidence offered was anecdotal, based on individual interviews, and some of the statistical data on in- and out-patient populations do not support the claims made from them.

At about the same time a study of Gove and Tudor (1973, p. 823) concluded that "All of the information on persons in psychiatric treatment indicates that more women are mentally ill." The claim was made not only in the sense that more women were becoming mentally ill, but also in the sense that more women than men are mentally ill. While the claim in the first sense was statistically supported, the claim in the second sense rested on an extremely narrow definition of mental illness that excluded diagnostic categories such as alcohol disorders, drug disorders, organic brain syndromes, personality disorders, and transient situational disorders of childhood and adolescence, in all of which men predominate.

In truth, not enough was known about the relation of women and mental health to be able to separate fact from mere assertion. Hence, the first phase of the study singled out this problem as a place to begin. A collaborative study was conducted by Harvard University and the National Institute of Mental Health, called the Women and Mental Health Services project, and the Co-Directors were Marcia Guttentag at Harvard and Susan Salasin, the project officer at NIMH. Statistical data provided by NIMH's Division of Biometry and Epidemiology included trend data on sex differences in utilization rates and data on use of community mental health service facilities. This was added to the data on use by women and men of State and county mental hospitals, publicly supported facilities, and private psychiatric treatment, out- and inpatient care in general hospital psychiatric units and in private mental hospitals.

All these sources of statistical data were brought together and analyzed to see whether there are sex differences in the use of mental health services and in what categories of illness such differences may occur. But this only indicated the data for people seeking treatment. It did not indicate the sex differences and prevalence of these illnesses out in the general population. The latter would be needed, too, in order to decide what the problems were, how large, and then what might be done about them. So to the data analyses of use of services were added reviews of the epidemiological literature on prevalence and incidence of mental illness, both nationally and internationally.

Findings

Women and Depression

Women are more likely to be depressed than men. Epidemiological studies show that more women than men show symptoms of depression, and utilization rates show that women have a much higher rate of treated depression than do men. Among women, nonwhites generally show higher rates of mental illness than do whites. The highest rates are found among separated or divorced men and women. Among women the highest rates are in the 25-44 age group. Among married women depressive symptoms are most common among women who have no children or women whose children are living with them. Older women, whose children have left home, do not show such high mean depression scores. The percentage of women and men diagnosed as having personality disorders, neurosis, and schizophrenia are roughly equivalent, yet twice as many women as men are diagnosed as suffering from *depressive* disorders (Redick 1974). These peak for women in the the 25-44 age group. Depression is the leading diagnosis for women, except in State and county mental hospitals, where schizophrenia is first. In contrast, for men, alcoholic disorders, schizophrenia, and personality disorders, in that order, are the leading diagnoses for State and county mental hospital admissions, and schizophrenia and personality disorders in community mental health centers. In developed nations mental health utilization figures show significantly greater numbers of depressed females than males (Weissman 1975). Nearly all studies of treated cases of depression show a marked increase in young females diagnosed as depressed during the past two decades. Recent epidemiologic studies confirm the preponderance of depressed women (Radloff 1975; Pearlin 1975).

The rate of depressive disorders seems to be increasing. In 1971 the single diagnostic category with the largest number of additions was "affective and depressive disorders." It is the leading diagnostic category for both white and nonwhite women. These increases do not appear to be the result of diagnostic bias or changes in psychiatric labeling. If one looks beyond treated cases to evidence from the world at large, epidemiologic studies of suicide *attempters* show them to be overwhelmingly young females, mostly between the ages of 20 and 30, with an increase among married and separated/divorced women. Several studies of the personality of suicide-attempters have found most of them (about 80 percent) to be clinically depressed at the time of the attempt. The typical suicide-attempter tends to be a young woman from a lower middle-class background who has a recent history of serious interpersonal conflict, especially divorce, separation, or a rocky marriage (although the numbers of actual suicides are disproportionately male). One recent study found that the most depressed women were those who were poorly educated, were working at low-status jobs, and were married, with children at home. Scores indicate, too, that the lower the age of the youngest child, the higher the likelihood of depression. It is the young, married, working low-income mother who is most likely to be depressed (Radloff 1975). These findings are also supported by community studies in other developed countries. Further, economic hardship, social isolation, and parental responsibilities are life conditions that impinge most sharply on the single-parent family head, who is nearly always (97 percent of the time) a woman (Pearlin 1975).

These findings provide a clue to some causes of depression. The findings are, however, at odds with hormonal theories that place menopausal women as particularly at risk for depression and with psychological "empty nest" theories about mothers of similar age confronting homes without children and hence lives bereft of their main purpose and function.

In response to the findings an hypothesis emerged about some causes of depression consistent with them. High rates of depression seem to be associated with stresses that derive from life conditions such as single parenthood, low income, poor education, and responsibility for young children. An additive stress theory is consistent with several findings. Women with young children at home show higher mean depression scores than women whose children have left. The fact that larger numbers of nonwhite than white families have a single parent is consistent with the higher rates of mental illness in black than white women. The hypothesis of the additive stress theory is that, cumulatively, different sources of stress increasingly put one at risk for depression. Added stresses become too much to bear, and if there is no relief from them, the risk of depression increases.

There is a close connection between Seligman's concept of learned helplessness and the powerlessness of many women's roles . . . .

But there is a second part to the hypothesis. The sex differences in rates of depression may be related to *conditions of* *helplessness* in responding to stresses. According to Seligman, the etiology of a particular depression includes a past history of learned helplessness which creates susceptibility in the person (1974). Further, a current situation of helplessness is the immediate environmental agent of the depression. The hypothesis assumes that the role society teaches many women encourages them to learn helplessness: to be passive, not to be aggressive, not to seek power but to trust others, to nurture others and put their needs before one's own, to appreciate mastery in others and not threaten them with one's own, and so on. Thus, there is a close connection between Seligman's concept of learned helplessness and the powerlessness of many women's roles which may help explain the greater prevalence of depression among them.

Recent research (Dohrenwend 1973) has tried to relate stressful life events to physical and mental symptoms and in an additive way to health problems of all kinds. Examples of stressful life events are divorce, loss of a spouse, loss of a job, relocation, and even minor stresses such as quitting smoking or dieting. Epidemiologic studies show a high correlation between such stresses and mental health symptoms. So still a third part of the hypothesis is that lives of depressed people may show a greater number of precipitating life-stress events. We should distinguish these *life events* from the more general and long-lasting life *conditions* that are the subject of the first part of the hypothesis, such as being poor, living alone, and raising small children.

There are thus three aspects of this hypothesis: stress of life *conditions*, learned helplessness, and stress of life *events*. According to this socio-psychological explanation of depression, we should expect to find it among people with the highest rates of stressful life conditions and life events with which they must cope, and at the same time the fewest actual possibilities for mastery over them. This hypothesis is consistent with biochemical theories. Although learned helplessness and the stress of life conditions and events may combine to cause depression, biochemical studies of depression indicate that there are biochemical correlates of these states. (Indeed, although this study does not test for biochemical correlates of depression, there may be a feedback system between the biochemical and psychogenic aspects of depression.) It remains for the second phase of the study to begin to investigate the validity of this hypothesis.

Other Findings

- Women are more likely than men to be diagnosed as neurotic, and men are more likely than women to be diagnosed as having alcohol disorders.
- The data are ambiguous about whether men or women are at greater risk for mental illness. Men show higher rates of admission to State and county mental hospitals, while women show higher rates to community mental health centers. Before any comparisons can be made, the type of mental illness must be expicitly defined.
- Though data are sparse and subject to different interpretations, available information suggests that people from lower social classes have a higher risk of mental illness than people from higher classes.
- People who are separated or divorced show higher rates of mental illness than people in other marital-status categories. Further, the data imply that rates of mental illness are much higher among single men than among single women.
- Regarding age, the highest rates of mental illness for women are in the 25-44 age group, the second highest are in the 15-24 age group. For men, these two groups also have the highest rates, but the order is reversed. In addition, men in the youngest group, 18 and under, have a much higher rate of admission to mental health facilities than females in that age group.

THE SECOND PHASE

The burden of findings from the first phase led the Harvard team to focus for its second phase on depression in mothers of young children in low-income families. The objectives were to investigate the kinds of stresses that lead to their high rates of depression and to study the effects of these stresses and depression on their young children.

An Intensive Field Study

The members of the team now turned from broad gauge epidemiologic studies of depression prevalence in treated and untreated populations to an entirely different research approach and design, an intensive field study of 43 low-income mothers and their children. This was zeroing in from a national picture to an intimate look at people in a family.

The age of the women varied from 21-44 with a median of 30. They were racially divided, 21 black, 22 white. By marital status 20 were single—never married, widowed, separated or divorced, and 23 coupled—12 legally married and 12 living with a man. Most had some high school education, almost two-thirds had a diploma. Their median age at the birth of their first child was 19. At the time of interview, 32 of the 43 were receiving Aid For Dependent Children benefits. The median number of household members was 4.6, and the median per capita yearly household income was $1,452.

The women were recruited from three Boston area neighborhoods, one mostly black, one mostly white, and one mixed. Contacts were made through community groups, settlement houses, political groups, day-care centers, housing projects, and schools. A financial incentive was offered for participation. An attempt was made to keep income and educational differences between married and single women and between black and white as small as possible. Conversely, women were selected with a wide range of educational and working histories, with from one to many children, living with from none to many additional kin.

Two researchers worked with each family. One interviewed the mother. The other observed family interaction in the home over a series of sessions, interviewed the children about their relationship with their parents, and interviewed the parent(s) about child-rearing practices. Black women were interviewed by a black woman and white women by a white one. All of the interviewers were women, but some of the child observers were men. Work with each family extended over 3 or 4 months with weekly or biweekly visits. Usually the researchers visited the family separately. Researchers were usually graduate students at the Harvard School of Education experienced in working with low-income mothers and children. Some were middle-aged with families of their own, many had community experience. Most achieved high rapport with their families. No family dropped out of the study after work with them had begun.

The Interviews

One objective of the interviews was to determine the rate of depression among these mothers. A widely used self-report measure of depressive symptoms, the CES-D Scale, was administered to each of them, once toward the beginning of the work with them and once toward the end of the study. The measure asks such questions as "whether their appetite was poor, whether everything they did was an effort, whether they had crying spells, felt lonely, or could not 'get going.'" Twenty such questions covering the past week were asked. A self-report measure was also given for each of three other mental health indicators—anxiety, self-esteem, and locus of control. The measures were the Zuckerman Adjective Checklist for measurement of Anxiety, Rosenberg's Self-Esteem and Stability of Self Scales, and Pearlin's Mastery Scale.

A second objective was to see whether depression correlated in these women with their life *stresses*. This was complicated by the fact that most life-event-stress scales developed up until now have been derived from and are hence possibly unique to middle-class men, though across several races. Dr. Vivian Makosky, of St. Lawrence University and the Stress and Families Staff, is responsible for constructing the life-event and life-condition-stress measures. Her working hypothesis was that these event scales might be missing stressful events unique to women, overlooking or misevaluating stressful events unique to low-income people and, lastly, losing an important distinction between stressful life *events* and stressful life *conditions* (1978). Life-event scales quantify and weigh changes in one's life that additively predispose one to increasing risk for mental or physical disease (Holmes and Rahe 1967). Makosky's hypothesis was that some of the stress in one's life is not related to how much things change (events), but to how much an oppressive condition stays the same where conditions are ongoing, enduring aspects of one's life (Makosky 1978). What needed development, then, were ways of quantifying stressful life *conditions*, considering both severity and duration, in addition to a new life-events scale which would include events more appropriate for women. Both the event and condition measures would include stresses that low-income people experience.

The first part of the Life Events measure asked the mothers for the most recent events that had interrupted or changed their lives. They were then presented with a list of 107 specific events and were asked whether the event happened to them, or to someone important to them, during the past 2 years. If so, each was asked to assign a rating of intensity and duration to the stress. Lastly, each was asked if there were important events within the last 2 years *not* asked about or events older than 2 years that were still causing problems. The reason for asking whether events had happened not only to them but *to someone important to them* was to test a "contagion of stress" hypothesis, to see whether women may add to their own stress by experiencing stress from events that happen to others.

The Life Conditions measure was designed to tap ongoing aspects of these lives that were likely to be stressful. For example, money *events* included a drop in income, foreclosure of a mortgage or loan, and so on, while money *conditions* included lack of financial security and the unpredictability of income. Parenting events included changing child-care arrangements or losing custody, while parenting conditions included having children who were less than 2 years apart, children with handicaps, having no one for child care if one wanted to go out, and so on. Mothers were asked about conditions in the areas of employment, extended family, friends, physical and mental health, intimate relations, law, housing, money, education, and parenting (exhibit 1).

The Discrimination Interview developed by Jacquelyn Mitchell (exhibit 2) tried to assess how powerful a source of stress *discrimination* was, whether related to socio-economic status, race, sex, single-parenthood, or place of residence. The categories of discrimination were determined by each woman herself, not predetermined. She was asked to describe herself in terms of social status, ethnicity, and race and give her own rating to what, if any, kinds of discrimination she believed she had experienced. The interviewer also asked for the setting (welfare offices, schools, jobs) where the discrimination occurred, who was most likely to do it, and what its effect was. Mothers were asked to rate the stressfulness of these experiences.

EXHIBIT 1

Case Study of "R"—Stress and Depression

(Note high correlation of high-depression score with high-stress score. In a typical community survey, anyone with more than 5 life-stress events per year [or 10 per 2 years] would be in the extremely high-stress group. Life events for these mothers ranged from 27-116 per 2 years.)

CES—Depression Score = 36

Event	*To Whom*	*When*	*Stress*
Son assigned to custody of State by father (R lost custody)	Self	2/77	8
R's boyfriend had surgery	Boyfriend	9/77-10/77	8
R hospitalized with bronchitis	Self	12/76	8
Involuntarily unemployed due to illness	Boyfriend	6/77	7
Three members of friend's family died	Friend	1/75-3/75	8
Son had psychological distress (hospitalized)	Son	'77	8
Child left household	Self	6/75	8
Victim of robbery	Self	7/77	8
Victim of beating	Self	8/77	8
Rifle through car window	Mother	9/75	8
Beaten by R's husband	Daughter	8/75	8
Joined a self-help group	Self	6/77	8
Friend arrested	Friend	–	6
Been on probation	Son	10/77	8
Loss or death of a pet	Self	12/75, 6/76	8
Conditions			
Being on welfare	Self	'69	8
Breakup of marriage	Self	'70	8
Illegitimate child	Self	'73	8
Child gets in serious trouble at school	Self	–	8
Lost custody of child	Self	'71	8
Nervous breakdown	Self	3/71	8
Patient in mental hospital	Self	3/71	8
Made appearance in court	Self	'71	8

EXHIBIT 2

A Case Study: Excerpts From Discrimination Interviews

Some blacks and whites feel discriminated against by the same institution.

White Respondent: "There is discrimination by Welfare. They're doing more for blacks than for whites."
Black Respondent: "It was some time ago . . . they (Welfare) were giving out furniture, etc. The blacks were never told. If we found out, we found out through knowing a white friend.

Single parenthood emerged as a major stressor.
Respondent: "I found that as a single so-called 'separated parent,' going to school to attend to my children's affairs had put me in jeopardy—many a day, because there was no man with me. I don't feel that quite deeply anymore. I don't feel that if I would go up by myself, if the children's father wasn't there, around to go with me, then I'd get someone, a man to go. I would not go there by myself anymore . . . ."

Another respondent expressed attitudes she experiences because of her marital status.
Interviewer: "Have you ever felt or been discriminated against because you had a child out of wedlock?"
Respondent: "Yes. Like agencies you go to, for jobs. Like, people look at you, write down how many children you have, and [when] you say you're not married, [you get] the expression."
Interviewer: "How do they express it?"
Respondent: "Like, you know, the expression, like it shows in their faces. Like you catch them whispering or mumbling. You know . . . other people too."
Interviewer: "What other kind of people?"
Respondent: "Like people on the street in general"
Interviewer: "Maybe they'll say, 'Oh, you know, wow! So many kids and not married!'"

Dr. Deborah Belle, the Project Director, and Cynthia Longfellow were responsible for the social aspects of the study. Being part of a *social network* of friends and relatives is often regarded as a buffer against stresses of life and depression, and for this reason each woman was asked to describe the kinds of support she received from other people in her social world. Questions were asked about intimate social support ("When you have a very personal problem that you want to talk about, whom do you speak to first?"), and questions about her close friends (how often were they seen, where they lived, how long she had known them). Questions were asked about neighborhood sociability and exchange of favors, contact with relatives, people at work, friends, recent changes in the network.

Strategies for *coping* are also a useful defense against the stresses of life. For this reason an interview on coping designed by Jacqueline Martin (exhibit 3) was included to investigate the ways in which stress is experienced and managed by the women. Given the diversity of their life conditions and unique quality of some of their problems, an open-ended interview was conducted. Four problem situations were selected for in-depth discussion with probes devised to elicit the strains incurred and on whom, the amount of stress experienced, their perceived control and mastery, the social resources available or lacking, and what learning was derived from the experience. Mothers were also invited to list areas in which they wished: (1) more help, (2) more information, and (3) more control. They were asked to discuss what they found hardest to handle when feeling depressed or under stress; to list what was most useful to alleviate these feelings; and to evaluate their current life and coping capacity. One thing interviewers were careful not to do was categorize the mothers as "good, bad, effective or defective copers."

An interview was designed by Kristine Dever to elicit how adequately the social services institutions—welfare, food stamps, and health care—met the needs of the mothers. It explored both what specific programs alleviated stress and what stressful experiences these institutions provoked. Interviewers probed for the kind and quality of service and isolated areas that were a source of stress. The method sought to recognize that the mothers were the best guides in deciding what was valuable and what was better changed.

A *nutrition* interview designed by Polly Ashley included questions about what had been eaten in the last 24 hours and about patterns of food preparation and family meals. Poor nutrition may result from lack of money for food, lack of knowledge about nutrition, or the disinterest or overinterest in food that often accompanies depression. Poor diet may be a significant source of stress in itself, as may also lack of enough food or inadequate means for storing and preparing it.

EXHIBIT 3

A Case Study Excerpt From A Coping Interview

Respondent's Description of a Highly Stressful Situation:

"I was living with a man who was violent. I was constantly in a state of fear. He would beat me up periodically. I got steadily sicker and sicker. I lost weight. I had to get my gall bladder out; and my jaw won't be the same again. Emotionally I got so full of fear. I couldn't talk on the phone or go out of the house. I jumped a lot at nothing at all."

Coping Strategies:

"I saw a counselor once a week."
"I got right in a cab with the kids. We sat on the floor of the cab. We went right over to her place (friend's), and she let us stay overnight."
"Then we went to RESPOND."
"I went over to the Cambridge Hospital Mental Health Outpatient Department. I asked them to admit me and have the kids placed in foster homes."
"I joined a support group—a battered women's group connected with RESPOND."
"I also joined ALANON."
"My family helped for awhile."
"A very distant friend called me just by chance after I got beat up bad."
"They [RESPOND] gave me shelter and even took me to the hospital for X-rays."
"They also stayed with the kids so I could get over to ALANON. They also helped me with transportation."
"The only thing that helped me at all was that I would get out of it—the feeling that one day in some way I would be out of this."
"I also thought that I would eventually learn all the things that made him so angry and that I wouldn't do them anymore."
"I remember trying constantly to control everything so he wouldn't flip out."

Strains and Consequences of the Problem:

"I had no appetite and as I said, I lost weight. I slept a lot but had a lot of nightmares. Patience? Ah, I had plenty of that. You might say I was in a total coma. I got to the point where I couldn't feel anything. Tears, hate, anything. I couldn't feel sad. I forgot what 'happy' meant, just fear, that's all I could feel. There was terrible tension in the air all the time and nothing was spontaneous. Everything was mechanical. The children were in the same shape I was in: tense."

Wisdom Learned from the Experience:

"Now I see that I had a great deal of power. Looking back, I can't think why I gave up all my power. I had it all the time and 'it' couldn't have happened three years earlier. My self-esteem was low when it happened, in a way that's why it happened."

Parent-child relationships were investigated with Cynthia Longfellow and Phyllis Zelkowitz carrying major responsiblity. In each family a target child was picked and observed through six half-hour periods. The child's behavior and interaction with others, especially the mother, was coded to provide an objective record of family interaction patterns, not subject to the mother's or the child's interpretation. The data were used to test hypotheses about the effect on children of stress or depression in mothers as well as the effect of children on mothers in exacerbating stress or depression.

After the six half-hour sessions were finished, Zelkowitz was responsible for seeing that each mother (and father or boyfriend, if present and willing) was interviewed on her *parenting* philosophy and practice. Questions explored her view of the parental role, her opinions on obedience, aggression, dependency, training for responsibility, aspirations for her children, and sense of control over their behavior. Embedded in the interview was an adjustment checklist asking the mothers to report problem behaviors in the target child, which was used as an outcome measure to assess the effects on child development of living under stressful circumstances.

And finally, each of the children had two open-ended interviews to explore their views of the parent-child relationship, eliciting the nature of the emotional ties to the mother, the parental demands and controls used, the sources of conflict and their means of resolution, their understanding of the relation and their attempts at coping. Each child also answered three questionnaires. One was a nurturance scale designed by Elizabeth Saunders to show whom they considered their main sources of support. The second was the Bronfenbrenner punishment scale designed to show whether they perceived the parents as accepting or rejecting. The last was the Swanson Child-Parent Relationship Scale designed to show whether children perceived the relationship as happy, tense, or stressful.

FINDINGS

This extraordinarily intensive and comprehensive schedule of interviews produced an expectably enormous amount of data for analysis. On the CES-D scale, half the women rated as depressed, with a very high mean sample score, as high as those in one study of people who had experienced marital separation wihin the year and, in one site, of people who had recently experienced the death of their spouse. Scores on this measure indicate the extent of depressive symptoms and unhappiness. About a third of the women had received treatment for mental health problems within the past 2 years, most of them without being hospitalized.

All of the women lived in high-crime neighborhoods, but the phrase does not accurately reflect the extent of violence present in their lives. Over one half of them reported that they were victims of crime or household violence or were unwilling participants in sexual acts during the past 2 years. Two thirds reported that either they or someone important to them had experienced crime, household violence, or sexual assault, in that order of frequency.

Both life-*event* stress and life-*condition* stress are strongly associated with the experience of depressive symptoms. The life-conditions score had two parts, one reflecting the objective difficulty of ongoing conditions and the other the result of asking the women to indicate how much stress they felt in each of eleven areas: employment, extended family, friends, physical health, mental health, love and marital relationships, the law, living conditions, money, education, and parenting. Both of these measures correlated more highly with the depressive symptoms score than did the recent life-events score. The "contagion of stress" hypothesis, that women may be stressed by events happening not to them directly but to others on whom they are dependent or for whom they are responsible, was not strongly supported. The high correlation of the life-event score, which included items special to women and to low-income people, lends credibility to the hypothesis that previous stress research has underemphasized the kinds of events experienced by women and especially low-income women.

Frequently named sources of discrimination included the welfare department, rental agents, employers, restaurants, schools and teachers, salespersons, patrolmen, and taxidrivers. Both black women and white women reported more incidents of discrimination by white than by black people. White women were significantly more likely to say they were treated differently after becoming single again than black women.

The network of social support available to a woman has appeared from earlier research to be a powerful buffer against depression and other mental health problems. Living in the same neighborhood for a few years, having good friends nearby, or kin, a network of acquaintances, were all thought to be a protection against depression. But the analyses showed most of these elements of social support were by themselves not sufficient to prevent depression among these highly stressed women. Most of the women had close friends of long standing and did not report that they lacked a confidante. There were no significant differences in depression scores between women who lived with a man and those who did not, or between women living with some other adult in the house and those who did not, or between women who saw their mothers at least once a week and those who did not. Depression was not significantly correlated with length of residence in the neighborhood, number of friends or relatives seen at least a few times a month, or number of close friends.

For women who lived with a man, legally married or not, those who turned to him for emotional support were less likely to be depressed than those who did not. Nine of the 20 such women never mentioned the man as a source of emotional support, a situation that might itself be associated with depression. But several of these nonconfiders said they did turn to their spouses when they had very good news. An hypothesis to explain this might be that when conditions are chronically stressful, women censor themselves so as not to overburden their spouses with further pain. Both the depression and the lack of confidences may result from the same chronic life stress. Perhaps stress acts to destroy marriages of the poor by first making confidences painful and finally impossible.

As an aid to coping, the overwhelming majority of both depressed and nondepressed women would have liked more time to themselves, but there was a quality of desperation to the statements of several of the depressed women. "I can only get time when I steal it, pretend I am going to the store and stay for 2 hours," said one. Another said, " . . . If both the kids were in school . . . to go somewhere and scream would make me feel better." Some relief from the constant presence and responsibility of children was one of the most strongly felt aids to coping.

Most of the women were clients of the Aid to Dependent Children program and virtually all received either food stamps or Medicaid. An anomalous finding was that women with *high* depression scores were *less* likely to report stressful encounters with the welfare system. These findings may indicate that women with high depression scores have accommodated themselves more completely to a loss of privacy and control. An alternative hypothesis is that this indicates an inability to express anger. They may in fact be considered "good recipients" compared to women who are not depressed. Women with *low* depression scores reported more instances of learning to manage the system by playing a role or learning to act according to the expectations of welfare workers and by informal knowledge. Eighteen percent of them reported having helped other welfare clients as a result of their own experiences. None of the high depression score women reported having taught others to do this. They appeared less likely to take these assertive steps and more likely to feel helpless. Feelings of helplessness about the system and consequent stress were tied to the cumbersomeness of the process, the inadequacy of information about welfare benefits, and the difficulty of obtaining it.

Of those receiving Medicaid assistance, half reported being unable to obtain through Medicaid one or more medicines prescribed by their physicians. Sixty-nine percent reported being unable to obtain one or more dental services, such as dentures, fillings, extractions, or root-canal work. Other women reported not being able to obtain either orthopedic shoes with braces or intrauterine devices.

The diets of many of the women are nutritionally inadequate. Over three quarters of the women did not take enough iron in a typical day. About half of them reported diets deficient in Vitamins A, B1, B2, Niacin, and Calcium. About half the ~~women~~ did not receive an adequate number of calories and almost a quarter had too great a caloric intake. Most of the deficiencies found were not related to depression. There was, however, a significant association between both deficient calcium and caloric intake and depression, intriguing because calcium has been implicated in studies of depression. More information on nutrition was a frequent request.

Depression appeared to take a toll on mother-child relationships, according to the six half-hour observation sessions. Depressed mothers spent more time prohibiting or prescribing action and less time in nurturing with help, emotional support, or goods. They were also more likely to use dominating and hostile-aggressive styles with their children. Depressed mothers were less likely to comply to their children's requests. High-life *condition* stress scores also correlated significantly with the mother-child variables of low nurturant actions and high prohibiting and prescribing behavior. Interestingly, mothers' life *event* stress scores were not associated with these variables. Both depression and stressful life conditions may so deplete a mother's energy that she may be less responsive to bids for nurture that draw on her emotional resources. Many of the depressed mothers pointed this out themselves.

Children of depressed mothers were more likely to report themselves unhappy with their mothers and turned to their mothers for emotional support less frequently than children of less depressed mothers. Children of depressed mothers also more frequently reported that they were punished or rejected at home. The interviews showed that children ~~tend to~~ be sensitive and understanding of the stresses in their parent's lives, as long as they feel loved by them. Depression appears to seriously impair a mother's ability to convey the sense of being loved, and hence the relationship of mother and child. Stress in itself does not appear to do this.

Future Research

The Stress and Families Conference, held in July of 1978 in Aspen, Colo., brought together experts from the fields of journalism, the mass media, the Federal bureaucracy, National and State legislatures, and the academic community. It was in a sense the Second Act Finale for the Project, leaving Act Three yet to be played out.

Unlike many research projects, which limit themselves for better or worse to publication of findings for the world to ignore or adopt as fate and the winds blow, the Stress and Families project was actively seeking ways to make a difference. Thus, in bringing together these presumptively worldly experts, the Project was deliberately foregoing a detached research rôle and seeking to replace naivete with a grasp of political, legislative, and fiscal realities. The researchers wanted to help women they had come to care for and more generally to be effective in mitigating depression and other effects of stress on low-income single-parent mothers.

The Project members presented their findings and solicited critiques of the Project and advice for interventions. Expectably, they were warned by some and encouraged by others for mixing research, concern, and social activism.

More germanely, two participants outlined approaches to the general issue of planned social change, its limits, pitfalls, and justifiable expectations. Several participants provided a host of possible interventions that had been tried in other contexts in other Federal and State programs. Two Federal participants laid out detailed analytic strategies for deciding and refining intervention payoffs and then linking these to cost-effectiveness evaluations. Several State legislators and administrators described in some detail the course of developing and effecting social legislation of the kind the project might want to see developed. One "old Washington hand" gently chided them for not having already cultivated close and continuing contacts with staff of their own State and Federal representatives. Three seasoned journalists suggested the difficulty of even attracting, much less mobilizing, public interest for a project in many ways more appropriate to the populist 60s than the quiescent 70s. There appeared a consensus that new monies available for social projects such as this would be unlikely or limited. Even so, in the high, light summer air of Aspen the Conference generated an infectious spirit of spacious possibility. People wanted to help and wanted the Project to do well.

Sorting this embarrassment of riches inaugurated Act Three, which is still to be written. One of the cautionary notes of the Conference had been not to proceed, from the urgency to do *something* for the distressed women of the study, so quickly as to sleight thoroughness in analyzing the data. The quality of this analysis is a necessary condition for canny choosing and shaping of effective interventions. The "hard data" findings from that knowledge base also provide the *lingua franca* of persuasion and the justification for legislation. Thus, much of the time since the Conference has gone to further analysis of the voluminous data for a final report.

There is to be a followup study of the 43 families to provide longitudinal data and to let respondents know the conclusions of the study. There is to be a meeting to decide on interventions.

Thus with due deliberate speed the Stress and Families Project moves toward the convergence of its different goals. It is too early yet to say what will come of it. The many-tiered and intricate progression through the vastly different skills and processes adumbrated at the Aspen Conference will need to be informed by a polymath intelligence. The number of years of sustained and focused purpose to convergence will need poise and circumspection not often perdurable in group collaborations. But there may be in the Project's goals and how it has proceeded the germ of a somewhat novel and possibly powerful social idea. Sprung from the combination of research and social activism, the Project has proceeded as if it were piecing together what amounts to a kind of vertical industry, with the potential power of economy and efficiency that implies, though the Project does not seek ownership but knowledge. Just as the vertically integrated industry grows the peas and then, for efficiency and cost-effectiveness, harvests, cooks, cans, distributes, and sells them from its own stores, so the vertically integrated social activist, presaged here, might some day identify each stage of necessary knowledge or process and skill, to identify and characterize a social problem, and then to create and put into effect interventions that help to solve it.

References

Belle et al. "The Plight of Low-Income Mothers and Their Children." Paper presented at Stress and Families Conference, Aspen Institute for Humanistic Studies, Aspen, Colorado, July 6, 1978.

Belle et al. "The Impact of Stress on Mothers and Their Children." Paper presented at American Psychological Association Meeting, August 28, 1978.

Chesler, P. *Women and Madness*. New York: Avon Books, 1972.

Dohrenwind, B.S. Life events as stressors: A methodological inquiry. *Journal of Health and Social Behavior*. 14, 167-175, 1973.

Gove, W.R., and Tudor, J.F. Adult sex roles and mental illness. *American Journal of Sociology*. 78(4):812-835, 1973.

Guttenag, M., and Salasin, S. Women, men and mental health. In: Cater, L.; Scott, A.; and Martina, W., eds. *Women and Men: Changing Roles*. Aspen Institute for Humanistic Studies. New York: Praeger Press, 1976.

Holmes, T.H., and Rahe, R.H. The social readjustment rating scale. *Journal of Psychosomatic Research*, 11:213-218, 1967.

Makosky, V.P. Stress and the mental health of women: A discussion of research and issues. In: Guttentag, M., and Salasin, S., eds. *Families Abandoned: The Cycle of Depression*. New York: Academic Press, 1968.

Pearlin, L.I. Sex roles and depression. In: Datan, N., and Ginsberg, L.,eds. *Life-Span Developmental Psychology: Normative Life Crises*. New York: Academic Press, 1975.

Pearlin, L.I., and Johnson, J.S. "Marital Status: Lifestrains and Depression." Unpublished paper, 1975.

Radloff, L. Sex differences in mental health: The effects of marital and occupational status. *Sex Roles*, Vol. 1, 249-256, 1975.

Rahe, R.H. The pathway between subjects' recent life changes and their near-future illness reports: Representative results and methodological issues. In: Dohrenwend, B.S., and Dohrenwend, B.P., eds. *Stressful Life Events: Their Nature and Effects*. New York: John Wiley and Sons, 1974.

Rednick, R.W. Utilization of psychiatric facilities by persons diagnosed with depressive disorders. *NIMH: Statistical Note 103*, March 1974.

Seligman, M.E.P. Depression and learned helplessness. In: Friedman, R.J., and Katz, M.M., eds. *The Psychology of Depression: Contemporary Theory and Research*. Washington, D.C.: V.H. Winston and Sons, 1974. pp. 82-126.

Weissman, M.M., and Klerman, G.L. Sex differences and the epidemiology of depression. *Archives of General Psychiatry*, 34(1):98-111, 1977.

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THE MENTALLY ILL AT HOME: A FAMILY MATTER

Principal Investigator: John Clausen, Ph.D.

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One evening during World War II, John Clausen went to the Washington, D.C., home of a black sociologist friend. The friend—call him George Smith—had returned the previous night from a trip to U.S. Army camps. Clausen listened as the agitated and outraged Smith told his guests about the abuses that black soldiers had endured in the camps. The situation had so upset Smith that he'd been unable to sleep the night before. At 5 that morning he had called a top-ranking general to demand that camp conditions be improved immediately. The general, too, became angry. At Smith. He ordered Smith's superior officer to dismiss the sociologist.

That morning in their office at the old War Department, Smith had told Clausen and his other coworkers about the trip. That night, as Clausen heard the story unfold for the second time, he noticed that his friend was embellishing parts of it, recasting others. He knew about the incident with the general. As he listened, Clausen came to realize that his friend was unable to distinguish actual experiences from imagined ones. There was something about Smith's manner, his growing hysteria, and his inability to organize an oft-told story that worried Clausen. Others at the gathering, some of them members of Washington's wartime "Black Cabinet," had not heard that morning's account. They took the story at face value. Because black people suffered grievously throughout society then, they found even a bizarre report about mistreatment of black soldiers all too believable. They set to work planning how to help the soldiers.

John Clausen sat wondering how to help his friend. Later that evening, he suggested to Smith's wife that her husband might need psychiatric help. "I know," she said. "This happened once before."

She recognized what was happening to her husband because he had already gone through one schizophrenic episode. But how had she known the first time? How does anyone know when a husband or wife, mother or father, child or friend has stepped over that line where everyday emotional upheavals become mental illness? How do they know, when the line itself fades off into a large gray area, shaded by pain suffered and pain inflicted, by moments and days when all seems normal, by the era's agreed-upon codes for reasonable thought and seemly conduct? How long does bizarre behavior pile up before those who live with it define it as madness? How do family members perceive what is going on? When do they finally seek help? How do they go about getting it? What happens to those left behind when mother or father goes to the mental hospital? What do the children know about their parent's illness? What are they told? What happens when the patient returns home? Is the job still open? Friends still friendly? Does life—for patient, spouse, child, family—ever settle down to normal again?

Searching for answers to these questions has occupied John Clausen during much of his professional career as a research sociologist. His interest was sparked that night at his friend's house, years before he earned his doctorate. His studies are reaching a denouement now as he nears retirement from the Department of Sociology at the University of California in Berkeley. There, Clausen and his colleagues are poring over facts and feelings told to them by mental patients and their families. Some families were interviewed in the 1950s and then again in the 1970s to learn what has happened in the intervening years. Other families in which a husband or wife was recently treated for mental illness have also been interviewed. Clausen's team is comparing the new group's experiences to those of the families of patients hospitalized in the early 1950s—a time when the powerful tranquilizing drugs were not in general use, and patients were kept in the hospital for months, even years, longer than they are today.

Are the new treatment practices less disruptive to families? Or does the presence of a symptomatic mother or father pose a greater threat to the survival of the family unit or the well-being and emotional development of the patient's children? Along with his interest in the long-term consequences of mental illness for marital relationships, work careers, family cohesion, and children's lives, Clausen is trying to learn if the families of mental patients fare better in the 1970s than they did in the fifties.

PRACTICAL PROBLEMS, HUMANITARIAN CONCERNS, THEORETICAL ISSUES

Clausen's family research began in the spring of 1952, when he was made chief of the newly created Laboratory of Socio-Environmental Studies at the National Institute of Mental Health (NIMH) in Bethesda, Md., a suburb just outside of Washington, D.C. Clausen and his coworkers chose to study, as the laboratory's first major project, the consequences of mental illness for patients' families. Surprisingly little was known about the subject. Until then, the only systematic research attention given to the families of mental patients was often unwanted attention, because it focused on the family members' possible role in causing the disorder, not the problems they faced as a result of it.

At the outset, Clausen was interested in these problems as a practical matter. He had witnessed the ambiguity of mental illness, the uncertainties family members felt, the turmoil they endured. He wanted to learn the details of these experiences, through systematic and impartial research. By describing how mental illness affects family life, Clausen thought he might be able to identify the kinds of support that families needed to cope with the crisis.

