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**Proceedings
of
*The Sixth Annual Rosalynn Carter Symposium
on Mental Health Policy***

**FAMILIES COPING WITH MENTAL ILLNESSES:
IMPROVING PUBLIC UNDERSTANDING**

Sponsored by
The Carter Center of Emory University

October 18, 1990

The Carter Center
Atlanta, Georgia

***The Sixth Annual Rosalynn Carter Symposium
on Mental Health Policy***

**FAMILIES COPING WITH MENTAL ILLNESSES:
IMPROVING PUBLIC UNDERSTANDING**

Rosalynn Carter, Chairperson

Thomas E. Bryant, M.D., J.D.
Co-Chairperson

Donald E. Manning, M.D.
Co-Chairperson

Geri Scheller-Gilkey, Ph.D.
Coordinator

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Dinner Address:

Families and Psychiatric Treatment -- Changes in Relationships

Roy Menninger, M.D.

October 17, 1990

Tom Bryant, J.D., M.D.

Dr. Menninger is the President of the Menninger Foundation and there is not a person in America who is interested in the mentally ill and cares about the mentally ill, and cares about what America has done or does not do for the mentally ill who does not know who Roy Menninger is. Roy is carrying the torch and has been for a while as President of the Menninger Foundation. He's been with us at the Rosalynn Carter Mental Health Symposium several years, he is a close personal friend of most of us in this room and it's a very special pleasure that I introduce Roy to talk to us this evening. Roy, would you come up here please?

Roy Menninger, M.D.

Being asked to talk a bit about families is hazardous, especially to such a sophisticated and diverse group as this. It is perhaps a little like walking to the end of the gangplank and taking a look over the edge: challenging, exciting but risky! After all, most of us are members of families now, and each one of us has been a member of a family in the past. In one sense or another each one of us is some kind of expert on the subject, and the experiences of each, compelling as they have been, intensify a sense of knowing what a family "really" is or is not. Add to that the wide variation in technical and professional perspectives that we collectively represent. Perhaps for these and other reasons as well, no other idea has been so divisive within the mental health field as the complex concept of "family", particularly regarding its role in creating or suppressing or exacerbating or alleviating mental illness. I suspect a sampling of comments from those of us present tonight would illustrate this phenomenon in spades. I think that President Carter's earlier comments about the Carter Center goal of bringing disparate groups together in a variety of areas are particularly relevant to this point. To my knowledge no other place gives people of such diverse experience in the mental health field a similar opportunity to come together, to talk, and to become better acquainted, as a means of assisting us in working together more effectively on behalf of the mentally ill. We are indebted to the Carters for making this kind of meeting possible.

In contemplating my strategy for speaking here tonight, I thought of some provocative things to say; I thought of some reassuring things to say; I thought of some things I didn't want to say, but

most of all, I thought about how I might approach this complex issue in a way that would give each of us, however varied our points of view, some sense of recognition and common ground in my presentation.

I thought ultimately that the best approach would be simply to talk a bit about our work with families at the Menninger Foundation. Our experiences in Topeka are not radically different from those in other places. The family's role in the past has been considered subordinate to the treatment; the parents of children in treatment were usually told very little about the diagnosis, the prognosis or the treatment itself. Little was explained, few questions answered. Parents were expected to cooperate passively, to wait patiently, while the "real work" of treatment was carried out by the mental health professionals.

Though I speak of our experience in Topeka in historical terms, I am painfully aware that there are many places still in which the family is viewed in depreciated, even negative terms - as a major part of the problem or even its cause, as presumably having no contributions to make to the treatment (aside from paying the bill), and probably in the way.

Given this pervasive point of view in the past, it was no wonder that many families everywhere developed the view that having a sick child meant dropping them off at the hospital and returning in six weeks on the assumption that he/she will be "fixed." Or, alternately, some families who understandably came to feel that they were at risk of losing the child to the treaters, responded by becoming oppositional, working to prevent "the system" from psychologically removing the child from them.

In Topeka, where we are proud of our professionally enlightened points of view, I had thought that the families of our patients were always important to us and that we never viewed families in such depreciated ways. One of my now-retired colleagues told me that he recalled regularly going down to the train station forty years ago to meet the family of a new patient. He brought them out to the hospital and then took the family back to the train station for their trip home.

As I listened to him, I thought how good it was to know that so long ago we considered the family in such thoughtful terms; but then he went on. He said, "Of course you understand that my role was to placate the family and to keep them out of the way so the treatment could go on without their interference." That's the way we did it forty years ago. But in spite of having no family to deal with, there were other consequences. One was an occasional split in the care-giving system. In the absence of the real family, the physician in the hospital would sometimes fight with the social worker responsible for working with the family over who "owned" the patient, as if there were a soul to be possessed, and as if there

were no other family but the treaters themselves! In retrospect, we can see how this rationalized exclusion of the real family complicated the treatment. In total ignorance of developments in the patient's treatment, the family could be of no help to the process, and re-entry into the family was made far more difficult.

About 15 or 20 years ago, family therapy was introduced at the Menninger Foundation. This was a remarkable development. Even now, there are not many psychiatric hospitals that actively use family therapy to the extent that we do. This is partly because family therapists are often out-patient oriented, or even often anti-hospital in their perspective. And partly, this reflects the fact that hospitals are run by doctors whose disciplinary perspective makes it hard to share the responsibility for their patients with other professionals.

Family therapy did introduce an important therapeutic concept new to our institution: the notion of family as a system in which no longer was there an exclusive focus on an individual called "the patient" -- a single person in whom the illness could be localized, on whom attention could be focused, and in relation to whom all treatment could be organized. The concept of family-as-system meant a different focus of therapeutic attention -- on the family as whole, in which the problems of the so-called "index patient" might be seen as symptoms of a troubled group, the family.

At first, it sometimes meant that we saw the family as the primary problem, treating it as the patient, even in instances when the families were as much the victim of the illness as the patient. To be sure, some families were "sick" and in need of treatment, and some families were important contributors to the psychological problems of their members. And certainly, some families resented being seen as "part of the problem," feeling that this implied blame and they didn't deserve and responsibility they didn't feel.

Because parents clearly do affect the lives and worlds of their children, they are likely candidates for blame, even when their offspring's problems stem from non-psychological causes. It is clear that parents of severely ill children experience a very special kind of stress that is hard for others to understand or appreciate. Even those of us who treat such patients do not fully understand the resulting responses and counter-responses, some of which are hurtful, or destructive or even pathogenic.

But the introduction of family therapy into our clinical system did something of great consequence. Seeing the family as a system allowed mental health professionals to understand complex interactions that comprise many family patterns, in both sickness and health. This systems view sharply diminished the earlier tendency to split the patient from the family and to point the finger of blame for the patient's problems at the family. For the first time, it became possible to see more clearly and more

accurately how the patient's problems exacerbated family tensions, how parental responses were as frequently a response to the patient's illness as a contributor to it, and of great therapeutic importance, how the strengths of the family might be better utilized to help the patient.

A second step in this direction occurred in 1983, when we started the "Survival Skills Workshops" for families with schizophrenic or psychotic patient members. These educationally-focused programs were quite specifically intended to acknowledge the families' understandable confusion and their perplexity and to address their burden of guilt and shame. They also represented an important shift in our perspective towards a view of the family as also victimized and beleaguered, and not simply the creator of the patient's problems.

these workshops, still continuing, provide information about what is known about severe mental illness, as well as what is not known; there is an effort to clarify, as best we understand them, the etiologic roles of genetic factors, psychological factors and environmental factors. Recognizing the great benefit of an improved understanding of the treatment process as well as the illness, the workshop examines the role of medications, their benefits and side effects, as well as the importance of developing an adequate environmental support system to sustain improvement and minimize the risk of relapse. There is also some effort made to illustrate the special, hard-to-describe mental world of severely ill patients, to share descriptions of the painful nature of mental illness for the patient. To this end, we have successfully used videos prepared by patients which try to explain what that world is like to those of us who don't live in it.

I think these workshops also help families to understand how their style of interacting with their ill relative can make the patient's situation worse, and how it is also possible to alter habitual interaction patterns for the better.

The reasons for our success in this undertaking are several.

The first is the common finding that bringing struggling families together does a great deal to help destigmatize the experience for them. They discover that they are not the only people in the world who have such problems, and that sharing experiences with others is supportive.

The second is a testimony to the benefits of enabling some intellectual and emotional mastery of subjects which are profoundly disturbing. Knowledge is powerful.

And finally, there is the benefit of making families full partners in the treatment process. Rather than simply expecting the family to heed the expert, the family is recognized as a major treatment

resource, able to use the new understanding of mental illness and ways to manage it to the benefit of the patient as well as themselves. moving out of the traditionally dependent role in relation to the experts is a liberating experience.

We have been pleased to see that the results of these psychoeducational workshops have had significant consequences for the patients themselves: they have managed on lower levels of medication, they have shown a reduction in relapse rates, they have experienced an improvement in the quality of their lives, and what is perhaps most indicative of success, they have expressed considerable consumer satisfaction.

Working closely with families whose children are hospitalized is vitally important if treatment is to be successful. From the beginning of our work with disturbed children this has been true. Traditionally, this work was relegated to the social worker, whose tasks were largely limited to taking a social history, talking the parents into doing the right thing (i.e., to sell them on the treatment plan defined by the physician and the treatment team), and regularly bringing them up to date with news about the patient and the progress of treatment. The social worker was an information-gatherer and a communications link between the physician and the family, but the family was seen as a peripheral part of the process.

Over the years, how we work with the families has changed considerably. Although here is still the important initial task of obtaining information about the patient and family, the emphasis has shifted to a collaborative interaction of family and hospital. Now, at the time of admission, the family spends two days meeting the 15 other patients on the unit, and will have lunch with the staff and patients. They meet and talk with the physician and the treatment team. They meet other families whose children are also hospitalized. about half way along in this six week evaluation period, the family returns for another two-day stay, the latter part of which is devoted to a discussion with the physician and the social worker about what happens next. In short, the new role of the social worker is to engage the family as a member of the treatment team.

This means that the social worker may now call the parents every day or to with news about whatever is going on: trivial details about what happened or what the patient did that day - the good things that happened, not just the bad things. And all the decisions, whether major or minor, are discussed with the family first. Their opinion is sought; their advice is welcomed.

The fact that they are now members of the team is evident in their behavior. When they come to visit their child, they share information with us that they may previously have felt too ashamed

to talk about or were concerned that it might be seen as another indictment of them as they feel respected; and they are better able to bring their strengths to bear on the difficult tasks of helping their troubled child.

Dr. JoAnn Myers, the director of our child and adolescent treatment program in Topeka, told me she thought one of the most important things that had changed is that the mental health professionals -- especially the psychiatrists and social workers -- now feel less need for pressuring the family to think just the way we do. That is quite a change for people who have spent their lives becoming experts and who have every reason to say, "I do know the answers; let me share them with you." For them to acknowledge that "I don't necessarily know what is really best," is significant. It is a recognition that there are no single answers, especially to complicated problems, and that persons with other perspectives (like the parents) have some relevant and helpful ideas. It is a recognition that in the last analysis the parents, not the professionals, are responsible for their children.

Just three weeks ago, some 50 of our Menninger Foundation trustees and their spouses met in Topeka. The usual pattern for such meetings in the past has been the "talking head" approach: I give a speech, the chief of staff gives a speech, and various staff members give speeches. We are good at that! I suspect we've sometimes got more to say than other people may want to listen to!

But this year we did something different. In fact we did something we have never done before, something that made us a bit anxious in anticipation. We invited two sets of parents of children presently being treated in our system to come back and talk to our trustees for an hour and a half about their experiences. They agreed to do it, but we had very little idea what they would say. We did know that the children in each case were doing well, but not everything is perfect: they could have said things which would have left us embarrassed, or uncomfortable, or defensive.

The experience was a transfixing one. One child's parents talked about the agony of what it's like to have a child whose behavior they don't understand and can't manage, whose behavior is upsetting, embarrassing, even threatening. They spoke of how necessary it became to find a place that would not only help the child, but help them as well.

The other child had had a serious problem with drug abuse with all kinds of rebellious, defiant, anti-social behavior. He was expelled from the local high school after having been caught selling drugs and was subsequently thrown out of three other schools for his drug-related behavior. He was unwilling or unable to conform, to live at home, or successfully manage his own life. Ours was the third hospital his family had come to. As you might expect, they walked through our doors convinced that failure would

once again be the rule, that we would or could do no better with their child than others had before.