His approach was strictly empirical until Marian Radke Yarrow, a research psychologist, joined the laboratory's staff some months after the project began. Clausen credits Yarrow, who became his principal collaborator on the NIMH study, with greatly enriching the conceptual dimension of the research. The objective of the original study remained largely practical, however. Perhaps, through such research, the investigators could learn how to soften the blow to a family when a member became mentally ill.

If Clausen's landmark research was important for simple humanitarian reasons in the fifties, it has become a potential source of insight into a major social issue of the seventies. The theoretical issues Clausen and his colleagues have addressed over the years—issues involving society's response to mental illness—have acquired more than theoretical interest today.

Clausen and other sociologists have observed that our "heritage of attitudes and practices regarding the insane" has been one of "putting the patient away." During the last quarter century, we have begun to move away from that heritage. In 1979, the treatment of choice for persons who become psychotic involves little reliance on the type of large institution so dramatically criticized by Ken Kesey in *One Flew Over the Cuckoo's Nest*. Today, the mentally ill spend much more time among us, even while symptomatic. Their presence forces everyone they encounter—particularly their families—to come to terms with them. And it forces all of us to come to terms with the irrational and unacceptable strains in our own mental makeup. How we respond to mental illness and the mentally ill—with understanding and tolerance, or fear and rejection—is a subject of theoretical interest to John Clausen, the sociologist. It is a subject that has practical social significance to the contemporary community of which he is a part. And it has day-to-day personal consequences for patients and their families.

Recent History—From Hospital to Community

The transformation in treatment of the mentally ill in recent years came about with little attention paid to the social context. Such neglect is astonishing, since preserving the patient's place in society was the motivating force behind many of the changes that took place. As events converged to move patients into the community—out of the big hospitals that were society's isolated islands of deviance—repercussions were inevitable.

When Clausen and his colleagues began studying the families of mental patients in 1952, a person hospitalized for a psychosis might very well expect to spend many months in a mental hospital. This was particularly true if the disorder was diagnosed as schizophrenia. Psychiatrists offered little hope to families. It was common to view mental illness as a permanent condition requiring long-term hospital care for the sake of the patient and the well-being of the family. Another motive was often hidden beneath this altruistic concern, however. As Clausen has put it, large public mental hospitals "served the manifest function of caring for mental patients believed to be incapable of life in the community, but they served the latent function of isolating and hiding the mentally ill." This practice, he says, provided "a form of institutionalized denial of the existence of mental illness while at the same time producing chronic patients incapable of functioning in the community."

Treatment of the mentally ill slowly began to change after World War II when mental hospitals—particularly in Great Britain—experimented with open wards, enlarged their staffs, and adjusted other administrative policies to give patients more freedom and better care. It was the wonder drug, chlorpromazine, introduced into this country in the mid-fifties, that brought dramatic changes, however. The first of the "major" tranquilizers now routinely used to treat schizophrenia, chlorpromazine could ameliorate symptoms—the unseen voices, the bizarre thoughts, the paranoia, the unfitting emotions—in a way that no sedative drug could. By taking chlorpromazine regularly, patients could at least function at home and on the job (albeit with some impairment and discomfort). Before long, other antipsychotic drugs were introduced; among them were powerful mood-elevating drugs that can lift severe depressions, and lithium, a common element that can reduce the frequency and severity of manic attacks. While not without their side effects, some of which are serious, the psychiatric drugs introduced since Clausen began his research have produced a revolution in the treatment of psychotic conditions.

By the early sixties, largely because of the new drugs, it was possible for the Federal government to begin underwriting a nationwide system of community treatment centers where mental patients could receive short-term, in-hospital care and continuing support when they returned home. Separations from the family became much shorter, return to work easier. For some enthusiasts, mental hospitals seemed a thing of the past. Recognizing the chance to save public money, States began closing the hospitals down. Patients were released to the "community," where theoretically they had access to treatment as outpatients and could expect tolerance from their neighbors.

The possibility of relieving symptoms with psychoactive drugs and the promise of community care together changed attitudes about the prognosis for mental illness. Reformers began to deny society's right to treat the mentally ill any differently than everyone else. A few theorists asserted that *mental illness* was no more than a repressive label used by society to control unwanted behavior. Some suggested that the label caused more serious problems than the deviancy itself and, indeed, stabilized the symptoms. Riding the tide of the sixties' dedication to individual rights, activists took the case of the mental patient to court. In 1975, the Supreme Court ruled that patients could not be committed to mental hospitals unless they received appropriate treatment once they were there. This ruling, plus increasingly stringent commitment procedures, accelerated the trend toward treating new patients in community settings and releasing—sometimes expelling—chronically hospitalized patients into the bewildering world outside.

Clausen and his colleagues are addressing issues that were largely ignored in the early days of the community mental health movement.

Meanwhile, ignoring idealistic expectations, the real community began to notice what was happening. Still-symptomatic ex-patients were wandering city streets. The "shopping bag lady" became the butt of jokes on late-night talk shows. Terrified at newspaper reports about former mental patients who committed violent crimes, the public began to fear all mental patients, not realizing that many of them are more frightened than frightening. In the last few years, reaction has set in. Halfway houses and community treatment facilities have been zoned out of neighborhood after neighborhood.

And many families live with the "patients" in their midst, happy to have her home, relieved that he won't be consigned to a back ward, but still troubled by the events that led to hospitalization in the first place; still brooding over the unuttered question: Will it happen again?

Life in the Community

By trying to understand how a family is affected by the mental illness of one of its members, Clausen and his colleagues are addressing issues that were largely ignored in the early days of the community mental health movement. Introduction of the antipsychotic drugs awakened mental health workers to the possibility of community treatment. Reformers worked toward the goal of emptying the mental hospitals and keeping new patients in the community. They too seldom considered the community itself—its fears, its prejudices, its level of tolerance. And they forgot the patient's family, that part of the community most directly affected by mental illness. Clausen and his coworkers, in long conversations with these families, are learning what life is like out there in the community. They are learning how such labels as *mental patient*, *psychotic*, or *schizophrenic* affect patients and their families. And, because "mental illness can be regarded only partly as a private affair," they are also learning how we as a society respond to the mentally ill among us.

EXPLORATIONS INTO UNKNOWN TERRITORY

Clausen's original research on families of patients broke new ground in the study of mental illness. When he began his work at NIMH, so little was known about the impact of mental illness on the family that he and his colleagues were forced to use methods that were "frankly exploratory." Their first sensitively probing interviews were designed to identify the characteristics of families who were coming to terms with a mental illness in the husband or wife. Later, when they understood the dimensions of the problem, they would generate hypotheses that could be tested systematically.

The research and clinical literature provided some clues. Because surveys had consistently shown that the public held fearful and rejecting attitudes toward the mentally ill, Clausen assumed that families of patients would be reluctant to admit—to themselves or others—that one of their own was deviant enough to be hospitalized. Other public surveys, however, had found that when asked to comment on specific signs and symptoms of mental illness, most people explained the behavior in some other terms—terms within the range of normal experience—even when the symptoms were dramatic or severe. Clausen wondered if a person who confronted these symptoms in a family member would still explain them away. As for the effects of mental illness on families, case histories reported in professional journals had documented that family routines and relationships are disrupted when a member falls ill. Other factors that needed to be explored were suggested by research on families in crisis. Recent work on social role theory, deviance, and social perception was also considered.

The research literature, then, led Clausen and his colleagues to consider such issues as: the family's perceptions of deviant behavior in one of its members; its responses to that deviant person and their consequences; its efforts to maintain morale and cohesiveness; and its shifting of roles (provider, caretaker, etc.) as the illness progressed and resulted in hospitalization.

Guided by these issues and assumptions about the problems families might face, Clausen's group formulated a number of research questions. Among them:

- How does the spouse understand the meaning of a mate's illness and then deal with it?
- How does the illness affect relationships within the family—before, during, and after hospitalization?
- How does the family maintain itself psychologically and materially?
- How does the illness of a husband or wife influence the spouse's relationships with others?

Clausen and his colleagues chose a research strategy that would give them the most insight into specific details of the family's experience. They would use only a few subjects and interview them in great depth. Although some questions would always be asked, the interviews would be open-ended—allowing the conversation to follow whatever direction the family member chose. They would keep their minds open. They would record every comment. What they would hear might come as a complete surprise. They would continue the interviews over a year or more, if necessary, and they would come back to the same questions again and again. Maybe this week's account would contradict last week's. They would have to sort it out later.

In selecting the patient sample, the researchers were guided by their wish to study, first, how mental illness was recognized and defined and, second, what happened to the family when a spouse and parent was hospitalized. They would choose patients who were being admitted to the hospital for the first time—those least likely to have been previously diagnosed as mentally ill. To minimize gross cultural differences among the families, they would not include minority group members and recent immigrants. The patients, of course, had to be married and living with their spouses just prior to hospitalization. And they had to be permanent residents in the Washington, D.C., area so that the study team could interview their spouses during and after the hospital stay. (This last constraint disqualified several patients who might otherwise have been included in the study. In early pretesting, Clausen discovered that a number of persons experiencing schizophrenic episodes had come to Washington because it was the National Capital; some had come to see the President. They had been sent home as soon as their permanent residences were established.)

The first study included only male patients because Clausen had reason to believe that their families could provide the most comprehensive information over the entire period of crisis. In those days families often temporarily dissolved when a wife and mother was hospitalized; children were cared for somewhere away from the parental home. Wives of male patients, by contrast, usually kept their children with them. Since Clausen wanted to learn how children were affected by a parent's illness and absence, and what they were told about it, he would focus first on families that would probably stay together until the patient returned.

Clausen further decided to limit the original study sample to patients who received a diagnosis of schizophrenia, manic-depressive psychosis, psychotic depression, or severe psychoneurosis. He excluded patients with such organic conditions as senile psychosis or arteriosclerosis because they were "likely to be defined as permanently lost to the spouse and family." He also tried to exclude patients with long-standing drinking problems, but this proved to be difficult (1).

By choosing this intensive approach—studying a small number of families of functionally psychotic or neurotic male patients—Clausen's group sacrificed the prospect of generalizing its findings to families of all mental patients. The study would, however, prepare the way for later research—when the dimensions of the families' experience were clarified, when the investigators understood the variations in the families and the sources of these variations. The next phase of the research could then be more focused and also expanded to include larger, more varied samples. St. Elizabeths Hospital, the public mental hospital for Washington, D.C., agreed to inform Clausen when men who met the study criteria were admitted so that he could get in touch with their wives. During 1952 and 1953, his research team asked 35 women to participate; 33 agreed.

For scientific purposes, the 33 families comprised a nonbiased sample of families of married, white, working and middle-class men who were hospitalized for mental illness for the first time. Judging from their occupations, education, and home addresses, they were fairly typical of Caucasian families living in Washington, D.C., at the time. Three in five were in the middle class, the rest in the working class. All were white, as were two out of three Washington residents in 1950. All were either born in this country or had lived here most of their lives. In many respects, they were like their neighbors—reasonably well-liked, respected and responsible members of the community.

The 33 families had all crossed a line separating them from most of their neighbors, however. They had all witnessed their fathers and husbands change in a way they could no longer understand. Most had finally reached the conclusion that treatment was necessary. All had suffered through the arduous, wrenching process of witnessing or participating in the hospitalization of a family member.

Ideally, to study the process leading to hospitalization, the researchers should have interviewed the wives "as they struggled with the developing illness." Because this was impossible—the problem was not a "social fact" until help was sought—the next best solution was to interview the wives immediately after hospitalization, when memories were fresh. The interviews were repeated—in the ideal case, first at weekly, then monthly intervals—until 6 months after the husband returned home. By scheduling interviews close together, the researchers were trying to obtain "a continuing record of the wife's effort to cope with the 'shifting ground' and the problems attendant upon these shifts." The majority of the women were interviewed at least five times and some as many as 18 times. Most were seen in their own homes when they were alone with the interviewer.

A Short-Order Cook Takes on Einstein

The stories related during those first intensive interviews are full of the bewilderment wives felt about their husbands' behavior. Typically, they found some explanation—any explanation—that would make the changes in their husbands understandable. Mrs. Foster (not her real name) was one of these wives who, over an unusually long period, desperately tried to make sense of her husband's disturbing behavior.

> She had been married to Robert Foster, a short-order cook, for about 3 years before he was admitted to St. Elizabeths Hospital with a diagnosis of schizophrenia. Early in their marriage, she had noticed that he was nervous and tense. He was often sick, which, he explained, could be traced to the malaria he had contracted during the war. He perspired a lot. He was crabby. Noticing that Mr. Foster's friends seemed nervous too, Mrs. Foster concluded that "maybe I was happy-go-lucky and everyone else was a bundle of nerves." She got used to her husband's frequent illnesses and sporadic work, but grew annoyed because he wouldn't see a doctor. "I was beginning to think he was getting lazy because there wasn't anything I could see that was wrong," she reported.
>
> Others noticed a change in Mr. Foster. A friend of his told Mrs. Foster that her husband was "more nervous than I have ever seen him," and Mr. Foster's boss observed that he "seemed very much worried about something." Mrs. Foster talked to more friends about her husband's unwillingness to consult a doctor. Her tolerance was strained. She tried to understand him, coming up with one explanation after another. Then she got fed up. "I got disgusted and said if he didn't go to a doctor, I would leave him." She asked Mr. Foster's boss to talk to him. "I begged, threatened, fussed." Mr. Foster then made one visit to a Veterans' Administration doctor. He told his wife that the doctor had said he was all right. On the day Mr. Foster was scheduled for a second visit, he overslept, missed the appoint-

ment, and never returned. Mrs. Foster didn't talk to the VA doctor.

There were periods when Mr. Foster was well and working. Mrs. Foster forgot about his troublesome behavior during those times. "You live from day to day. When something isn't nice, I don't think about it," she told the interviewers. "If you stop to think about things, you can worry yourself sick." She worked as a clerk in a small store and enjoyed meeting people there.

Mr. Foster would occasionally talk of a coming revolution during which Negroes and Jews would take over the world. Mrs. Foster learned that she dare not dissent from these ideas, so she just tried to change the subject.

About a year and a half before Mr. Foster was admitted to St. Elizabeths, he began waking his wife at night to tell her of nightmares about his wartime experience. Three months later, he quit his job. He began to write a book about the war and science. "If you saw what he wrote, you couldn't see anything wrong with it," Mrs. Foster recalled.

While she was at work, socializing with the customers and other clerks, Mrs. Foster could forget about her husband's strange behavior. At home, it wasn't as easy. She found it increasingly difficult to ignore the seriousness of his condition. She was also concerned that he wasn't making any money.

One evening her husband told her that he wanted to discuss his ideas with Einstein. He planned to pay a visit to the great scientist. Mrs. Foster thought it was a silly thing to do. She wondered why he couldn't just talk to someone closer to home. But later she told the interviewers that she had driven to Princeton, N.J., with her husband. She said they had parked outside the building where Einstein's office was located, and when he emerged Mr. Foster engaged him in conversation for about 10 minutes. According to Mrs. Foster's account, Einstein told Mr. Foster to see his secretary, who told him to put his ideas into writing before attempting to discuss them further with the scientist.

The day before Mr. Foster was finally admitted to a hospital he went shopping with his wife, something he had never done before. He worried that he might lose her while shopping, Mrs. Foster reported. Later that day, Mr. Foster thought he was the subject of a TV program and that the set was "after him." By this time, Mrs. Foster could see that her husband's behavior was "rather strange."

That night, Mr. Foster talked incessantly. He reproached himself for not making enough money to give his wife surprises. After a second thought, he changed his mind. He did have a surprise for his wife, he exclaimed. He was going to kill her. Scared now, Mrs. Foster asked him what he meant. He began to cry. She must not let him hurt her, he wailed, but do for him what she would want him to do for her. She asked him what was wrong with him. He said he had cancer. Then he began talking about the worm growing out of his grandfather's mustache. Remembering that she had earlier seen him watching worms in the fish bowl, Mrs. Foster thought she knew where this idea came from. Mr. Foster said he had killed his grandfather. He asked Mrs. Foster to forgive him. She became convinced that her husband's mental state was not what it normally was. "But I wouldn't say that he was insane or crazy, because he had always bossed me around before," she reported.

Mr. Foster talked all night, but by morning he "seemed to straighten out" and drove his wife to the store where she worked. At noon, he walked into the store. "I couldn't make any sense of what he was saying," Mrs. Foster said. "He kept getting angry because I wouldn't talk to him." Her boss told her to go home.

On the way there, Mr. Foster told his wife that his male organs were blown up and little seeds covered him. Mrs. Foster assured him that she couldn't see them. She announced that she planned to call his mother. At this, he began crying, and she was forced to promise that she wouldn't. "Don't you think you should go to a psychiatrist?" she asked. "No," he responded. "There's nothing wrong with me."

At home, he suddenly chased his wife around the apartment, growling like a lion. She screamed. Her husband ran out, and she slammed and locked the door behind him. "When he started roaring and growling, then I thought he was crazy. That wasn't a human sound. You couldn't say a thing to him."

Later that night, Mr. Foster went to a nearby church and created a scene. The police took him to the psychi-

> atric ward of a general hospital. At the commitment hearing that followed, however, he seemed quite normal. It was recommended that she arrange for his hospitalization at the VA hospital. During the days they waited to get in, Mr. Foster again became disturbed. On the tenth day after the hearing, he assaulted a friend. Mrs. Foster then spent 2 hours calling hospitals, and finally she got D.C. (District of Columbia) General Hospital to accept him. A fire department ambulance took him there.

Early Findings

After analyzing the interviews with Mrs. Foster and the other 32 wives, Clausen and his group had a fairly clear picture of the kinds of experience families encountered before, during, and after husbands were hospitalized for mental illness. The most salient of their findings were later noted by Clausen:

- Like Mrs. Foster, most wives had difficulty perceiving the nature of their husbands' problems. They tried to see their husbands' behavior as normal, variously attributing it to weak character, somatic illness, normal response to stress, or passing events. Their interpretations changed as pressure mounted, as conflict with their husbands became more intense and frequent. "Only when alternative interpretations could no longer be sustained was the hypothesis that the spouse was 'mentally ill' entertained seriously."
- If the wife recognized that her husband required treatment, she was repeatedly frustrated in her attempts to get it; usually she encountered roadblocks and deadends such as those Mrs. Foster found. Seldom were these wives able to get their husbands into a hospital without great difficulty. "Most families did not know where to turn for help, and even those professionals who are commonly seen as gatekeepers to psychiatric care frequently rebuffed patient and family in their search for help."
- Although most wives denied that mental illness carried any stigma, their behavior and comments showed otherwise. They avoided friends and acquaintances. They misrepresent-

ed the nature of the husband's illness to young children, distant family, and employers. They worried about the hostility and criticism they and their children would encounter. "Particularly at the time of hospitalization and when the husband returned home, communications with friends and relatives often tended to become a source of great anxiety and ambivalence."

Refinements

Conclusions drawn from the first intensive study of 33 families of male patients were reported in all the richness of detail possible through the investigators' research methods in an entire 1955 issue of the *Journal of Social Issues*. Other reports were published later by Harriet S. Murphy, a social worker and researcher, and Charlotte Schwartz, a research sociologist. Both had worked on the project in the NIMH Laboratory.

After they had analyzed the data on the first 33 families, Clausen and his coworkers were able to define the research questions more clearly. It was now possible to design a series of four structured interviews made up of sharply focused questions. The researchers planned to expand the study to include women patients and draw their sample not only from St. Elizabeths, but also from hospitals serving the Maryland suburbs of Washington, D.C. As Clausen contemplated this larger scale, longer term study, however, he realized that his research staff would have to work less intensively on it than on the first study. "The kind of interviewing we were doing was wearing and often anxiety-producing," he recalls. He found it especially difficult to recruit men who were good at such interviewing and who also enjoyed it. It was their lot to interview the female patients' husbands, who were less willing to talk than were the wives of male patients.

Nevertheless, the work continued. Only Harriet Murphy gave all her time to the project. Throughout the rest of the 1950s, she and her coworkers interviewed 55 more families. In 31 families the wife and mother was the patient, in 24 the husband and father was.

The investigators learned that this second group of families had just as much difficulty in recognizing mental illness for what it was as had the first 33 families. These families also had similar difficulties in getting the patient into treatment and felt as much stigma as had the first 33 families. Although the data were fully analyzed only recently, Clausen did examine the prehospitalization marital relationship of 24 of the new couples in a way that was not possible with the earlier data. He presented a paper based on this analysis at the 1959 American Sociological Association meeting. (Findings from this and the earlier papers will be discussed below.)

Influenced by the initial reports on Clausen's NIMH research, as well as by generally increasing interest in rehabilitating mental patients, other investigators took up the study of the consequences of mental illness for the family. A California group led by Harold Sampson, Sheldon Messinger, and Robert Towne intensively studied the interactions leading to hospitalization in the families of 17 women diagnosed as schizophrenic. Designed in part to complement Clausen's project, the California study was much more probing; patients as well as spouses were interviewed for up to 3 years following a patient's return home. On the average, 50 interviews were conducted with each family. For Clausen, this careful research was later to hold more than the usual interest of one investigator in another's work.

In 1960, Clausen moved to Berkeley, where he became Director of the Institute of Human Development at the University of California. He had planned to get back to analyzing data from the NIMH family study once he settled into the new job. But he found that his new research, along with administrative and teaching duties, took up all his time. For the next 10 years, except for devising procedures for coding his data, Clausen was unable to work on the family study.

A RETURN TO THE FAMILIES

"In 1970," Clausen says, "I realized that if the study was ever to be completed, I should have to get started before retirement." He decided then that, in addition to analyzing the data on all the families first studied in the fifties, the study would be much more valuable if he also did followup interviews with them. When Sheldon Messinger learned of Clausen's plans, he suggested that Clausen might also follow up the schizophrenic women whom he, Sampson, and Towne had studied in the late 1950s.

In addition to the families originally interviewed in the fifties, Clausen's group would also interview families of a new group of patients hospitalized for mental illness in the 1970s; this time, they would interview both patients and their spouses. New patients would be found in the same areas as those in the original study. Financed by a grant from NIMH, Clausen began the new study in April 1971. His principal assistant was Harriet Murphy, who had interviewed about a third of the families in the fifties. For the first few months, she coordinated the field work in the Washington area. When illness forced her to give up her position, she was replaced by Carol Huffine, who was soon to be awarded a doctorate in sociology at the University of California. Huffine joined the project in early 1972 and has continued to be Clausen's principal professional colleague on the study through the years.

Doing it the Hard Way

For a man nearing retirement, Clausen was taking on an enormous job, requiring a mixed bag of skills and sensitivities. He had, however, already proven himself adept at this type of intricate sociological research. He goes at it the hard way. He insists on working "close to his data." For example, he interviews some families himself. He pays attention to them, hears what they have to say, keeps an open mind so that unexpected responses don't pass by. He and the other interviewers go in to learn about the nitty-gritty details of mental illness from those affected by it—not to "administer a questionnaire." His research design now involves using enough subjects to allow for statistical analysis. In collecting, quantifying, and analyzing his data, Clausen is a hard-headed scientist. He attends to detail, teases out the hidden biases, checks and rechecks reliability. To avoid becoming enamored by these quantitative findings, he then turns back to the cases—the stories told by the people being studied.

The first task Clausen's group undertook in 1971 was to locate the families who took part in the studies in the fifties. Dogged detective work was required to track down the families—most on the other side of the country from Clausen's Berkeley[7] headquarters—in rapidly changing urban centers. Public records had to be checked for names of patients who had died, hospital files examined, phone books scanned, rumors pursued. Surprisingly, more than half of the families had remained in the area in which they had first been studied. Most of those who had moved had merely gone from city to suburbs, but many had moved several hundred miles away.

Over the months, Clausen's team was able to account for about 85 percent of the total group of patients—whether living or dead, whether subsequent treatment had been required, and current whereabouts. Once the families were located, Clausen and his colleagues had to step back and consider whether reinterviewing them might entail risks to their welfare. Would recalling their experience with mental illness touch off new reactions to old troubles? In some cases, where a patient had committed suicide or died soon after returning from the hospital, Clausen's group decided not to subject the families to further interviews.

Of those they tried to interview, one in 10 of the patients or spouses refused. When the spouse was dead, refused to be interviewed, or could not be located, the interviewers turned to the patient or a relative such as a grown child.

Sometimes they could find no one. All of the "lost" cases involved female patients. Clausen believes that name changes and the instability of many of the female patients' husbands account, in part, for his group's inability to locate some female patients' families. He notes, however, that these families were difficult to study in other respects as well. Wives of male patients were better educated and much more willing to participate and to respond fully during the interview than were husbands of female patients. Clausen remembers that the wives of male patients in the first study welcomed an opportunity to talk with a sympathetic listener, and many established close ties with the interviewers. The husbands of female patients, by contrast, could talk with coworkers and other confidants. They were not the kind of men who liked to talk about their feelings—with their wives or with an interviewer. At followup, they had not changed markedly. As a result, information on female patients is skimpier than that for male patients.

Interviewing the families took the better part of the first 2 years of the renewed project. In most cases, the spouse was asked about the patient's treatment history, the couple's marriage, the occupational careers and social participation of both spouses, and the children's development and current status. The well spouse was also asked to assess the overall impact of the patient's illness on the life of the family. Those who were separated or divorced were asked additional questions about that experience. Over the next 2 years, the research team spent long hours painstakingly coding and recoding the verbal responses into quantitative form. Clausen was scrupulous about reconciling all discrepancies in the coding, because his sample size was too small to allow room for technical errors in the data. The coding job turned out to require "little short of herculean" effort, says Clausen. In addition to the followup interviews themselves, data from Sampson and Messinger's original California study had to be coded to match Clausen's study. Changes in computer technology meant that his own interviews from the fifties had to be recoded. Background data on the families and clinical records were also coded. Just developing codes that would render data from several samples comparable proved to be a difficult and slow task.

Deadline-defeating gremlins kept popping up. Grant money was delayed and coders had to be laid off. A careless research assistant failed to follow instructions, and some of the coding had to be redone. Clausen's grant was reduced during a period when the NIMH research budget had been cut and all projects were scaled down. As a result, Clausen and his staff were forced to give less time to the project.

New Rules, New Wrinkles

Meanwhile, for the second part of the study involving new patients, Clausen was negotiating with State and local mental health facilities to obtain access to records. One mental health center was closed to him because the city's attorney adamantly opposed such research—perhaps a sign of the public's increased sensitivity to the rights of patients. Clausen, himself acutely aware of the stigma of mental illness, willingly agreed to sign affidavits pledging that all records would remain confidential.

Because treatment practices had changed so dramatically in recent years, Clausen had first to monitor the flow of past admissions to the participating hospitals and clinics to learn where patients meeting his research criteria could be found. When he began the new study in 1971, he had assumed that many of the patients he wished to study would now be treated in outpatient settings. He had, in fact, hoped to compare families of patients who were hospitalized to those of patients who were not. His assumption proved wrong. In the counties included in the research—Maryland's Prince Georges and Montgomery Counties and California's Alameda and Contra Costa Counties—very few patients meeting the research specifications were being seen as outpatients. (The new group of patients, like the old, were to be white, married, living with their spouses, between 20 and 50 years old, not previously treated for mental illness, but now diagnosed as schizophrenic, manic-depressive, severely depressed, or psychoneurotic.)

Contrary to Clausen's expectations, few of the husbands and wives who broke down in the seventies were treated as outpatients.

Another difficulty arose as a result of stricter procedures for protecting patients' rights. State and Federal regulations, as interpreted by Berkeley's Committee for the Protection of Human Subjects, required that Clausen obtain the signed consent of both patient and spouse before interviewing them. Several patients refused to sign. Like most researchers, Clausen enthusiastically supports the need to protect patients' rights and privacy. But he thinks that local committees charged with that responsibility too often rely on the signed consent form and fail to consider alternative mechanisms. For his study, for example, he preferred giving the patients and their spouses a statement, signed by him, that would explain what the study was about and spell out their rights as subjects and his duties and responsibilities as investigator. Clausen explains that many respondents, particularly those in the working class, have heard over and over that they should never sign *anything*. Among Clausen's prospective subjects, this reluctance to sign forms was compounded by the fact that both patients and spouses understood that the research had nothing to do with the services they were receiving. They knew their participation was wholly voluntary and that they would be offered no services by the research team. Clausen's group asked them to take part in the study merely because it might help the researchers understand the problems of families, so that eventually other patients' families might be served better.

Clausen believes that if he had been able to forego consent forms in favor of a statement of explanation and commitment, he would have been able to come up with a more representative sample than he did. Patients who refused to sign consent forms either had strongly paranoid symptoms (a few patients refused because they saw the research as "stealing their secrets") or were from families in which there had been intense conflict before hospitalization. As a result, their families may be underrepresented in the new sample.

The brief time that patients are hospitalized today also introduced unexpected problems. Typically, patients spend only a week or two in the hospital on their first admission. Frequently, they are released only to be readmitted shortly thereafter. In some cases in Clausen's new sample, therapists of patients who had been in and out of the hospital advised against trying to interview them. In other cases, patients persuaded their wives and husbands to end participation beyond the second interview. Some patients were hospitalized for such brief periods that they were lost to the study. Clausen estimates that a third of the potential population meeting the study's criteria was lost.

Of the 41 patients who finally comprised the new group, 18 were men, 23 women. Only one, a woman, was treated in an outpatient setting. The majority were seen in the psychiatric services of general hospitals or local private psychiatric hospitals. After interviewing the new patients and their families, the research team again coded and recoded the information. They also prepared detailed clinical summaries on the patients, which were mixed with similar summaries from the "old" patients and independently diagnosed by a psychiatric consultant, Dr. Carlos Sluzki. Clausen took this precaution to assure that patient groups were similar, because he wished to compare the new patients' experience to that of patients first hospitalized in the fifties (2).

Reporting Back

In the 8 years since Clausen returned to the study of families of mental patients, few reports on the work have reached professional audiences. The research has required far more time than Clausen had anticipated. He acknowledges that he originally underestimated the complexity and cost of the work he had set out to do. As a result, he has been short of funds and staff during much of the project. He also admits to trying to do too many things at once. While working on the family study, he continued doing research at the Institute of Human Development, directed a large training-grant program, and served as Chairman of Berkeley's Department of Sociology for 2 years.

By its very nature, longitudinal research in the social sciences is enormously time-consuming, however. Unlike physical and biological sciences, where definitive laboratory experiments can often be done in relatively short order, collecting data about social and behavioral processes is slow-going. And as it progresses, hindsight becomes clearer and clearer. Clausen notes that "in the later stages of any research, we wish that we had done some things differently." In the family project, some interviews, inevitably, "would lead to new hunches and to revisions of some of our classifications." But many revisions suggested by the clear vision of hindsight could not be made without starting over. To maintain comparability from one subject to the next, one sample to the next, Clausen, like other social scientists, has been forced at times "to live with imperfect measures."

Clausen resigned his department chairmanship in mid-1978. Now he and Huffine are, indeed, living with their measures—perfect and imperfect. Well along with their analysis of the full set of data, they are examining how each patient's sex and diagnosis are related to the process of defining mental illness and the consequences of mental illness for the patient and the family. They are also attempting to weigh the effects of social class, the quality of the marital relationship, and personality features in both patient and spouse on these same factors. Because of the small number of cases in each subsample (e.g., male schizophrenics), each possible source of variability in responses to mental illness is being examined separately.

Much of the analysis of data on the long-term consequences of mental illness has already been done and several articles have been accepted for publication. Comparisons between the fifties and seventies families are well under way. During the next year, Clausen and Huffine will prepare a monograph which will describe the entire project and report their findings. The results given below are drawn from four sources: articles and papers based on the fifties' studies, grant applications and interim reports on the new project to NIMH, several already completed papers reporting analyses of the followup data, and interviews and correspondence with John Clausen.

FAMILIES OF MENTAL PATIENTS—THEN AND NOW

In their analyses, Clausen and Huffine are comparing the experience of the 41 families of patients first hospitalized in the seventies to the 80 families from the fifties who met the study's original sampling requirements in every respect (3). Many of the comparisons contrast the families of schizophrenics to families of patients who received other diagnoses (psychotic depression and manic-depression, severe psychoneuroses, reactive depression, depressive neurosis, or personality or character disorder).

In the new group, proportionately fewer (50 percent) were diagnosed schizophrenic than the fifties group (70 percent). Half of the new patients were 37 years old or younger when hospitalized. The fifties patients were a few years younger at the time of their first admission—perhaps reflecting the fact that there were more schizophrenics among them, and schizophrenia typically appears at a younger age than do the "affective" disorders. The new group, as expected, left the hospital much earlier than did the fifties patients (measured in weeks rather than months), and far more were markedly symptomatic when they left.

Recognizing Mental Illness

In families studied in the 1970s, Clausen's group gave special attention to learning the "grounds of normalcy" in each home. Their earlier interviews had taught them that the process of recognizing mental illness was always affected by the family's longstanding perceptions of what was "normal" for them. The relationship between husband and wife has a life of its own, influenced by, but sometimes very different from, cultural norms. The spouse is most likely to try to fit unusual behavior into the pattern of perceptions accumulated over the years. As the NIMH group noted: "Symptomatic reactions which are intensifications of long-standing response patterns become part of the fabric of life and are not easily disentangled as 'symptomatic.'"

Before one spouse became mentally ill, nearly all of the families in both old and new groups had been established long enough for the husbands and wives to have developed stable expectations of each other. The fifties patients had been married for an average of 10 years, the seventies group for nearly 15 years. The marriages in which the husband eventually became mentally ill, however, were much happier than those in which the wife became ill.

For those hospitalized in the fifties, four out of five female patients' marriages were unsatisfactory to one degree or another. Many had been torn by pervasive conflict for years. Even before the wives experienced symptoms—hearing voices, for example—their husbands saw them as disturbed. The men characterized their wives as jealous, suspicious, nervous, moody, shy, immature, or complainers. Male patients had much better marriages, rarely marked by longstanding conflict. As often as not, their wives saw them as essentially normal and healthy before symptoms appeared. Some described their husbands as weak in character, spoiled, or physically ill. By and large, however, they saw their mates as mentally normal.

Clausen says that he is not sure if the harsh characterizations of the female patients reflected what were, in fact, very inadequate personalities, or were simply expressions of "the male's stereotypic tendency to see the female of the species as more neurotic than the male."

In the families of patients hospitalized in the seventies, there was far less overt and bitter conflict than in the fifties group. The investigators speculate that, among other factors, this change could be related to duration of psychiatric problems or today's easier divorce procedures. As with the fifties families, male patients' marriages had been better before the onset of symptoms than had female patients'.

Most of the wives in the fifties group were unable to point to a single strange or disturbing reaction that convinced them that their husbands were mentally disturbed. Most, like Mrs. Foster, endured, unable to separate the bizarre from their overall knowledge of their husbands' personality and family expectations. The problems usually began at home, within the family—physical complaints, expressions of inadequacy or hopelessness, withdrawal, nervousness, deceptiveness, slovenliness, aggressiveness, suicidal behavior, delusions, hallucinations. All piled up and eventually spilled over into more public domains. Excessive drinking and indecent or bizarre behavior in public often occurred then.

Some patients themselves expressed the fear that they might be mentally ill, a fear that family members often protested.

The husbands of female patients were slow to take serious notice of their wives' symptomatic behavior. A wife might accuse the husband of being unfaithful, move out of the marriage bed, withdraw psychologically. Then she'd let the housework go. For many, symptoms went on for a year or more before the husband sought help. "In several instances where conflict had been rife," says Clausen, "husbands maintained an almost incredible tolerance of deviance for many months without communicating with anyone outside."

Like the fifties group, when the well spouses in the seventies first noticed that something was wrong, they interpreted it as nervousness or irritability. "Again," says Clausen, "a majority of wives and husbands initially saw the patient's problem as something other than mental illness or severe emotional disturbance." Again, spouses perceived the onset of problems as gradual. The investigators found that, in the new group, husbands of older women were still often interpreting their wives' distress as a sign of menopause—"an old husbands' tale that persists," notes Clausen. While one in six wives interpreted her husband's changed behavior as serious emotional disturbance requiring treatment, only one in 20 husbands came to that conclusion about a mentally ill wife. Another fourth of the male patients' wives and a fifth of the female patients' husbands considered the possibility of emotional disorder but found other explanations equally plausible.

In both the fifties and seventies groups, some patients themselves expressed the fear that they might be mentally ill. (It was not uncommon for their families to protest such fears, to deny that they were mentally ill.) In other cases, the patients had told their spouses that they felt either persecuted, seriously ill physically, or guilty of sin or some terrible act. In many cases, the patient simply withdrew, and the spouse was unable to tell the investigators what the patient felt was happening.

In the fifties, if the disturbed spouse's symptoms had been persistent, the household's day-to-day routines became seriously disrupted in the month or so before hospitalization. None of the couples was getting along well by then. If the marriage had been good, the spouse's initial anger might have turned to worry. But in bad marriages, anger, fear, and ridicule continued. Hostile comments that were typical: "You should have your head examined." "If you're not careful, you'll be a mental case." The same patterns were also found in the seventies families. The spouses again dealt with the problems by coaxing, begging, pleading, and sometimes berating or avoiding the troubled partner.

In the fifties, children were not usually involved until this late stage before hospitalization. Especially where mothers were psychotic, child neglect and, less often, abuse prompted the spouse to seek hospitalization. In other cases, assaults on the spouse or suicide attempts were the final straw. But until just before hospitalization, many mothers (especially those in happy marriages) continued to care for their children, and many men continued to perform on the job. "Indeed," says Clausen, "these seem to be the minimal role functions that must in general be sustained if the family is to go on at all."

Just before hospitalization, roughly seven in ten of the seventies patients were showing bizarre or aggressive behavior that reached levels the spouses could not ignore. (Most of the other patients were depressed or acutely anxious.) As with the fifties families; the marital relationship was impaired long before other major roles became affected. And, as in the old group, the male patients' performance on the job and the female patients' performance as mothers were not markedly impaired until just before hospitalization.

In the 1970s families, Clausen's group asked for details about the patient's effect on the children. The symptomatic fathers tended either to withdraw and not respond to their children, or they became more critical. "Mothers were also sometimes less responsive but more often were reported to be critical, severe, or (occasionally) hostile or bizarre in dealing with the children," Clausen and his colleague, Carol Huffine, report.

Reaction of the Spouses

Clausen and Huffine found that spouses in the new group were more sympathetic toward their mentally ill mates than were those interviewed in the 1950s. But in both groups, wives of disturbed husbands were, on the average, more sympathetic and understanding than were the husbands of female patients. In the new group, where the patient was interviewed, the well spouses' perceptions of their own reactions were largely confirmed by the patient spouses. In the new group, two-thirds of the wives were reported as more accepting than rejecting of their symptomatic husbands, and some of the rest became more accepting once they recognized that their husbands were mentally ill. By contrast, four in ten husbands were seen as rejecting their mentally ill wives in some fundamental way.

As might be expected, the happier the marriage before the breakdown, the more likely it was for the spouse to react sympathetically. In marriages that had turned sour, even the wives could be extremely sarcastic and harsh in assessing their psychotic husbands. In marriages that had been close, the spouses remained sympathetic no matter how annoyed or angry they might be with the patients.

The Search for Help

Wives of the original 33 patients in the NIMH study seldom knew where to turn for help. Many consulted family physicians; but in half these cases, the physicians failed to recognize the psychiatric problem. In several families, the wife turned her husband over to his parents, who sometimes did arrange for hospitalization. In other cases, clergymen were consulted or the police brought in. They, too, often failed to help the wife clarify what was wrong. As a result, "the paths to the hospital were beset with obstacles and traumata for husband and wife."

Attempting to explain the difficulty these wives encountered in the fifties, Clausen's group pointed out that with mental illness, unlike physical illness, "the diagnostic process must, in general, go much further within the family itself." Even after the illness had been recognized, however, the route to treatment was long and snarled for these families.

Families encountering mental illness for the first time in the 1970s had a somewhat easier time. In the fifties group, spouses often reported that their most difficult problem had been getting the disturbed spouse into the hospital once they had recognized that it was necessary. In the seventies, only one spouse in eight saw the process of hospitalization as the most difficult problem.

Nevertheless, patients still often underwent prolonged symptomatic treatment for physical symptoms or for "nerves," even when they exhibited bizarre psychological symptoms. Nearly 80 percent of the patients consulted a physician about their problems at one time or another. While female patients usually went on their own initiative, male patients went at their wives' insistence. Half saw a physician more than a month before they were hospitalized. And in more than half the cases where seen, the physician failed to advise consultation with a psychiatrist or to actually refer a patient to one.

As with the fifties group, it was most often the spouse or a professional who first suggested that the patient's problem was mental or emotional. Physicians decided that the patient should be hospitalized in the case of nearly half of the female patients. Most often the patient agreed to the move. The great majority of the other patients were hospitalized because their spouses, or they and their spouses together, decided that it would be desirable. A sixth of the male patients decided on their own to be hospitalized. Parents of the seventies patients were much less often involved in getting the patient hospitalized than were parents in the fifties families.

Clausen and Huffine found that, to their surprise, an unhappily married woman was more likely to get into treatment within 3 months after a breakdown than was a woman who had a good relationship with her husband. They believe that this difference might be attributable, in part, to suicide attempts or other acts that precipitated hospitalization. But another factor may be that husbands whose wives were extremely sick, but who had sound marital relationships, were reluctant to seek psychiatric treatment. Because the sample is small, Clausen says he doesn't want to make too much of this difference. "But there is a suggestion that wives today are somewhat more active in their own behalf, even when mentally ill, than they were two decades ago."

Only one in five of the new patients was committed, compared to three in five of the original 80 patients. In one of ten of the seventies cases the spouse called the police to take the patient to the hospital. The police were also involved in six cases where there was a court order committing the patient. Nearly half of the families had become involved with the police in the 1950s.

Based on their analyses to date, Clausen and Huffine conclude that it is *not* much easier for a husband or wife today to recognize mental disorder in a spouse than it was 20 or 25 years ago. But once the problem is recognized, the mentally disturbed spouse gets into treatment more quickly and with much less trauma than was the case in the 1950s. Clausen believes that today's greater availability of community resources for treating mental illness makes the hospitalization process much easier. "Moreover," he says, "if physicians do not always recognize a psychosis when it is first presented to them, they at least know where to refer the patient once they have recognized it."

An Absent Partner and Parent

Families suffer major disruptions in their normal routines, roles, and relationships while one member is becoming increasingly more disturbed. For those in the fifties, hospitalization brought even greater upheavals. Mothers or fathers, wives or husbands were gone for months at a time. Patients in Clausen's fifties' sample spent an average of 3 to 6 months in the hospital, but six of the 80 patients were there for a year or more. When the husbands in the first group were hospitalized in St. Elizabeths Hospital, their wives were told to prepare for a long absence. Many were advised to take jobs, unless they had some other source of financial support. Most did not move; most kept their children with them. A few moved in with their parents; a few left their children with their parents during the day.

As Clausen and his colleagues had anticipated, when wives were hospitalized in the fifties, their families frequently broke up temporarily. Children were often cared for by their grandparents or other relatives, who sometimes lived far away. Unlike the families in which the father was the patient, very young children were usually placed somewhere outside their parental home when their mothers were hospitalized. "Even when wives of male patients worked," report Clausen and Huffine, "they gave higher priority to the child's needs than did husbands of female patients."

Families in the seventies suffered far less disruption when a parent was hospitalized. With the hospital stay usually under 3 weeks, children were rarely placed with relatives except for care during the day. Unless the patient remained seriously symptomatic, the arrangements were temporary. Not one wife in the recent group took a job because her husband had been hospitalized. "On the contrary," say Clausen and Huffine, "a substantial proportion of mothers who had been working took time off from the job or put in shorter hours." This was also true of husbands.

Children often have the most problems when their parent returns from the hospital.

Although they did not systematically inquire about children's visits to their hospitalized parents in the original sample, Clausen and his colleagues have the impression that such visits were much less frequent than they were in the recent group. Hospitals are more readily accessible in the seventies. The great majority of the new patients were visited by their children as often as they might have been if they had been physically ill.

The researchers also asked the new group of families how the children responded to their parent's absence. The wives of male patients usually saw signs that their children were upset or concerned, but husbands of female patients as frequently reported that children were not concerned. If there had been longstanding conflict, the children might even be reported as relieved. Clausen and Huffine are skeptical about these reports, especially those of the husbands. Their recent interviews with the now-adult children of patients hospitalized in the fifties suggest that many children are far more distressed than their parents seem to realize.

The wives of male patients hospitalized in the fifties often learned some valuable lessons. When the interviewers asked them how the experience with mental illness had affected them, the wives frequently said they had learned to recognize their own competence. A typical comment was, "It made me realize that I could handle things myself." Some, especially those who expressed a need for autonomy, kept their jobs after their husbands came home and returned to work. Others who had quit jobs when their husbands returned from the hospital went back to work when their husbands' symptoms reappeared. "They wanted to control their destinies, and not have to depend on somebody who might be in and out of the hospital." Few wives, in fact, stayed with husbands who continued to be symptomatic.

Husbands had the opposite experience. They were far more likely to report that they didn't realize until their wives became ill that they weren't able to do many things. They were also more likely to stay with wives who continued to be symptomatic, often participating very fully in some homemaking chores.

Explaining to the Children

Clausen was surprised to learn that when a mother or father becomes mentally ill today, the spouse receives no more guidance in dealing with children's reactions than parents did 20 or 25 years ago. At least this was so for the families he studied. "Despite all the talk about family therapy," he complains, "only a few of the husbands or wives in our new families were called in for an interview by the treatment staff." As far as Clausen has been able to determine, none of the patients' spouses was even asked about the children. In the past quarter century, mental health educators have made repeated attempts to distribute materials advising families how to deal with mental illness. Some of the 41 families in the 1970s had read books or pamphlets that contained suggestions for coping with mental illness. But none of the material was given to them by the treatment center. In the early fifties, he recalls, "one of the most difficult things for people to deal with was communication with the children as to what was going on." The spouses didn't know what to say. "They tended to shy away from talking about mental illness. They still do."

Clausen describes a typical parental response in a family with several young children. The mother had been taken to a State hospital and diagnosed as schizophrenic after she was arrested for trying to sell what she said were military secrets. Her neighbors noticed her absence and assumed she was away on a visit. Then one neighbor learned that she was in the hospital. He waited for a few days before broaching the subject, and he found that when he finally did, the husband was relieved. The husband said he hadn't been able to bring himself to say anything about it to his friends and neighbors.

The neighbor offered to help with the children. It was then that the husband had to admit that he hadn't been able to talk with them about their mother's breakdown. No one at the hospital had asked him if he needed help with the children. No one offered advice.

While the wife was hospitalized, the husband was relieved to learn that most of his neighbors were supportive. They brought in meals and helped care for the children. The youngest child was especially troubled by his mother's absence. He started sucking his thumb and wetting his bed—habits that he had broken before his mother left. When she returned home, she did not seem to know how to relate to her children. She said that she felt her authority in the family had been undermined. She subsequently abandoned her family.

In the families Clausen studied in both the fifties and seventies, less than a third of the well parents who had children old enough to understand the problem told them what was happening. "The parent will either say, 'They're too young to understand,' or 'They know what's going on.'"

How do they explain the ill parent's absence? The well parent will often tell young children that their mother or father is suffering from some physical ailment—a toothache, a tummy ache, trouble with a leg. "All of the conflict that preceded hospitalization—and there's usually a lot of conflict when someone becomes sufficiently symptomatic to be hospitalized—all that is brushed under the rug."

Older children might be taken into their parent's confidence, particularly their mother's. Clausen says that the mothers seem to find it easier to discuss their feelings with their children and to recognize that they may feel guilt and confusion. "The fathers are much more likely to deny that there's any effect on the children, at least that they've noticed. Fathers typically say something like, 'No, they just take it in stride.' Mothers are much more likely to notice."

Explaining to Others

When Clausen and his colleagues asked the spouses in the fifties families to characterize how their partners' mental illness had affected them socially, the investigators learned that most felt stigmatized. Again and again, these spouses said they expected hostility and criticism. Wives feared for their husbands' jobs, worried that old friends would avoid them, and were anxious that their children might be excluded from play groups or be taunted by other children. They were concerned that their family name would be hurt. With family, friends, and employers, they dissembled, concealed, and denied; in only a few cases did spouses talk openly about the situation.

Two typical comments were: "I live in horror—a perfect horror—that some people will make a crack about it to Jim [child], and suppose after George gets out everything is going well and somebody throws it up in his face. That would ruin everything. I live in terror of that—a complete terror of that."

"Of course it was all new to me. I had never known anyone like this before. At first I was a little ashamed, but now I'm getting to understand it better. I know that mental illness is just like physical illness. I don't think people think about mental illness the way they used to. Of course, I have cut out seeing all but a couple of our friends. There are especially some I have cut out. In fact, Joe asked me not to tell his friends while he was in Saint Elizabeths Hospital."

Two out of three of these families studied in the fifties had parental families living nearby. Most knew of the illness and hospitalization, but the communication between the psychotic husband's wife and her own family differed greatly from that with her husband's family. While wives rarely sought help from their own families before hospitalization, they often turned to them for help and emotional support after they were left alone with the children. Their interactions with their husbands' families, on the other hand, were laced with hostility. "Accusations and counter accusations are made. Patience is short and criticisms are easy and frequent." The wife blamed her husband's family for his illness; they blamed her. "The husband's illness seems to have the effect of consolidating or accentuating the prior relationships between the wife and the parental families," the researchers reported in 1955. Wives frequently complained that in-laws had little appreciation of the difficulties they experienced. As one wife said, "I feel hurt and feel they have not considered me. All they are concerned about is my husband."

In their communication with outsiders, some wives tried "aggressive concealment," cutting out all social encounters. Sooner or later, however, they would have to tell someone—an employer, for example. Lies and evasions were cumbersome and difficult to maintain. Isolation would distort the wife's perception of what others thought.

The reaction of others was sometimes kind and understanding, but at times it was cruel. The wife might be kidded by coworkers about her lack of a sexual partner or subjected to advances from male friends. Also, while the husband was hospitalized, "there was rather thorough-going avoidance by friends and acquaintances," the investigators noted. "Normal expressions of concern for the welfare of one who is ill such as visits, written messages or gifts are avenues little used for the mental patient."

Although Clausen and Huffine have not completed their analysis of the data on the new families' social interactions, Clausen has the impression that they are much less traumatic than they were for families in the fifties. The well partners seem to feel less stigma than did their counterparts 25 years ago. One indication of this difference is that the spouses seem to be more open about discussing mental illness with their neighbors than they were in the 1950s. The apparent change in attitudes may be attributed, in part, to the fact that far fewer of the seventies patients were sent to State mental hospitals. Clausen says that another reason may be that mental health professionals are themselves more hopeful about the prospects for the future of psychotic patients.

The extended family also appears to be less involved today. Unlike the fifties wives, a wife in the seventies was not likely to blame her husband's parents for his problems or turn him over to them. In fact, three out of four couples either did not inform the husband's parents of his hospitalization until after it had occurred or did not tell them about it at all. About a fourth of the female patients' parents were involved in their daughter's hospitalization, while slightly less than half either knew nothing about it or weren't told about it until afterwards.

The Returning Patient

In the fifties, when patients returned home after a long stay in the hospital, their husbands and wives found them very dependent. They demanded displays of affection. They tried to please the spouse by helping out around the house and doing extra chores. Clausen says that while this phase did not last long, some spouses found the readjustment "unanticipated and unnerving."

Many of the former male patients were anxious about returning to work. Very few men lost their jobs because of their illness or had trouble finding a new job. But, says Clausen, those who did have trouble were devastated by it. Contrary to their fearful expectations, most men who returned to old jobs found few problems in relating to their coworkers.

The men first hospitalized in the seventies were much more likely to return to their old jobs than were those who first suffered a psychotic breakdown in the fifties. This difference, say Huffine and Clausen, is probably partly due to the shorter duration of hospitalization in the seventies group. But other differences in the groups also may contribute to the change in experience. The men in the new group were older, on the average, than in the old—a factor which in itself was positively related to job retention. They also had somewhat higher levels of occupational attainment, another factor which, in both old and new groups, was positively related to returning to an old job.

Today's Treatment Practices

The revolution in standard treatment practices for the mentally ill has solved some old problems and introduced new ones for families. For the most part, the short hospital stays seem to be less disruptive for families than the long hospitalizations common a quarter of a century ago. The short stay is much easier to handle—like a hospitalization for a physical illness—according to Clausen. Being treated in the psychiatric ward of a general hospital or small private hospital is far less stigmatizing than going to a State hospital. In the earlier study, wives whose husbands were treated in a Veterans' Administration hospital felt less stigma. The wives could just tell friends, "My husband's in the VA hospital." They didn't have to mention that he was on a psychiatric ward.

Long periods of hospitalization did have some advantages, however. There was more time to heal the wounds opened in the period of turmoil before hospitalization. When the patient was gone longer, some families would go through a honeymoon period after being reunited. This is less common today. In some of the families who experienced a first hospitalization in the seventies, the cooling-off period was not long enough, Clausen concedes. "Some patients are returning home while there's still so much turmoil, and they may still be symptomatic or so heavily drugged that they don't relate." The patient more often returns to the hospital in short order. Patients hospitalized in the fifties, on the other hand, "would be allowed to go home for a weekend. Then they might be given a longer pass—maybe an indefinite pass—and be discharged a year or so later. They were kept on a string tied to the hospital." Clausen and Huffine also discovered that, despite the reduced chance of breaking family ties because of long separations, the families in the seventies more often dissolved after the initial hospitalization than did those in the fifties.

What is the optimum length of a hospital stay? One that is long enough to allow family frictions to cool down and patients to recover? One that is short enough to prevent patients from becoming chronically dependent on the hospital and/or estranged from their families? Clausen thinks there is no optimum for all patients; much depends on the patient's symptoms, the family's composition and internal relationships, and the resources available to it. "Some studies suggest that patients who have been hospitalized until their symptoms have considerably subsided do better upon return than patients who have been maintained in the community on drugs and psychotherapy," he notes. While this issue is far from resolved, treatment staff must always keep in mind "the alternative considerations of giving the family a moratorium, on the one hand, and yet not completely cutting the patient off, on the other."

Like the patients, many spouses were afraid of psychiatric drugs. They were often concerned that improvements may not be "real." One husband said, "I don't know how much of her personality is her's and how much stems from the pills."

The powerful psychiatric drugs, on which many once-hospitalized patients depend, present problems of their own. Clausen and other critics have observed that drugs are often prescribed indiscriminately or inappropriately, especially for patients in the community. Clausen and Huffine collected some data on drugs being prescribed to patients in both their old and new samples. They also have information on the method of monitoring drug use and how family members influence the patient's use of drugs. Clausen observes that in some instances very high levels of drug dosage are being prescribed with almost no monitoring. "Wide varieties of drugs are used in rapid succession, sometimes for patients whose problems appear to be relatively minor—patients who have been coping quite effectively for a decade or more but have sought help in the face of an extremely upsetting situation."

Female former patients are much more likely to be receiving medication than are the male former patients. Some of the women hospitalized in the fifties and now in outpatient treatment "are being given far more drugs than they need," Clausen says. "They get what amounts to an open prescription, with physicians saying, in effect, 'Don't bother me, I'll give you what you want in the way of drugs.' It's rather appalling to find out the prescriptions some of these women have—the whole range of major and minor tranquilizers." Clausen learned in one interview that a former patient was taking four times the maximum dosage of one commonly prescribed, addictive tranquilizer. She couldn't function without it, yet she and her husband were very unhappy with her dependence. They arranged for her to go into a hospital for withdrawal, but when she got there, she stayed only one night. The experience of the State hospital 15 years earlier hit her so hard that she couldn't stay, she reported.

In some instances, husbands control and manipulate their wives' medication. They often have qualms about their wives using the drugs. But "only in a tiny minority of cases" have treatment staff explained to the spouse either the nature of the patient's condition or the rationale behind the drug treatment. "In general," says Clausen, "we have found that the family tends to be ignored almost as much now as it was 20 years ago."

An analysis done by Carol Huffine calls into question a common belief among mental health workers that patients who live with others are more likely than socially isolated patients to take medication as prescribed because their intake is supervised. Using data from the followup interviews with the fifties patients and interviews with seventies patients and their spouses, Huffine compared attitudes toward the use of psychotherapeutic drugs to the patients' actual use. She found that, like the general population, many patients and spouses in this study hold negative attitudes toward psychoactive drugs. A minority complained of adverse side effects, but others feared the drugs, felt that taking them carried a stigma, thought that they threatened the patient's autonomy and independence, or denied that they were necessary or effective. Huffine found that the spouses' attitudes largely mirrored those of the patients. Even those who perceived real improvement in the patient's behavior or demeanor were often concerned that the change may not be "real"—that it may reflect only the drug's power to mask symptoms. Huffine quotes one husband [illegible] saying, "I don't know how much of her personality is her's and how much stems from the pills."

Nevertheless, despite the "fears, sneers and side effects," most of the patients in the new group of patients took their medication as prescribed for at least a month after hospitalization. Some patients who appeared not to be complying with a prescription were, in fact, manipulating the medication schedule to minimize side effects that interfered with day-to-day activities. Some patients and their spouses apparently found that the benefits outweighed the negative aspects of the drugs. Others were able to cut down the drugs' costs by manipulating the prescribed regimen.

Huffine suggests that therapists should seriously take into account the attitudes of patients and their families toward medication. Brushing aside fears and opinions is simply not enough, she says. The patients' past experiences and the opinions of spouse and friends are likely to prevail. A clinician should not only take the time to explain what a drug is and why it is prescribed; he should also alter the dosage and timing of medication if patients complain about side effects.

LONG-TERM CONSEQUENCES OF MENTAL ILLNESS

In the analyses of the long-term effects of mental illness, John Clausen and Carol Huffine have focused on the same 80 families from the 1950s samples that they are using for comparisons with the 1970s sample. Interviews with 66 of these 80 families were completed by mid-1973—between 14 and 20 years after the patients were first hospitalized. Clausen's analysis of these families' experience is informed by his years of research on long-range normal development at the Institute of Human Development. He and Huffine are also making systematic comparisons between groups within the study sample: The adaptation of families of schizophrenic patients, for example, is compared to that of families in which the patient had an affective disorder or severe psychoneurosis. Families with a mentally ill wife are contrasted to those with an ill husband. Using these and other characteristics to define groups within the study sample, Clausen and Huffine are examining the effect of mental illness on marriages, the children, work careers, relationships with others, and changes in roles.

There were some differences among the subsamples of patients. Most nonschizophrenic men were older than the schizophrenics. The female patients were less educated than the men, and their families were of a lower social status than those of male patients. The women were first hospitalized after 1955, when tranquilizers were widely used; as a result, their first hospital stays were considerably shorter than they would have been a few years earlier and were slightly shorter than were the men's. But their symptoms at that time and during the succeeding years were more serious and persistent than were those of the male patients.

Whatever life held in store after the patient's first mental breakdown, none of the patients or their families saw the experience as an ultimately rewarding one. It was, says Clausen, "a horrible family trial." Some seemingly denied that it had ever happened. Clausen says a typical reaction in these families was, "Well, we don't know what happened then." But few families could forget the experience, because, in the majority of cases, the patient subsequently needed mental health care.

Mental Illness in the Interim

By the early 1970s, half of the former male patients had received further treatment at some time since the initial episode. By contrast, nine out of ten former female patients, most of whom were schizophrenic, had been treated again. The majority of all patients who received treatment were also hospitalized again—an average of three times. Most spent only short periods in the hospital when they returned. Some, however, remained symptomatic and continued to receive treatment as outpatients after they went home.

At the time of followup, four patients were either in psychiatric hospitals or on their books. Another woman had been transferred from a State hospital to a boarding home, where presumably she will spend the rest of her life. Of the 80 patients in the sample, seven men and four women were dead. Three of the men and two of the women had committed suicide; two men had killed themselves while on leave from their initial hospitalization, and another did so during a subsequent hospitalization.

Less than half of the men diagnosed as schizophrenic in the fifties were currently receiving any form of mental health treatment—a smaller proportion than any other diagnostic group. Clausen and Huffine point out that married male schizophrenics are, among mental patients, a blest group. They typically have a better prognosis than the other types of patients included in this study. "Marriage (or the establishment of an intimate heterosexual relationship) is undertaken by a minority of males who are at any age diagnosed schizophrenic," they note. "Those who do marry have repeatedly been found less likely to become chronic schizophrenics."

What led to further treatment? In two out of three cases, the interview respondents said that symptoms similar or identical to the original ones had recurred. These symptoms were seen as moderate to severe in two-thirds of the schizophrenic women and the nonschizophrenic men. In most of these cases, the spouse considered the patient to be mentally ill.

Divorced Couples

By the early seventies, a third of the marriages had ended in divorce. Most broke up within the first 3 years after the first hospitalization—almost always when symptoms had reappeared. Most of the later separations came after a subsequent hospitalization. The spouse was usually the one to ask for the separation. In families with an affectively disordered patient, the couples were more likely to have agreed upon the need to separate, and, in a few, the patient initiated the break.

In most of these families, the spouse asked for a separation after the patient's behavior had become intolerable. The wives of most of the schizophrenic men who continued to be symptomatic had left by the time of followup. Persistent symptoms in mentally ill wives did not, by contrast, often lead to a marital breakup. "Separation was not a clear-cut event" in many families of female patients, according to Clausen and Huffine. Sometimes the families just never got back together again after the wife returned from a hospital stay. Husbands didn't seek divorces unless they wanted to remarry. "Some families were so amorphous that it would be hard to say whether or not they remained intact," the researchers remark.

To their surprise, whether a couple remained together until the time of followup seemed to bear no relationship to their ratings of how happy the couple had been before the initial hospitalization. Some conflict-ridden marriages had endured;

some that had seemed rewarding in the fifties had ended in separation or divorce. Another finding that surprised the researchers was that middle-class families more often broke up than did lower-class ones, especially when the wife was the patient.

Several couples who fought constantly finally separated after their children left home—usually at an early age. In one, a schizophrenic mother encouraged her three daughters to be sexually provocative. When she invited the lover of the 16-year-old in, her husband tried to prevent it. He moved out because he was unable to.

Married Life Over the Years

Of the 34 couples who were still together at the time of followup, a few seemed to be happy. Most were either locked in intermittent conflict or had worked out a truce maintained by spending little time or emotional energy on each other. A few were at war. Yet, two out of three spouses characterized their mates in positive terms, sometimes mingled with descriptions of symptoms. A third dwelled on the symptoms and inadequate personalities of their mentally ill spouses.

In the families that remained intact, half of the patients' spouses had considered separation at some time. A number of the wives and one or two husbands of patients are still contemplating divorce, while several patients' wives have resigned themselves to unsatisfying marriages. In most of these families where separation had been considered, the patient's symptoms had persisted and often included violent behavior.

Among those who had never considered separation, a fourth of the husbands and wives go their separate ways. Far more of the couples who expect to remain together are highly dependent on each other, however. Where the wife was the patient, one out of three couples seems bound together by mutual pathological dependence, despite frequent outbursts of hatred. Few of the families where the husband was the patient depend on each other in this way; instead, most "have worked out lives that touch lightly under the family roof." Their mild involvement with each other keeps conflicts and tension at a low level.

"On the whole," say Clausen and Huffine, "wives of male patients seemed to cope much more competently with the dual roles that were thrust upon them when their husbands were incapacitated." In a few families, roles were actually reversed; the husband stayed home and the wife continued to hold a job. Mr. and Mrs. Foster, whose experience during the early 1950s was described above, are one of these families. They are still together and, by Clausen's estimation, have a good relationship. Mrs. Foster went back to school after her husband's breakdown. For many years now, she has taught school and been active in organizing professional training for herself and other teachers. Mr. Foster has never held another formal, paid job, but has done a good deal of volunteer work. Although he has been very anxious at times, he has never been hospitalized. The couple has no children.

Over the years, the families of male patients were generally less rocky than those of female patients; the patient-husband was not often symptomatic, usually held a steady job, had smoother relationships with his spouse, and shared more interests and activities. "By and large," Clausen says, "their families have been more stable than families of most sociologists and psychiatrists."

Half of the wives of former patients were unhappy about the disproportionate amount of responsibility that fell to them because their husbands did little to keep the household going. These men did "even less" around the house than the typical American male, say Clausen and Huffine. But that pattern had started early in the marriage and hadn't changed much over the years. By contrast, former female patients tended to carry less and less responsibility for household work as the years went by. Their husbands did much of it. But only one in five of these men complained about the arrangement.

Families in which the husband had an affective psychosis appeared to get along "reasonably well except during symptomatic episodes, when the patient was often completely out of control." These husbands were less abusive at home than were husbands of schizophrenic women. During manic episodes, they acted out away from home. When they were depressed, they were depressed at hom

Regardless of the patient's sex or diagnosis, in most conflict-ridden marriages the fighting started over either spouse's objections to the other's behavior or because of disagreements about the children; in more than a third where the wife was the patient, sexual relationships were an early focus of trouble.

Whether the patient was man or wife, the conflict was most often moderate, leading to two-sided screaming sessions or to the wife's withdrawing from the argument.

Despite the continued and often bizarre symptoms in the female patients, their husbands stayed with them more often than not. But, for most, it hasn't been a happy life. The husbands of schizophrenic women often had histories of problems themselves—bigamy, poor work records, assaults, arrests. Several have themselves been hospitalized or treated for mental disorders, and, Clausen observes, several others show marked psychopathology. They often drank to excess, or took off, "leaving the children to cope with their mother's difficulties." They not only berated their wives and children, but physically abused them as well. "One can't imagine why the wives or older children put up with this. Perhaps the wives *have* to stay because they are so often sick."

Clausen recalls one case where, after the father had been interviewed about the mother's history, a daughter phoned and asked if she could come in and talk. She wanted to counter the lies she was sure her father had told. Telling the interviewer that her father was extremely brutal, she described how he beat up her mother, her sister, and herself. She said, for example, that he didn't like her mother's smoking. If she lit a cigarette, he'd stub it out on her face. This young woman was college, which was rare among daughters of schizophrenic mothers, and she lived away from home during the school year. But she returned to live with her parents during the summer. "We couldn't understand why she came home," Clausen says. "Perhaps she stayed at home to defend and protect her mother." In a few families with a patient-wife, however, the husbands have been "incredibly humane," Clausen adds. A few altered their occupational plans, gave up chances for advancement that would have forced the family to move, took new jobs that gave them more time at home, or retired early.

Some who had led unstable lives settled down. One man, for example, had held 14 jobs in 13 years before his wife's breakdown but has held the same job since she was first hospitalized. "He's gotten his life together. He's organized." His wife has been in outpatient treatment a good part of the time since her first breakdown.

But this man, like many others, does not give his wife much emotional support. "He manages not to be around the house a great deal. This is one of the strategies whereby most of the families that stay together cope with the patient's symptomatology. The well spouse will have union meetings, church activities, take on extra jobs in the evening, and in that way avoid intense interaction with the patient."

Unwittingly, the well spouses may be helping their marriage partners by avoiding too much interaction with them. Research done by a group of London investigators (Brown, Birley, and Wing 1972) suggests that patients engaged in intense emotional involvement with a spouse or another significant person in the home are much more likely to be rehospitalized. This likelihood is even greater if that significant person is critical of the patient. The more hours per week that the patient interacted with the spouse or a "significant other," and the greater the emotional involvement with that person, the more likely the patient would return to the hospital.

Away From Home

The social life of the former patients and their families appeared to be quite restricted. Few entertained or had a wide circle of friends. Extended families were important to a majority. About half of the schizophrenics were very close to some member of their original families and frequently visited with relatives.

Other than these relationships with close family members, the patients derived most pleasure from their family life at home. This was especially true of male schizophrenics, a majority of whom had no close friends; their social activities were almost exclusively centered on their wives' social life and friendships. Nonschizophrenic men, by contrast, went out with friends alone more often than with their families. Among all the patients, four out of ten were said to have no close friends. Less than half of the families belonged to organizations, usually a church. Church activities were particularly important to the wives of male patients.

Growing Up With Mental Illness

Concern for children of psychotic parents has grown as community treatment has become more common. Mentally ill parents are now more likely to remain at home with their children, except for short stays in a hospital. Many of them are still symptomatic when they return home. Many break down repeatedly. At those times, they may neglect or even abuse their children. Their mere presence offers the opportunity to involve the children directly in disordered thought processes and behavior, or to transmit distorted perceptions of reality.

Several children had been particularly bothered by their mothers' hallucinations. One said of his mother, "Like my father hides his liquor, she hides her thoughts."

Sensitive to these potential hazards, Clausen and Huffine have analyzed reports on 150 children of patients first hospitalized in the fifties. They have given particular attention to the sex of the ill parent, the supportiveness of the well parent, and the patient's diagnosis. The research team has systematically analyzed the development of the children along a number of dimensions—their educational attainment, when they left home, their problems, and their relationships with their parents. Because most of the children have reached young adulthood, they and their parents could look back with some dispassion (and some anguish) at how needs were met and symptoms experienced. It is these remembrances, especially those of 13 of the children themselves, that provide a vivid picture of what it was like to grow up with a mentally ill parent.

Children with a mentally ill father had an easier time than did those with a mentally ill mother. During childhood, they were more likely to have two parents—a father who usually held a steady job (despite occasional problems) and a mother who was sympathetic and supportive. Family life was stable and routine. The mother disciplined the children with little interference from the father. If the parents separated, the children always went with the mother.

Growing up with a schizophrenic mother was a much less positive experience. Sons had particular difficulty communicating with their mothers. Fathers often failed to provide the support and stability the children needed. Young children were shunted between relatives when the mother was hospitalized again.

Serious Problems

The researchers obtained from the parents' reports and clinical records some information on serious developmental problems. They did not attempt to interview any children except those readily available. From the evidence they do have, Clausen and Huffine conclude that the children of these patients are not "exceptionally problematic." But a number of them have had severe emotional problems or have gotten into trouble.

Because most of the children had not yet reached the age of maximum risk, Clausen's group does not know how many will break down with a mental disorder. At least three had already been hospitalized, however. Clausen and Huffine have evidence that at least seven children (all of whom had schizophrenic parents) have had brief psychotic episodes—far more than would have been expected. On the other hand, eight children, only about 5 percent of the total group of patients' children, had been treated for what appeared to be a nonpsychotic emotional disturbance; Clausen and Huffine believe that a similar proportion of such disorders would be found in the general population.

Children of schizophrenic mothers more often had serious problems than did those of other patients. More than a fourth of this group had attempted suicide, become psychotic, had illegitimate children, or were seriously delinquent, according to reports from parents or other direct evidence. The investigators have indirect evidence that another tenth of the children had similar problems.

Social class was related to serious problems in children of mentally ill mothers but not in children of mentally ill fathers. In working-class families, 44 percent of the children with a mentally ill mother had serious problems, while in middle-class families, only 9 percent of the patient-mothers' children had such problems. Serious psychological problems and deviance did not occur more frequently in the children of divorced parents than in those whose parents remained married.

Contrary to their expectations, the researchers did not find that serious problems were most prevalent among young adults who were under age 2 when their mothers were first hospitalized. While none of the eight children in working-class families who had been under 2 experienced serious problems growing up, seven in ten who had been 2 to 6 had experienced such problems. Children in these families who were 6 to 12 at the time of the first hospitalization also frequently had problems.

The Children's Accounts

Several researchers who have examined the incidence of mental disorder in the grown children of psychotic patients have concluded that living with the patient made little difference; genetic vulnerability to mental illness seems to be the more powerful influence in bringing on a breakdown in the children. But the stories told by the grown children from several families in Clausen's study poignantly demonstrate that even if living with a mentally ill parent doesn't cause a child to become psychotic in later life, it is nevertheless a stressful way to grow up.

Several of the children mentioned that they had been particularly bothered by their mothers' hallucinations—a mother who talked with someone the child couldn't see, another who couldn't hear her child's questions and comments because she was listening to an unseen voice. One young man related how his younger brother repeatedly became "so bugged" that he'd run away from home. The last time he left the house his mother said, "If you go, I'll kill myself." The brother left despite this coercive threat. And the mother did kill herself.

Two other children who recognized their parents' manipulativeness were greatly annoyed at this "dishonesty." Even recalling such incidents as adults, they could not accept it. One said of his mother, "Like my father hides his liquor, she hides her thoughts." The other was convinced that her father used his symptoms to control her. He became delusional whenever he disapproved of, or was threatened by, something she wanted to do.

The worst memories of childhood came from the young adults whose ill parent had been disabled by symptoms over long periods and whose well parent was abusive or unavailable. One child of a schizophrenic mother and a "hard-drinking, abusive father" reported that, when she gets together with her brothers and sisters, they talk about the "hell" they went through together, and little else. "Such meetings are always followed by nightmares," Clausen and Huffine note. "All of the children in this family appear to suffer from emotional problems." None has received treatment. "Indeed, a daughter reports that no member of the family 'will ever go near a psychiatrist.'"

Some of the young adults recalled being extremely resentful about not being told what was happening, or why certain behavior upset the parent who had been a patient. Clausen interviewed one young woman who was 8 before her mother explained why her father acted in ways she couldn't understand. Her father's initial breakdown came during the McCarthy era. He feared that he would be accused of being a "red." The daughter recalled:

> There were many things that were never sayable in this household, and many clothes, many colors, I could never wear in front of [father]. No red, no pink, no purple, no brown. And there were many kinds of jokes that could never be said, and unfortunately I often didn't find out about them until after I had made them. And then my mother would jump down my throat. [Clausen and Huffine 1979, p. 205.]

Several children were old enough at the time of the initial breakdown to feel responsible for it. But many others felt guilty about subsequent breakdowns. The well parents would often control their children's behavior with comments such as, "If you keep this up, he'll end up back in a mental institution."

The Importance of the Well Parent

Clausen and Huffine have evidence from clinical records that a few patients physically abused their children. "One child was brain-damaged when the mother threw it against a wall," the investigators report. The child has remained in a State institution. Another mother, who believed someone was filling the house with poison gas to kill her children, broke windows to let in fresh air, and then attacked the children with a broom handle.

"On the whole, however, except during episodes when delusions guided their behavior, the patients abused the children less than did some of the spouses, especially husbands who were heavy drinkers," Clausen and Huffine report. In families where the "well" spouse turned to alcohol as a means of coping, "the children have a double burden to bear, and it is our impression that some of these have had the most difficult time emotionally."

In many families, the well parent spent as much time as possible outside the home. The children not only had to cope with the patient's upsets and idiosyncrasies but lacked the support the well parent might have provided in dealing with their own problems of growing up. "In such families," say Clausen and Huffine, "children expressed bitterness toward both parents."