Their remarks, even the factual reports of what had happened, did convey the pain of their experience -- and that was as compelling as one might expect. But it was the unexpected things they said that had a special impact. They talked about how much difference it made to be just as important to the treatment process as we professionals were, and how important it was that we professionals dealt with them as equals, not as impediments to treatment or marginal to the process. They talked about how this involvement had changed them: what it had done to diminish their self-doubts and sense of inadequacy as parents, and how it had helped them recapture a sense of pride and competence.

They were surprised to have been invited to come and speak; they had never been asked by anybody to talk about such personal things to anyone, let alone to an audience. It was an illuminating experience, for them as well as for us and our trustees. It strengthened and reaffirmed their views of what had happened to them and why, and brought a kind of experiential insight to our trustees they had never had before.

Both children are still in treatment. They're both out of the hospital in aftercare programs. They're both doing well. Although reverses are still possible, their progress has been impressive, and the parents are more comfortable and more confident than they have been for a long, long time.

While I'm proud of the progress the kids have made, the point of my example and the point that warrants emphasis here is to underscore the benefits which a collaborative approach with the parents can bring to them as well to their children in treatment.

* * * *

In summary, and to return to our presence here tonight at this dinner meeting, I would note that we human beings are fundamentally interactive systems. We do affect each other. Why, otherwise would we all gather here to talk together? As the 17th century poet John Donne said "No man is an island entire unto himself." (No doubt the 20th century pressure for "correct thinking" would have us revise the wording somewhat: "No self is an island entire unto itself." -- but that phrasing is hardly as poetic!)

He underscores the point: we do depend on each other, we do need each other, and we do learn from each other. We have the power to affect each other, for good or ill. This is a fundamental consequence of the relationships we establish with each other. Over and over again, therapists are brought to realize that the bedrock for successful treatment is the relationship. It is through positive, significant relationships that mental illness can be addressed, that self-esteem can be enhanced, that a vital sense

of self-worth can be generated, and that healthy changes can occur.

In the same way, relationships among my fellow professionals in Topeka are of the highest importance; they provide the "glue" that holds a treatment system together in the face of the ceaseless and exhausting demands from seriously ill patients; relationships sustain treatment teams and therapeutic organizations; they provide a modicum of gratification that helps offset the frustrations of this difficult work. By extension, the relationships we develop with the trustees in our organization shape our future and the relationships we establish with our donors provides us needed funds to support education and research.

We are not here to think big thoughts or to impress others with our wisdom and our brilliance. We are here because we are looking for ways by which we can supplement the efforts of each other so that the combination is thereby more effective. Though we are brought together by this common interest, we too will be successful only to the extent to which we also establish abiding relationships.

That is the potential which the annual Rosalynn Carter Mental Health Symposium offers us. I think that the heart of what the Carters have built in to the core of their work is this catalytic power of relationships. I am tempted to call it magic, but that not only demeans its real role, it's not even true. But it feels magical because it is so simple. We are so busy in our competitive worlds, so eager to prove that each of us is better than the other, that relationships -- acknowledging them, sustaining them, enhancing them, reenforcing them -- move to a very low priority on the agendas of many. The poser of this meeting is that fundamentally it's about forging relationships. I think this is tremendously powerful and ultimately the basis of any success we may collectively achieve. The vital presence of strong and effective relationships will be remembered long after each of us has left the scene.

Thank you.

FAMILIES COPING WITH MENTAL ILLNESSES: IMPROVING PUBLIC UNDERSTANDING

Rosalynn Carter, Chairperson

October 18, 1990

PROGRAM

- 8:00 - 8:45 a.m. Registration
Coffee & Bagels
- 8:45 - 9:00 a.m. Welcome and Introductions
Rosalynn Carter
Chairperson
Thomas E. Bryant, M.D., J.D.
Chairman, Non-Profit Management Associates, Inc.
Donald E. Manning, M.D.
*Professor and Acting Chairman, Department of Psychiatry,
Emory University School of Medicine*
- 9:00 a.m. Program Chaired by
Daniel X. Freedman, M.D.
Judson Braun Professor of Psychiatry and Pharmacology, UCLA
- 9:00 - 9:20 a.m. WORK WITH THE ENTERTAINMENT INDUSTRY: AN UPDATE
Rosalynn Carter
Chairperson
- 9:20 - 10:10 a.m. SCHIZOPHRENIA: PUBLIC IMAGE, PRIVATE REALITY
Samuel Keith, M.D.
Deputy Director, Division of Clinical Research, National Institute of Mental Health
- 10:10 - 10:30 a.m. Response by a Panel of Discussants
Paul Fink, M.D.
Past President, American Psychiatric Association
Don Richardson
Past President, National Alliance for the Mentally Ill
Jerilyn Ross, M.A.
President, Anxiety Disorders Association of America
- 10:30 - 11:00 a.m. Coffee Break
- 11:00 - 12:00 noon FAMILIES AND MENTAL ILLNESS: THE NEWS COVERAGE CONNECTION
Panel Moderator:
Everette Dennis, Ph.D.
Executive Director, Gannett Center for Media Studies
Discussants:
Carrell Dammann, Ph.D.
Family Therapist and Director, Open House, Inc.
Monica Kaufman
Anchor, WSB-TV, Cox Broadcasting, Inc.
Melvin Konner, M.D., Ph.D.
Professor of Anthropology and Psychiatry, Emory University
Judge John S. Langford
Senior Judge of the Superior Courts of Georgia
Rona Schpeiser, M.S.W.
Retired Assistant Director, Jewish Family Services of Metro Atlanta
Steve Smith
WXIA-TV, Gannett Broadcasting, Inc.
- 12:00 - 12:30 p.m. Concluding Remarks
Jeffrey L. Houpt, M.D.
Dean, Emory University School of Medicine
Rosalynn Carter
Chairperson

The Following Individuals are the Official Representatives of their Organizations to the Sixth Annual Rosalynn Carter Symposium on Mental Health Policy:

American Academy of Child and Adolescent Psychiatry
David Pruitt, M.D., *Chairman, Work Group on Consumer Issues*

American Association for Marriage and Family Therapy
Mark R. Ginsberg, Ph.D., *Executive Director*

American Association of Retired Persons
C. Kermit Phelps, Ph.D., *Past Chairman*

American Mental Health Fund
David George, *President*

American Nurses' Association
Hattie Bessent, Ed.D., R.N., *Deputy Executive Director,*
Ethnic/Racial Minority Fellowship Program

American Psychiatric Association
Paul Fink, M.D., *Past President*

American Psychological Association
Raymond D. Fowler, Ph.D., *Chief Executive Officer*

Anxiety Disorders Association of America
Jerilyn Ross, M.A., *President*

Black Psychiatrists of America
Isaac Slaughter, M.D., *President*

Compeer, Inc.
Bernice Skirboll, M.S., *Executive Director*

National Alliance for the Mentally Ill
Donald J. Richardson, *Past President*

National Association of Private Psychiatric Hospitals
Doyle I. Carson, M.D., *President*

National Association of Social Workers
Richard L. Edwards, Ph.D., A.C.S.W., *President*

National Depressive and Manic-Depressive Association
Helen Hintz, *Member, Board of Directors*

National Federation of Society for Clinical Social Work
Marty Wakeland, M.S.W., *President, Georgia Chapter*

National Mental Health Association
Elisabeth Rukeyser, *Chair of the Board-Elect*

National Mental Health Consumers' Association
Paul Dorfner, *President*

Project SHARE/National Mental Health Consumer Self-Help Clearinghouse
Joseph A. Rogers, *President*

World Federation for Mental Health
Beverly B. Long, *Regional Vice President - North America*

Morning Symposium Program

October 18, 1990

Thomas E. Bryant, M.D., J.D.

My name is Tom Bryant and I would like to be the first, this morning, to welcome all of you. This is, as you can tell from the program, the Sixth Annual Rosalynn Carter Symposium on Mental Health Policy. Those of us who have been involved with Mrs. Carter and her activities and efforts on behalf of the mentally ill for several years now know that this is a highlight of every year--coming to Atlanta, coming to the Carter Center and using this as an opportunity to catch up and see what has happened in the course of the year and not only renew old friendships, but get a real feel for what national organizations and local organizations are doing. This is a unique opportunity for all of us who work in this field, and it is something that we like to think we help keep moving forward. And one of the reasons that occurs is that new ideas come out of meetings like this.

The main impetus for this Rosalynn Carter Symposium in the beginning, and it remains the same now, is one individual--Rosalynn Carter. What she has done for the mental health field and what she has done for the mentally ill in this country and around the world is almost beyond description. There has been no one in the position of authority she has had who has made such a personal commitment to a cause who has had such an impact. Her impact has not only been on policy issues that affect the day to day lives of the mentally ill and their families, but also on those of you and those around the world who work in this field. One of the nice things about this particular meeting every year is that it gives us all a chance to thank Rosalynn Carter. For the sixth year in a row, I want to do that, and I would like to ask Rosalynn Carter to come up and say what she wants to say to get us started. Thank you.

Rosalynn Carter

Tom is a good friend to say those things. Well, I am really pleased to welcome you here this morning, I am glad to see all of you and I want to thank again, the van Ameringen Foundation and the John D. and Catherine T. MacArthur Foundation for making this symposium possible. Every year, as many of you know because many of you have been here all six years, we choose a different topic area to focus on in our meetings. This year, we have chosen the family.

I am sure that you are all aware of the current thinking about the causes of major psychoses, that they are the result of a variety of causes. They are no longer considered to be primarily the result of environmental factors, a term that many parents of individuals who suffer from mental illnesses interpret as "bad parenting." And although many more people are becoming knowledgeable about mental illness, the initial shock of recognition of a family that a member has a serious mental illness is always painful and difficult. For most families, it is the beginning of a long and difficult journey. There are many traumatic points along that journey as the family of Jack and Joanne Hinckley describe in their book called **Breaking Points**.

In the last 20 years, the frequency of care in the home has increased with de-institutionalization. It is estimated that about two thirds of the people who are discharged go home to their families. And yet it is often the case that the responsibilities and burdens, as well as the opportunity for rehabilitation within the family, are ignored as the mental health care delivery system focuses on the individual. Last night, we heard Dr. Menninger talk about the family and his institution and how they involved the family with the patient in the treatment, in the consultations, and in getting them working together. I wish, and I think we all wish, that everybody had that kind of care available to them. If families are to be required to participate in the care of their sick relative, they must be given the tools to make sure they can do so effectively.

One of the reasons that families are not adequately supported is the negative stigma. (We always come back to stigma.) But individual family members are themselves likely to have typical misconceptions about mental disorders, with the result being that they are often not comfortable asking friends and neighbors for the support they need. And also, the friends and neighbors probably have the same negative stereotypes in mind and misconceptions and so they distance themselves from the family when they could be supportive. Unfortunately, professionals like family practice physicians, as well as mental health professionals, when confronted with the pain, despair and anger of the family, often react by subconsciously creating distance instead of encouraging a sense of cooperation with the family. Mental health professionals are often not trained to help the family in dealing with severe mental disorders. They don't learn what to say or how to answer the questions that the families have. Rather than forming an alliance with the family members, they may simply avoid them and concentrate, as I have just said, on the individual who is suffering.

I think one of the most important changes in the last 10 to 12 years is the joining together of family members in groups like the advocacy and family organizations represented here today. I think the power and the force of the wave of advocacy and family

organizations that has swept through our country is remarkable. It has been exciting over the past 10 years. Most all of you have been in the mental health field for a long time like I have, and it has been exciting to see this development. And I think we saw evidence last week, during Mental Health Awareness Week, of the strength of our movement because there were more activities than ever before and all of these activities impact on the public and help create a better understanding of mental illnesses. This powerful movement has helped individual families and relatives feel less helpless and isolated. When somebody in this community gets in touch with me about a mental illness in the family, when it first happens and they have no idea where to go, there is always an advocacy group that I can send them to. It has helped address the issue of widespread misconceptions and stigma, and it has stimulated new sources of support for research and services.

By working together, professional organizations and advocacy groups have been mutually beneficial to each other, and have had a greater impact on our common objective of improving the well being of those who suffer from mental illnesses. I would like to believe that our mental health symposiums have been helpful to all of us. I think by communicating openly, and working together, we stand a better chance of eradicating stigma and putting mental illnesses right up there with Muscular Dystrophy, Cancer and Diabetes as a socially acceptable cause. Communication and collaboration can occur when we come together and mount a collective effort.

So, I am thankful that you're here today, really pleased to see all of you, and to have us all working together in a common effort. Thank you for being here.