Children whose mothers were mentally ill had particularly difficult times. In the few instances where fathers were supportive and sympathetic, the children were better able to cope with their problems. It was, however, the wives of male patients who most often showed the strength and competence necessary to provide firm regulation and warm support for their children while still coping with the needs and problems of their ill husbands. Children of mentally ill mothers, especially those in the middle class, may sometimes have found support and help with their problems from teachers and friends.

The evidence suggests, say Clausen and Huffine, that children of schizophrenic mothers were more likely to deal with their family problems by turning outside the home for response and intimacy; others rebelled, quit school, then entered the service or drifted. Children of affectively disordered parents were more likely "to throw themselves into their schoolwork," note Clausen and Huffine. "A manic-depressive father might be a terror to live with at some times, but at other times he might be seen as 'a knight in shining armor' to use the words of one of the grown sons we interviewed." Unlike the recurrently symptomatic schizophrenic parents, a depressed or manic parent might function very effectively when not troubled by symptoms.

Whatever else the children of mental patients experienced, they all were profoundly uncertain about what was happening to them. "Conflict and recrimination frequently pervaded the family life space. With no explanation from a trusted caretaker, those children fortunate enough to have siblings seem often to have clung to each other for support and hope," the investigators note.

Many not only survived the ordeal but achieved "a sense of competency and maturity far beyond what would normally be expected at their ages." As with so many other childhood experiences, this achievement was usually possible only where the well parent or another close relative gave the child support. Among working-class families, adolescent daughters sometimes took over the mother's role, caring for younger children and doing the housework and cooking. Some of these daughters took their responsibility in stride and were even, at times, resentful at having to give up their autonomy when their mothers returned. Others, however, felt they had lost their childhood.

Despite "great hardships and uncertainties," many children with close relationships with brothers and sisters and support from their well parents had warm feelings and pleasant memories about their family life. Whichever parent was mentally ill, "children are more likely to retain a warm relationship with the mother," according to Clausen and Huffine. They say that this is especially true of daughters. "Relationships between children and both parents are predominantly warm only in intact families of male patients."

Children of parents who eventually separated were much more likely to leave home permanently before they were 18. Early departures were most frequent in working-class families where the mother was the patient; more than half of these children left before they were 18. The number of children who remained with their parents past 20 is equally impressive, say Clausen and Huffine. It happened most often in intact families. "Several of the most deviant and disturbed of the children" remained past age 18, either because it was convenient to do so, or because they were intensely dependent; some of these dependent young adults were also strongly hostile toward their parents.

The Future

As for the future lives of these children, one aspect that can be predicted is their work careers, which depend largely on their performance in school. Clausen and Huffine note that, in the population at large, social status has been shown to be the "most potent influence" on how well a child does in school. And so it was with the children of mental patients in their study. Among those who were over 18, 78 percent from middle-class homes graduated from high school, while only 55 percent of those from working-class families earned high school diplomas. A few children, mostly from middle-class families, attended college; a few had graduated by the time of followup. Social class was also related to the influence of an intact family on the children's education. Working-class children whose parents separated left school earlier than those whose parents stayed together; this difference was not found in middle-class children.

As in most families in the general population, children of nonschizophrenic parents exceeded their parents' educational attainment. But children of schizophrenic parents reached only the level that their parents had reached. The children of schizophrenics also dropped out of school earlier than did those of nonschizophrenics; this pattern was especially apparent among middle-class children, who would have been expected to continue in school longer.

Clausen and Huffine speculate that growing up with a mentally ill parent may be even more difficult than their evidence suggests. Their data came largely from parents, "who naturally wish to give the best possible account for themselves." The turmoil and trauma the children encountered in these families were probably greater than the parents realized or were willing to recall. It was evident, say Clausen and Huffine, that many of the parents "could not provide role models for competent performance and emotional control."

While Clausen and Huffine were left with no doubt that parental mental illness often impairs a child's normal development, the problems in these families are not unique. As they point out, many families face conflict and disruption, many parents abuse or neglect their children.

While their study leaves many questions unanswered, the evidence that Clausen and Huffine do have attests "as much to the resilience of the developing child as to the deficits that parental mental illness may entail for the child."

Labeling and Stigma

Most patients in Clausen's study did not suffer serious long-term consequences simply because they had once been labeled *mentally ill.* Nor were their symptoms less serious or more labile before they were recognized as mentally ill. These and other findings tend to discredit a theory that has influenced a good many social scientists in recent years. Offered as an alternative to psychological and psychiatric interpretations of mental illness, "labeling theory" emphasizes social over intrapsychic or biological processes. Labeling theorists assert that social response to deviance not only perpetuates mental illness but causes it in the first place.

Does Labeling Cause Mental Illness?

According to labeling theory, mental illness begins with minor deviations from culturally defined expectations. For one reason or another—organic illness, stress, mischievousness—we all break the small rules governing behavior. These rules are so inconsequential that we take them for granted (making eye contact with someone we're speaking to, for example). When we break the rules, those around us usually just refuse to acknowledge our behavior or find some plausible excuse for it. Most of us stop this "deviance" before it gets us into trouble. But the person destined to be found mentally ill somehow gets caught in the psychiatric net—because those around him get irritated and are sufficiently powerful to force him into treatment, or because the deviance is too publicly visible or troublesome. Once a person is diagnosed as mentally ill, says labeling theorist Thomas J. Scheff, he is "launched on a career" of chronic mental illness.

How this comes about is quite simple in Scheff's formulation. He assumes that, as children, we learn stereotyped imagery of mental illness—the image of craziness—and this view of the mentally ill is reaffirmed as we grow older. The role of mental patient is well-defined and widely recognized. The person so labeled tends to act out the part. He accepts the role because a crisis has made him vulnerable to suggestion. He is encouraged to continue playing it by being rewarded when he does and punished when he doesn't.

> ***These families rarely saw their members as "crazy." Frequently, a spouse would point out differences between his or her hospitalized mate and other patients who are "really" mentally ill.***

Clausen's research discredits this assertion that the label itself causes a person to act in ways expected of the mentally ill. Patients in his study exhibited psychotic symptoms long before their families considered the possibility of mental illness. Their behavior caused the families tremendous conflict. But the families cast about for other explanations for the behavior. "We have overwhelming evidence," Clausen says, "that symptomatology need not be labeled *mental illness* to become stabilized and reach its most florid manifestations."

The "florid manifestations" of symptoms may, however, be fed by the stigma mental patients felt, Clausen says. He and others have pointed out that all societies set the mentally ill apart, assigning them roles that clearly distinguish them from seers and prophets. Modern-day urban America is no exception. At best, social response to the mentally ill is "negative and derogatory," and at worst, "punitive and utterly rejecting." Even to consult a psychiatrist in this society "is to threaten one's public identity as a responsible person." The labeling calls into question the person's ability to control himself and his relationships, according to Clausen. But labeling does not *cause* mental disorders.

Clausen's families rarely saw their members as "crazy," despite the conflict and hostility engendered by the patients' symptoms. The spouses' perceptions of the symptomatic behavior simply did not fit a stereotype of raving madness. And those perceptions did not change once a diagnosis was made. "One frequently finds a spouse pointing out differences between his or her hospitalized mate and other patients who are 'really' mentally ill," say Clausen and Huffine. Patient and family speak of emotional upset or disorder, or a nervous breakdown, but not *mental* illness or disorder. Instead of collaborating to affirm the stereotype of mental illness, these families tried desperately to deny its presence.

Stigma on the Job

When the male patients returned home and went back to work, both they and their wives were very much attuned to possible signs of stigma. Few former patients actually experienced it on the job. "Indeed," say Huffine and Clausen, "most men either perceived no change in their relationships with coworkers or found their colleagues to be sympathetic or conciliatory." Only a few felt overt hostility from coworkers. "Apprehension and lack of confidence were common in the early days of return to work, but ability to perform in the job dispelled self-doubts."

Among male patients first hospitalized in the fifties, those who remained free of serious symptoms continued in their work careers without major setbacks. Huffine and Clausen report that nearly half of the schizophrenic men from the fifties' group have been relatively symptom free and have been stably employed at a level equivalent to or higher than that enjoyed before hospitalization.

Men who continued to experience symptoms as the years went by more often were failures on the job. They were also younger than the successful men at the time of their first episode of illness, and they had been symptomatic for longer periods before they entered the hospital. But "even continued symptomatology of significant proportions is not assurance of downward drift" in the work careers of these men.

The most powerful factor that seemed to determine whether a man could continue working and taking on responsibility was his job performance before the breakdown. Those who had established their competence before they were hospitalized stood "a good chance of surviving the ravages of prolonged, even severe symptomatology," according to Huffine and Clausen.

Compared to the husbands of female patients, the former male patients had been on their jobs somewhat longer, held jobs of at least equal status and responsibility, and felt better about their work; fewer male former patients than husbands of female former patients were unemployed at followup.

One man who has remained as symptomatic as when he was first hospitalized has continued to hold a responsible professional job over the years. He still lives with his paranoid fears. Clausen says that he may be a case of the "old, true paranoid who, operating outside that delusional system, can do whatever he has to do." He does well on the job. He keeps his delusions in check when he's away from home. But the moment he returns, his litany of persecution and abuse resumes. Another patient diagnosed as manic-depressive has, when functioning, been his company's top salesman, Clausen reports. Lithium treatment has kept his symptoms in abeyance in recent years.

Where Labels Count

Huffine and Clausen believe that being labeled mentally ill does not, in and of itself, impair work careers or social relationships. The stereotype of mental illness held by most members of society is so extreme that it rarely fits a real mentally ill person. They cite the work of Walter R. Gove, who has noted that although "the public holds a highly negative stereotype of the mentally ill, there is little evidence of actual discrimination." When an employer and coworkers have known a person for some time before an initial breakdown, the popular notions of what it is to be mentally ill simply do not square with their personal knowledge of this particular person who has been mentally ill.

The stereotype of mental illness held by most members of society is so extreme that it rarely fits a real mentally ill person.

One context where Huffine and Clausen note that the label, *mental illness*, can have a powerful effect is the psychiatric setting. Most of the population is not schooled in what to expect from mental patients and how to interact with them, y say: "Psychiatrists, psychologists, social workers, mental health researchers; these are people who have learned a pattern of interaction *vis-a-vis* the mental patient." These are the people who can be expected to give undue weight to the status of being a mental patient in interpreting the patient's behavior. "Being a schizophrenic in a hospital is very different from being a nurse or a doctor or even a manic-depressive," they note. Labeling is important, they say, only to the extent that it is taken seriously. "And it's taken seriously by psychiatrists primarily." It is in the hospital or clinic that the course and consequences of mental disorder can be made worse by the label. Wrong diagnosis, premature classification, reified beliefs, together with institutionalization, can cause the patient more problems than the initial symptoms had.

A MODEST PRESCRIPTION

Despite the care John Clausen has taken with his study of the families of mental patients, the research does have limitations. Because minority group members were systematically excluded in both the 1950s and 1970s samples, the study results may not reflect their experience. When he began the study, Clausen was exploring uncharted territory. He wanted the sample of families to be as large as possible without being too large to preclude intensive and prolonged interviewing. The sample also had to be as homogeneous as possible, without the confounding effects of minority status. In addition to these considerations, there were no minority group members on the laboratory's staff to conduct interviews and contribute to the analysis of the data. The same factors, plus Clausen's desire to keep the samples as comparable as possible, made him decide to exclude minority families from the new cohort.

The lack of formal comparison groups also somewhat limits interpretation of a few findings. The children's educational achievements and emotional problems, for example, might be compared to the same characteristics in children with similar backgrounds whose parents did not break down. But such a ontrol group would sharpen the researchers' answers to only one or two questions. Each o[illegible]e variable might require a separate control group. Even [illegible]re possible to select a group of "normal" families matched to the patients' families in all respects—and Clausen believes that would be impossible—

the cost of the study would double, while the usefulness of the findings would be increased only slightly. Despite the lack of a formal comparison group, Clausen and Huffine are comparing some of their family data to other research findings, particularly those from the long-term study of normal development that has been going on at Berkeley's Institute of Human Development for half a century. Other comparisons are being made between subgroups of families in the study—schizophrenics vs. nonschizophrenics, bizarre vs. mild symptoms, male patients vs. female patients, old vs. young patients, and middle-class vs. working-class families.

Clausen's study remains among the best—if not *the* best—of its kind done to date. It is possible that, because of the huge amount of time and money that would be required, no better study can be done. Furthermore, it is hard to imagine it possible to find another investigator who could bring to the work Clausen's combination of work habits and personal traits. His scholarship is thorough, his methods rigorous, his attention to details about his subjects unusual, and his patience apparently endless.

"It appears that no one now takes the time to meet with the well spouse and the children, to assess their needs for information and guidance. With all the lip service to community mental health, we find this a distressing state of affairs."

What has Clausen learned about the families of mental patients after all these years? First of all, he's learned that in the face of tremendous difficulty many of these families show resiliency and a tenacious will to make the best of what life has handed them. They learned to cope. Some wives of male patients and some children were especially remarkable in this respect. Second, he has learned of the limited choices that some patients, particularly the women, had available; many of the schizophrenic women seemed especially prone to marrying on whom, often selecting husbands who were not only unsupportive of them and their children, but cruel as well. Third, he is dismayed by the lack of attention paid to the family even today. "It appears," say Clausen and Huffine, "that no one now takes the time to meet with the well spouse and the children, to assess their needs for information and guidance. With all the lip service to community mental health, we find this a distressing state of affairs."

Clausen believes that few psychiatrists have learned to think in terms of their patients' ongoing social systems. "Too many are preoccupied with narrow aspects of psychodynamics." He thinks psychiatrists should not only take the patient's family into account, but actively involve the spouse in therapy. And they should "drop in on the children and talk with them, to get some feeling for their degree of upset and need for help." In the families that Clausen and his colleagues studied, there was no evidence that such a visit ever occurred.

Many of the patients and families expressed extremely negative views of psychiatry when the interviewers talked with them 15 to 20 years after the first breakdown. They felt that, during the period of crisis, they had no alternative but to depend upon mental health professionals. "Nevertheless," says Clausen, "many of the husbands and wives do not feel that they were really heard." Many felt that, by contrast, the interviewers who had first talked with them for the research project had been sympathetic and had listened well. Clausen thinks the memory of these sympathetic interviews was one reason the families agreed to be interviewed again recently, even when they wished to forget about the crisis that had occurred so many years before.

"Perhaps our research can speak to mental health workers in a way that the husbands and wives of patients feel they have been unable to," says Clausen. He has the impression that there now may be somewhat less tension between the family and hospitals than there was 20 or 25 years ago. The problems that do exist in treatment settings today will be examined in the late stages of Clausen and Huffine's data analysis.

The researchers have a few words of advice to families that might be encountering mental illness for the first time. If one spouse is concerned about the other, he or she should try to discuss the problem and try to convince the troubled partner to seek help. The couple should shop for a psychiatrist who will agree to see them both and one with whom the disturbed spouse feels comfortable. If the patient sees a psychiatrist as too threatening, a trusted physician should be consulted. And if hospitalization is recommended, the best choice would be the psychiatric service of a general hospital or another, similar facility in the community.

Children should be told as much about what is happening as they can understand. Young children might be told that the hospitalized parent was upset, needed rest for a time, and would be back soon. Older children, who may have witnessed or participated in conflict, need more thorough explanations. If possible, some of the child's own overwhelming experiences might be used as an example of how problems can get the best of people at times. Clausen and Huffine strongly advise *against* telling children that their parent has a physical illness—or even using physical illness as an analogy. "At the very least, children should be told that all the screaming and shouting and threats in the home before hospitalization were brought about by emotional upset. The children should be made to understand that they weren't responsible for it."

Children often have the most problems when their parent returns from a hospital stay. Clausen has some doubts about the best way to warn children, or whether to warn them, about conflict that might persist. "Do you suggest to the children that they should act as if nothing has happened? One would hope that they would act as they would if their parent had been in a hospital for a physical illness. But if the parent is still symptomatic, the children must be protected without being alienated." He suggests that the family might have a quiet reunion—just as they might have if someone were coming home from a hospital stay of any other kind. "There's so much apprehension that it's important just to be together and do something."

Clausen thinks that the single most important factor in helping children deal with mental illness—indeed, in keeping the family functioning—is the behavior of the well parent. "If the other parent is so locked in hostile interaction with the patient, then the cost for kids is really tremendous." A warm, sympathetic, and supportive spouse can help a patient, hold a family together, and spare children from the ill effects of mental disorder in a parent. At the moment, it appears that these well parents get little or no help in meeting such extraordinary demands from mental health treatment teams.

Notes

(1) It was often difficult for Clausen's group to be sure that their original specifications were met. "Some patients, for example, turned out to have had treatment earlier, even though the hospital record showed them as first admissions, and the spouse did not report earlier treatment until we had conducted several interviews," Clausen explains. "This was especially true if the earlier episode had taken place during military service or prior to marriage. Also, occasionally organic conditions were misdiagnosed as severe psychoneurosis or schizophrenia." Some patients were included in the study sample even though they were over 50. And some turned out to have severe drinking problems, even though these were not initially reported as long-term problems. Clausen notes that "since many acutely disturbed patients with functional disorders will go on alcoholic binges, it was sometimes difficult to know whether we were dealing with drinking as a secondary symptom that had recently developed or with patients who had long had problems with alcohol."

(2) Psychiatric diagnoses tend to change with time, location, and purpose. Those made in treatment settings, for example, are less systematically based on explicit criteria than are those made for research purposes, where homogeneous diagnostic groups are important. Dr. Sluzki used diagnostic criteria established in the International Pilot Study of Schizophrenia.

(3) After they were well along with their interviews of the 41 new families, Clausen and Huffine learned that two patients had previously been hospitalized. Data on these two patients' families will be excluded from all analyses of the process of recognizing and defining mental illness. As explained in note 1 above, several patients in the fifties studies were either too old to meet sampling specifications or had eventually been diagnosed as having an acute or chronic organic disorder. The researchers included these patients in their followup to determine at least the patients' present status. The 25 who did not meet sampling requirements were dropped from the analysis of data, however. The proportionately greater number of schizophrenics in the followup sample is largely due to the inclusion of

Sampson and Messinger's sample, made up entirely of schizophrenic women.

References

Brown, G.W.; Birley, J.L.T.; and Wing, J.K. Influence of family life on the course of schizophrenic disorders: A replication. *British Journal of Psychiatry*, 121(No. 562):241-258, 1972.

Clausen, J.A. "The Marital Relationship Antecedent to Hospitalization of a Spouse for Mental Illness." Paper presented at the Annual Meeting of the American Sociological Association, Chicago, 1959. Mimeo. Copies available from author.

Clausen, J.A. The impact of mental illness: A twenty-year follow-up. In: Wirt, R.D.; Winokur, G.; and Roff, M., eds. *Life History Research in Psychopathology*. Vol. IV. Minneapolis: University of Minnesota Press, 1975. pp. 270-289.

Clausen, J.A. Sociology and psychiatry. In: Freedman, A.M.; Kaplan, H.I.; and Sadock, B.J., eds. *Comprehensive Textbook of Psychiatry*. Vol. 1. 2nd ed. Baltimore: Williams & Wilkins, 1975. pp. 373-382.

Clausen, J.A., and Huffine, C.L. Socio-cultural and social-psychological factors in social response to mental disorder. *Journal of Health and Social Behavior*, 16(4):405-420, 1975.

Clausen, J.A., and Huffine, C.L. The impact of parental mental illness on children. In: Simmons, R., ed. *Research in Community and Mental Health*. Greenwich, Conn.: JAI Press, 1979. pp. 183-214.

Clausen, J.A., and Huffine, C.L. "Living with Mental Illness: Some Preliminary Findings of a Twenty-Year Follow-Up." Working paper. Mimeo. Copies available from authors.

Clausen, J.A., and Yarrow, M.R., eds. The impact of mental illness on the family. *Journal of Social Issues*, 11(4):entire issue, 1955. (Individual articles listed under author(s) names.)

Clausen, J.A., and Yarrow, M.R. Introduction: Mental illness and the family. *Journal of Social Issues*, 11(4):3-5, 1955.

Clausen, J.A., and Yarrow, M.R. Paths to the mental hospital. *Journal of Social Issues*, 11(4):25-32, 1955.

Clausen, J.A., and Yarrow, M.R. Further observations and some implications. *Journal of Social Issues*, 11(4):61-65, 1955.

Clausen, J.A.; Yarrow, M.R.; Leasy, L.C.; and Schwartz, C.G. The impact of mental illness: Research formulation. *Journal of Social Issues*, 11(4):6-11, 1955.

Deasy, L.C., and Quinn, O.W. The wife of the mental patient and the hospital psychiatrist. *Journal of Social Issues*, 11(4):49-60, 1955.

Gove, W.R., and Fain, T. The stigma of mental hospitalization: An attempt to evaluate its consequences. *Archives of General Psychiatry*, 28(April):494-500, 1973.

Huffine, C.L. "Attitudes of Patients and Spouses Toward Psychotherapeutic Drugs: Some Notes on Compliance." Mimeo. Copies available from author at Institute of Human Development, 1203 Tolman Hall, University of California, Berkeley, Calif. 94720.

Huffine, C.L., and Clausen, J.A. Madness and work: Short and long-term effects of mental illness on occupational careers. *Social Forces*, in press.

Murphy, H.S. Differences in interview responses of wives of schizophrenic and nonschizophrenic inpatients. *Psychiatry*, 26:381-390, 1963.

Sampson, H.; Messinger, S.L.; and Towne, R.D. *Schizophrenic Women: Studies in Marital Crisis*. New York: Atherton Press, 1964.

Scheff, T.J. *Being Mentally Ill: A Sociological Theory*. Chicago: Aldine, 1966.

Scheff, T.J. Schizophrenia as ideology. *Schizophrenia Bulletin*, No. 2:15-19, Fall 1970.

Schwartz, C.G. Perspectives on deviance—wives' definitions of their husbands' mental illness. *Psychiatry*, 20:275-291, 1957.

Yarrow, M.R.; Clausen, J.A.; and Robbins, P.R. The [illegible] meaning of mental illness. *Journal of Social Issues*, 11(4):33-48, 1955.

Yarrow, M.R.; Schwartz, C.G.; Murphy, H.S.; and Deasy, L.C. The [illegible]gical meaning of mental illness in the family. *Journal of Social Issues*, [illegible]24, 1955.

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HEREDITY AND MENTAL ILLNESS

Principal Investigators: David Rosenthal, Ph.D., and Elliot S. Gershon, M.D.

*Author: Herbert Yahraes**

Recent research confirms and extends earlier findings of an important hereditary element in both groups of the most serious mental illnesses—schizophrenia and depression.

Consider schizophrenia:

- The rates of schizophrenia among the parents of schizophrenics have been found by a number of investigators, cited by National Institute of Mental Health psychologist David Rosenthal, to run as high as 12 percent. Among the brothers and sisters of the patients, the rates are somewhat higher. In the general population, the rate is 1 percent.
- When the children of schizophrenic parents are raised by normal foster parents, a greater proportion of them, as compared with foster children whose own parents were not schizophrenic, become schizophrenic, too.
- For identical twins, who have the same genetic inheritance, the chances are about even that if one twin becomes schizophrenic, the other twin will also. When this happens, the twins are said to be concordant for schizophrenia.

Now look at the major depressive illnesses:

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*See note at end of chapter.

- A strong genetic element in depression has been documented in numerous studies of depressed persons and their relatives. For instance, Elliot S. Gershon, a National Institute of Mental Health psychiatrist and geneticist, and his associates examined 524 relatives of people in Israel with psychotic depression. Of these relatives, 49 had some form of major depressive illness, as compared to 4 out of 619 normal controls. In other words, there was about 10 times as much depressive illness within families of depressed people as within families that were not depressed. Also, depressed patients had about eight times as many relatives with moderate depression and cyclothymic personality in which periods of depression and elation occur regardless of external circumstances. However, people who tend to be a bit moody and depressed are found no more frequently among the relatives of people with mood disorders than among the relatives of controls.
- If one identical twin has a psychotic depression, the chance that the other twin also has it, or eventually will have it, ranges—varying with the study—from 60 to 90 percent or even higher.

STUDYING HOW HEREDITY WORKS IN SCHIZOPHRENIA

Granted that schizophrenia and depression have a large genetic element, how can it be explained? What mechanisms are involved? And how does one explain the other diseases in what Rosenthal has named the "schizophrenic spectrum"? These include, in addition to the psychosis itself, borderline schizophrenia, paranoia, and schizoid personality disorders, such as oversensitivity, seclusiveness, avoidance of close relationships.

From the standpoint of the number of genes involved, there are two ways of explaining heredity's contribution. One view is the monogenic theory: All the disorders in the schizophrenic spectrum are influenced by a single gene. The extent to which this gene is expressed in a person's behavior depends upon environmental factors. Where there is very severe stress, the genetically predisposed person becomes, according to this theory, schizophrenic. Where the stress is much lighter, he or she becomes the borderline schizophrenic, the paranoic, or the schizoid. Where the stress is still lighter, the person is normal.

If the single gene were dominant, the rate of schizophrenia among the parents and children of schizophrenics—assuming that only one parent carried the gene—would be 50 percent. If the gene was recessive, the rate would be 25 percent. As noted earlier, the actual rate in families where there is schizophrenia is much lower than either of those figures, though much higher than the rate for schizophrenia in the general population. On the basis of studies cited by Rosenthal, the rate among children with one schizophrenic parent is 9.7 percent; among children with two schizophrenic parents, it is almost four times as great—35 percent. If a recessive gene is involved, the latter figure should be 100 percent; if a dominant gene, it should be 75 percent.

> ***. . . many investigators believe that in an illness as complex as schizophrenia a number of genes must be involved.***

It will be recalled that genes come in pairs, one member of each pair having been contributed by each parent. Assume that the hypothetical gene for schizophrenia is labeled *A* if dominant and *a* if recessive and that both parents are schizophrenic. Then, if the gene is dominant, Rosenthal points out, "the parent's mating could be expressed as *Aa* x *Aa*, and the offspring would be 1/4 *AA*, 1/2 *Aa*, and 1/4 *aa*. Only the *aa* children (25 percent) would escape the illness. If schizophrenia was caused by a recessive gene, the parents would be *aa* x *aa* and all their children would also be *aa*, and all would be expected to develop schizophrenia.")

Such findings do not necessarily negate the single-gene theory. Recall the studies of identical twins. When all the conditions that are apparently related to schizophrenia are taken into account, the concordance rate rises from about 50 percent to about 90 percent.

Nevertheless, many investigators believe that in an illness as complex as schizophrenia a number of genes must be involved. Under their theory, both the apparently normal mother and father who produced a schizophrenic child carry many of the pathological genes but not enough to be clinically ill themselves; chance combinations of the genes, however, result in various frequencies of the illness among their children.

A parent who is actually schizophrenic carries more of the pathological genes, and the likelihood that his children will inherit enough of them to become sick will be greater. The median rate of schizophrenia among such children is, in fact, almost double the rate for children whose parents, though presumably carriers, are not sick themselves. Chance combinations of the genes could also explain why some children are at risk for schizophrenia itself and others to less severe but related disorders.

Psychiatrist Loren R. Mosher, chief of the NIMH Center for Studies of Schizophrenia, likens the inheritance of schizophrenia to that of height or intelligence. "These are genetically influenced," he explains, "but there is no gene for height and none for intelligence. Multiple genes are involved, and environment has a tremendous influence. You may be predisposed to high intelligence, but if you are raised with poor nutrition and in a poor environment, you may not grow up very smart." He adds: "Madness exists on a continuum, and people who are schizophrenic manifest things that we all have. It is not that schizophrenics differ absolutely but that they have less or more of certain qualities that we all have to some degree."

Under the polygenic theory, a person may inherit all the genes involved in schizophrenia and thus be at risk for a full-fledged psychosis or he or she may inherit only a few of the bad genes and thus be at risk for a lesser disorder. In each case, the trigger that sets off the disorder is assumed to be environmental stress.

Some children with a schizophrenic parent not only remain well but even become outstandingly successful. Jon L. Karlsson, an American pediatrician trained in genetics, studied seven generations of descendants of an Icelandic couple born in 1682. He reported evidence of an apparent association between whatever makes for schizophrenia and whatever makes for outstanding aptitude. This couple had a schizophrenic grandchild, and schizophrenics have appeared in each of the following generations. But many persons of superior quality have also appeared. Karlsson says that, "Individuals so placed in genetic pedigrees that they should be genetic carriers . . . seem not infrequently to be persons of unusual ability, such as leaders in society or creative persons with performance records suggestive of a superior capacity for creative thinking." In fact, the genes involved in schizophrenia "appear to have a survival value" except when they result in a full-blown psychosis.

Edward F. Foulks, a medical anthropologist, has advanced a similar idea. In view of the worldwide occurrence of schizophrenia, he suggests that, until quite recently, this disorder furthered the course of evolution because schizophrenics had the vision that enabled them to help people cope with social upheavals after traditional methods had failed. As an example, he cites a renowned woman who heard voices—Joan of Arc.

Schizophrenia can be looked upon, Karlsson suggests, "as the price which the human race must pay for its superior members."

The problem with findings like those of the study in Iceland, as Rosenthal points out, is that child production requires two parents. The superior intelligence seen in some offspring of a schizophrenic may indeed be attributable mainly to the genes of the sick parent. But it also may be attributable chiefly to the other parent. Moreover, and most likely, it may arise from some combination of genes from both parents. These last two possibilities have not yet been considered in investigations of the intriguing notion that genius and madness have a common genetic base.

That the higher incidence of schizophrenia is higher among the relatives of patients than among people in general indicates that a vulnerability to this condition can be inherited. Whether or not an inherited disposition leads to the disease depends both upon the extent of the vulnerability and upon the amount of stress encountered by the vulnerable individual.

In the case of mental illness, just what is it that can be inherited? What chemical and physiological processes are involved?

Genes work by controlling biochemicals called enzymes. Enzymes in turn work by controlling the millions of biochemical reactions constantly occurring in the body. For the last few years, many research teams have been paying particular attention to a certain enzyme called "monoamine oxidase," or "MAO."

The function of MAO is to break down one of the chemical substances, called "neurotransmitters," responsible for the transmission of information from cell to cell in the nervous system. The neurotransmitter of interest here is norepinephrine. This brain chemical is closely related to epinephrine, more widely known as adrenaline, the hormone that helps the body respond to stress.

When a message is to be transmitted in the nervous system, norepinephrine (or another neurotransmitter) is released at the terminals of a nerve cell. The chemical enters the space between two cells (called the "synapse") and changes the permeability of the next cell's membrane. This change produces an electrical impulse that leads to the release of a neurotransmitter at the next synapse, thus starting the process all over again. In this fashion, electrical messages are propagated for long distances along thousands of brain cells, without loss of signal. Instead of causing cells to fire, the chemical message may heighten their readiness to fire or may inhibit them from firing. Man's actions and behavior, his emotional state, and his thinking are regulated through the sum total of activity at the synapses.

After the transmitter has done its work, it must be quickly cleared from the synapse to make way for the next message. In the case of norepinephrine, NIMH scientists have shown that the chemical is drawn up again into the nerve terminals, where some of it is stored for future use, *and the rest is broken down by MAO.* In other words, MAO's function is to break down part of the supply of a chemical—one of at least several such compounds—responsible for the transmission of electrical messages from nerve cell to nerve cell in the brain and the rest of the nervous system.

Studies of pairs of identical twins, at least one of whom is schizophrenic, have led to a provocative finding about this chemical. In both schizophrenic and nonschizophrenic identical co-twins, the level of MAO in the blood platelets is lower than in normal controls. (The platelets are tiny protoplasmic elements that assist in the formation of blood clots when needed.) The lower the amount of MAO, the greater the severity of the illness.

A RELATIONSHIP WITH DEPRESSION?

A further provocative finding by NIMH scientists is that MAO levels are also significantly lower than normal in patients with bipolar depression, more commonly known as "manic-depressive illness" (though some patients manifest either mania or depression, but not both). The levels were also significantly lower in the close relatives of these patients—siblings, parents, and children—even among those relatives who apparently were well.

Conceivably, the low level of MAO in the blood platelets of schizophrenic and manic-depressive patients is an indication that something has gone wrong, or may go wrong under certain conditions, at the synaptic junctions between nerve cells—vital elements of man's information system.

Researchers once considered it possible that a low MAO level would prove to be the long-sought biological marker, an abnormality indicating that a person carrying it was either psychotic or very likely to become so. With the discovery that a low level of the enzyme is a widespread characteristic of apparently healthy relatives of patients, this possibility seems to have vanished. In a patient's relatives, though, a low MAO level may serve as an indicator of increased vulnerability to mental illness, a possibility that remains to be studied.

Intriguing research problems now are how and why MAO levels are reduced in people with schizophrenia or manic-depressive illness; what role, if any, MAO plays in these disorders; and how, if at all, these psychoses are related. Adoption, twin, and family studies provide no evidence of a relationship between the two major psychoses, but clinical studies do point to some similarity in their manifestations. Specifically, the symptoms in one stage of mania are often indistinguishable from those of acute schizophrenia. Moreover, the major tranquilizers have antipsychotic properties that are effective not only in many cases of schizophrenia but also in some cases of depression. On the other hand, lithium carbonate, which seems to be a specific for the treatment of manic-depressive illness, is not effective against schizophrenia.

NIMH investigators suggest this possibility: Whatever hereditary element determines the level of platelet MAO may also determine in part the likelihood that a person will display some type of psychotic behavior, with other genetic factors determining just which type it will be.

Elliot S. Gershon is one of those investigators who believes that schizophrenia and depression are basically different disorders. Nevertheless, he tells of a man who had an apparently schizophrenic breakdown and with it a change in personality. He became antisocial. He had recurring episodes of psychotic behavior, followed by check forgery and displays of aggression. He seemed to be a classic case of schizophrenic deterioration. Yet he responded to lithium. Moreover, his sister developed mania and depression, and she, too, responded to lithium. Gershon sees the experience of these two as evidence that a person may appear, on the basis of clinical evidence, to have one major type of psychosis, whereas the biological or pharmacological evidence indicates that basically he has the other type.

There do seem to be intermediate forms. A person may have a mixture of symptoms—some depressive, some schizophrenic. Such cases occur in families with schizophrenia and also in families with depression.

There is also the case of a fairly prominent family—in the entertainment field, say—in which either depression or schizophrenia appears in almost every generation. The most recent case is a boy with manic-depressive illness. His parents seem well, but he has an aunt with the same disorder. A woman in the family has a combination of depression and hypomania. One of her sons, though, is a classic schizophrenic. Other cases of schizophrenia have occurred. Does this family carry genes for both schizophrenia and depression? Or are the biological bases of these disorders similar? Our present knowledge is too meager to provide an answer. It is known, though, that members of the family have made a number of consanguineous marriages. The closer the family relationship of the two persons in such marriages, the greater the likelihood that deleterious genes will find expression in their children.

OTHER RESEARCH ON THE BIOCHEMICAL BASIS OF DEPRESSION

In work undertaken more recently than that on MAO, an enzyme known as "cathechol-O-methyl transferase" (COMT) has been identified as a possible biological marker. COMT is responsible for the first step in breaking up biochemicals essential for the transmission of electrical signals throughout the nervous system. Thus, its function is similar to that of MAO, which, as described earlier, has been implicated in the breakdown of one of the neurotransmitters.

Gershon and an associate found that COMT activity was significantly higher in patients with psychotic depression than in normal persons. Usually, it was also significantly higher in patients than in their nondepressed relatives—a finding which seems to stamp it as a better investigatory tool than MAO. Further, COMT activity is inherited, but whether or not the genetic factor is the same as, or closely associated with, the genetic factor in depression is still speculative.

Attempts to define the nature of the genetic predisposition to depressive illness also include the search for "linkage" between the genetic factor and chromosomal markers.

A "chromosome" may be visualized as one long line of genetic information. Each bit of the line is the code for a particular function—not necessarily related to the function of the adjoining bit. Bits are known as *loci* (plural of the Latin *locus*, meaning place). A biological marker is a locus that can be identified at any specific point along the chromosome.

Distances from one locus to another can be mapped by the extent to which inheritance of a characteristic at one locus is associated with inheritance of the characteristic at another locus. For example, if a person with one kind of color blindness turned out to have the same blood type as the rest of his or her relatives who were color blind, the geneticist would infer that color blindness and the blood type apparently associated with it were controlled by loci—actually, by the genes occupying those loci—which were very close together. Either characteristic—blood type or color blindness—would serve as a chromosomal marker, an indication that if one was present the other probably was also. The characteristics would be considered "linked."

In one major type of depressive illness, an association with a type of color blindness has been found. The psychosis is manic-depressive illness, or bipolar depression. Out of 10 manic-depressive men in a recent study, all turned out to be color blind. However, the available information is as yet too slim to say whether or not the locus for color blindness can serve to identify the location of at least one gene involved in depression.

The locus for the type of color blindness under study is on the sex chromosome *X*. Since a man has only one *X* chromosome (his other sex chromosome being *Y*), any characteristic such as color blindness governed by the *X* chromosome will show up. In a woman, though, the same characteristic may not show up because she has two *X* chromosomes. And the second of these may have, at the same locus as the one for color blindness in the first, a dominant or counterbalancing characteristic. Or it may not have. Researchers must take into account the intriguing fact that more women than men are afflicted by depressive psychosis. The ratio of female to male patients has been found to be almost 3 to 1 in the case of pure depression—known as "unipolar"—and almost 2 to 1 in the case of the bipolar illness. These ratios are compatible with the hypothesis that a disposition to the disorder is indeed transmitted by the sex chromosome *X*, but other findings are not. The difference in prevalence between males and females, NIMH scientists suggest, may turn out to be caused by differences either in environmental conditions or in factors governed by chromosomes other than the sex chromosomes.

An answer to still another question relevant to understanding the strong genetic element in depressive psychosis waits on research: Do the two major forms of psychotic depression—unipolar and bipolar—actually have different bases? There is evidence that they do, since bipolar patients are more likely than unipolar to have afflicted relatives, and since lithium acts more effectively against bipolar illness than against unipolar. Moreover, if one identical twin has one form of depression, the likelihood that the other twin will not only be afflicted but also afflicted with the same type is about 50 percent. Still, a clear-cut diagnosis is sometimes hard to make, and some investigators believe that the two forms are merely different manifestations of the same basic illness, the unipolar form being the less severe.

GETTING ADVICE ON THE ROLE OF HEREDITY

At medical centers genetic counseling is widely available to help prospective parents weigh the chances of producing a child who may be vulnerable to a serious mental illness. Sometimes, for instance, a couple asks Gershon about the likelihood of their offspring developing a manic-depressive psychosis. If only one of the questioners has that disorder and the family tree of the other is free of major depressive illness, the answer is: "About 10 percent."

The same answer applies for schizophrenia if one of the questioners is schizophrenic but the other is not and is not related to a schizophrenic. In both cases, the child will also be at greater risk than other children for troubles related in some way to schizophrenia, but less serious.

Nongenetic factors, too, must be taken into account. Medicines for the control of manic-depressive psychoses and the less serious forms of depression are considerably more effective than those available at this time for the control of schizophenia. Moreover, if the schizophrenia is chronic, a normal family life will be just about impossible.

What about amniocentesis, the analysis of the fluid surrounding the embryo in the womb? Many conditions likely to make for abnormality can be thus detected. If a grave abnormality is predicted, an abortion can be requested. And it should become possible to correct some of the diagnosed defects while the child is still in the fetal stage. Despite great advances in our understanding of the psychoses, however, biochemical abnormalities that contribute to them or indicate vulnerability to them have not yet been certainly identified. But investigators are hopeful that one day the enigmas of schizophrenia will yield to scientific efforts.

References

Gershon, E.S.; Dunner, D.L.; and Goodwin, F.K. Toward a biology of affective disorders. *Archives of General Psychiatry*, Vol. 25, 1971.

Gershon, E.S., and Bunney, W.E., Jr. The question of X-linkage in bipolar manic-depressive illness. *Journal of Psychiatric Research*, 13:99-117, 1976.

Gershon, E.S., and Liebowitz, J.H. Sociocultural and demographic correlates of affective disorders in Jerusalem. *Journal of Psychiatric Research*, 12:37-50, 1975.

Kety, S.S.; Rosenthal, D.; Wender, P.H.; and Schulsinger, F. Mental illness in the biological and adoptive families of adopted schizophrenics. *American Journal of Psychiatry*, Vol. 128:302-306, 1971.

Kimble, G.A.; Garmezy, N.; and Zigler, E. *Principles of General Psychology*. 4th ed. New York: Ronald Press Co., 1974.

Leckman, J.F.; Gershon, E.S.; Murphy, D.L.; and Nichols, A.S. Reduced platelet monoamine oxidase activity in first degree relatives of individuals with bipolar affective disorders: A preliminary report. *Archives of General Psychiatry*, 34:601-606, 1977.

Leckman, J.F., and Gershon, E.S. Autosomal models of sex effect in bipolar-related major affective illness. *Journal of Psychiatric Research*, 13(4):237-246, 1977.

McClearn, G.E., and DeFries, J.C. *Introduction to Behavioral Genetics*. San Francisco: W.H. Freeman, 1973.

McKnew, D.H., Jr.; Cytryn, L.; Efron, A.M.; Gershon, E.S.; and Bunney, W.E., Jr. Offspring of patients with affective disorders. *British Journal of Psychiatry*, 134:148-152, 1979.

Rieder, R., and Gershon, E.S. Genetic strategies in biological psychiatry. *Archives of General Psychiatry*, 35:866-873, 1978.

Rosenthal, D. *Genetic Theory and Abnormal Behavior*. New York: McGraw-Hill, Inc., 1970.

Rosenthal, D. *Genetics of Psychopathology*. New York: McGraw-Hill, Inc., 1971.

Van Eerdewegh, M.M.; Gershon, E.S.; and Van Eerdewegh, P. "X-chromosome Threshold Models of Bipolar Illness." Paper presented at American Psychiatric Association meeting, Miami Beach, May 1976.

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POOR FAMILY COMMUNICATION AND SCHIZOPHRENIA

Principal Investigator: Lyman C. Wynne, M.D., Ph.D.

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A number of respected investigators believe that a major element in the development of schizophrenia lies in parental behavior, including, in particular, how the father and mother communicate with each other and the children.

Chief among the authorities who stress the importance of family relationships, including both corrective and deviant parental communication, as factors in schizophrenia and its prevention is Lyman C. Wynne, M.D., Ph.D., a professor in the department of psychiatry at the University of Rochester School of Medicine and Dentistry. He was formerly head of the Adult Psychiatry Branch of the National Institute of Mental Health (NIMH), where his research on this subject began in 1954. His principal associate has been Margaret Thaler Singer, a psychologist who is clinical professor of psychiatry in the same department as Wynne's and also a professor in the department of psychiatry at the University of California at San Francisco.

These researchers emphasize the widely accepted view that genetics contribute to the vulnerability, or predisposition, to schizophrenia, but that it does not necessarily produce the disturbing psychiatric symptoms of the illness. The best evidence for this conclusion is that when schizophrenia appears in a pair of identical twins, who have exactly the same heredity, it usually strikes only one twin. If one identical twin develops this psychosis, a number of studies have found, the probability

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*See note at end of chapter.

that the co-twin has already become or will become schizophrenic ranges from only a few to about 45 percent. There are a number of conditions considerably less severe than schizophrenia but believed to be related to it. The co-twin who does not become schizophrenic has perhaps a 45 percent chance of developing one of those related afflictions. Something besides heredity appears to be at work.

Oddities in the way parents habitually communicate apparently contribute to increasing the vulnerability of a child already at risk because of his biological heritage.

Wynne and his associates do not believe that family communications alone, even when most seriously disordered, can cause schizophrenic disorders. Rather, they believe that deviant parental communications may lie between the inherited predisposition and whatever is the immediate cause of the schizophrenic breakdown. This immediate triggering cause, the investigators suggest, may be common-life events that have more disastrous effects than usual because the vulnerability has become so high. Loss of a loved one, too much stress at college or at work, or any one of a host of other factors appear to trigger the actual onset. Oddities in the way parents habitually communicate apparently contribute to increasing the vulnerability of a child already at risk because of his biological heritage. Identifying these oddities in the way parents communicate, the Rochester group believes, may prove highly useful in helping to predict the likelihood of schizophrenia in an offspring and also in fostering preventive efforts.

Yale psychiatrist Theodore Lidz, as well as Wynne, Singer, and other investigators, have been reporting for years that parents of schizophrenics, though they have not usually been diagnosed as schizophrenics themselves, usually do possess communication oddities that are difficult to pigeonhole. The Rochester group is attempting to describe these oddities and to discover their effect on offspring. The investigators believe that a person's form of thinking is related to the way he derives meaning from outside stimuli, such as the black or colored splotches of the Rorschach test, and the way he shares and interprets common foci of attention with others. When parents are abnormal in these respects, the investigators postulate, a child trying to relate to his parents may end up with his thinking and communication processes disturbed—one of the hallmarks of schizophrenia.

The University of Rochester Child and Family Study is designed in part to discover connections between parental characteristics and patterns of family interaction and communications on the one hand and, on the other hand, both competence and maladaption in the children. The study of communication, which is the subject of this chapter, is only one main aspect of the research.

The researchers first study each parent's communication with a stranger—the person administering a test. Then the researchers study how the parents communicate with each other—for example, when they are asked to reach consensus on the pictures seen in the inkblots of the Rorschach test. Finally, the investigators observe how all family members interact when they work together on such a task.

The 150 families being observed in this longitudinal project—meaning a project that follows its subjects over a period of years in an attempt to identify factors in the earlier years that are related to outcomes later in life—include a group in which one parent has schizophrenia. Children in such families are considered at genetic risk to this mental illness. Another group of families has parents who have suffered from a psychotic depression, and a third group has parents who have had a psychiatric illness requiring hospitalization but have not been psychotic. The child selected for attention in each family is a son who was 4, 7, or 10 years old at the time the family entered the study.

ANALYZING COMMUNICATION

The Rochester team is less interested in *what* a person says than in *how* he goes about saying it. In analyzing communication, the team uses a long transcript of conversation. This may be obtained from a tape recording of a psychological test in which the only persons present are a parent and one of the investigators. Or it may be a record of both parents trying to reach agreement on a test. Or it may involve the whole family.

From the start of their research, when Wynne was at NIMH, the scientists have used a variety of tests to obtain a record of conversation. These have included the Object Sorting Test, in which a person arranges a variety of objects into groups and explains as he does so why he is assorting them that way—because of their size, their color, their function, or whatever. There is also the Thematic Apperception Test, in which a person looks at pictures on cards and tells what he thinks the characters are doing or thinking. And there is the Rorschach test, in which a person looks at a series of ink blots printed on cards and tells what he sees in them.

None of the transcripts of these tests is regarded in the usual way, as projections of a person's innermost thoughts and emotions, but simply as samples of communication styles, which can be analyzed and oddities noted. Moreover, the transcripts help clarify family relationships.

The investigators consider the Rorschach test, as they employ it, to be especially analogous to what happens in daily life when persons try to establish a shared view of something. As Wynne describes the process, "One person offers a focus of attention, labels what he 'sees' and offers his interpretation to the other. In turn, this person then responds to the offered focus of attention in some way. The Rorschach offers a relatively standardized starting point for sampling to what extent attentional foci and meanings are mutually shared during such a verbal transaction."

Singer puts it this way:

> In the transaction with a person administering the individual Rorschach, a subject is asked to say aloud what he thinks each blot looks like. His words can be regarded as the outward, visible products of his attentional processes. First, he has to join the focus offered by the investigator who has proposed the task of telling what he sees in the ink blot; then attend to the images and ideas that come to awareness in his own mind and select appropriate ones to express aloud. . . . Thus, this person's spoken words reflect the orderliness, or lack of it, of his attentional processes as he is using them at that moment. . . . It is assumed . . . that

> these samples of attention and language . . . are representative of how a person deploys his attention and uses language in similar labeling and descriptive exchanges with other persons.

Manuals for scoring individual, husband and wife, and family Rorschachs have been developed. In the husband and wife procedure, the spouses are asked to view a Rorschach card together and see how many ideas they can agree upon as to what the card looks like. The procedure is videotaped so that the conversation later can be analyzed. Then their children are invited into the room and are given a second card. In this procedure, known as the family Rorschach, the parents are asked to teach or explain the task to the children, and each person contributes ideas about the inkblot; the ideas are then discussed until the members of the family feel they have reached agreement on as many as they can. Most families find this task absorbing, lively, and fun. The Rochester investigators and others use a variety of other methods also for having families talk together; in one of these, for example, members are asked to plan something they can do together as a family.

Relationships within the family as revealed when members work together on a task are considered more important than oddities in communication style. Nonetheless, 32 categories of communication oddities have been identified that appear in the Rorschach records of parents of schizophrenics significantly more often than in the parents of other psychiatric patients or in the parents of normal persons. The categories fall into the following six main groups or factors:

- Odd, hard-to-follow, ambiguous remarks, such as unintelligible sentences and the peculiar or out-of-context use of ordinary words or phrases.
- Failure to maintain attention to the task, such as forgetting what one has said, hopping around among responses, and interrupting the examiner.
- Unstable perceptions and thinking, such as giving two responses that are incompatible and expressing views with great uncertainty.
- Describing one's own ideas, as well as the whole task, as meaningless or as understandable only in private, idiosyncratic terms.

- Extraneous, illogical, contradictory, or derogatory comments.
- Abstract, indefinite, and wandering vagueness.

One assumption of Wynne and Singer has been that some forms of verbal behavior are strongly influenced by the way the speaker is paying or not paying attention to the subject at hand. Singer reports:

> When one person is conversing with another, his remarks reveal aspects of how his attention processes are functioning. To select and arrange his words, he must properly deploy and guide his attention. He must attend to his inner thoughts, keep his listener in mind, handle outer stimuli, and plan ahead to his next remarks. That is, he must deploy his attention to search, select, formulate, and state his ideas. . . .
>
> Many . . . rules of conversation carry the expectation that the listener should be able to attend in regular and predictable ways to what is being said. When a speaker phrases his thoughts in ways that affront such attentional expectancies, his remarks are experienced negatively and a listener, even when he does not comment, is usually bothered or distressed.

These Rochester investigators find two broad types of attentional problems—attentional repetitions and attentional breaks—that can be detected in many parents of schizophrenics.

In one form of attentional repetition, a person seems stuck. He may say: "I uh, I uh, I can't think of anything. Nothing comes to my mind. I just can't think of anything."

In a second type of attentional repetition, the speaker seems unable to drop an idea or a phrase. For example:

> A man viewing Rorschach Card IV said: "That looks like a boot. Well you *put your foot* in here. *Your foot*, it fits in there, and it's ok through right that part. Put your foot through the top of the boot. You know what I mean? Just like these boots I got on. *Put your foot* through the top of the boot, slide it in." Here we see the phrase and idea of "put your foot" continuing to intrude into the passage. Such mental processes catch up the speaker's attention, and he is seemingly unable to let go of an idea.

Two other Rochester investigators, in a separate study, have reached the same conclusion. They call this type of dysfunction "the inability to disattend from stimuli."

The second major form of attentional deficit, termed *attention breaks*, occurs when the speaker's words suggest that he "has jumped to another idea without connecting the old idea to what he is now saying." The result is to engender in the listener "a sense of bewilderment because he has not been supplied with the connections" between the ideas expressed. For instance, a young woman's response to a Rorschach card went as follows: ". . . this looks like a part of the southeastern United States coast from side and side, with this being Florida and vaguely this, and the saying that goes: Life is neither black nor white but different shades of grey—which are my sorority colors, excuse me, you know what I'd like to do sometime? Is take all the charts and records and mail them off to a ghost author and get nine-tenths of the property. No, I'll write myself. I want a book that might interest him."

Early in their work with families in which at least one person was schizophrenic, Wynne's group has recalled, the therapists had "singularly different" experiences from those of therapists with families in which another kind of mental disorder was present. Experiences with the schizophrenic families were described as "maddening" and "exhausting." For example:

> In a session which was not unusual for this family, the mother of Mary, who was severely schizophrenic and much of the time demurely paranoid, openly dismissed the therapists as lunatics. Her manner was almost disarmingly affectionate, thus both augmenting and obscuring the murderous character of the assault: They were obviously harmless, well meaning and even amiable lunatics, but to take them at all seriously was patently absurd. Both the therapists in this group were men, and the mother had frequently made her position (or something of her position) abundantly clear to anyone who listened to her—a category which seldom included herself—that men were inherently unreliable and abandonment by them was inevitable. Thus, the fact that they were also child-like, ineffectual, and stupid was perhaps less than tragically consequential. It was within the framework of this position, and in the immediate context of the comments about the

lunacy of the therapists that the mother angrily reproached her daughter for "not really wanting to get well," since otherwise she would trust the doctors and confide in them.

The father of this family spent a great deal of time delivering weighty and protracted homilies to his wife and daughter. The tone of his remarks was generally kindly and detached, condescending, and moralistic; their content included pedantic reminders of why they were present, platitudes about maintaining a "positive outlook," injunctions about facing the truth, no matter how unpleasant it might be, and repeated eulogies of the virtues of the analysis of motive and meaning. His decidedly pompous air neatly complemented his wife's uniformly depreciating fondness. He invariably agreed with anything that was said by either of the therapists, and, as invariably, the character of his agreement, as this was reflected in restatement, was—conspicuously outside of his awareness—one of elusive parody, partly in its grave solemnity. He dealt with his daughter's intense distrust by gently lecturing her on the need to rely on others. While it was clear, he said, that untrustworthy persons existed, the majority were decent enough human beings, and her distrust was "just a part of her illness" which she should try to put out of mind. At the same time he maintained a constant vigilance over the therapists, watching them closely during the sessions. He often interrupted his wife, scolding her for having interrupted Mary. He would sometimes sternly reprimand her for failing sincerely to acknowledge the fact that Mary was seriously ill, but otherwise seldom failed to refer to this as anything but "her little nervous trouble."

During one session, Mary launched into a diatribe about her roommate's selfish appropriation of their bathroom and utter lack of consideration for others, which she judged as outrageous. Mary was immediately condemned by her mother for her appalling selfishness "which is not like you" and for "not appreciating that this girl is sick—otherwise why on earth do you imagine that she is in the hospital!" After rudely rebuking his wife for her lack of understanding and sympathy, the father turned to Mary and went on patiently to explain that the other girl was "not very well" and that Mary should really try to be more tolerant.

The transcript is clearly filled with contradictory remarks, but when the therapists called them to the parents' attention, both denied having made them.

Wynne and his coworkers carried out numerous studies in which an investigator, knowing only the results of the tests, would predict whether or not a family contained a young schizophrenic.

PREDICTING UNSEEN WHETHER OR NOT A FAMILY MEMBER HAS SCHIZOPHRENIA

Singer, in particular, scored very well in blindly matching parents and patients. She would first study the transcripts of what the parents had said, while other psychologists were administering tests. Then she would deduce the type of illness suffered by the sick offspring, and also its severity. For instance, of 20 young people who had been diagnosed as schizophrenic, unknown to her, she was right 17 times. Of nine borderline schizophrenics, she was right seven times; of six neurotic patients, four. There was less than 1 chance in 1,000 that her predictions could have been made accidentally.

Then she studied transcripts of the *patients'* tests and predicted to which family each person belonged. She was right 33 times out of 36.

In one study by the Wynne-Singer group three teams separately tested, diagnosed, and scored the communications of 114 families. High scores of communication deviance correctly foretold that 20 pairs of parents would be found in which either one or both had borderline schizophrenia or worse. High scores also correctly identified an additional 24 pairs of parents who had a schizophrenic child even though neither parent was schizophrenic or had an illness related to it. The parents of the schizophrenics, it should be noted, were not totally different from other parents. Rather, they varied along a continuum or dimension so that they overlapped with the parents who had borderline schizophrenic offspring. Moreover, this continuum, related to diagnosis, applied to all members of the families, including those who were not patients. The well siblings, though, had lower scores than the parents. The findings suggest that the family system as a unit is involved.

In another study, the six main factors, summarized earlier, distinguished the parents of schizophrenics from those of borderline schizophrenics, of neurotics, and of normal children. Also, the results for parents of a psychotic child who did not have remissions differed somewhat from those of parents of a psychotic child who did have remissions. The frequency of communication deviations was much the same in one group of parents as in the other. However, the parents of remitting schizophrenics made significantly *more* derogatory, extraneous, illogical, and contradictory remarks than the others. The Wynne group suggests that such parents have communication features which "may be distressing but often are clear enough to permit or even stimulate disagreement. . . ." These parents also had significantly *fewer* instances of failing to sustain the task set. On the other hand, the parents of nonremitting schizophrenics were more vague and ambiguous. Significantly, they were also much more likely to have had a schizophrenic-like illness themselves. This suggests that interaction between a genetic factor and deviant communication can contribute to chronic or nonremitting schizophrenia in the offspring.

Why does usually only one child in a family with deviant parental communication patterns become symptomatically ill? Wynne observes that children in the same family, unless they are identical twins, normally vary widely in their intellectual endowment, temperament, and vulnerability to illness. Additionally, children, partly because of differences in sex and birth order, have different roles in the family. Children's experiences outside the family, as well as physical problems, differ also. Finally, the relationship of each child and the parents differs considerably, partly because of the individual differences already mentioned, partly because parents as well as children change over time, and partly because how each child fulfills or disappoints parental expectations produces great variety in the kinds of relationship and communication. Although Wynne and Singer have shown that brothers and sisters are somewhat more similar to each other in communication styles than they are to children in other families, differences within a family in both vulnerability and actual illness patterns are entirely reasonable and expectable.

HEREDITY AS A FACTOR IN SCHIZOPHRENIA

Many researchers have produced apparently strong evidence of a powerful genetic factor at work in the development of schizophrenia. Wynne believes that an inherited disposition does play a role but not as exclusively as often implied. To throw more light on this question, he and Singer and a coworker, Margaret L. Toohey, recently made a "blind" assessment (meaning that they did not know which parents had a schizophrenic child and which did not) of the transcripts made some years earlier by another group of investigators (psychiatrists Paul H. Wender and Seymour S. Kety, and psychologist David Rosenthal), who hold that heredity is highly important. Three groups of parents had been studied: those with an adopted child who later became schizophrenic; biological parents of a schizophrenic child; and a control group of parents with an adopted child who was normal. Wynne and his associates found that the parents of a schizophrenic, whether the child was their own or had been adopted, all tended to score high in communication deviance. This was not the case with parents in the control group.

The original group of investigators found that the biological parents showed the most severe psychopathology, the parents of adopted children who became schizophrenic showed less, and the control parents the least.

The findings reported in the preceding two paragraphs, Wynne and his associates hold, "are consistent with a gene-environment interaction viewpoint. . . ." In other words, both genetic and environmental factors, acting together, may be essential if schizophrenia is to develop. A child may inherit a gene or genes predisposing to schizophrenia. But the illness may never develop unless some environmental factor interacts with the genetic material. The environmental factor in which the Wynne group is most interested is, of course, family relationships—parental communication styles in particular. Other research suggests that other types of stress may well be the environmental factor in many cases.

Wynne and Singer assume that communication deficits are likely to *predispose* to schizophrenia rather than to precipitate it. Such deficits, they think, increase a person's vulnerability, brought on by both genetic and other factors. The illness itself may be precipitated by a variety of circumstances.

Vulnerability or predisposition to schizophrenia is defined, in Wynne's words, "as the individual's characteristic threshold beyond which stressful events produce decompensation, manifest in the clinically diagnosable symptom picture."

Like most other investigators, Wynne does believe that heredity plays a strong—and sometimes a central—role in the development of schizophrenia. But, he says:

> The genetic components of vulnerability are inevitably shaped from conception onward as the result of transactions of the individual with the psychosocial and physical environments. Furthermore, the transactional point of view implies feedback loops in which the individual modifies the same environment that continues to be formative of his personal qualities. . . . Interchanges or transactions at each developmental phase build upon the outcome of earlier transactions. . . . Constitutional and experiential influences recombine in each developmental phase to create new biological and behavioral potentialities which then help determine the next phase.

This viewpoint implies that prevention and treatment can take place at many stages of development. And it recognizes that the child influences the parent, as well as the other way around.

A person's vulnerability may be either increased or decreased by what Wynne calls "response dispositions," which he thinks are partly inherited. These dispositions include the modulation of attention; the susceptibility to stimulus overload (that is, the relative ability to react healthfully to such stimuli as parental or family discord or to a variety of emotional problems outside the family); and patterns of cognitive and emotional controls, such as degree of impulsivity.

No such factor in itself is probably specific for schizophrenia, Wynne notes, but some or all together "may potentiate, inhibit, or mask the clinical manifestations." As an example, "a high readiness for rage, perhaps inborn, could make schizophrenic breakdown more likely, whereas controls of rage learned in the family environment" could forestall it. Wynne goes so far as to conjecture that the environmental factors may turn out to be the *specific* contributions to schizophrenia. The genetic factors with which they interact, he suggests, may be *nonspecific*. In any event, he agrees with the general belief among researchers that both heredity and the environment have major roles in the production of this major psychosis.

MAY DISTURBED FAMILY COMMUNICATION BE DUE TO ABNORMALITY IN THE CHILD?

Wynne points out that only longitudinal studies, such as the one his group is conducting at the University of Rochester, can give an answer to what he suspects is probably a chicken vs. egg kind of question. Some critics have argued that the behavior of a preschizophrenic child might be so abnormal as to induce abnormal communication patterns in the parents. And there is some, quite scant, research to suggest that this may indeed be so. For example, Joan Huser Liem, a Harvard Medical School psychologist, used a word game to study communications in 11 families with a schizophrenic son ranging in age from 17 to 25 years and in 11 families with a normal son. In this game, the parents worked together, and the son separately, to describe to a tape recorder a common object or concept. The aim was to make the descriptions so clear that what had been described could be quickly identified when the tape was played. The parents then listened to and responded to tapes made by their own sons, and next—forming artificial families—to tapes made by the schizophrenic and normal sons of strangers. In turn, the sons responded to tapes made by their own parents and by the parents of other young men, either normal or schizophrenic.

As expected, schizophrenic sons showed more disorder in their talk than normal sons and their parents. But the parents of schizophrenics did *not* show more abnormal communication patterns than normal parents and normal sons. Moreover, all parents made more misidentifications in responding to schizophrenics than in responding to normal young men.

The Rochester group comments that the communication disorders studied by Liem were not the same as those studied by Wynne, Singer, and their associates. Also, a study of artificial families cannot sample the longstanding feelings and relationships of natural families. The Liem study does show that people have a hard time understanding psychotic talk.

Wynne also notes that in one of his studies the scores of young schizophrenics on communication deviance, like those of their parents, who were not schizophrenic, were *lower* than the parents' scores. Moreover, Wynne, Singer, and two associates at Rochester analyzed communication deviance in a group of parents of neurotic offspring who were so severely ill that they had to be hospitalized for long periods. Most of the parents of these nonschizophrenics were very upset by the delinquencies and disturbed behavior of their sick offspring; often, in fact, they believed mistakenly that the offspring were schizophrenic. Nevertheless, the parents showed markedly lower scores on communication deviance than the parents of schizophrenics who were housed on the same unit as the neurotics. As Wynne points out, then, psychiatric illness in an offspring is naturally upsetting to parents but apparently does not force them to express themselves deviantly. These findings suggest that it is the parent who is influencing the child, rather than the other way around. However, Wynne emphasizes, nothing can be sure until the returns from the longitudinal studies are in. There are some 20 of these being conducted in the United States, but only a few are concerned with communication deviance as well as with other aspects of family life.

Preliminary findings from one of the investigations that do take into account abnormalities in communicating have recently been reported by psychologists Michael J. Goldstein, Eliot H. Rodnick, and their associates in the University of California at Los Angeles Family Project. This project is studying relationships in the families of emotionally disturbed adolescents seen at an outpatient clinic. The scoring system for communication deviance is based on the one developed by Wynne and Singer. When parents both had about the same number of communication deviations as the parents of a child already diagnosed as schizophrenic, the troubled son of these parents was considered at high risk to schizophrenia.

Five years after the initial tests, the investigators have reported on the psychological health of 23 sons, all 20 or 21 years old at the time of the followup. Five years earlier, they had been troubled but nonpsychotic. Now 11 of them, or almost one-half, were diagnosed either as schizophrenic or as falling within other categories of the schizophrenic spectrum (schizophrenia or milder but related conditions). Moreover, parents who had high scores in communication deviance were significantly more likely than other parents to have children in the schizophrenic spectrum group at young adulthood.

Still, the investigators report, "We cannot reject the hypothesis that the deviant parental communication styles may have been reactive to the nonpsychotic adolescent psychopathology or to more subtle temperamental characteristics of the adolescent." For a final answer, the researchers agree with Wynne, longitudinal studies starting earlier in life are essential. The Wynne group and a few others are engaged in just such studies.

In a 3-year followup, so far completed for about one-third of their families, the Rochester investigators have found a number of significant effects of family communication patterns. Where these were deviant, as measured in the Rorschach tests of individual parents and of several kinds of interaction of the family as a whole, the children ~~of parents~~ with frequent communication deviations were doing worse in school than other children. The differences in these children were not only in intellectual and academic competence but also in social skills as viewed by their classmates and teachers.

In a few years we should have clearer answers to schizophrenia's predictability, prognosis, and remediability, and to the old question of whether it is the deviant offspring or the deviant parents who make for disordered, "maddening" communication styles in families that eventually produce—for more than one reason, undoubtedly—a schizophrenic offspring.

References

Garmezy, N. Current status of a sample of other high-risk research programs. In: Wynne, L.C.; Cromwell, R.L.; and Matthysse, S., eds. *The Nature of Schizophrenia: New Approaches to Research and Treatment.* New York: Wiley, 1978.

Goldstein, M.J.; Rodnick, E.H.; Jones, J.E.; McPherson, S.E.; and West, K.L. Family relationships and communication. In: Wynne, L.C.; Cromwell, R.L.; and Matthysse, S., eds. *The Nature of Schizophrenia: New Approaches to Research and Treatment.* New York: Wiley, 1978.

Lidz, T. Egocentric cognitive regression and the family setting of schizophrenic disorders. In: Wynne, L.C.; Cromwell, R.L.; and Matthysse, S., eds. *The Nature of Schizophrenia: New Approaches to Research and Treatment.* New York: Wiley, 1978.

Morris, G.O., and Wynne, L.C. Schizophrenic offspring and parental styles of communication. *Psychiatry,* 28(1):19-44, 1965.

Schaffer, L.; Wynne, L.C.; Day, J.; Ryckoff, I.M.; and Halperin, A. On the nature and sources of the psychiatrists' experience with the family of the schizophrenic. *Psychiatry*, 25(1):32-45, 1962.

Singer, M.T. "Impact Versus Diagnosis: A New Approach to Assessment Techniques in Family Research and Therapy." Paper presented to the Nathan W. Ackerman Memorial Conference, Cumana, Venezuela, Feb. 12, 1974.

Singer, M.T. The Rorschach as a transaction. In: Rickers-Ovsiankina, M.A., ed. *Rorschach Psychology.* 2nd ed. Huntington, N.Y.: Robert E. Krieger, 1977.

Singer, M.T. Attentional processes in verbal behavior. In: Wynne, L.C.; Cromwell, R.L.; and Matthysse, S., eds. *The Nature of Schizophrenia: New Approaches to Research and Treatment.* New York: Wiley, 1978.

Singer, M.T.; Wynne, L.C.; and Toohey, M.L. Communication disorders and the families of schizophrenics. In: Wynne, L.C.; Cromwell, R.L.; and Matthysse, S., eds. *The Nature of Schizophrenia: New Approaches to Research and Treatment.* New York: Wiley, 1978.

Wynne, L.C.; Singer, M.T.; and Toohey, M.L. Communication of the adoptive parents of schizophrenics. In: Lorstad, J., and Ugelstad, E., eds. *Schizophrenia 75.* Oslo, Norway: Universitetsforlaget, 1975.

Wynne, L.C.; Singer, M.T.; Bartko, J.J.; and Toohey, M.L. Schizophrenics and their families: Research on parental communication. In: Tanner, J.M., ed. *Developments in Psychiatric Research.* London: Hodder & Stoughton, 1977. pp. 254-286.

Wynne, L.C. Psychopathological aspects of psychoses: Nongenetic factors in the family setting. In: *Research on Disorders of the Mind: Progress & Prospects.* 100th meeting of the National Advisory Mental Health Council. Washington, D.C.: U.S. Department of Health, Education, and Welfare, 1977. pp. 38-44.

Wynne, L.C. Family interaction: An alternative starting point for evaluating risk of psychosis. In: Anthony, E.J., ed. *The Child and His Family: Vulnerable Children, Vol. IV.* New York: Wiley Interscience, 1978.

Wynne, L.C.; Toohey, M.L.; and Doane, J. Family Studies. In: Bellak, L., ed. *The Schizophrenic Syndrome.* New York: Grune and Stratton, 1978.

Wynne, L.C. From symptoms to vulnerability and beyond: An overview. In: Wynne, L.C.; Cromwell, R.L.; and Matthysse, S., eds. *The Nature of Schizophrenia: New Approaches to Research and Treatment.* New York: Wiley, 1978.

Wynne, L.C. Concluding comments. In: Wynne, L.C.; Cromwell, R.L.; and Matthysse, S., eds. *The Nature of Schizophrenia: New Approaches to Research and Treatment.* New York: Wiley, 1978.

Wynne, L.C. Knotted relationships, communication deviances, and metabinding. In: Berger, M., ed. *Beyond the Double Bind.* New York: Brunner/Mazel, 1978.

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DETECTION AND PREVENTION OF CHILDHOOD DEPRESSION

Principal Investigators: Leon Cytryn, M.D., and Donald H. McKnew, Jr., M.D.

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"I am the biggest troublemaker in my family," said a worried-looking 10-year-old girl. "I cry a lot and feel weird a lot."

Between spells of crying, a 12-year-old boy said, "I think I am the stupidest kid in class . . . . I never really try to kill myself, but sometimes I think to drown myself."

A dejected 8-year-old girl declared: "I feel ugly and like a dumbbell . . . . Sometimes I would like to kill my friends or my own stomach or arm . . . . Friends make fun of me all the time."

These children were talking to child psychiatrists at the National Institute of Mental Health (NIMH). Although none of these children was psychotic, all had high depression scores, as derived from two scales designed to measure depressive symptoms in children. The subjects were among the 30 children or grandchildren of 14 consecutive patients recently admitted to NIMH for observation and treatment of a depressive psychosis. The children were between the ages of 4 and 15. Of the 30 child subjects, more than half were considered "overtly depressed" at the time of the interview.

A considerably lower rate of childhood depression had been reported by earlier investigators—perhaps, according to the NIMH team, because the earlier workers either did not get to know the children or else either did not realize or agree that

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*See note at end of chapter.

the symptoms of childhood depression might be less marked than, or even different from, those of adult depression. At any one time, various studies indicate, as many as 20 children in 100 may be suffering from symptoms of depression. Just how many suffer from a formal clinical disorder is, however, open to question. Though the incidence of this disorder used to increase steadily with age, as a recent report points out, "the growing rate of depression in the young has brought about a peak period in youth that outstrips middle age and is exceeded only by the elderly."

MASKED DEPRESSION

Child psychiatrists Leon Cytryn and Donald H. McKnew, Jr., who were two leading members of the NIMH investigatory team, agree with Dr. William E. Bunney, Jr., Chief of the Adult Psychiatry Branch, NIMH, that many children diagnosed as hyperactive may actually be depressed. Certainly, they report, among children with *masked depression*, which is the commonest childhood type in these investigators' experiences, hyperactivity is common. This type of depression may also be masked by school problems, delinquency, and either behavior or psychosomatic disorders. Every once in a while, though, such children are likely to actually look or act depressed. The investigators arrived at their diagnosis when they discovered that many children who were not obviously depressed nevertheless manifested in their dreams and fantasies the same depressive elements—such as frustration, despair, and hopelessness—as those shown by the clearly depressed children.

To gently remove the mask and get at the underlying trouble, these child psychiatrists, who work not only with the NIMH group but also at George Washington University Medical School and at Children's Hospital, Washington, D.C., use several measures. One is a psychiatric interview which notes any background of depressive signs—such as sadness, despair, feelings of hopelessness or helplessness, and thoughts of suicide. The investigators also evaluate what the child thinks of himself; that is, his self-esteem. And they elicit "fantasy material" by having the children make up stories, interpret pictures, and recount their dreams.

As an example of masked depression, these authorities tell about Albert, a 12-year-old boy, who had been sent to them because of his disruptive behavior in school. He was aggressive and hyperactive. His grades were poor and his social adjustment marginal. A look at the home situation suggested two major probable causes. The mother held a full-time job, was usually unavailable to her children, and had once been investigated for child abuse; the father was an alcoholic who assumed no responsibility for the family and who frequently beat Albert. In sum, the child, like many others with a similar condition, had experienced both rejection and depreciation.

. . . many children who have a behavior problem may be basically depressed.

Throughout the interview, Albert was apathetic and sad. "He described himself as dumb, as the laughingstock of his schoolmates, and expressed the belief that everyone was picking on him." He saw himself as inadequate and helpless. "On the fantasy level the boy showed a strong preoccupation with themes of annihilation, violence, explosions, and death, invariably with a bad outcome for the main figures . . . ."

Albert did not improve. In fact, 1 1/2 years later he was sent to a residential school for delinquent boys. The investigators suggest that the boy's delinquency and aggressiveness were attempts to escape from a basic depression. They admit that such a defense is self-destructive, but "it helps ward off the unbearable feeling of despair" and, on the basis of the newest evidence, seems to be far commoner than most of us think. In other words, many children who have a behavior problem may be basically depressed.

If a child is marked by hyperactivity, delinquency or other behavior disorders, school difficulties, or psychosomatic complaints, Cytryn and McKnew believe it would be a good idea to have him or her checked for depression.

The family members of the children with a masked depression, report these investigators, "often presented a picture of disorganization and severe psychopathology, usually in the form of a character defect, but gave no history of a clear-cut depressive illness."

ACUTE DEPRESSIVE ILLNESS

In addition to masked depression, Cytryn and McKnew have found two other types of depression among children: *acute* and *chronic*.

In the *acute* type, there always seemed to be a clear cause, usually the loss of a beloved relative or someone else very close. Though the loved one had died in some cases, usually he or she—for any one of a variety of reasons, such as personal problems or a move—had simply reduced or cut off the love and care that the child had been counting upon and the loss of which was seen as rejection. In the case of 6-year-old Beatrice, the precipitating cause was traced to the rape of an older sister, 17, who had been serving as a mother substitute because the mother herself worked full time outside the home. "After the incident the sister became withdrawn, preoccupied, and less attentive," and within 3 months young Beatrice was admitted to a psychiatric ward because she had gradually withdrawn from activities, was failing in school, slept poorly, and lacked appetite. "Her mood," the psychiatrists report, "was markedly depressed, as evidenced by a sad and tearful facial expression, slowness of movement, monotone voice, and verbal expressions indicating hopelessness and despair."