Thomas E. Bryant, M.D., J.D.

Now, it gives me pleasure to introduce my Co-chairman, Dr. Donald Manning. Dr. Manning is a professor and is Acting Chairman of the Department of Psychiatry at the Emory University School of Medicine. Don has been here for a while, and has been coming to these conferences. The Department of Psychiatry at Emory has co-sponsored these conferences since the beginning. As I think all of you know, there is a special relationship between The Carter Center and Emory University. And there has been this special relationship between the Department of Psychiatry and The Carter Center and The Rosalynn Carter Symposium every year since its inception. So, I would like to call on Dr. Manning, who will get us started for the day's program. Thank you very much.

Donald Manning, M.D.

It is my pleasure to extend the third welcome of the morning, this time on behalf of the Department of Psychiatry. I was going to talk about the special relationship between the department and the Carter Center and the Rosalynn Carter Symposium, but since Tom took care of that for me, I will go on. I have been to all six of

the symposia, have watched the excitement and the dynamic process develop, have watched the potential of these symposia actualize, and the excitement continues again today. I think the catalyst for this kind of coalition, (which is the theme of the Carter Center) the only catalyst who can bring this about is Rosalynn Carter. We've long watched her efforts on the part of mental illness and mental health nationwide. We have long heard of her commitment and her energies for the underserved in general.

I wanted to take a minute to tell you about two activities that you may not be aware of that we have been involved in with her -- both locally. One, called Project Interconnections, is a unique coalition of community, government, professional, political and corporate leaders to raise funding to serve the mentally ill. The other is Phoenix House, a unique coalition of county and federal governments and private foundations which provide housing for the mentally ill homeless. The list of her contributions goes on and on. I think those of us in mental health do owe her deep gratitude and appreciation.

It is also my pleasure to introduce our morning moderator. Daniel X. Freedman is the Judson Braun Professor of Psychiatry and Pharmacology and the Executive Vice Chairman of the Department of Psychiatry at the UCLA Neuropsychiatric Institute. From 1966 to 1983, he served as Chairman of Psychiatry at the University of Chicago, and earlier was a professor at Yale. As a leading researcher, Dr. Freedman has spent the last 35 years advocating and advancing psychiatric research. He has pioneered a number of areas of research, in brain chemistry, drugs and behavior. His accomplishments are truly innumerable. But briefly, and pertinently, he chaired the pharmacology, toxicology and substance abuse cluster of the President's biomedical and behavioral research panel. He served on the selection committee of President Carter's Commission on Mental Health, and chaired its research task force. He has served as editor of the Archives of General Psychiatry, and has been past president of almost every important organization in American psychiatry: the American College of Neuropsychopharmacology, the Association for Research in Nervous and Mental Diseases, the American Association of Chairmen of Departments of Psychiatry, The American Psychiatric Association, and the Society of Biological Psychiatry. He has edited numerous books, over 200 scientific publications, and we are fortunate to have him this morning moderating the panel. Dr. Freedman...

Daniel X. Freedman, M.D.

Well, thanks for that life review, Don. The reason I'm here (besides the fact that I got infected in February, 1977) is that I met Rosalynn Carter in the overheated basement of an East Room in the White House where something like this was a gleam in her eye. I've been marching ever since, and marching with great pleasure and astonishment at the family that keeps growing out of that signal change in American psychiatry and it's relationship to

the public and it's patients. I really have done all those jobs that you talked about, Dr. Manning, largely because I always delivered the goods on time. We are going to do that this morning, I hope. We have been welcomed by Mrs. Carter. I can't believe that she would allow me to do an extensive introduction of her since she is not only the Chairperson of this group but a participant. And this morning, she is going to talk to us about work with the entertainment industry, and give us an update. Mrs. Carter...

Rosalynn Carter

I wanted to tell Don, when we were talking about Project Interconnections a few nights ago, that I went to the Georgia Women's Forum meeting. They have three meetings a year, and they were saying, "We need a project." I said, "I have a great idea." And so now I have the Georgia Women's Forum interested in Project Interconnections which is a program to help get homeless mentally ill individuals off the streets of Atlanta. They are all very excited about it and we're meeting tomorrow afternoon with some of them to see if we can work things out. I am thrilled about that.

In June of this year, I and a few other people in this room, met with members of the Hollywood creative community. Most were writers of T.V. and movie scripts and we met to discuss ways to improve public understanding about mental illnesses through the entertainment media. This morning I want to share some of the suggestions and plans that emerged from that meeting.

I think you are already aware of this effort because Entertainment Industries Council members, Dr. Tom Backer and Brian Dyak, have been here for most of our symposia, and we have always talked about stigma in our meetings. Even when we had other subjects, we stressed stigma because one of the most important things we have to do is to try to overcome the stigma that surrounds mental illness. Another reason that we have talked about stigma is because I have always thought that maybe this is the area in which I could help. If I could talk about mental illnesses, I could hopefully get some public attention for the problem. Back 20 years ago, when nobody was talking about mental illness openly, if I called a mental health meeting the only people who came were those in the government and they came because the Governor's wife had called a meeting. This has changed, and I'm pleased about that today. But stigma is something that all of us are aware of and all of us have worked on for many years.

At our symposium last year, after the morning session, we met together in groups and talked about what we call "depictions," things that can be incorporated into television programs and movies that will portray those who suffer from mental illnesses in a more accurate way and help overcome the stigma. So often people suffering from mental illnesses are portrayed as violent or mad and all of us know that more often they are shy and retiring. Many of

the suggestions and ideas that we discussed with the people at our June meeting in Los Angeles came as a result of these symposia. So we consider all of you who participate with us, and many of you have been here from the beginning, as partners in what we call the Carter Center Mental Illness and Entertainment Media Initiative. You have helped us shape our hopes and dreams about what the initiative can accomplish, and our dream is to stimulate humane accuracy throughout the film and television entertainment media of the realities of mental illnesses.

At this time, we are focusing on three things: the portrayal of mental health professionals by the entertainment media, reducing the negative stereotypes we so often see of evil or incompetent therapists and also equally unhelpful, the portrayal of therapists as God. We are focusing on the portrayal of mental health facilities and services for the seriously mentally ill. Again, we are trying to reduce the negative stereotypes. And, we are encouraging people to deal more positively with public concerns about mental health facilities in local neighborhoods - the N.I.M.B.Y. phenomenon, "Not In My Backyard." And a final focus is the portrayal of families of mentally ill individuals, eliminating the erroneous depictions of them as responsible for causing the mental illness of a family member.