After several days of hospital care and attention, but with no specific treatment for depression, Beatrice "became outgoing and started to eat and sleep regularly, her mood brightened, and she was sociable, active, and alert . . . ." Two years later the mother reported that the girl was still maintaining her gains.

Interestingly, Cytryn and McKnew report that such improvement, "despite the absence of any formal treatment program," has been "almost universal" in cases of acute childhood depression, such as Beatrice's. They suspect that it occurs because the child has been removed from one or more noxious environmental circumstances, "coupled with the rallying of the family around the child who is labeled ill because of the hospitalization." Many such children, whether or not they had availed themselves of followup psychotherapy, were found to have maintained their improvement, initiated during a brief hospital stay, even after 5 years.

CHRONIC DEPRESSIVE ILLNESS

Children afflicted with the third type of depression, *chronic*, report Cytryn and McKnew, differ from the others in these major respects: They have a chronically depressed parent, evidence that a genetic element is probably at play; they have been separated several times, from infancy on, from persons they had counted upon, evidence of an environmental force; and no single precipitating incident can be found.

Consider Caroline, who was referred to Cytryn and McKnew as an emergency case at the age of 7. She couldn't sleep, couldn't eat, and for several months had had screaming episodes. She had often threatened suicide because she was "a bad girl" and nobody loved her. Part of the problem was the girl's mother, a helpless woman overwhelmed by family responsibilities, poor self-esteem, a tendency toward frequent depressions, and who had conceived Caroline out of wedlock. "Her subsequent marriage was stormy, Caroline's stepfather had beaten the child severely; then he and his wife had separated, but only for a while."

The trouble may have started many years before Caroline was born. For there is evidence that her mother, as a child, had been neglected by her own mother and been brought up in an atmosphere of violence. Evidence has been found that a condition which might be mildly described as "poor parenting" often is passed on from generation to generation, particularly in the case of child abuse. The abusing parent, investigators often have shown, is frequently the individual who was abused himself, or herself, as a child. Some children who were physically assaulted or otherwise maltreated as youngsters manage as adults nevertheless to become good parents; many others do not.

One of the most important persons in Caroline's life as an infant had been her paternal grandmother, but suddenly, when Caroline was 1 year old, her chief care had been shifted to a maternal aunt. The mother herself, when Caroline was 1 1/2 years old and again when she was 4, had left her for several months.

After Caroline had been discharged from the hospital, she again "became depressed and developed abdominal cramps and diarrhea. When the mother again separated from the stepfather, these symptoms rapidly disappeared."

TWO FORCES: HEREDITY AND PARENTAL BEHAVIOR

In their observation of many children having at least one manic-depressive parent, Cytryn and McKnew found that more than 50 percent of the offspring were at least moderately depressed when interviewed—usually overtly so. Environmental forces were undoubtedly at work, because the shifting moods of the bipolar patient lead to "a sense of uncertainty and bewilderment on the part of the child."

Research by other investigators demonstrates that hereditary forces were probably heavily involved, too. Among the general population, the incidence of manic-depressive psychosis has been estimated at less than 1 percent; among close relatives of manic-depressives, it hovers around 10 percent. Further, studies of identical twins have shown that, if one twin has this condition, the likelihood that the other twin also has it ranges from 50 to 100 percent. All of which is to say that the strength of the genetic element has been demonstrated but is not, usually, the whole story. Obviously, in addition to heredity, the parent-child relationship is of prime importance.

Cytryn and McKnew found that many of their parents had "suffered rejection and depreciation by their parents or loved ones either all during their lives or at least over a period of many years." Such rejection may take many forms: blunt statements stressing the child's inadequacy; attitudes and actions that indicate a lack of respect or caring; a constant barrage of criticism and humiliation. Sometimes there was no frank rejection or depreciation, just "a void in the parent-child relationship." The investigators say that the parents "may or may not be consciously aware of their behavior." They say, too, that "depreciation of the child can be shown through overprotection as well as through rejection; both attitudes convey the basic message of the child's inadequacy and worthlessness." Conceivably, the child's depressive outlook is caused either by "identification with this negative view of himself" or "by a sense of alienation from important love objects," or by both.

Studies in Denmark strongly suggest that the relative importance of the two factors can be readily assessed. In children who are at risk for psychosis because they may have inherited a predisposition for it, the genetic factor, rather than the quality of the parent-child relationship, is of primary importance. When there is no reason to suspect a genetic factor, however, the quality of the child's mental health seems to be strongly influenced by that of the parent-child relationship.

DETECTING CHILDHOOD DEPRESSION EARLY

Indications of depression in children—particularly when something has gone wrong at home, playground, or school—are quite common, as Cytryn and McKnew point out. Usually, though, they do not last long. The problem is judged to be depressive illness when it continues for at least several months "and is associated with severe impairment of the child's scholastic and social adjustment and with disturbances" in eating and sleeping. "In more serious cases the child's thinking is affected by feelings of despair and hopelessness, general retardation, and, in the severe form, by suicidal thoughts."

In the best position to detect early indications of childhood depression, these investigators say, is the pediatrician or the family physician. Each knows the family's history and the parent-child relationship "and can observe the child directly for any sign of depressive mood and behavior." Also in a strategic position is the school or child guidance clinic.

The doctor's role may be particularly valuable in suspected cases of masked depression, "in which the child is usually regarded by the family [and often by the school] as delinquent or lazy." The doctor may try to investigate the case himself "through the use of simple playroom techniques which will elicit fantasy material in drawings, dreams, or selected projective tests or he may . . . refer the child to a psychiatrist. In either case, if the suspicion of a masked depressive reaction is confirmed, the all-too-frequent mishandling of such cases will have been avoided."

Any person evaluating or treating a depressed parent, Cytryn and McKnew advise, should "inquire about the emotional status of the patient's children . . . ." Conversely, all child psychiatrists, when seeing depressed children, "should consider that a similar disorder may exist in the parents and siblings."

TREATING DEPRESSED CHILDREN

When the child is younger than 8 years old, and when the illness has not been very severe or of long duration, Cytryn and McKnew select parental counseling as "usually the treatment of choice." Through such counseling an attempt is made to change parental or other family practices, including depreciation of the child and preventable losses of loved adults, which are damaging to the child's feeling of self-worth. Otherwise these authorities advise family therapy, which includes the affected child, often coupled with individual psychotherapy for the young patient. Where the child has lost a major loved one, "the family needs help and guidance in providing adequate substitutes either from its own ranks or from outside resources. Where there have been frequent early losses, the family is encouraged to help compensate by increased involvement with the child."

These psychiatrists point out that many families, particularly those in which a child has a masked depression, "respond better to direct guidance and emotional support" than to the traditional interpretive and nondirective form of psychotherapy. "Of course," they add, "there are situations where traditional psychiatric intervention of any kind is not feasible. In such cases, the psychiatrist may have to collaborate with community resources such as juvenile court, halfway houses, foster homes, and even the police."

In adults, a wide variety of antidepressive drugs—including lithium carbonate, which is virtually a specific for treating manic-depressive, or bipolar, illness and then for preventing or markedly reducing the frequency and intensity of future attacks—have been proved efficacious. Bipolar illness is rare in children, so lithium is rarely used with them. The other antidepressives are being more widely used, but no comprehensive evaluation has been made of their effectiveness. However, in laboratory work with Rhesus monkey babies that had reached the stage of despair (retreating to a corner of the cage, ceasing to vocalize, and refusing food and water), antidepressant drugs have been shown to reverse the symptoms.

Another major question for research, in addition to the effectiveness of antidepressant medication in youngsters, is whether or not childhood depression leads, or predisposes, to adult depression.

References

Cytryn, L., and McKnew, D.H., Jr. Proposed classification of childhood depression. *American Journal of Psychiatry*, 129:149-155, 1972.

Dutchess County, N.Y., Society for Mental Health. Depression touches the young, too. *Poughkeepsie, N.Y. Journal*, Nov. 11, 1976.

McKnew, D.H., Jr., and Cytryn, L. "Detection and Treatment of Childhood Depression." Paper presented at American Psychiatric Association Meeting, May 1975.

McKnew, D.H., Jr., and Cytryn, L. Historical background in children with affective disorders. *American Journal of Psychiatry*, 130:11, 1973.

McKnew, D.H., Jr.; Cytryn, L.; Efron, A.M.; Gershon, E.S.; and Bunney, W. E., Jr. "Offspring of Manic-Depressive Patients." Paper presented at American Psychiatric Association meeting, 1976.

On Understanding Depression. A report on the 1975 National Conference on depressive disorders. Arlington, Va.: The National Association for Mental Health, 1975.

Intramural: NIMH
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NEW LIGHT ON AUTISM AND OTHER PUZZLING DISORDERS OF CHILDHOOD

Principal Investigator: Donald J. Cohen, M.D.

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Micky at birth weighed almost 8 pounds and appeared to be perfectly healthy, yet he showed no pleasure when held by his parents and did not respond to their smiles or other shows of affection. His motor development was normal, and he walked when he was 16 months old. But he never babbled. When he was 18 months old, he said something that sounded like "no"; it was his first and last word. By the time he was 2 1/2 years old, he was completely uninterested in social relations and totally unconcerned by separation from his parents. During the next few years he remained easily distracted and very hyperactive. He was either extremely anxious or extremely lethargic. He also swung between periods of aggression directed at himself and periods of aggression directed at others.

At 7 1/2, Micky was attractive and bright eyed, but his only attempts at communication were "whining to his mother to indicate hunger" and aggressive lunges toward the medical staff of the hospital where he had been taken for treatment. The doctors could find no specific neurological or biochemical abnormalities. They prescribed one of the phenothiazine drugs commonly used against schizophrenia. For a while he improved, showing decreased activity and increased social relations, "and for the first time he was able to follow simple instructions." After 4 months, though, he lost these gains, and

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*See note at end of chapter.

"even with manipulation of the medication, there was no way of reducing his activity and destructiveness." Because life was becoming harder and harder for his family, Micky was admitted to a residential treatment institution.

> During the first 4 months in the school, he made educational and social gains. Then, again, at age 8 1/2 years, he had another radical mood shift, which left him uncontrollable, banging his head all day, and bruising himself. During this time, he seemed uncontrollable, and at times he required restraints to prevent him from hurting himself. He then had another shift, and he would sit for hours, holding a nurse's hand, apparently in great distress and muttering "uh, uh." He pulled his hair, leaving wide areas of baldness. A detailed neurological and metabolic evaluation was performed, revealing him to be thinner, more distressed, and even more socially unresponsive than he had been 1 year before, but otherwise with no indications of any central-nervous-system disturbance.

Micky suffers from "primary childhood autism." His story is told by child psychiatrist Donald J. Cohen, Associate Professor of Pediatrics, Psychiatry, and Psychology at the Yale University School of Medicine and Child Study Center. Cohen, who is also Psychiatric Director of the Children's Clinical Research Center, Yale University School of Medicine, is one of the country's leading authorities on autism and several other neuropsychiatric disorders of children which are discussed in this article. Although these disorders still have many puzzling aspects, authorities such as Cohen are making progress in distinguishing one from the other, elucidating subgroups, getting at the basic causes, and testing drugs and other forms of treatment.

In addition to Micky's classical or primary autism, there is a condition known as "secondary childhood autism." Development and behavior in this type may be almost the same as in the other, but the trouble seems to be secondary to recognized disturbances, such as brain damage associated with measles or with lead poisoning, inborn errors of metabolism, and a type of blindness (retrolental fibroplasia) sometimes following the administration of too much oxygen to premature infants at birth.

One child out of every 3,000 has autism. The condition may be noticeable from the very start. The child's attention may fade in and out. He is likely to be uncomfortable when held. He may cry almost without let up, or he may seem unusually quiet. Around the age of 1, his main occupation may be looking at his fingers or banging his head against the crib—for hours—or he may become occupied with one toy and reject everything else.

Research concerning autistic and other developmentally disabled children requires an integrated team of experts with special competencies and interests. The core research team at the Yale Child Study Center working with Cohen includes a developmental psychologist and educator, Barbara Caparulo; a research child psychiatrist, Dr. J. Gerald Young; and other research associates. They work in collaboration with other clinical investigators—Dr. Bennett Shaywitz, a pediatric neurologist who heads the section on pediatric neurology at Yale; Dr. Myron Genel, the chief of the section on pediatric endocrinology; and Dr. Julian Ferholt, a child psychiatrist who specializes in psychosomatic disorders of early childhood. In addition, neuroradiologists, pharmacologists, psychologists, and human geneticists join in collaborative research projects which no one could undertake alone.

Biologically oriented clinical research with children is expensive. During research hospitalization, disturbed children require private nursing care and the almost full-time attention of a researcher. Specialized tests and laboratory procedures may cost hundreds of dollars. Thus, a several-day research study of one autistic child may cost over $1,500 in time, laboratory studies, and hospital costs. The research of the Cohen group is funded by several sources, both public and private. The Children's Clinical Research Center is supported by the Division of Research Resources, National Institutes of Health. A special Mental Health Clinical Research Center will be opened as the result of a 1977 award from the National Institute of Mental Health; co-directors will be Cohen and psychiatrist Malcolm Bowers. Private foundations, such as the William T. Grant Foundation and the Ford Foundation, have funded certain aspects of the research. Most gratifying, according to Cohen, has been the support of private donors whose involvement in the research stems from being parents of children who have the disabilites being investigated.

THE SADDEST DISEASE

Of all the afflictions of childhood, primary autism may well be the saddest because its core symptom, in Cohen's words, is "the inability to relate to people and social situations in a normal way." Even to the mother, the autistic infant may respond no more warmly than to a piece of string or a flashlight. This inability is accompanied by aloofness, inaccessibility, and lack of interest "which superficially may resemble the picture presented by the most severely mentally retarded child. However, the autistic child's usually normal developmental landmarks and relatively normal physical development differentiate this type of disorder from mental subnormality."

Yet some autistic children display amazing word recognition skills. They can read very well, and they can also repeat complex sentences read to them. They cannot explain, however, what they have read or heard. "Autistic children," Caparulo and Cohen report, "are notorious for their abilities to repeat strings of sentences, to remember routes to places months or years after first being exposed to them, to notice changes in the placement of furniture or the presence or absence of toys in an office, and to remember dates and numbers . . . ." What seems to be impaired "is the *significance* or *meaning* of the objects, events, and people, and relations among them, reflected in the written or aural communication." Examination usually uncovers nothing neurologically wrong.

For many years, as even occasionally today, autism was laid at the parents' feet. Fathers and mothers were judged to be cold, to show little more than a polite interest in their child, to be incapable of extending love. Many parents—in particular, many mothers—grieved for years because of the surmises of child experts.

Cohen puts it this way: "The hope during the 1940s and 1950s that one would find parents to blame was both mean and, yet, optimistic. If autism could be caused by parental feelings and action, we would have a much greater sense of conviction in the power of environmental provision and optimism about what could be potentially undone. Today, however, parents of autistic children are considered to be like the parents of other handicapped children whose care poses inhuman burdens. Parents are usually unhappy, worried, angry, discouraged, and exhausted. But they are not, as a group, unconcerned or unloving." Many of the parents of the autistic children studied by Cohen keep their children home rather than send them to a residential treatment facility. And for these parents, "marital strife, separation, and divorce are almost expected outcomes," because an autistic child places an "impossible stress" on a marriage.

Instead of environment, congenital endowment may somehow be playing a hand. A number of investigators, including Cohen's group, have found a "relatively high incidence of depression, language difficulties, severe psychological disturbances, and anxiety or eccentricity in the blood relatives of autistic children."

Notions about the root of the trouble are beginning to accumulate, and these have nothing to do with relationships within the family. One basic problem appears to be the autistic child's inability to generate rules for dealing with information received through the senses—or even to understand these rules when they are explained. Caparulo and Cohen, for example, have studied a bright, autistic 10-year-old who liked to draw a popular restaurant over and over again. His drawings were accurate; obviously he had a sense of size. Yet, when he was asked to arrange eight geometric shapes according to size, he was baffled. In other words, he could draw a building according to scale, but he could not understand the concept of smaller and larger.

In some autistic children, another problem seems to be an abnormality or dysfunction in the body's system for regulating the state of arousal and attention. For example, the rate at which the heart works and the blood flows usually changes as states of attention change. But Cohen and an associate found that in the most disturbed children such rates did not follow the normal pattern. Such children apparently were actually rejecting sensory messages that in other children led to higher levels of arousal. Cohen believes that such rejection is not voluntary but is caused by some abnormality in the ability to process external stimuli. Recent work in the laboratories of Cohen and other investigators suggests that the most disturbed of the children may be almost habitually in a state of hypervigilance. Such a state "may be associated with recurrent cognitive confusion and a compensatory withdrawal and turning inward of attention to avoid environmental bombardment."

Far from trying to be contrary or to cause pain and grief, the autistic child, impaired cognitively and attentionally, may be simply trying "to impose order on his world." Many of his symptoms, the Yale investigators point out, "may be seen as compensatory mechanisms." As one 16-year-old movingly explained: "I am sad about my body, but it's no good to be sad. You should try to make jokes when you're feeling sad."

Some aspects of autism, Cohen speculates, may be associated with overactivity of the dopamine system. Dopamine is one of the so-called "biogenic amines" essential for proper brain functioning. It is, in fact, a neurotransmitter. Like other neurotransmitters, each apparently acting in its own portion or portions of the central nervous system, it carries from one nerve cell to another, at an unbelievable speed, the electrical signals propagated in the brain. A transmitter serves in effect as a bridge over the synapses, or the tiny clefts between nerve cells.

Cohen notes that drugs, such as haloperidol and phenothiazines, which inhibit dopamine action, have therapeutic value in some cases of autism, while drugs such as the stimulant, dextroamphetamine, which increases that action, exacerbate the symptoms. Moreover, in the cerebrospinal fluid of severely autistic children, he has found greater quantities of dopamine breakdown products. This discovery suggests that in these children an excess amount of this brain chemical is being manufactured and broken down. Its release and catabolism have been shown to be greatly affected by stress. It may well be that, as seems to be the case in schizophrenia and depression, in autism a disturbance in the neurotransmission system may help cause the stress, instead of the other way around. However, as Cohen is the first to point out, a great deal of research by a number of investigators will be needed to establish the truth or falsity of these and related ideas.

Nonetheless, the recent discovery by other scientists of two groups of neurotransmitters quite different from those found earlier seems only to strengthen the transmitters' importance to mental health. The new groups have been named the "enkephalins" and the "endorphins." Chemically, they are peptides, or combinations of amino acids, which in turn are the building blocks of protein. Cohen and J. Gerald Young point out that the newly found compounds affect the processing of sensory and emotional signals and "may be involved in modulating pain and pleasure." They have wide implications for understanding and treating a variety of mental illnesses. Among the subjects to be investigated, or re-investigated, as the result of the new findings, these researchers list "the turning away from sensory stimulation and the unusual sensitivities of some autistic children," the hypervigilance of psychotics, the inability of clinically depressed persons to experience pleasure, and the nature of drug dependency.

Other investigators have found that one of the main hormones, triiodothyronine, produced by the thyroid gland, makes for improvement in some cases of autism. Cohen's group, in turn, finds that some autistic children show marked swings—ranging from *hypo*thyroid to the *hyper*thyroid level in a few days—in the amount of thyroxine, another principal thyroid hormone. Because of these and earlier findings, Cohen and other researchers are studying the way in which thyroid hormones affect the metabolism of brain neurotransmitters.

One role of thyroid hormone, Cohen suggests, may be to sensitize neurons to the effect of the various transmitting agents. When the flow of thyroid hormones is reduced for some reason, the brain tries to maintain a steady state by increasing their production and use. On the other hand, when these compounds are produced too rapidly, the brain signals the thyroid to ease up.

The marked swings of a thyroid hormone noted in severely autistic children may go hand in hand, under this hypothesis, with broad swings in behavior. Thus the effectiveness of thyroid medication may be related to its "dampening of fluctuations."

Another factor apparently at work in at least some cases of autism is a higher-than-average amount of lead in the blood, which even in normal children can lead to disordered behavior such as irritability and lessened attention. The Yale investigators found these higher levels—in some cases well above the toxic mark—among autistic children as a group. Presumably they arise because many such children take into their mouths a wide variety of inedible material, some of it containing lead. The lesson is that autistic children should be tested for the presence of lead in the bloodstream, though they rarely are. Lead does not cause autism, but it can add to the problems.

What happens to autistic children as they grow into adolescence and then adulthood? Most of them remain in institutions or are placed there. Cohen and his fellow workers report the feelings of a devoted mother, who had spent every day with her son during his first 17 years, when she first brought him to a residential center. "I knew that as soon as I brought him there," she said, "he would be as happy as he was at home. He didn't seem to miss me for a minute." But Cohen estimates that there are a "fortunate 10 to 15 percent of older autistic individuals with language abilities and improved social relations who may seem merely odd, eccentric, or very immature." In social situations, their behavior:

> . . . usually lacks spontaneity and reflects the hard work they and their parents and teachers have put into education. They must be taught social conventions, for example, how to say "fine, thank you," instead of honestly responding with a discussion of their daily lives when they are asked how they are doing.
>
> In school, such autistic individuals may show areas of high intellectual ability and may learn to read well, yet their comprehension may be relatively limited, and the information they acquire may be of very questionable value. The older autistic individual's speech usually remains deliberate and stiff . . . .
>
> In spite of major improvements, these older individuals remain anxious and perhaps depressed as they recognize their limitations; they may have odd mannerisms or flapping behavior, especially when they are upset or excited, and they may be unable to engage in imaginative activities or work or play in a mutually meaningful way with others.
>
> For the less fortunate autistic child whose language does not progress, behavior during the school age and adolescent years remains clearly continuous with that of the preschool years. His overactive behavior may decrease with training but his ability to communicate . . . or relate with peers or adults may be extremely limited.

CHILDHOOD APHASIA

Perhaps the most common symptom of preschool children referred to child-development clinics, Cohen reports, and certainly the most common symptom that brings autistic children to child-development specialists, is slowness in beginning to talk. Among such children is a subgroup diagnosed as having primary childhood aphasia, "usually defined as the failure to develop, or difficulty in using, language and speech in the absence of mental retardation, deafness, or a primary emotional disorder." (Other terms used for the same condition are "congenital aphasia" and "idiopathic acquired aphasia," both meaning essentially that the cause is unknown.) It differs from adult aphasia because the latter is a *loss* of language—following brain damage caused by a stroke, tumor, accident, or illness. In childhood aphasia, though, there is a failure to *acquire* language.

Among 30 children with primary childhood aphasia studied by Cohen and Caparulo, many if not most had been diagnosed at some time as autistic. However, "characteristically their gestation and delivery were normal; the first year or two of life was completely uneventful, and the child was thought to be a healthy, socially attentive youngster by his second birthday. Then, sometime between age 3 and 4, the family became increasingly anxious about slow language development. Usually, by the late preschool years, the child began to show increasing activity, difficulties in deploying attention, and irritability. If seen in a psychiatric facility, the diagnosis of childhood autism might have been made, although parents were quite clear that the child showed warm, social attachment, particularly to his mother, and could make use of mime and gesture in a meaningful way . . . ." Autistic children, in contrast, "do not establish meaningful affective relations, and they often actively resist making social contact . . . ." However, aphasic children do become "increasingly agitated and disturbed as they recognize their difficulties in communicating." Among children with primary or congenital aphasia, some have an additional difficulty: They cannot distinguish environmental sounds, such as a cat's meow or a dog's bark. Earlier investigators designated their trouble as "congenital auditory imperception."

There are several other groups of childhood aphasias, sometimes less severe than the congenital condition. One major group is called "developmental" because it occurs slightly later in childhood. Children with that type may achieve the use of sentences, Cohen reports, while children with congenital aphasia generally do not develop the use of even phrases. In general, child aphasics comprehend language much better than they produce it. They are alike, too, in having more social attachments with their parents than autistic children have, and sometimes with many other people as well. And they give evidence of a well-integrated imaginative life.

Some clinicians believe that autism and childhood aphasia are related, but Cohen points to a fundamental biological difference. The electroencephalograms, or EEG's, of autistic children tend to be "normal or borderline abnormal, often showing some immaturity or lack of symmetry." But the EEG of an aphasic child "most often reveals dramatic, seizure-like patterns of discharge." These "may be most clear overlying the areas of language function, but may also exist in the occipital or in the minor hemisphere. The EEG seizure patterns are not associated with clinical seizures [as in epilepsy]; in fact, they may occur several times a moment without any clinical change."

Interestingly, though, the use of medicines that generally prevent or reduce the number of seizures in an epileptic does sometimes work with aphasic children. Cohen reports: "The reduction of paroxysmal EEG activity by the use of anticonvulsants such as Dilantin has, in our hands, sometimes led to very gratifying improvement in the language and behavior of the aphasic child." This suggests "that the paroxysmal EEG abnormality may represent a cortical disturbance and one intimately involved with the child's organ of language and ability to learn and use language."

This investigator continues:

> Aphasic children may create for themselves a rich repertoire of signs and gestures and may often take to the use of the American Language of the Deaf with great facility and pleasure. Learning to communicate opens up new avenues of social interaction and allows the child, sometimes for the first time, to meaningfully express abstract ideas. Mute autistic children may also be instructed in the use of the American Language of the Deaf, and we have seen how several of them have

> shown improvement in their general functioning and the ability to learn a reasonably extensive repertoire of signs. However, in contrast with children with aphasia, those with autism remain severely limited in their use of gestures, which they never acquire spontaneously, and their gesture and mime language remain stereotyped and directed by immediate needs, rather than by the wish to make social relationships more accessible.

Still, says Cohen, there are just as good reasons for associating childhood aphasia with primary childhood autism as there are for completely distinguishing between them. "Perhaps the most persuasive evidence of a fundamental relationship . . . comes from studies of sibships." The Yale group is studying several families, each of which has several children. And in each case, one of the children has symptoms of autism, another of aphasia, a third of a delay in acquiring language. Further, "The family histories of children with autism sometimes reveal relatives with delayed language characteristics, and this is a finding which is quite characteristic of the families of children with childhood aphasia."

Continued study of the likeness and the differences among many childhood disorders, Cohen is sure, will lead to enhanced means of treatment. He points out, for instance, that autism, obsessive-compulsive "character disorders," mental retardation, and a condition discussed later, Tourette's syndrome, although all seemingly quite disparate, do have one feature in common—the display of repetitive, stylized behavior. If researchers can find the basis for controlling such behavior in one disorder, they can go on to show how that behavior is biologically linked to or set apart from the other disorders.

As the aphasic child grows older, Cohen reports, "every investigation has found increasing hyperactivity and lack of ability to attend." Other universal behaviors include "aggressiveness, distractibility, memory defect, immaturity and silliness, seclusiveness, social withdrawal, reduced ability to deal with abstract thinking, and variability of performance on IQ tests."

This investigator notes that "the sense of immaturity and silliness observed in most aphasic children is heightened by an intensely clinging and symbiotic mother-child relationship, in which the child sees his mother, who is often the only person who understands him, as representing the only stable and reliable source of emotional and social support."

Cohen points also to the misery caused by disagreement among physicians. "Disturbances in the parent-child, usually mother-child, relationships also stem from the difficulties encountered in the course of seeking a diagnosis and treatment. As parents persevere in trying to find appropriate education and care for their child, they often receive conflicting and confusing opinions. For years they may be the only ones who remain convinced that the child is not hopelessly retarded or autistic. In the process, they may become progressively more protective and defensive."

As one example of the confusion and misery visited upon parents, Cohen cites a 1969 report by another investigator: During a 5-year period, out of 24 children diagnosed as schizophrenic or autistic and referred by child specialists or psychiatric units to special schools, "26 percent were found to be primarily aphasic with secondary autistic reaction."

What happens as the aphasic youngster grows up? Usually, Caparulo and Cohen agree, the language difficulties persist well into adolescence: "Most often the child increases his word dictionary, sometimes at a startling rate similar to the early vocabulary spurt of normal 2-year-olds. Combining these words into syntactically correct sentences remains difficult, however . . . . Words connoting abstract qualities like temporal relations and affective states or emotions remain elusive . . . ."

In addition to the treatment procedures mentioned earlier, behavior-modification techniques have been used successfully with aphasic children and also with autistic children to control hyperactivity and to increase attention span. Basically, these techniques reward a child immediately for behavior desired by the teacher, therapist, or parent and ignore other behavior (or immediately punish the child for it).

For the treatment of severe language impairment, whether associated with childhood aphasia or with autism, Cohen offers several recommendations. Such impairment, he observes, requires "intensive, individualized, and often one-to-one special education in which the acquisition of verbal and basic cognitive skills is stressed. With specialized education and a minimal number of interruptions, lasting over years, some of these children may make remarkable progress. It has appeared to us that 'summer vacations' from special educational programs are to be avoided, as these often lead to loss of skills acquired only with a great deal of energy from child and teacher. Children do best with a teacher with whom they may work over the course of several years. This continuity is especially important for the most developmentally disabled children. For some of the aphasic children, in particular, the introduction of a sign language (American Language of the Deaf) has proven to be extremely valuable . . . . Instruction in sign language provides the child, and family, with a broader range of gestures. We have also observed changes in the behavior of several mute, autistic children once they were able to communicate in a more symbolic way with adults."

ATYPICAL PERSONALITY DEVELOPMENT

Cohen calls this name "a grab-bag term." He uses it to describe those children who from the very first years of life seem to have marked deviations in personality development and in the formation of warm and appropriate social relations. Another designation for this group is "early onset, nonautistic, childhood psychosis." At every age these atypical or psychotic children seem to have some deviations in the way they relate to people, difficulties in the control of impulses, and problems in acquiring age-appropriate skills.

. . . children with atypical personality development can be helped to modulate their anxiety and to progress slowly in forming trusting relations with adults.

As the investigator notes, these are very much like the difficulties of autistic children. But the children with atypical personality development do become attached to other people. Moreover, they have discriminating attachments: They become attached to their mother, for example, but not to a stranger. Autistic children, though, will go off as readily with a stranger as with their mother.

Then, too, children with atypical personality development have much more organic impairment. They have a history of traumatic deliveries; their EEGs are abnormal; their facial appearance is often unusual. Autistic children tend to look much like their parents and siblings, while those with atypical personality development "often look as though they belong to another family." Moreover, their disturbance is less severe than the autistic child's, though later on it may develop into childhood schizophrenia. Finally, Cohen has found, the children with atypical personality, unlike those with autism, tend to come from families that are stressed or disorganized.

A variety of causes or of symptoms suggesting a cause has been found in Cohen's group of such children. Among them are brain damage from lack of oxygen at the time of birth, epileptic-like seizures, and hypothyroidism. However, "often, the biological predisposition seems compounded or even overwhelmed by the strains in the family and the stresses imposed on the child." This finding contrasts with what the investigator has found in childhood autism.

Children with atypical personality development, suffering from anxiety, learning problems, and difficulty in forming social attachments, Cohen notes, can sometimes be very much helped by early psychotherapy. In individual treatment or in treatment in small groups, such as done under the direction of Dr. Sally Provence at the Yale Child Study Center, children with atypical personality development can be helped to modulate their anxiety and to progress slowly in forming trusting relations with adults. In addition, their parents can benefit from guidance that helps them to understand their child's individual sensitivities and needs, as well as to deal more effectively with their own interpersonal and psychological problems.

Strengthening the family life and improving parental competence can have immediate impact on the child's development. Some children with atypical development may benefit from medication; many will require special education or education designed to be more responsive to their individual needs.

Recently, atypical personality development has been conceptually related to one end of the spectrum of childhood difficulties known as "minimal cerebral dysfunction" or "minimal brain damage" (MBD). Children with MBD often suffer from cognitive problems, hyperactivity, impulsiveness, and immature personalities. It has been hypothesized that the most extreme form of this disturbance may be, or may appear to be, one type of atypical personality development. For some children with MBD, stimulant medication may help.

PSYCHOSOCIAL DWARFISM

Yale investigators in the Children's Clinical Research Center and Child Study Center are also working to elucidate the causes and treatment of another peculiar and disturbing condition in children known as "psychosocial dwarfism." It is characterized by a marked reduction in physical development and by immaturity in behavior. It does not respond to growth hormones. And it seems to occur only in families facing an abnormal amount of stress.

When psychosocial dwarfs are hospitalized, Cohen and other researchers have found that they show "a remarkable acceleration in physical growth." Before or at the start of the hospital stay, tests show that their production of the growth hormone has been blunted. With hospitalization, though, this production swings back to normal. "Such children, in hospitals," Cohen says, "often display a voracious appetite, abnormalities of sleeping, and short attention. However, improvement may come within a few weeks, or a few months at most. It brings normalization of sleeping patterns, and appetite, and better social relations."

More and more such cases are being seen at university and other hospitals with large child-care departments because, Cohen suspects, such children used to be diagnosed as having an endocrinological abnormality. "But now," he continues, "we can test much better for pituitary function, and we can say, 'No, they're not like those other children'—those with real pituitary disease, the hypopituitary dwarfs. Those are children from a normal environment who fail to grow. They respond to growth hormone; the psychosocial dwarfs . . . do not."

The condition occurs in all social classes but probably in only the most disorganized families. Cohen's colleagues, Drs. Fesholt and Genel, have studied several such children over long periods of time. One child studied by Cohen was brought to the hospital for evaluation when he was 12 or 13 but looked 6 or 7. Various doctors had suspected a chronic gastrointestinal problem or perhaps a chronic pulmonary disease. The boy came from a middle-class family and had developed normally during the first few years. But when his father left to serve in the army for several years, the mother became depressed and the child greatly reduced his eating. Just before it was time for him to start school, the boy was eating hardly anything; by first or second grade, his linear growth had stopped. When brought to the hospital, he was very small, very immature, and depressed. But endocrinologically he was sound. His growth hormones were normal.

How do doctors treat such a child?

Cohen answers: "We give them psychological support, love, an atmosphere in which they are not constantly experiencing anxiety, and the opportunity to learn how to take pleasure in normal eating.

"For any long-term success, though," Cohen continues, "the parents have to be educated, or re-educated, to parenting." Among other things, this means they must recognize the need for calmness, order, and discipline in the home; the importance of the parental presence; and the need for parental interest in the child—not feigned but genuine interest so that the child really knows he has someone who will listen to and help him do something about his troubles and worries. And children have more worries than most adults either remember or believe. Where there is no capable parent available, an appropriate substitute must be found.

The investigator calls attention to a disorder known as "anorexia nervosa," or refusal to eat because of psychological overconcern about obesity, which occurs primarily among adolescents and young adults and results in dangerous weight losses. "Why in some ways," he asks, "isn't the appetite disorder in these psychosocial dwarfs similar to what we see in some young people later on?" He and his group have been intrigued by the possibility that psychosocial dwarfism is provoked by the stress and anxiety of the preschool years, while anorexia nervosa is in some way triggered by the endocrinological changes of adolescence. But he is inclined to think that the two conditions are separate rather than related.

At the basis of the trouble in psychosocial dwarfism, Cohen hypothesizes, is a disturbance in the metabolism of the brain chemicals known as "biogenic amines." This disturbance affects the functioning of the hypothalamic-pituitary gland system, whose many jobs include the arousal or suppression of appetite.

Why, usually, is only one child in a stressed family afflicted? Cohen answers with another question: Why, usually, is only one child in a family autistic? In the former case, Cohen reports, "most investigators have looked for, and have found, difficulties in parent-child relations." But Cohen wonders if psychosocial dwarfism does not, at least in part, result from an aberration in some of the children themselves. In other words, there may be something in the child—something in the workings of the brain chemicals—that with more than average ease goes out of kilter under family stress. To Cohen, such an hypothesis is consistent with the observation of the disturbances in parent-child relationships produced by autistic children. He hopes "it will not be necessary for a generation of parents of children with psychosocial dwarfism to be made to suffer the same torment at the hands of caregivers as have the parents of autistic children from 1943 until the early 1970s."

TOURETTE'S SYNDROME

The Cohen group has also studied and successfully treated a strange and disconcerting condition, less rare than commonly believed, known as "Tourette's syndrome" or "chronic, multiple-tic syndrome." It is first manifested by tic-like blinks and grimaces in the early school years. As the investigator points out, transient tics are quite common in kindergarten and first-grade children. But in children with Tourette's syndrome, the behavior spreads. Instead of involving just blinking and grimacing, it comes to include shoulder jerks, body jerks, and then, often, repeated movements such as shoulder shrugging, hand jerking, or kicking. The person also makes little noises, "which may sound like whispering or the whistle of little mice"; later he may say words aloud; finally, without apparent reason and with no means of control, he may loose a torrent of vulgar and obscene language, to the dismay of those around him and to his own distress—particularly, as is often the case, if he is a sensitive, intelligent person.

The investigator tells of 13-year-old Bernard, whose trouble had first shown itself in kindergarten but who, in spite of his jerking, writhing, and uncontrollable sounds, became expert in both baseball and basketball. Reports Cohen: "His movements were attributed to 'an allergic or asthmatic personality' by a pediatrician. At age 12, he appeared to be a very husky, friendly youngster, whose language comprehension and production were normal, whose intelligence was within the normal range, and who was able to form warm and meaningful social relations," even though he was teased for his jerks, grimaces, and sounds.