We have a lot of suggestions from our meeting in June: an annual media award, educational seminars for writers, producers, and other creative people in Hollywood, among a variety of other things. We hope to proceed with these in the future. We all know that the entertainment media are enormously powerful influences on people's attitudes and beliefs. Research about impact of the mass media has shown repeatedly that the single most important source of information for Americans about social problems such as mental illness, is television.

In December of last year there was a national survey done about public attitudes. It showed that only 25% of Americans describe themselves as being very well informed about mental illness. Six in ten say that they should know more about mental illnesses, and only one in three people describe T.V., radio and newspaper stories about mental health as very believable. That survey also showed that the average person is shown on television 45% of the time as being violent. In comparison, the mentally ill person is shown on television 80% of the time as being violent! Research conducted by Dr. Tom Backer and others shows that entertainment media have particularly great potential for changing underlying values and beliefs, especially when the topic involves strongly held opinions, as in the case with mental illnesses. Thus, our initiative is concentrating on entertainment, T.V. and film programming, and we will also be doing some work with the news media as well. Dr. Backer and Bryan Dyak, who are both in the audience this morning, are working with me in coordinating our initial efforts. They helped us arrange the June meeting in Los

Angeles, and afterwards, they drafted a background paper and a series of depiction suggestions which we plan to distribute to more than 2000 entertainment industry professionals later this year. We are working together closely and, as we can find funding support, we plan to continue our efforts with the entertainment media.

Our dream is for families and professionals, for caregiving institutions, and for people with mental illnesses themselves to be understood and accepted. We've worked on that for a long time. We want to use the tremendous power of the entertainment and news media in improving the quality of life for those people whom we are all concerned about, those who suffer from mental illnesses. Thank you.

Daniel X. Freedman, M.D.

That was an exciting meeting in Los Angeles. The follow-up is something that's a consummation devoutly to be wished for. I think it can happen. There was an interview on T.V. this morning of the Congressional Panel and a reporter (I think on CBS) said "Well, you guys can't vote on this budget, nobody seems to agree with each other." One of the Congressmen said "Oh, we really are united, we are united in schizophrenia."

Well, that started off this morning well for me! And that is the point. "Schizophrenia: Public Image, and Private Reality" is an issue that should be directly engaged by this group, and there is nobody better to do it than Sam Keith, who is going to address us. There will then be a panel, which I will later introduce, to respond to Sam. There is no one whom I know of more equipped in this country than Sam Keith to address the topic since long before mental health had hit a national agenda, he was the "guardian of schizophrenia," and schizophrenia research. As a devoted public servant at NIMH, as a rare breed of science administrator and scientist. He brought to fruition in 1987 (I guess it takes patience) the National Plan for Schizophrenia, which is a remarkable study. About 150 scientists throughout the world got together in various forums led by Sam and the outcome was a document that really contains marching orders I think for the field for a long time to come.

I'm particularly happy to welcome Sam here, not only for his service, not only as a fellow editor; he is editor of Schizophrenia Bulletin, which is an important archive of new science and perspective on the science and schizophrenia. But Sam, you should know, is a graduate of Emory. He received his M.D. there. I think that makes it especially fitting that you lead us off this morning with your remarks on "Schizophrenia: Public Image, Private Reality."

Samuel Keith, M.D.

In addition to being the most recent introduction I have received, that was also one of the nicest. Thank you Danny, I can only say that I wish my Mom and Dad could have been here to hear this, because Dad always liked to hear nice things said about me, and Mom sometimes even believed them. Thank you.

There must be something truly unique about mental illness that separates it from the equitable, reality based judgments accorded other illnesses. Could it be fear? Misunderstanding? Their mind altering quality? There are certainly illnesses that have caused fear -- AIDS, leprosy; there are illness we do not fully understand -- cancer, multiple sclerosis; there are illnesses that affect the mind -- Huntington's; yet none of these combines the misgivings, the misunderstandings, and the misperceptions assigned to mental illness. From the public fear of the newspaper lead-in "former mental patient held..." to the public shame assigned to parents for causality to the public derision of people who "just don't want to help themselves," mental illness, the mentally ill and those who care for and about them stand alone.

One could choose any number of mental illnesses to exemplify these points -- depression, bipolar disorders, anxiety disorders, schizophrenia. Yet from among this group, perhaps none stands out more strikingly than schizophrenia.

Extent of the Illness: Schizophrenia is an illness which continues to alter the expectations of 2 million Americans during the course of their lifetimes. Two million Americans will experience the onset of an illness which will decrease and far too often eliminate the possibility of completing an education, beginning a career, or enjoying a life once filled with such promise. Many will continue an existence without control of that most human of qualities -- the human mind and its unique ability to distinguish reality from fantasy, friend from foe, joy from sadness. Yet the two million Americans bearing this diagnosis are far from the only people who have suffered from the scourge of schizophrenia. Each of those suffering from schizophrenia have family and friends who care deeply about them and who have suffered, if differently, equally as much. Along with the illness and its private reality of personal and familial suffering and disability, comes an enormous cost to our society -- a cost compounded by ignorance and fear.

Although numbers and cost data do not capture the full extent of schizophrenia, I would like to give you an idea of the extent of this problem. Schizophrenia is five times more common than multiple sclerosis, six times more so than insulin-dependent diabetes, and eighty times more so than Huntington's disease. Twenty five percent of people suffering from schizophrenia will never recover. An additional 50% will experience disabling symptoms intermittently throughout life -- spawning further

associated health problems and social and occupational disabilities.

Small wonder that the economic burden posed by schizophrenia is so severe. On any given day people with this illness occupy more hospital beds than any other illness known to man -- more than cancer, heart disease, lung disease and diabetes **combined** -- but what is worse is that people with this illness occupy more park benches and heating grates than any other illness in the history of mankind.

No statistical data -- either of prevalence or economics -- can portray the full impact of schizophrenia in human terms. It was once wishfully believed by some that those engulfed by schizophrenia do not actually suffer -- that they are so far removed from the real world that their awareness of their burden is dimmed. Unfortunately, that consoling notion cannot be sustained. Victims of schizophrenia are very much aware of their condition and their agony. They are tormented and frightened human beings -- confused lonely and in despair. Many will not return to a course of life in which they were once active participants. I have a young patient named Paul, who came into my office one day and said, "Dr. Keith, I don't think you understand how bad this illness is. It's like there's a whole world out there, covered with superhighways, with cars and buses and planes and trains, and I just don't have a ticket to ride."

Small wonder that one in four patients with schizophrenia will attempt suicide; ten percent will complete the suicide in the first ten years of their illness. Age corrected rates of mortality further show that the person with schizophrenia is twice as likely to die of all causes at any age.

Despite this impact on our society and on the private lives of patients and their families, schizophrenia remains an illness shrouded with fear and cloaked in ignorance. Much of this fear and ignorance about schizophrenia has been driven by etiologic theories which emanated from one of mental health's cruelest epochs. It focused on the familial etiology of generating, precipitating or exacerbating the illness. Much has been written thoroughly and systematically examining what was wrong with the early "research" in terms of its tautological hypothesis which ignored such issues as direction of effect, inappropriateness of measurement, and variability of outcome. Spurious associations, for example were made with schizophrenia which led to an era of family pathogenesis as the preeminent etiologic hypothesis. Nowhere in medical science would this be tolerated except with mental illness. No one would examine the families of children with cancer and note the behavioral patterns of anger, denial, increased religious fervor or grief and conclude that this was what **caused** the cancer instead of this being a **response** to the cancer. Yet with schizophrenia, this is exactly what happened. The iatrogenic damage to patients

and their families was the result of a misinformed era of understanding about schizophrenia and about mental illness in general. Unfortunately the historical antecedents of assignment of blame and the absence of data are legion. Moral infirmities, demonic possession and schizophrenogenic mothers are all examples of this phenomenon. And, yes, we have all seen the results of contemporary de Torquemada's. The anguish, caused by people who were wrong, is no less painful because they believed they were right. Undeniable is the damage of the generation of familial causality of schizophrenia. And undeniable as Georges Santayana's position--those who forget history are condemned to repeat it. History has led us to a better understanding of the need to assign blame for mental illness. No one likes to accept blame for failure. In the treatment of schizophrenia, until the advent of a more successful psychopharmacology, failure was indeed a common outcome. Clinicians who faced failure with their approaches assigned blame to families and assigned the patients to distant human warehouses like Central State Hospital in Milledgeville, Georgia that housed 13,000 patients in the 1960's. Schizophrenia became the leprosy of its era--its patients shunned and its families blamed. Further, society does not wish to feel that mental illness is relevant to them--it is someone else's problem. It is something that others have through their own failings, or their family's causality. The net result of this was not too dissimilar to how cancer within a family was managed 30 years ago--no one talked about it--a veil of private and public silence fell; and the families isolation increased to match that of patients housed in isolated areas of the states in large mental institutions. But veils of silence can be raised. It has been raised on cancer; it can also be lifted off mental illness. It will require us to provide an education to patients families and society that supports the position that schizophrenia is an illness with a biologic component as strong as any other medical illnesses, with a genetic component equally as strong and with treatments which incorporate pharmacology and education about the illness. We can move toward a position of dignity and respect for everyone so afflicted--for those whose lives have been all too often irretrievably altered and for those who have so long labored to help their family members with insufficient tools and the cruel double punishment of an illness in a loved one and an accusation of causality. It deserves noting that schizophrenia has not been the only illness that has family blaming as an underlying misconception. Many others have as well--anorexia/bulimia; depression; anxiety--but for some reason with schizophrenia it hit harder and stuck longer. And I fear that in the minds of the general public it still lingers. That is why perhaps our education process had to begin with the family while such illnesses as depression and anxiety could move more rapidly into a public forum.

How did this family educational process begin? It began with a confluence of a strident family advocacy voice together with a growing body of research data pointing to schizophrenia being a "no

fault illness." As I am reasonably certain that Don Richardson, the past president of the National Alliance for the Mentally Ill will address the family advocacy movement in his discussion in a few moments, I will leave that critical area to him and spend some time on the development of the clinical and research foundation that has been growing this past decade. It began with a validating of the exchange of information between families, patients and clinicians who are able to accept and appreciate that each had much to contribute to the other about the clinical understanding of the illness. But it is important to emphasize is that the real change required was a validation of the family--exchange of information between patient and clinician was the time honored tradition in mental health care. But now a new ally had been enlisted and it is to this new ally that I would like to turn for a moment to describe the impact of recent research and to examine whether this validation process can lead to a better appreciation by the public of schizophrenia, in particular, and of mental illness in general.

The past decade has approached the role of the environment in mental illness with a keen awareness of the need for new scientific rigor. No longer was it satisfactory to use association for causality or negative outcomes for tautological verity. Examples of such research came from people like Marvin Herz, who in research conducted here in Atlanta and later replicated in Buffalo, N.Y. was able to provide compelling evidence that listening to family members about the early signs of relapse was a valid and successful means of preventing an untoward event. As obvious as this may seem today, for family members who had been given complete responsibility in many instances for caregiving and support and treatment failures and yet had been excluded from the treatment process as being "toxic," this work was a major step forward. Education, however, is a two way street. The acceptance of information from the family is one direction; the provision of information to the family is another. In order to be a more effective ally, the family needed to be seen as more than just providers of useful information--they also needed to be given the very best information to help manage the illness in their family member.

There are a number of reasons why the family was potentially so important in the management of schizophrenia:

1. Over 65% of schizophrenic patients discharged from the hospital return to their families. If only patients recovering from early episodes of psychosis when the potential for improvement was at its maximum were considered, this figure would be much higher.
2. Families are a natural support system. They provide an interested, involved and available resource which cannot be readily reproduced. The family advocacy movement speaks volumes to this interest and involvement. In addition, the family environment is a natural setting for context dependent

learning, seemingly so essential for full recovery to take place.

3. The recent interest in family environment as shown through the research work in the positive benefits of lowered environmental intensity and affect have shown an impact of a measurable phenomenon on relapse--and further, there are positive outcomes involved--the recognition that the family contributes to positive outcomes was refreshingly new. Further of importance is that an identifiable environmental component is amenable to change through psychosocial interventions and this change has a direct bearing on outcome. (See Appendix A.)