To treat the youngster, Cohen used slowly increasing doses of haloperidol, a drug often used in treating schizophrenia, though probably not to the same extent as chlorpromazine and other phenothiazines. These slowly increasing doses "completely eliminated all the symptoms," Cohen reports. At a certain level of medication, Bernard was able to say that he felt like making a movement or saying a word, but could inhibit it. At a higher level, he no longer felt the urge. When the medicine was reduced, several of the movements reappeared. When it was increased a little, the movements were again controlled.

In the case of this grimacing, jerking, spontaneous sound-making condition, how does haloperidol work? Apparently the same way it seems to work in schizophrenia. Against that major psychotic illness, haloperidol and certain other compounds appear to act by blocking, at least to some extent, the action of the neurotransmitter known as "dopamine." This action was discussed earlier in the section on autism.

Children like Bernard, Cohen suggests, may have a normal amount of dopamine (in any event, their spinal fluid contains a probably normal level of dopamine's breakdown products) but may be abnormally sensitive to it. This reasoning is based on the children's responses not only to a dopamine-blocking agent, haloperidol, but also to a stimulant drug. When a child like Bernard is given such a drug, his symptoms increase, "presumably because of increased dopamine in a system which is already oversensitive to it."

Cohen and Shaywitz have also thrown light on what may be at least one basic biological disorder in hyperkinetic or hyperactive youngsters—excitable children who have trouble concentrating. The dopamine turnover rates in the central nervous systems of such children, meaning the rates of production and use, "appear to be relatively reduced," an indication that their supply of dopamine may be lower than average. Cohen points out that such children benefit from stimulant drugs, which presumably increase the availability of dopamine, just as in his view they would be expected to do. On the other hand, children with either Tourette's syndrome or autism have elevated levels of dopamine turnover, an indication that they are producing too much of this transmitter. As expected, stimulant drugs make these children worse.

Each of the severe disturbances of early childhood—along with its subgroups—discussed here reflects in Cohen's view "a variety of interacting metabolic, genetic and environmental forces." Basic to each may be disturbances in the brain systems whose proper functioning depends upon the correct amount and functioning of dopamine. And at least one ameliorative factor seems to be medicine that controls the output or use of that brain chemical.

DETECTING AND DOING SOMETHING ABOUT DEVELOPMENTAL DIFFICULTIES

How can parents recognize when they need help?

When the child is an infant, Cohen points to a number of cautionary signs—for example:

- Slow motor development: not crawling by 7 months for instance, or not walking by 16 months.
- Failure to form social attachments, such as smiling at a few months of age, knowing the parents as special people by 6 months, showing separation worries at 8 or 9 months.
- Slowness in comprehending language and in talking: for instance, not saying a single word at 1 year, not responding to his/her name or to voices, not using many words by 18 months.
- Unusual sensitivities and irritability.
- Problems in eating or in sleeping.
- Failure to show normal physical growth.
- Failure to demonstrate normal feelings of pleasure and pain.

During the toddler years, indication that the parents need help is provided, for example, by the child's hyperactivity, aggressiveness, and failure to advance his language skills.

During the preschool and early school years, some of the help-needed signals are troubles in learning, particularly in reading, unusual fears and preoccupations, or problems in paying attention.

When parents notice such problems or are worried about anything else they consider abnormal, what should they do? Cohen advises: Turn to specialists for guidance. The first of these is the child's pediatrician or the family doctor. If the parents feel that the physician has not understood or seems uninterested in the problem, or if both the physician and the parents feel the need for further advice, they should seek out specialists—mainly child psychiatrists and psychologists specializing in children's development—who can perform developmental evaluations.

Just what is involved in such an evaluation? Cohen answers:

> The developmental evaluation of a young child should include thorough physical evaluation, including assessment of general health, sensory functioning (hearing, sight), and neurological status. Often, this may require laboratory tests such as urinalysis, screening for genetic disorders, an electroencephalogram (EEG), blood tests, and other procedures, depending on the nature of the child's problems. Careful observation and developmental testing, performed by a specially trained professional, may require several visits to assess a child's developmental level and areas of particular difficulty. Repetition of such testing over the course of months may be needed to determine if there is progress or deterioration. Since children's development occurs in the context of family life, careful social evaluation of the family is generally required. A social worker, physician, or psychologist may spend a number of hours with the parents, learning about their own histories and the way in which the family's current functioning might influence the child. On the basis of careful assessment, a diagnostic team may arrive at a specific diagnosis which can be conveyed to the parent. The major function of the diagnostic assessment is to formulate a plan of action or remediation, not to decide on a "label" for a child. There are several possible results of a diagnostic assessment: The parents may be reassured that their child's development is within the normal range or that his difficulties are transient.

> They may be given parental guidance about how to relate to a specific aspect of their child's personality, e.g., how to deal with his sensitivity or irritability, or how to help the child through a particularly difficult period. The child may require special psychiatric, psychological, or educational help, and the diagnostic assessment can help the parents and professionals structure a comprehensive program for a child when this is necessary.

As a child with developmental difficulties proceeds toward adolescence and beyond, Cohen reminds us, his needs must be constantly reassessed to make sure that he is receiving the appropriate type of help. A medicine or other therapeutic procedure that may have been helpful at one stage of growth may be useless at another. Contrariwise, new discoveries may have made more effective treatment available. The best hope is that well-trained professionals—most likely to be found in clinics and other institutions associated with medical schools—will work together as the child's advocate. This means working to advance his cause on all fronts—medical, rehabilitative, educational, governmental, and social.

The challenges are strong and numerous. "While remaining appropriately and judiciously optimistic about further understanding of the biology of development," Cohen notes, "we should keep in mind that the best we can offer most children with severe developmental disturbances today is good humane care." He adds that "for the vast majority of children with autism in the United States today, even these basic needs are not satisfied."

In the long run, as Cohen emphasizes, the best hope for the prevention or amelioration of the major disorders of early childhood lies in research. The training of more researchers and the support—governmental and private, including individual—of more research into the basic causes and treatment of these disorders would certainly pay off. Within a year? Perhaps not. Within a decade? Very probably, particularly if the move toward more and more cooperative research (cooperative both *within* and *among* institutions) continues. Yet within recent years, government policy has been toward *less* support.

CONDITIONS HELPING EMOTIONAL HEALTH

Asked what he would say to a parent who wanted to know what he/she could do to ensure the emotional health of her child, this child psychiatrist replied:

"Oh, I would say, 'Have fun with your child; have fun with your husband or wife.' The most important thing a parent can do—assuming that the child is within the range of normal health—is to enjoy what he or she is doing with their children. I would say: 'Don't worry—there are no gimmicks or gadgets that are really important, and there's no curriculum they should use with their 1- or 2- or 3-year-old child. An overzealous concern about mechanical things will distract them from something very important—the sense of pleasure in doing something gratifying and watching something grow.'"

Among other essentials for a child's healthy development, Cohen believes, are these:

- The parents should be sufficiently available so that the child can form a trusting relationship with them.
- The parents should respect the child's individuality as well as their own special needs and competencies.
- There should be consistency in handling. The child should not have to experience either numerous or disruptive changes but should be given enough new experience to be stimulated.
- The parents should feel comfortable in asking for guidance when they need it.

References

Caparulo, B.K., and Cohen, D.J. Cognitive structures, language, and emerging social competence in autistic and aphasic children. *Journal of the American Academy of Child Psychiatry*, 16(4):620-645, 1965.

Cohen, D.J. "Childhood Autism and Atypical Development." Taboroff Memorial Lecture, University of Utah School of Medicine, 1975.

Cohen, D.J. The diagnostic process in child psychiatry. *Psychiatric Annals*, 6(9), September 1976.

Cohen, D.J.; Caparulo, B.K.; and Shaywitz, B.A. Neurochemical and developmental models of childhood autism. In: Serban, G., ed. *Cognitive Defects in the Development of Mental Illness*. New York: Brunej/Mazel, 1978.

Cohen, D.J.; Caparulo, B.; and Shaywitz, B. Primary childhood aphasia and childhood autism: Clinical, biological, and and conceptual observations. *Journal of American Academy of Child Psychiatry*, 15(4):604-645, 1976.

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BASIC TRAINING FOR PARENTS OF PSYCHOTIC CHILDREN

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> *As the parent of an autistic child, one is more ridiculous than heroic—like a sludging, sloshing infantry soldier in a nuclear age.*
>
> —Josh Greenfeld, *A Child Called Noah*

TEACCH is, loosely, the acronym for Training and Education of Autistic, Psychotic and Related Communications Handicapped Children. Division TEACCH is the organization that does the TEACCHing. It is something like a boot camp for the parents of troubled children, a training ground where mothers and fathers are shaped into teachers and therapists. At five TEACCH centers scattered across North Carolina, parents learn the techniques that the professionals use to reach and train psychotic children. These parents become their own professionals, experts at helping their own children.

Parents need special training just to raise a psychotic child. Skills and habits that normal children master as a matter of course—dressing, going to the toilet, bathing—are, for some psychotic children, major battles to be won. A word, a gesture, or a facial expression can take months to learn, if ever learned at all. Every week, parent and child go to a TEACCH center for guidance in working out the drills that help the child learn such basic skills. At home, every day, they carry out the drills—slogging their way toward some sort of imperfect victory.

For a place that depends so heavily on drill instruction, a TEACCH center has an oddly casual air about it. There's nothing in dress or manner to distinguish a staff worker from a parent. There's little to suggest a hierarchy among the staff. Therapists, administrators, and teachers wear their professional credentials like old uniforms grown too snug to be buttoned comfortably.

During their first visit or two, mothers may be noticeably distressed, fathers nervous. Their worries soon subside. Parents learn that they can afford the program, because they pay little or nothing in direct fees. They learn that they will no longer have to be passive witnesses to therapeutic manipulation of their psychotic child, that they themselves can do something to help. They learn that they can nurture this child and are as indispensable to him as they are to a normal one. They are assured that they won't have to surrender their troubled son or daughter to institutions and professionals. But they also are awakened to their child's limitations. Most learn that there is nothing they or anyone else can do to assure normal lives for their children. And they get help in trying to live with this hope-shattering realization.

Division TEACCH is a statewide, largely State-supported program, which is closely allied with the public school system. In addition to the five diagnostic and treatment centers, it operates some 25 classrooms that are located near the centers, in regular public school buildings. Administrative headquarters are on the second floor of an old nurses' dorm across an alley from the sprawling hospital and medical school complex at the University of North Carolina in Chapel Hill.

TEACCH director and cofounder, Dr. Eric Schopler, is a psychologist who has spent the better part of his professional career working with psychotic children and their parents. Like the program itself, Schopler has no discernible pretensions. If he's running the rough equivalent of a boot camp, then he does it with no hint of a lockstep style. He and his staff march to the tune of each child's requirements, each family's resources. His method is pragmatic, flexible, and humane. It seems to work, and it seems to keep Schopler tied to the real world when he steps back to examine the nature of childhood psychosis. Theoretical flights-of-fancy, common in this subject, are not evident in his work.

PARENTS AS THERAPISTS

It was evidently Schopler's down-to-earth traits that first got him interested in training parents as cotherapists. Early in his career he began to question, examine, and finally reject the belief that parents were to blame for their child's psychotic condition. In Schopler's view, that belief grew out of the need of professionals, especially psychiatrists, to find a scapegoat for their scientific and therapeutic failures. He became convinced that if psychiatrists were not wedded to their theories, they could see what was in front of them. What Schopler saw were parents who were "more like the victims than the creators of their child's psychosis." He saw parents who desperately wanted to help their children, who spent time and money they didn't have trekking around the country in search of a cure. Could anyone be more motivated to help a child than his own parents? Could any professional do as well when parents spend so much more time with the child? Does anyone better understand or care for a child? Who, after all, is responsible? Who is most likely to have a continuing relationship with the child 10, 20, 40 years hence? Who must plan for that future? Schopler's questions led him back repeatedly to the parents.

Could anyone be more motivated to help a child than his own parents?

A Pilot Study

By 1966, Schopler was ready to test the idea that if parents were taught the right techniques, they could "treat" their own psychotic children. The idea was compelling not only because parents were highly motivated to help their children, but also because there simply were not enough professional therapists to provide the ongoing, day-to-day treatment that seemed to be required. Few mental health facilities would even consider admitting children diagnosed as autistic or severely psychotic. Schopler started a pilot program for training parents as cotherapists. Despite his dim view of psychiatric beliefs about psychotic children, Schopler received the blessing and support of the Department of Psychiatry in the University of North Carolina School of Medicine, where he had been Director of Research Development in the Child Psychiatry Unit since 1964. Robert J. Reichler, a child psychiatrist who had joined the department in 1965, collaborated on the pilot project. Except during Reichler's 2-year absence between 1967 and 1969, he and Schopler have together guided the research and treatment program through the years. Their close collaboration ended when Reichler moved to Seattle in 1976 to become Director of the Department of Behavioral Sciences at Children's Orthopedic Hospital and Medical Center and also Professor of Child Psychiatry at the University of Washington.

During the early pilot project, Schopler and Reichler were working toward the goal of preparing very young psychotic children for school—an emphasis reflected in the fact that the project received some support from the U.S. Office of Education. At the time, they and other specialists believed that psychotic children, like those who were otherwise developmentally disabled or "culturally deprived," would be able to achieve some success in school if only they were identified and trained to overcome their handicaps before they started first grade. The pilot project was directed at specifying the "precursors to school failure in childhood psychosis," as well as developing training techniques that could be taught to parents and clinicians.

Like other investigators, in the mid-1960s Schopler and Reichler believed that the "first-order handicap" afflicting psychotic children, especially autistic children, was the inability to relate to other people. The assumption was that this fundamental problem in human relatedness produced impairments in the child's emotional life and in his cognitive abilities (that is, in perceiving, recognizing, conceiving, judging, and reasoning). Experience and research have convinced Schopler and Reichler that the social withdrawal characteristic of psychotic children *results* from their impairments of perception, intelligence, and language—rather than the other way around. But the investigators' early emphasis on relationships reflected their commitment to involving parents in the treatment process, and it put them on the right track as they looked for specific techniques.

Schopler and Reichler set out to improve the interaction between parents and child as a first step toward ameliorating the child's handicaps. Their team would approach each child on his own terms to learn his strengths and weaknesses, talents and deficiencies. Then it would guide parents as they learned to reach their child through whatever perceptual channels were open. Schopler and Reichler would also teach parents how to control the troublesome behavior problems—such as wandering away, temper tantrums, and bizarre body movements—that create turmoil in the family and angry and anxious feelings in its individual members.

The pilot project proved that the treatment model had promise. Parents welcomed the training they received. Not only did it seem to help their child, but it helped them to regain confidence in their abilities as parents. Many parents even devised therapeutic techniques of their own. Their children became easier to live with—a source of occasional pleasure and pride. Because of this apparent success, in 1967 Schopler applied to the National Institute of Mental Health (NIMH) for a grant that would allow him to expand the pilot project and test the treatment model systematically. NIMH supported the Child Research Project for 6 years.

Division TEACCH

As part of the treatment program, parents and project staff met together one evening a month. Video tapes of each parent and child were shown and discussed. Though not required, attendance at these meetings was high. Despite the parents' wide differences in education and social status, they all participated in the discussions. At the end of the Child Research Project's first year, Schopler reported that the meetings had given parents the opportunity to share problems and support each other in learning to accept the limitations of their children.

About that time, Schopler and Reichler reminded the parents that the research program would be ending long before they would be ready to give up the help it provided. At the end of the program's second year, Schopler reported that the parents had accepted this challenge by forming themselves into the North Carolina Chapter of the National Society for Autistic Children. At first, the group worked to increase its membership, raise funds, and promote research and special education in public schools. Then the parents became politically active. They pressed for legislation that would provide public education for children with autism and related disorders of communication. Reichler drew up a draft of the legislation. The bill that was finally passed (without a dissenting vote) created TEACCH—the Institute for the Training and Education of Autistic and Communications Handicapped Children. It was to become a division within the University's Department of Psychiatry.

Division TEACCH, as it has come to be called, is one of the rare cases where a successful, federally funded, experimental treatment program was expanded and continued as an ongoing part of State and local services. NIMH paid for a major share of the cost of the experimental phase, and then the State of North Carolina took over to provide continuing services for psychotic children. The importance of this achievement should be emphasized. The transition was orderly, the expansion was gradual, and there were few breaks in service to the children in the experimental program. Even more remarkable, the TEACCH program has been extended to serve most of the State without sacrificing its ability to treat one child at a time according to his or her needs. Because it offers services democratically and has resisted the pressure toward becoming bureaucratic and uniform, Division TEACCH may be the most effective statewide program available to psychotic children in this country.

Elsewhere, many parents of psychotic children continue to be turned away when they seek help. Or they are frustrated and dissatisfied with the treatment their children do receive. Whole families still organize their lives and their bank accounts around taking care of one psychotic child.

It is difficult to imagine how one small child can create such turmoil. What is this disorder? Why is it so intractable? How do these children differ from other mentally handicapped children?

CHILDHOOD PSYCHOSIS

Psychosis in a child may be the most difficult of all mental disorders to understand, the most heartbreaking to witness.

Here is a condition marked by paralyzing fear, an affliction that suggests some awful despair grown out of defeat and resignation. Yet it is visited on the very young, who are inexperienced in the ways of the world, too young to know guilt, too innocent to understand. They may act tortured, as if they suffer unspeakable dread and unbearable pain. They might scream for hours with a shrillness and panic that psychoanalyst William Goldfarb has likened to the crying of a colicky or hungry baby. Or they might close up, turn off, tune out, and spend as many hours quietly rocking their bodies, flapping their hands, twiddling their fingers, spinning their wheels. They are the inscrutable ones, the wanderers in the night, the lonely little creatures imprisoned by one of nature's jailers. It is little wonder that they stir deep passions in their parents and those who try to treat them and understand the nature of their disorder.

Until the turn of the century, psychotic children were probably grouped with brain-damaged or retarded children and treated accordingly. About then, the medical community began recognizing the unusual speech and behavior of these children and came to see them as psychotic. In 1943, Johns Hopkins University psychiatrist Leo Kanner published a now-classic article describing 11 children with a pattern of symptoms which he eventually called *early infantile autism*. Other investigators identified groups of children with other symptom constellations and coined such diagnostic labels as *childhood schizophrenia*, *symbiotic psychosis*, *borderline psychotic*, and *atypical child*.

Even when these groups are considered together, psychoses of early childhood are rare. The best studies to date have found that about 450 or 500 of every million children born are eventually diagnosed as having a childhood psychosis. This figure may be far from accurate, however, because confusion over diagnostic labels makes it likely that many children are misdiagnosed. One puzzling but frequent observation is that children from low-income families are not often diagnosed as autistic or psychotic. Beginning with Kanner, investigators have reported again and again that disproportionate numbers of autistic children come from middle class and professional families (the reverse of the pattern for adult schizophrenia, where working and lower class patients predominate). Children in the TEACCH program, who have access to treatment regardless of their family's income, come from all socioeconomic groups. Whatever the meaning of this fact, it illustrates that much of what is known about childhood psychosis is open to question simply because diagnostic and treatment practices have been inconsistent even by the standards of psychiatry, where diagnosis and treatment are always controversial topics. (For discussions of this issue see Rutter 1978a, Schopler 1978b, and Schopler and Rutter 1978.)

There is little dispute over two characteristics of childhood psychosis, however. Like other developmental disabilities, boys are affected far more often than are girls. Four times as many boys as girls are diagnosed as psychotic. Investigators also seem to agree that psychotic children are a remarkably diverse group. Each one seems to have a unique pattern and sequence of attaining maturational milestones—when they are attained at all. A psychotic child's abilities range up and down the developmental ladder; he may piece together complex puzzles when very young, yet never learn to speak. Behavior varies widely, too. Some psychotic children are hyperactive, but more are slow and phlegmatic. Some scream and shout and have temper tantrums, while others are abnormally quiet and withdrawn.

The TEACCH Children

Partly because of this variability, investigators have spent huge amounts of time and energy over the years attempting to define just what characterizes psychotic children. Recognizing that the issue was far from settled, Schopler and Reichler developed a "broad but descriptively explicit" system for rating the presence and severity of psychosis in children referred to their project (Schopler and Reichler 1968 and 1971). Their 15-point rating scale was based on nine criteria formulated by E. Mildred Creak (1963) and her "British Working Party." Of these criteria, four were later identified by British psychiatrist Michael Rutter (1978a) as being the cardinal features of young (under age 5) psychotic children:

- Severely abnormal or delayed use of language and "prelanguage skills" (such as the normal 2-year-old's rich babble)
- Seriously impaired relationships with other people—aloofness, negativism, or empty and impersonal interactions

- Strange mannerisms—stereotyped and repetitive movements (such as rhythmic rocking, spinning, and head banging)—and resistance to change
- An onset of these symptoms before the age of 30 months.

Schopler and Reichler followed Rutter's suggestion that the term *childhood psychosis* be used to designate severely disordered children in whom these autistic characteristics are prominent. They came to use the term *autism* interchangeably with *childhood psychosis* because the autistic features seem to be central.

Most psychotic children are seriously retarded.

All of the children in the pilot project and the Child Research Project were psychotic or autistic by this definition. Most were "classically autistic," with the pattern of symptoms that Kanner had described. These are the children who are often the most seriously disturbed. Half never learn to speak; those who do speak usually use language as if they don't know what it means. Some reverse pronouns, using *you* when they mean *I*, for example. Some parrot back whatever is said to them ("echolalia," in psychiatric parlance). Some reverse prepositions. Autistic children are those who seem most alone. They don't greet their parents when reunited after a separation. They don't follow them around the house the way normal toddlers trail after their parents. They don't lift their arms in anticipation of being picked up. They seem profoundly indifferent. Their play is repetitive and monotonous. They rarely imitate adults at work. They can't seem to tolerate the slightest change in routine, room arrangements, clothing, or the pattern of play. Some perform amazing feats of memory and calculation—the children psychologist Bernard Rimland (1978) has called the "autistic savants."

Most psychotic children, however, are seriously retarded—even those who might show islets of normal intelligence or even genius. As many as 60 percent score 50 or less on tests that measure IQ by means that do not require a knowledge of language; only about 20 percent score over 70 (Ritvo and Freeman 1977). Unlike most retarded children, autistic children have uneven levels of ability. A 5-year-old autistic child whose verbal abilities are comparable to those of a normal 2-year-old might have the arithmetical skills of any child his age.

About half of the children in the TEACCH program today are rated as psychotic. The rest have a wide range of communications disorders and, usually, behavior problems as well. They are accepted into Division TEACCH because their needs for special education are very similar to those of the autistic children. Of the entire TEACCH group, only a few children achieve IQ scores in the normal range. Their retardation, their difficulties with language and other forms of communication, and their troublesome behavior are all problems that the TEACCH techniques were designed to control in children who also have psychotic symptoms.

A visit to a TEACCH center can be a disquieting experience simply because peace reigns there. New parents might show some distress, their children some obvious symptoms. But the wild child of the books is a rarity. And, despite the old and still commonly held notion that parents of psychotic children—particularly mothers—are emotionally cold, there is not a "refrigerator mother" in sight. The children have a disarming appeal and attractiveness, some elusive charm. Many parents and clinicians think that autistic children are unusually beautiful.

Above all, psychotic children are enigmatic. Trying to understand them and to master the anguish they cause, parents have written enough books and articles to fill a small library. These reports and the professional literature illustrate the wide range of symptoms and behavior exhibited by these troubled children. Here are fragments from the experiences of several young psychotic children, as related by their clinicians or parents (including some from TEACCH):

Short Takes

As a baby, Charles was inactive. He lay in his crib just staring, as if hypnotized. Because he seemed to enjoy music, his mother played records for him. By the time he was a year and a half, he could discriminate between 18 symphonies. His mother reported that as soon as the first symphonic movement began, he would blurt out the composer's name. At about the same age, he started spinning toys, bottle lids, and cylinders, an activity that would cause him to "get severely excited and jump up and down with ecstasy." Later, his interest shifted to light reflections. "When he is interested in a thing," his mother said, "you cannot change it. He would pay no attention to me and show no recognition of me if I entered the room." His mother was most impressed by his detachment and inaccessibility. "He walks as if he is in a shadow, lives in a world of his own where he cannot be reached." He repeated the exact words that others said, spoke of himself in the second or third person. "He is destructive; the furniture in his room looks like it has hunks out of it. He will break a purple crayon into two parts and say, '*You* had a beautiful purple crayon and now it's two pieces. Look what *you* did.'" He hid feces around the house. But he never soiled himself in the nursery school. He waited until he got home. "He is proud of wetting, jumps up and down with ecstasy, says, 'Look at the big puddle *he* made.'" (Kanner 1973, p. 25.)

When Sally was less than a year old, she would scream when other family members failed to sit in their usual chairs, and also when "the routine of the daily walk was changed, if the order of the dishes on the tray was altered, or when she was hindered in going through one special door leading into the garden." She was obsessed with body functions. At 6, she had trouble relating to people; she spent a lot of time alone. Her memory was "phenomenal," and she was unusually good at solving puzzles that were too difficult for others her age. (Kanner 1973, pp. 192-193.)

At 3, George would wander out the back door "like a little zombie," not looking where he was going, his head turned up to the sky, his fingers moving as if he were playing imaginary castanets. When his mother had finally taught him to stay in the yard, George suddenly started riding a tricycle "like he'd been riding it for years, like he'd been born to ride it." As far as his mother knew, he had never been on it before. He played in his sandpile. He also started playing with his swingset, which before then only the neighbor kids and his brother and sister had used. He began to swing "like an old pro." One day his mother looked out the window and saw 3-year-old George blithely marching barefoot over the top of the swingset, perfectly balanced on a metal pipe. At 6, George couldn't speak. He banged his head against the wall for hours at a time. He slept in his parents' bed. Any change in the household's routine would set off a temper tantrum. His mother recalls that "every stitch he put on his back had to be color coordinated, and George had to wear exactly the same little costume every day. He wouldn't wear shoes. He seemed so incredibly dumb in some ways. He was in no way ready for school. But he was so *keen* about other things. He would pick door locks and get out of the house in the middle of the night or in the wee hours of the morning." (Reported by George's mother.)

"Donna was frightened lest her body fall apart. In one instance she was observed to be staring at her hand and crying agitatedly 'Will it fall off?'" (Goldfarb 1969, p. 155.)

Hank and his family came from some distance for their weekly sessions at the TEACCH center in Chapel Hill. They stayed overnight near the University campus in the Carolina Inn. Hank always referred to the Inn as the "Carolina Out." The pun was not intentional, but a confusion of meaning coupled with a habit of reversing prepositions. (Reported by Schopler.)

"Daniel clutched at his abdomen, ran wildly about his room, and screamed with such apparent distress that he was examined for the possibility of an acute abdominal condition. However, in time it became clear that he reacted to bowel urgency with panic and in each instance, he gave no evidence of remembering and grasping the familiar, rhythmic nature of normal bowel stimuli." (Goldfarb 1969, p. 155.)

Richard's mother described her son, who was almost 3, in these words: "I can't be sure just when he stopped the imitation of word sounds. It seems that he has gone backward mentally gradually for the last two years. We have thought it was because he did not disclose what was in his head that it was there all right. Now that he is making so many sounds, it is disconcerting because it is now evident that he can't talk. Before, I thought he could if he only would. *He gave the impres-*

sion of silent wisdom to me . . . . One puzzling and discouraging thing is the great difficulty one has in getting his attention." (Quoted in Kanner 1973, p. 12.)

A few months before he turned 4, Tommy was using about 200 words, one at a time, never in sentences. His parents enrolled him in a nursery school for normal 3-year-olds. They had thought that being around children who used more language than Tommy did would improve his speech. Shortly thereafter, over a period of months, Tommy stopped talking completely. His behavior also changed. He stopped showing affection. His mother thinks she made a mistake by putting him into the school. (Reported by Tommy's mother.)

At 4, Noah could neither eat nor use the toilet by himself. According to his father, Noah never spoke with expression, his attention span was too short to be noticeable, he rarely played with toys, he never came when called by name. "He was almost always lost in a world whose activities consisted solely of thread-pulling, lint-picking, blanket-sucking, spontaneous giggling, inexplicable crying, eye-squinting, finger-talking, wall-hugging, circle-walking, bed-bouncing, head-nodding, and body-rocking." (Greenfeld 1972, pp. 97-98.)

Growing Up Autistic

As autistic children grow up, their psychotic symptoms subside. At or around the age of 5, many impairments that mark the young autistic child's social interactions begin to clear up, according to the British expert Michael Rutter (1978a). Serious social difficulties usually continue, however. A child may be unable to play with other children cooperatively. He may fail to make friends of his own. Many children seem to lack the ability to put themselves in someone else's shoes, or even to perceive another person's feelings and responses.

Some autistic children who are only mildly retarded, if at all, become painfully aware of their limitations during adolescence, Rutter points out. They are often "deeply distressed by the gap between their newly found desire to make close friends and their continuing incompetence." For the most part, these children are unable to regain ground lost during their early developmental years.

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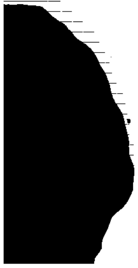
George's mother, recognizing that her son has some of the "balkiness that teenagers are known to have," tries to give him more freedom than when he was younger. "A teenager has to resist a little bit. He can't be treated like a robot."



In a 1977 article, TEACCH associate Jerry L. Sloan and Eric Schopler summarize the findings of a small number of followup studies on adolescents who were diagnosed as autistic when they were young children. Sloan and Schopler observe that:

- The "vast majority" of autistic adolescents are retarded in their intellectual functioning. Many have IQs of 70 or under.
- Probably no more than 5 to 15 percent of the children studied had a "good" outcome—doing well in academic, community, and social spheres. Neither were these children accepted by their peers. Between 50 and 80 percent of the children showed "grossly maladaptive behavior and were at home without adequate programs or were in institutions."
- About half of the children in the followup studies had developed the use of language; the earlier the child had succeeded in using language, the better his chances of a good overall outcome.
- Many had an obvious organic impairment, such as a seizure disorder (a condition developed by 10 to 20 percent of the children by adolescence).
- Few autistic adolescents—probably less than 5 percent—had ever been employed on a job.

In a subject so beset by debate, most investigators do seem to agree that one set of factors—IQ, language, and school performance—is most predictive of the autistic child's chances for the future. If the IQ persistently tests at 50 or below, the child will probably always remain "grossly handicapped" and never develop language or hold a job; he is likely to spend his life in an institution, and he is more prone to epileptic seizures than are other autistic children (Rutter 1978c). Children with normal scores on nonverbal IQ tests are likely to do well in school, but their performance varies widely. The "high-functioning" children, those with normal or above normal intelligence, are the ones who receive the attention of the popular press. Some have gone on to college and beyond. But at best, even these former autistic children often remain socially awkward. A recent report (DesLauriers 1978) describes the case of Clarence, one of the autistic children treated by Kanner. Through agonizing persistence and his therapist's help, Clarence was able to marry; he may be the only former autistic child described in the literature who did marry.

More typically, the autistic children who do grow up into an adulthood where they can hold a job and live independently show little interest in the opposite sex. When Kanner located 96 young adults whom he had diagnosed as autistic when they were children, he found that 11 were working and maintaining themselves in society.

> They have not completely shed the fundamental personality structure of early infantile autism but, with increasing self-assessment in their middle to late teens, they expended considerable effort to fit themselves—dutifully, as it were—to what they came to perceive as commonly expected obligations. They made the compromise of being, yet not appearing, alone and discovered means of interaction by joining groups in which they could make use of their preoccupations, previously immured in self-limited stereotypies, as shared "hobbies" in the company of others . . . . Life among people thus lost its former menacing aspects. [Kanner 1973, p. 211.]

THE EVOLUTION OF DEVELOPMENTAL THERAPY

During the 1960s, investigators tried a great many techniques for treating psychotic children—including, as Schopler and Reichler (1971) have noted, "custodial isolation, electroconvulsive shock, drug therapies, psychoanalytic therapy, operant conditioning, electronic typewriters, and megadose vitamin therapy." Parents were more or less excluded from all of these methods of treatment. In some cases, the exclusion was total: Many psychoanalytically oriented therapists performed "parentectomies." Believing that parents were causing the psychosis, these therapists thought it was their duty to rescue the children and provide institutional care for them.

Schopler saw no basis in fact for taking such extreme actions. His experience had convinced him that most parents loved their children and wanted to keep them. He acknowledged that, in relation to the psychotic child, parents often "show perplexity, confusion about child rearing, and a tendency to vacillate between indulgence and rigidity." But he thought such behavior was understandable. Psychotic children caused similar reactions in therapists. Why assume that the parents' behavior was anything else than a consequence of their child's extreme behavior? After all, these parents seemed to function adequately in other spheres of their lives and usually had other, normal children.

Schopler and Reichler wanted to develop a treatment model that was grounded in experience, observation, and experimental evidence.

Such was the reasoning that led Schopler to launch the pilot program that eventually became Division TEACCH. Aware of the history of overzealous application of unproven theory, he and Reichler were determined to develop a treatment model that was grounded in experience, observation, and experimental evidence. Their assumptions were explicit. In addition to their supposition that parents are normal, research evidence led them to conclude that:

- The *causes* of childhood psychosis are multiple, and it is rarely possible to determine the specific cause of any one child's disorder. In all probability, some brain abnormality is the primary cause. It is manifested in impairments in perception and understanding, which in turn result in the characteristic behavioral and language problems. Just which symptoms appear in any one child depends on the child's age, the time of onset, and the severity of the impairment.
- Every child's *development* is guided by both biological processes and interactions with parents. The psychotic child's biological impairments are bound to upset these interactions. By not responding to attention and care, the psychotic child tends to frustrate and alienate his parents—to give "negative reinforcement," in behaviorist terms.

Schopler and Reichler believed that if parents could learn to understand their child's abilities and limitations, they could adjust their expectations, rid themselves of guilt, and learn to get along. Then the way would be clear for them to get back to the business of helping their child grow and learn. Schopler and Reichler called their treatment model "developmental therapy" to underscore the point that all children change rapidly and that developmental therapy was designed to foster growth in children whose development is usually uneven. By emphasizing development, the investigators wished to remind therapists that they could understand a psychotic child and know how to help him by recognizing that, in some activities, he will respond much as a younger child would.

In devising their treatment method, Schopler and Reichler picked from a smorgasbord of techniques used to treat children with other kinds of handicaps. For example, to capture the attention of children who seemed unable either to hear or understand what was said to them, Schopler and Reichler took a lesson from the deaf, who compensate for their lack of hearing by depending on sight and other senses; the investigators believed that psychotic children, too, may be reached more easily through touch and sight. Schopler and Reichler borrowed from the Montessori model and provided play areas and classrooms that allowed exploration within limited boundaries only; they reasoned that psychotic children, who have trouble organizing their experience, would feel and behave better if some structure were imposed upon them. Schopler and Reichler decided to use operant conditioning techniques to control such problems as temper tantrums. Based on the age-old principle of encouraging desired behavior by rewarding it, operant conditioning had recently been used successfully with autistic children; some children, for example, learned to say a few words when they were rewarded with candy for making successively closer approximations to the correct sound. (It was later learned that the words were usually being parroted, not understood. But the conditioning techniques worked well for changing behavior.) The techniques had the further advantage of being easily taught, the kind of procedure parents could learn to use at home.

In Practice

By the time the 6-year, NIMH-supported Child Research Project got underway, Schopler and Reichler's developmental therapy was practiced in much the way it is today. It remains a flexible therapy, one which incorporates new ideas and new practices routinely. Techniques and methods have been refined over the years, and classrooms have been added to the program. But the experience of the first families, those who took part in the research project, was similar to what it is for families now at Division TEACCH. Perhaps the program's single most important feature is its continued emphasis on the individual child and his or her family's needs. For that reason, there is no *one* treatment plan.

With the first families, Schopler himself conducted the diagnostic session with the child. He would take the child into a playroom with a one-way mirror on one wall. Observers in an adjoining room rated the child's behavior. Using a box of toys, puzzles, and candy, Schopler would lead the child through a standard routine designed to elicit responses that would indicate the child's level of development and specific impairments. For example, to test the child's perception of sound, Schopler would call to him from ever-increasing distances.

While the diagnostic session was going on, the parents would tell another staff member what they had noticed about their child—their everyday observations and experiences. Then, each parent would take the child into the playroom, give him candy, play with him (using the child's own toys), then get the child to help put the toys back in a box. Meanwhile, in the observation room, the treatment team would evaluate strengths and disturbances in the child's relationship with each parent. The sessions also gave parents an idea of how they would be expected to work with their child at home. Not only was the diagnostic procedure used to determine whether the child met the study's criteria for admission; it also gave Schopler and his colleagues some idea of how to start the treatment program.

Once admitted, each child was evaluated for educational potential and assigned to a therapist, who largely determined the direction of the therapeutic program. Treatment decisions were based on very practical considerations: Were techniques available for reaching this particular child, techniques that could also be demonstrated to parents in an understandable way? The first problem was often a behavioral one. Many of the children were out of control by the time they had reached the Child Research Project. The parents, by then, had "adopted an air of resignation in accepting anything the child does."

In 45-minute sessions held twice a week, the therapist demonstrated how to reach or control the child while one of the parents watched from the observation booth. A "parent-consultant" sat with the other parent and pointed out what was going on or answered questions. The focus for each session was determined in advance by the therapist and parent-consultant together.

Once the child was paying attention, the sessions were likely to be directed at trying to improve the child's responsiveness to adults, his motivation to do well on various tasks, his communicativeness, and his perceptions. To improve responsiveness, for example, Schopler and Reichler would not allow the child to move about the room or use any object—or do *anything*—without the mediation of the adult. "Gradually, as the child takes the adult into account, increasing degrees of frustration are imposed, such as demanding some action or task before satisfying the child's wishes." For some children—those who seemed not to be able to see or hear—the therapists would swing the children or play with them in much the same way that a parent might play with an infant. The goal was to get the children to pay attention and to encourage them to imitate signals or words indicating that they, the children, wanted to play the game again.

Parents "need to become experts on their own autistic child."

In a 1971 article, Schopler and Reichler pointed out the advantages of demonstrating therapeutic techniques to parents:

- It avoids the "mystique and unfounded authority" of therapists reporting back from some private observation.
- It discourages therapists from making recommendations to parents which are "more easily made than carried out."
- It stimulates competition between therapist and parent and gives the parents a model to follow.
- Parents can understand direct demonstrations easier than they can verbal instructions or interpretations.

- It allows parents the chance to see that therapists, too, must struggle, become frustrated, and occasionally make mistakes. As a result, parents "become less self-critical and are better able to resume responsibility for the bond with their own child."

In the same article, Schopler and Reichler observed that before parents can draw on their own successful experience at rearing other children and adapt it to their psychotic child, they must develop "a degree of self-consciousness inappropriate to normal child rearing. Indeed, they need to become experts on their own autistic child."

Besides the demonstration sessions, parents were given a home program, which clearly spelled out objectives, methods, and materials for working with the child in daily sessions. In their work with the first families, Schopler and Reichler found that fathers sometimes were more ready and able to work with the child at home than the mothers were, especially just after treatment began, "when the mother felt most defeated and hopeless." Although both parents were expected to share the home sessions, mothers eventually worked more frequently with the children than did fathers.

Periodically, the parents demonstrated their home program in the playroom while the child's therapist and the parents' consultant observed. Although nervous at first, sooner or later most parents actually asked for additional sessions to show some new, proud development. The parents reported that they enjoyed the home sessions, when they set aside time to help the child control a symptom or learn a skill. Therapists found that designing the home program and training the parents to use such techniques as operant conditioning were relatively easy tasks. By contrast, problems in sleeping, eating, and toilet-training were trials. One example:

> One child did not go to bed until eleven o'clock. He sat in the living room rocking himself for a half hour every night, and then slept in his parents' bed every night. This had been going on for several years. The parent consultant helped the parents to divide this bedtime problem into several units. First the rocking chair was moved into the child's bedroom as was a radio he liked listening to. After he became accustomed to this change he was consistently moved from the parents' to his own bed. A difficult struggle

> ensued, requiring parents to move the child 15 times to his own bed during the first few nights. Within three weeks, however, he was sleeping in his own bed. [Schopler and Reichler 1971, p. 96.]

Parents were asked to keep logs on the child's progress. Every day, they noted changes in the child's responses to each part of the home program. Once a week, they rated the child's other behavior at home. This log, along with the demonstrations, was used to assess the parents' involvement and effectiveness.

By the end of the first year, Schopler could report that the parents met the heavy demands exceptionally well. Of the sessions that could have been held for all parents, for instance, only 8 percent were canceled, almost always for good reason. The parents were rarely late, and they turned in daily logs for nearly every day. Not only did they participate regularly, but they also eagerly conformed to the treatment structure. At first, when they were most insecure, they tended to be "excessively conscientious." As they became more comfortable with the role of cotherapist, they introduced innovations and occasionally even mustered the nerve to protest against the researchers' heavy demands.

The children progressed at greatly different rates. One child with a successful outcome was rated severely psychotic when he began treatment during the pilot project. He could not speak, was unable to relate to anyone, and had an IQ of 57. After 3 years, he was so much better that he could attend a regular grade school and not stand out from his classmates. His IQ by then was 101. Although he continued to be slightly awkward, his personality was appealing to both his teachers and peers. Schopler and Reichler speculated that it was "quite likely that the traces of this impairment will become sufficiently camouflaged with further development to be unnoticeable."

At the other extreme was a severely impaired boy with very limited abilities. Schopler reported to NIMH that at 3 the boy was unable to make communicative sounds or feed himself. After 2 years in treatment, the boy was able to relate to others and even enjoyed interactions with adults. His self-help skills developed extremely slowly. He could bring a spoon to his mouth but was unable to pick up food from his plate. His progress was slow and tended to disappear unless the task was practiced continuously. Schopler noted in a report to NIMH, however, that the boy's parents, who had four other children and had previously gone through great marital conflict, "rallied around him." Their marriage became more sound and "they feel that their boy has had a humanizing effect on every member of the family." Clinically, Schopler wrote, "these parents have achieved the delicate balance of accepting the child's limitations realistically without losing the enthusiasm and motivation to help him develop as best they can."

RESEARCH AND INNOVATION

By the time Division TEACCH was established in 1972, Schopler and Reichler were confident that it was both possible and practical for parents to treat their own psychotic children. During the 6-year, NIMH-supported Child Research Project, they systematically tested diagnostic and treatment practices they were using and developed others. Even their studies of the nature of childhood psychosis—such as Schopler's early work on perceptual processes in psychotic children—have clear implications for treatment. All of the work described below influenced the TEACCH program as it functions today.

Perception

Before Schopler went to North Carolina, he had studied the unusual way in which psychotic children perceive and process information. Many of these children seem to have trouble hearing but, when tested, are found to have intact auditory systems. Vision, too, seems to be impaired in some children, but again tests show their physiological systems are normal. Schopler (1965 and 1966) demonstrated that psychotic children tend to process information in ways that are more typical of infants than normal preschool children. They receive information and stimulation from the world around them from touching, mouthing, stroking, and smelling, rather than from sight and sound. "These receptor preferences have a profound effect on the manner in which the child obtains and distorts cues for learning about his environment," Schopler noted in his first grant application to NIMH. The socializing efforts of parents and teachers are especially affected by these preferences, he suggested.

Psychotic children experience sensations "at the sacrifice of learning and integrating the representation of sensory information in the external world." Schopler believed that it should be possible to help the child get beyond these infantile modes of dealing with the world. He and Reichler based many of their first treatment techniques on this understanding of the psychotic child's perceptual processes. They would try to reach the child through the perceptual channels that were accessible.

Research on perceptual processes in psychotic children has now gone beyond Schopler's insights. The best experimental work, according to Michael Rutter (1978b), has been done by British researchers Hermelin and O'Connor, who concluded that autistic children have a general inability to use signs and symbols, "a disability which principally involves a deficit in the coding, extraction, or organization of incoming information." Little research has continued on receptor preferences. Schopler himself lost interest in the topic when he learned that his research was being used to justify treatment techniques such as electroshock.

Parents as Scapegoats

By contrast, Schopler's writings on the parents of psychotic children have become classics in the literature. He was among the first, and the most convincing, to discredit the notion that parents were to blame for the illness in their children. In 1969 he published an analysis of the relationship between professional clinicians and the parents of psychotic children. Using Gordon Allport's formulation of the conditions necessary for scapegoating, Schopler demonstrated that these parents were in an ideal position to become scapegoats of professional failures.

He discussed six motives that clinicians have for using parents as scapegoats:

- The confusion and lack of knowledge about the nature of childhood psychosis put a frustrating burden on clinicians, who clearly [illegible] to know more about the disorder to justify their professional position.

- Such confusion "tends to weigh heavily on those clinicians charged with the treatment of autistic children," Schopler wrote. "This burden is often experienced as guilt," and projecting guilt onto others is "as old as history." Since the child can hardly be blamed, "his parents provide a most convenient substitute."
- The autistic child's negative attitudes, irritability, and aloof and destructive behavior produce a sense of helplessness that "is not easily expressed against the child, and considerable pressure develops to explain the child's impossible behavior in terms of his parents."
- When the causes of the child's disorder are unclear and treatment progress is uneven, the clinician's view of himself as an expert is threatened. High fees might put additional pressures on him to justify himself. Already existing parental guilt, insecurity, and desperation "form a convenient handle for explaining and rectifying the plight of both child and clinicians," Schopler observed. "The parents' perplexity may readily be interpreted as a primary cause of the psychosis."
- Colleagues around the clinician probably hold the same view, thus reinforcing the clinician's private views.
- Seriously considering all possible factors that might have caused the disorder is a difficult and time-consuming task. Simplifications and "tabloid thinking" are easier.

Schopler also saw that parents collaborated in this process. Allport's criteria for victims of scapegoating fit them well: They are conspicuous when they are out in public with a child who acts in bizarre ways. At the time Schopler wrote his scapegoating article, the parents had no organization that would give them a chance to object and retaliate. They become demoralized by their failures to get help for their children. They are, Schopler wrote, "ready and sometimes even willing victims." And, they are accessible. The parents also reacted like scapegoat victims: They tried to comply, often by undergoing extensive psychotherapy; they put in extra effort to learn about autism and wrote books and articles and developed their own treatment programs. Eventually they sought ameliorative action by forming their own organization.

Speaking before the second annual meeting of this parents' organization, the National Society for Autistic Children, Schopler noted that both parents and professionals are necessary for the welfare of the psychotic child. Professionals see more psychotic children than do most parents and thus have a wider experience in the variations of the problems, he said. Professionals also have the opportunity to compare, speculate, and conduct research with groups of children. But, Schopler points out:

"Though the professional may advise, only the parent bears the final responsibility."

> Parents, on the other hand, are continuously involved with the same child. They have the opportunity to observe most closely their child's unique characteristics, abilities, and disabilities. Although many professionals are capable of empathy and understanding of the parents' plight, the stakes for parents are higher than for the professionals. Parents must evaluate and deploy their limited family resources and energies in terms of their total family. They must consider the cost and payoff for special education or therapy for their autistic child against the cost and payoff of the education of their normal children. These are agonizing and difficult judgments. Though the professional may advise, only the parent bears the final responsibility . . . . I advocate that parents must become experts on their own autistic child. They have the most complete and relevant information available from their daily life with the child. They have the highest motivation for helping their child and maintaining their family equilibrium. [Schopler 1971b, pp. 75-76.]

Parental Thought Disorder and Understanding

In 1969 and 1970, Schopler, with his colleague, Julie Loftin, also published research into the supposed abnormal thought processes of the parents of psychotic children. At the time, most experts assumed that parents transmitted psychosis to their child through their disordered thinking—illogical concepts, fragmented or blurred attention, and inability to interpret and communicate meaning. In a series of studies, Schopler and Loftin showed that these parents, especially the mothers, did show more impaired thinking than did parents of normal children, but only when they felt confused and accused about their psychotic child. When asked about their normal children, parents of psychotic children did *not* show significantly more disordered thought than parents whose children are all normal. They suffered from a "situationally circumscribed anxiety" and not from a formal thought disorder.

Schopler and Loftin speculated that mothers are more affected by their child's lack of relatedness because "it is she who feels deeply rejected in her mothering role by a child who does not show the usual pleasures of infancy, the capacity to imitate and develop like other children."

As time went on and Schopler and Reichler had trained dozens of parents as cotherapists, they became more and more impressed by the parents' awareness of their children's strengths and weaknesses. They began to think that the difficulty these parents have in raising a psychotic child is the result of not knowing how to deal with a child whose developmental levels are "uneven and erratic," and is not the result of their inability to perceive the child's functioning realistically. To test these clinical impressions, Schopler and Reichler (1972) asked 87 parents to estimate their children's functioning, before each diagnostic evaluation had been done. Parents were asked about the child's overall level of development, language, motor and social skills, general ability to help himself, and mental age. The parents' estimates closely matched the results of standardized tests that the children later took. Parents of moderately or severely psychotic children estimated their child's development better than did parents of mildly psychotic children. All parents, however, seemed to be bewildered about what to do with, or expect from, this understanding of their children. "They appear to be uncertain about its meaning for the child's future, and what it means for his potential to achieve relative independence in his own life," Schopler and Reichler noted.

The Need for Structure

In another test of their clinical impressions, Schopler and his colleagues did a small-scale, tightly controlled experiment on the effects of structure on psychotic children (Schopler et al.

1971). They noted that in psychoanalytically oriented therapy, children were encouraged to explore and express themselves. Operant conditioning, by contrast, imposed a rigid structure on the child. Schopler and his group confirmed their impression that psychotic children would benefit from a relatively structured treatment setting. The most striking finding was that the children's reactions differed enormously, depending on their developmental age. The lower the developmental level, the more disorganized they were in unstructured settings. "As the children increase in developmental level, and organized response capacity, they seem to become less dependent on external structure for maintaining their own organization than do autistic children on a lower level of functioning." The impl tions of these findings for treatment and education are cl according to Schopler's group. "Perhaps the optimum learning situation," they say, "is one which has more external structure for acquiring new learning patterns and has relative freedom from structure for practicing these patterns which have been mastered and internalized."

Diagnosis

From the beginning of the Child Research Project, the degree of psychosis in each child was assessed with the psychotic rating scale Schopler and Reichler had developed from Creak's (1963) criteria. During the course of the project, they tested each of the 14 variables on the scale against clinical diagnoses of childhood psychosis. They found that impaired auditory responsiveness, verbal communication, and near-receptor responsiveness (e.g., touch) were better predictors of psychosis than more traditional indicators, such as faulty ability to relate and inappropriate affect (emotion). "The significance of this finding," they say, "is that it suggests that human relatedness may be composed of various specific functions, such as auditory responsiveness or the ability to understand or express language." Identifying such specific impairments, they believe, has greater potential for treatment than the vague construct *human relatedness*. (Further analysis of this construct is reported in Reichler and Schopler [illegible]. Their research also showed that by rating a child's behavior on the psychotic rating scale, they could reliably diagnose the presence and degree of psychosis in a child.

But they learned that other testing instruments were also necessary. They wanted to have some idea of the child's IQ because other research was making it clear that children with very low IQs did not change regardless of treatment, while the prognosis for children with IQs over 50 varied greatly depending on education and experience. The IQ score could also provide a basis for judging later improvements.

When Schopler's group began the Child Research Project, most clinicians and researchers believed that it was impossible to test the mental ability of psychotic children. The children were often unresponsive or negative. Some could not use language, some were hyperactive. Analyzing this problem of "untestability" in a 1973 article, Schopler and Reichler attributed it to three factors: the wrong psychological tests were used; clinicians refused to believe that a child's incorrect responses could actually reflect lack of ability rather than negativism; and some children, especially hyperactive ones, are difficult to test even if the right test is used.

Schopler and Reichler and their colleagues learned that most, if not all, children could be tested if they were given the right psychological test and if the staff was sufficiently patient. The tests now used at TEACCH include the Leiter International Performance Scale, a test designed for the deaf that requires no understanding of spoken language, the Bayley Infant Development Scales, and the Merrill-Palmer Scale of Mental Tests, which relies on language less than do most other intelligence tests.

Perhaps the most important diagnostic and evaluative tool used in the TEACCH program is the Psychoeducational Profile (PEP), which the staff developed to make it possible to identify the uneven and idiosyncratic learning patterns so typical of psychotic children. Seven types of functioning are assessed:

- Pathology—the child's ability to maintain eye contact, for example, or abnormalities in the use of the senses, words, or materials
- Imitation—verbal and motor imitative ability, both of which are important for language development
- Perception—perceptual skills, such as discriminating shapes and sizes

- Motor skills—gross and fine motor skills, such as climbing stairs and stringing beads
- Eye-hand integration—skills necessary for learning, such as scribbling, copying designs, stacking blocks, and coloring within lines
- Receptive language skills, such as sorting letters and pointing to pictures
- Expressive language—naming solutions of arithmetic problems or counting, for example.

Trained observers using the PEP rate children on each item as either passing, failing, or emerging (when a child knows something about performing a task but can't complete it without help). It is this last category that is most useful for planning the teaching program. The PEP, which has been widely used by other programs for handicapped children, has recently been published (Schopler and Reichler 1978) and a complete description of the TEACCH diagnostic procedure is now in press (Schopler et al., in press).

TEACCH TODAY

Schopler and Reichler built the results of their research into their treatment model, which has evolved and changed since the first families took part. Therapists, for example, are no longer chosen to represent various professions thought to be necessary for treating psychotic children. Schopler and Reichler learned that specialized training often made therapists insensitive to the child's total needs. One specialist, for example, did not consider it her job as a speech therapist to work on the control problems of a child defecating into the heat vents. Today, the TEACCH therapists are chosen for their interest in and willingness to help psychotic children. They come from several different disciplines, and they leave their professional identity at the door. Once in the TEACCH program, they alternate acting as therapists to the children and as parent counselors, so that they do not identify with either group. This is one of many practical measures Schopler and Reichler have instituted to assure that the focus of their treatment program remains on the individual child and family and not some preconceived notion of them.

Perhaps the most noticeable change in TEACCH since the days of the Child Research Project is the emphasis on education that is now apparent. Once the goal was to treat the child's symptoms so that he or she would be ready to join a normal first-grade class. Now it is known that most psychotic children cannot progress to regular classrooms. Nevertheless, as Margaret Lansing and Eric Schopler recently noted, research and clinical experience over the past decade has led many investigators to conclude that education is the treatment of choice. Recent Federal legislation requiring individualized education for all handicapped children has added an impetus to the trend toward educating rather than just treating psychotic children. The North Carolina legislation creating TEACCH carried a mandate that it provide individualized education for all psychotic children and those with related communications handicaps.

This shift toward education has changed several aspects of the TEACCH program, beginning with the diagnostic system. For educational purposes,

> . . . it is less helpful to know the precise catalog of the child's autistic characteristics than it is to know their educational implications. How much individual attention does the child require to function in the classroom? At what developmental level are his language and other cognitive skills? Which of his autistic behaviors are incompatible with his learning or disrupt the other children? This kind of information is needed to decide the degree and kind of classroom structure the child requires . . . the educator also needs to know what skills, if developed, will enable a child to better function—regardless of the environment he is in. [Lansing and Schopler 1978, pp. 440-441.]

The diagnostic system and instruments now used at TEACCH, particularly the Psychoeducational Profile, are geared toward meeting these educational needs as well as clinical goals. Parents are full partners in this process. Test data, for example, are formally integrated with information on the child's functioning at home, information supplied by the child's parents. As with the first families, parents in the TEACCH program today are never excluded from observation and evaluation of their children. They still watch diagnostic sessions through a one-way mirror. Their questions are still answered fully. They are given as much insight into their child's ability and potential as the TEACCH staff can supply. In fact, the involvement of parents in the TEACCH program is probably greater than it was during the first, experimental years.

Typically, a child now referred to TEACCH comes in with his or her parents for a day of diagnosis and evaluation. Later on the same day, the staff and parents agree to a tentative contract to work collaboratively; the contract sets out goals, responsibilties, and procedures for working with the child. During the next 6 to 8 weeks, the child and one or both parents come in once a week for hour-long clinical sessions. The child therapist and parents decide which problems are most troublesome, agree on techniques to try to overcome them, and set up a program for the parents to carry out at home. The parent consultant acts as an advocate—suggesting management techniques and self-help skills, arranging for medical services, helping with educational planning, and "above all being available to share the parents' burden and struggles in coping." (Marcus et al. 1977.)

After this extended diagnostic period is over, staff and parents again confer to set up a new contract that might involve less frequent visits. At this point, and sometimes after the initial day of evaluation, the child may be assigned to one of the classrooms that are now part of the TEACCH program. Some children receive treatment at one of the diagnostic and treatment centers first and then move on to a classroom. Some are in both at the same time, and a few only attend classes. Each classroom is staffed by a teacher and a teacher assistant and has five to eight children. Each is supervised by the clinical director of the regional center that it is near.

Classroom programs are, in many respects, like the clinic programs. The teacher, who has full access to diagnostic information, observes and experiments with each child on different tasks and collaborates with parents on the home program.

To illustrate, Lansing and Schopler have described how a teacher/therapist and parents selected tasks and worked with 6-year-old Susan. They knew from the diagnostic assessment that Susan could discriminate the shape and size of puzzle pieces. She knew enough words to label her immediate needs. But she couldn't dress herself. [illegible] school she showed no spontaneous interest in the task at hand and typically withdrew instead. The teacher and parent decided to teach her a task that was both within her ability and useful in daily life—in her case, the difference between *big* and *little* and the skill of buttoning her own clothes. Both the teacher and the parents had noticed that Susan was very interested in her mother's jewelry, that she watched her mother sew, and that she learned best through daily repetition of structured routines.

> Susan was quickly frustrated and rejected tasks that were clearly difficult. Buttoning her clothes was too difficult due to poor fine motor skills, poor visual attention, and lack of coordination between both hands. The buttoning task was broken down into steps: beginning with pushing large poker chips through a cardboard slot, then to large buttons, smaller buttons, and finally to buttons attached to cloth. Both parent and teacher worked simultaneously and observed Susan's rate of increased skill, keeping the tasks at a level of possible success. Big and little were taught first in sorting tasks using jewelry, serving utensils, and food as well as school materials. The objects were labeled by size, and once descriptive labels were understood, Susan was required to use these in daily routines—asking for a "big cookie," "a big swing," "the little earring," etc. Susan was inconsistent in her performance from day to day. As her mother described it, "Some days she seems to get out on the wrong side of the bed." Both parent and teacher observed that on her irritable uncooperative days they got better cooperation if they immediately simplified the tasks, reducing the number or using bigger buttons and giving increased help with her "big," "little" verbal responses. The process of task analysis continued from day to day. [Lansing and Schopler 1978, pp. 447-448.]

Susan's parents and teachers gradually moved on to other daily routines. The teacher thought the girl should be able to carry her tray to the school cafeteria, for example. Susan's mother began teaching her this task by requiring her to carry dishes to the table at home and to carry groceries from the car. Sometimes Susan tilted the dishes and spilled food. Her mother noticed that she would watch her own hands when she was carrying food she liked, so she taught Susan to avoid spilling her favorite foods by being careful and attentive. Soon Susan was carrying trays at the cafeteria.

It is this kind of respectful cooperation between teacher and parent that is similar to the interaction between therapists and parents in the TEACCH program. In recent years, the classrooms have become an integral part of the effort to teach and socialize the troubled children who come to TEACCH. Besides the classrooms, TEACCH has collaborated to establish a group home for older children, classes for adolescents, a summer camp, and summer recreation programs.

Some TEACCH children, about 30 percent, progress to regular classrooms. One way the staff [illegible] smooth the way for them is to bring normal children in [illegible] other parts of the school system to spend time in the TEACCH classroom. Schopler says that when this practice started, it precipitated a crisis. "The principals and parents thought our kids had something that was catching." After a few weeks, however, the visiting children became so interested that teachers started using the visits as a reward, even for second and third graders. Schopler is pleased. "It gives our kids a chance to have nice, constructive social interactions with capable, normal children. And the normal kid learns about handicapped children in a setting where he doesn't feel compelled to make fun or risk losing a baseball game."

Since the TEACCH program started in 1972, some 500 children have gone through the diagnostic evaluation. More than 600 have been seen since the beginning of the Child Research Project. Between 100 and 120 are now seen each year.

OUTCOME—DOES TEACCH WORK?

The advantages of the TEACCH program over most, perhaps all, alternative methods for treating and educating psychotic children are obvious. Families are kept together and parents are restored to their position as the primary nurturing agents in their child's life. The children are spared life in an institution. The cost of TEACCH is low. During the 1975-1976 fiscal year, for example, the State of North Carolina spent an average of $2,155 on each of 301 TEACCH families; when Federal and local funds are added, the cost comes to $2,255 for each family. By comparison, institutional care in North Carolina would have cost about $18,000 a year for each child; and many private institutions are much more expensive. Considering just the treatment provided at TEACCH centers, the cost came to about $8 an hour that year. The going rate for individual psychiatric treatment was then about $40 an hour.

And what about the children? How do they fare? Schopler and Reichler have reason to believe that developmental therapy may work better—for child and family—than traditional methods. Their own clinical impressions are that most children improve, and most families are more stable after they have been involved with TEACCH for a time. Casual chats with parents and children themselves lead an observer to the same conclusion. Parents voice none of the bitter resentment against TEACCH that they so often express toward psychodynamic treatment programs they have tried. Their few complaints are minor. They seem satisfied, even though they have foregone all hope of a miracle cure for their child.

TEACCH has some formal measures of its effectiveness. One is a small experiment that tested the parents' ability to function as cotherapists. The study, which will soon be published, was done by Lee Marcus, his colleagues at the Piedmont TEACCH Center, and Schopler. They found that mothers could significantly improve the teaching and control of their children in less than 2 months. Ten mothers in a clinic sample were asked to teach their own children an unfamiliar but uncomplicated task on two separate occasions—once before treatment began and the second time after the first treatment phase was over. The children had already been assessed, and a task was chosen if the PEP had shown that a child had emerging skill in performing it. All of the children were autistic and their median IQ was only 34. As the mother helped her child learn the task, observers rated the child for compliance and specific skills, such as behavior control and use of language. After the usual weekly sessions at a TEACCH center for the next 6 to 8 weeks, the mothers and children were observed again at a task at the same level of difficulty. Results showed that all of the mothers had improved as teachers and that they were able to generalize what they had learned. The children were all more compliant during the second testing session with one exception, a boy who had been extremely compliant in the first session. Mothers of younger children improved more than those of older children, which suggests that early intervention is important. Mothers from lower socioeconomic status (SES) groups showed greater improvement than mothers from more advantaged groups; both had done quite well at the first session, indicating that the lower SES group was actually more competent at the end.

> The excellent response of this group to the intervention program is especially gratifying, since historically lower SES families have not fared well in being identified or obtaining services for their autistic children. Clearly, educational or social advantages should not influence treatment decisions involving direct parent participation. [Marcus et al., 1978.]

The investigators concluded that while this small study lends support to the overall effectiveness of the developmental therapy model, it does not make it possible to separate out which parts of the treatment process produced the change in the children.

Another study now underway will show how parents rate TEACCH. All parents in the program have answered a detailed questionnaire, and their answers are being compared to responses to a similar questionnaire answered by all therapists involved with parents. Initial reports show that 84 percent of the parents have found the TEACCH program especially helpful in improving their children's behavior problems, language, and social skills. Details of this study will be analyzed later this year.

In a third study, supported in part by the U.S. Office of Education, observers are going into the families' homes and recording the children's behavior and child-parent interactions before treatment has begun. At several points after treatment has started, the observers again record what is going on in the home. Schopler reports that, so far, improvement has been seen in several dimensions.

What can be learned from such research is problematic, however. As Schopler noted in a recent grant application to NIMH:

> Most visitors to the home of a disturbed autistic child will agree that the child is *poorly adjusted* and that the family atmosphere is *unhappy*. These vague descriptors are quite real, and the desirability for improvement is rarely disputed. However, the factors contributing to these effects are more variable and complex than can reasonably be controlled in an experimental design. When changes are observed, any

> number of variables may have produced them. On the other hand, specific, contributing behaviors can be identified and modified (for example, a child's inability to tie shoe laces), but the demonstrated outcome may be regarded as too specific to be relevant.

Schopler believes that in a program required to treat all children with a range of handicaps, such as TEACCH, [illegible] way to evaluate how well it works is to measure the [illegible] between all parties involved:

> Treatment outcome for both specific and general goals is evaluated through independent interviews with parents, therapist, and teaching staff. Assessment of outcome is validated by the extent to which they agree on their evaluation of success or failure. This consensual validation . . . incorporates the recognition that family adaptation with an autistic child can have many different forms. What a given family decides they can and want to do for optimum adaptation in collaboration with their professional consultant may be closer to the truth than any external criteria. [Schopler 1978a, p. 4201.]

Schopler might have added that a consensus already exists about the value of TEACCH. In 1972 the American Psychiatric Association gave Schopler and Reichler its Gold Achievement Award for "productive research on developmental disorders of children and the implementation of effective clinical application." TEACCH has been the model for many other treatment programs here and abroad.

There's every indication that TEACCH will continue its practice of flexibly adapting to the children and families it serves and cautiously adopting new techniques and procedures as they come along. If there is one inflexible doctrine at TEACCH, it is that children, their parents, and their families are all unique and their needs must be found out and met in the best way possible.

Parents repeatedly confirm that this doctrine is practiced as well as preached. Tommy had been at TEACCH for 6 weeks when his mother compared it to other programs Tommy had been in.

> There, we spent a lot of time getting Tommy to sit in his chair or stop hitting. Here at TEACCH we come and work on teaching him specific skills and in the

> course of the work, his behavior has shaped up. But it's more than that. Here we're teaching him in a way that *he* can learn. The staff doesn't just assume that every child learns something the same way. They know that one method may be harder, another easier for Tommy.

Like many other parents, Tommy's mother thinks that one of the most important things she and her husband learned at TEACCH was to accept their son's limitations. Tommy's autistic characteristics have begun to subside, but he remains seriously retarded. His mother said she will be happy if the autistic symptoms completely disappear, and he grows up to be "a nice retarded person, able to live comfortably with others."

Perhaps the last word on TEACCH should go to the parents. Here is what one of the first mothers to participate had to say after she had been away from the program for a few years:

> Certainly, they brought out the best in me. Most parents who come to TEACCH don't have any idea that they have talents and that they can teach and train their own child. None of us, when we get married, think of ourselves as needing to have a unique or special quality in childrearing. They helped me learn to set things in motion and teach George some skills, how to help himself, to help him toward using his potential. I had always felt that inside George there were some abilities that we were not able to tap with an IQ test. He does some problem solving that is at a higher level than his overall functioning. When I'd say this in the yearly re-evaluation sessions, no one ever told me I was wrong or humored me. But they did help me keep George's future in perspective. It took me a long time to accept that there was no way George was ever going to be able to read. No way was he going to be able to understand math or social studies or history. They helped me to refocus my thinking—that it would be better for him to learn functional skills, to go after those things that would help him get along in a sheltered life, a sheltered job, perhaps living in a group home. They never promised miracles. They have been very careful. They learn from parents, then they take what they have learned and give it back to other parents.

References

Creak, E.M. Childhood psychosis: A review of 100 cases. *British Journal of Psychiatry*, 109(No. 458):84-89, 1963.

DesLauriers, A.M. The cognitive-affective dilemma in early infantile autism: The case of Clarence. *Journal of Autism and Childhood Schizophrenia*, 8(2):219-232, 1978.

DIVISION TEACCH: Treatment and Education of Autistic and related Communications handicapped Children. Brochure, 1978. Copies available from Division TEACCH, Administration & Research, 214 Medical School Wing B, 207 H, University of North Carolina, Chapel Hill, N.C. 27514.

Goldfarb, W. Anxiety and conflict in schizophrenic children. In: Masserman, J.H., ed. *Childhood and Adolescence, Science and Psychoanalysis.* Vol. 14. New York: Grune & Stratton, 1969. pp. 151-162.

Greenfeld, J. *A Child Called Noah: A Family Journey.* New York: Holt, Rinehart and Winston, 1972.

Kanner, L. *Childhood Psychosis: Initial Studies and New Insights.* Washington, D.C.: V.H. Winston & Sons, 1973. (Includes classic 1943 article, as well as later works.)

Lansing, M.D., and Schopler, E. Individualized education: A public school model. In: Rutter, M., and Schopler, E., eds. *Autism: A Reappraisal of Concepts and Treatment.* New York: Plenum Press, 1978. pp. 439-452.

Marcus, L.M.; Lansing, M.D.; Andrews, C.E.; and Schopler, E. Improvement of teaching effectiveness in parents of autistic children. *Journal of Child Psychiatry* 17:625-639, 1978.

Marcus, L.M.; Semrau, L.P.; and Schopler, E. "Division TEACCH: Toward a Statewide Network of Public School Services for the Autistic Child and His Family." Paper presented at the CORRC/MERRC Conference: Programming for the Emotionally Handicapped: Administrative Considerations. Washington, D.C., May 19, 1977. Mimeo. 38 pp. Availab[illegible]uthor at: Piedmont TEACCH Center, 505 South Wing, North C[illegible] Memorial Hospital, Chapel Hill, N.C. 27514.

Reichler, R.J., and Schopler, E. Observations on the nature of human relatedness. *Journal of Autism and Childhood Schizophrenia*, 1(3):283-296, 1971.

Reichler, R.J., and Schopler, E. Developmental therapy: A program model for providing individual services in the community. In: Schopler, E., and Reichler, R.J., eds. *Psychopathology and Child Development.* New York: Plenum Press, 1976. pp. 347-372.

Rimland, B. Inside the mind of the autistic savant. *Psychology Today*, 12(3):69-80, 1978.

Ritvo, E.R., and Freeman, B.J. National Society for Autistic Children definition of the syndrome of autism. *Journal of Pediatric Psychology* 2(4):146-148, 1977.

Rutter, M. Diagnosis and definition. In: Rutter, M., and Schopler, E., eds. *Autism: A Reappraisal of Concepts and Treatment.* New York: Plenum Press, 1978a. pp. 1-25.

Rutter, M. Language disorder and infantile autism. In: Rutter, M., and Schopler, E., eds. *Autism: A Reappraisal of Concepts and Treatment.* New York: Plenum Press, 1978b. pp. 85-104.

Rutter, M. Developmental issues and prognosis. In: Rutter, M., and Schopler, E., eds. *Autism: A Reappraisal of Concepts and Treatment.* New York: Plenum Press, 1978c. pp. 497-505.

Schopler, E. Early infantile autism and receptor processes. *Archives of General Psychiatry,* 13:327-335, 1965.

Schopler, E. Visual versus tactual receptor preferences in normal and schizophrenic children. *Journal of Abnormal Psychology,* 71(2):108-114, 1966.

Schopler, E. The tensions between research and treatment with childhood schizophrenia. In: Masserman, J.H., ed. *Childhood and Adolescence. Science and Psychoanalysis.* Vol. 14. New York: Grune & Stratton, 1969. pp. 162-168. (Discussion of Goldfarb 1969)

Schopler, E. Parents of psychotic children as scapegoats. *Journal of Contemporary Psychotherapy,* 4(1):17-22, 1971a.

Schopler, E. How they grow up—problems of management, training, and education. Introductory remarks to parents' panels. In: Park, C.C., ed. *Research and Education: Top Priorities for Mentally Ill Children.* Proceedings of the 1970 annual meeting of the National Society for Autistic Children, San Francisco. Rockville, Md.: National Institute of Mental Health, 1971b. pp. 75-76.

Schopler, E. Changes of direction with psychotic children. In: Davids, A., ed. *Child Personality and Psychopathology: Current Topics.* Vol. 1. New York: John Wiley & Sons, 1974. pp. 205-235.

Schopler, E. Towards reducing behavior problems in autistic children. In: Wing, L., ed. *Early Childhood Autism.* 2nd ed. New York: Pergamon Press, 1976. pp. 221-245.

Schopler, E. Treatment of autistic children: Historical perspective. In: Mittler, P., ed. *Research to Practice in Mental Retardation. Care and Intervention.* Vol. I. Baltimore: University Park Press, 1977. pp. 237-243.

Schopler, E. Changing parental involvement in behavioral treatment. In: Rutter, M., and Schopler, E., eds. *Autism: A Reappraisal of Concepts and Treatment.* New York: Plenum Press, 1978a. pp. 413-421.

Schopler, E. Limits of methodological differences in family studies. In: Rutter, M., and Schopler, E., eds. *Autism: A Reappraisal of Concepts and Treatment.* New York: Plenum Press, 1978b. pp. 297-301.

Schopler, E.; Brehm, S.S.; Kinsbourne, M.; and Reichler, R.J. Effect of treatment structure on development in autistic children. *Archives of General Psychiatry,* 24:416-421, 1971.

Schopler, E. and Loftin, J.M. Thinking disorders in parents of young psychotic children. *Journal of Abnormal Psychology,* 74:281-287, 1969.

Schopler, E., and Loftin, J.M. Thought disorders in parents of psychotic children: A function of test anxiety. *Archives of General Psychiatry,* 20(2):174-181, 1969.

Schopler, E., and Reichler, R.J. Psychobiological referents for the treatment of autism. In: Churchill, D.W.; Alpern, G.D.; and DeMyer, M.K., eds. *Infantile Autism: Proceedings of the Indiana University Colloquium.* Springfield, Ill.: Charles C Thomas, 1968. pp. 243-264.

Schopler, E.; and Reichler, R.J. Parents as cotherapists in the treatment of psychotic children. *Journal of Autism and Childhood Schizophrenia,* 1(1):87-102, 1971.

Schopler, E., and Reichler, R.J. How well do parents understand their own psychotic child? *Journal of Autism and Childhood Schizophrenia*, 2(4):387-400, 1972.

Schopler, E., and Reichler, R.J. Problems in the developmental assessment of psychotic children. In: De la Fuente, R., and Weisman, M.N., eds. *Psychiatry*. Part II. Excerpta Medica International Congress Series No. 274. Proceedings of the V World Congress of Psychiatry, Mexico, 1971. New York: American Elsevier Pub. Co., 1973. pp. 1307-1311.

Schopler, E., and Reichler, R.J. *Psycho-Educational Profile: Individualized Assessment for Autistic and Developmentally Disabled Children: Home Treatment Program*. Baltimore: University Park Press, 1978.

Schopler, E.; Reichler, R.J.; and Lansing, M.D. *Teaching Strategies for Parents and Professionals: Individualized Assessment and Treatment for Autistic and Developmentally Disabled Children*. Baltimore: University Park Press, in press.

Schopler, E., and Rutter, M. Subgroups vary with selection purpose. In: Rutter, M., and Schopler, E., eds. *Autism: A Reappraisal of Concepts and Treatment*. New York: Plenum Press, 1978. pp. 507-517.

Sloan, J.L., and Schopler, E. Some thoughts about developing programs for autistic adolescents. *Journal of Pediatric Psychology*, 2(4):187-190, 1977.

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