In working with families, however, it became critical that we bear in mind that the family's requirements must be given equal attention to the following areas:

1. Family burden. The illness of schizophrenia places tremendous burdens on the family and the treatment program must recognize this. In general, our experience is that early in the treatment process, the families are eager to learn the kinds of management skills necessary to help their family member to recover. But this cannot be seen as a permanent solution.
2. Family management as a transitional strategy. Mental health programs have frequently looked for new locations to house the chronically mentally ill from state hospitals to nursing homes. Families should not be expected to become the new "back wards" of our communities. The goal of family management strategies should be to promote independent living functions. The family is an available instrument for encouraging positive change and should not be expected to play the role of chronic care-giver. Failure to recognize this essential point will lead to burnout on the part of the family either from being asked to do too much for too long or simply from parents who become too old to provide the necessary care. Indeed, it should also be borne in mind that delivering services which involve the family should not mean that the patient is required to live at home. Many families and patients will want the home; others may not. A successful family program should be able to accommodate both perspectives. And this requires a major shift in the availability of community services. Major impediments exist in the public sector where the resources to care for the mentally ill never followed their move from the hospital to the community. And private insurers who have so struggled to rid their roles of the mentally ill because of the skyrocketing costs of hospitalization, are no nearer to grasping the needs of those attempting to live in the community than they were 20 years ago.
3. Family management as a disguised "finger pointing." Families,

as we noted earlier bear unjustified scars and justified anger at mental health professionals who have in the past accused them of causing schizophrenia. Although relatively few clinicians remain steadfast in this belief, the healing process from several decades of "finger pointing" is slow, and must be addressed early in any family management program. (See Appendix B.)

Eschewing the family pathogenesis theories of schizophrenia, this current work with families takes a psychoeducational approach to the illness with treatment principles relating to combining a refinement of the pharmacology with major attention also being given to the psychosocial context in which treatment is given-- education, stress reduction, problem solving and basic communication skills becoming critical.

Although pharmacology has been the central area of research for the past four decades, it is only recently that research emphasizing the positive role of the family in a treatment program has received attention. There are now six completed controlled studies of family treatment of schizophrenia -- and one now underway under auspices of the National Institute of Mental Health. Although the specifics of family management strategies may vary, common among them are the following:

1. The enlistment of the family in a positive clinical alliance.
2. The provision of educational material about schizophrenia.
3. The provision to the family of principles of management skills in the areas of:
 - a. problem solving
 - b. communication
4. Encouragement to families to expand their social networks particularly through mutual interest groups.

The family management programs that have been the focus of research study have differed in their location of delivery (home vs. clinic), their mode of delivery (individual families vs. multiple family groups), timing (acute vs. stabilized patients), and behavioral vs. more dynamically oriented principles, the results, however, are quite striking over the period of active delivery of treatment. For the first nine months and for the most recent five studies the results are as follows:

		Experimental % relapse	Control % relapse
Hogarty	family treatment	9	28
Leff	family treatment	9	50
Falloon	family treatment	6	44
Kottgen	family group	33	50
Tarrier	beh. family treatment	12	53

Based on these findings, the National Institute of Mental Health has initiated a five-site collaborative study of family management and neuroleptic dosing strategies under the direction of Nina Schooler and myself. The basic design focuses on refining dosing strategies for pharmacologic treatments -- an attempt to determine the least amount of medication possible, which I will not spend additional time on today -- and the interaction of these interventions with two carefully designed educational programs for families. The goals of this study are to determine a number of issues -- not the least of which is whether the kind of family work done in small studies just noted could be done on a large scale-- for public policy consideration--and whether it could be done by some one other than the inventor or the developer of the treatment. Studies of psychiatric treatments have all too often found that the treatment was dependent on the "great person" concept rather than the treatment itself. In other words, being in the presence of a charismatic, well-meaning individual has many benefits -- including those for schizophrenia.

In our study, the family treatments are based on a recognition of the role the family plays in supporting gains of schizophrenic patients in the community. The treatments share common principles based upon this understanding of the family role. They include: education of the patient and the family regarding the nature of schizophrenia as a major mental illness with both biologic and psychological psychosocial components; the importance of stress and the management of stress for such patients; the understanding that interpersonal relations, particularly those of a sustained close nature, are uniquely stressful for schizophrenic patients; the need to identify specific stressors and the means for coping with them; the provision of general case management support; and the importance of early identification of both the general and patient specific indicators of potential relapse.

During the period of the patients' hospitalization or immediately following it, families participate in an extended psychoeducational workshop modeled after the workshop format developed by Anderson and her colleagues conducted by clinical team members. The goals of the workshop are to: provide factual information about schizophrenia, introduce principles of family management based on communication, problem solving and stress reduction skills; establish a group affiliation designed to reduce isolation, stigma, and anxiety for family members; and enlist the family as a therapeutic ally. (See Appendix C.)

We talk about schizophrenia as a medical illness affecting the brain and its interaction with the outside world.

We talk about how it is diagnosed.

We talk about its genetic components.

We talk about its biological underpinnings and how we think our drugs may work.

We talk about the practical aspects of clinical treatment.

We talk about how important the family is to our clinical treatment team.

At the end of the workshop three booklets are given to each attendee: "What is Schizophrenia?," "Medication for Schizophrenia", and "The Role of the Family." No one leaves this program feeling responsible for causing schizophrenia in their child.

Following this early educational approach, we are examining two types of family programs -- one provided in the home and clinic and one in the clinic only. Home sessions capitalize on context dependent learning in increasing the generalization of skills training. Home sessions make it easier to include the patient, the patient's parent(s) or a family member acting in loco parentis and others, kin or not, who are actively involved in the family's day-to-day affairs. Providing the family treatment in a familiar environment also serves to reduce tension and encourage additional social network participation. Compliance with treatment is significantly enhanced. Although travel time for clinicians increases, missed appointments are rare.

In the clinic, patients and families are invited to and encouraged to attend monthly family group meetings, conducted by an FMC. The goals of the monthly group meetings include sharing of information and the provision of mutual support by families and patients experiencing similar problems of stress, burden and stigma associated with having schizophrenia or having a relative with schizophrenia. Each session begins with a brief presentation by the FMC on a topic from the **Psychoeducation Workshop Manual** or a series of curriculum outlines. Following the presentation, families and patients are encouraged to share their experiences and problems and to clarify information about schizophrenia (e.g., they often see newspaper articles about new "breakthroughs"). These monthly meetings seek to combine elements from a number of sources that have been observed to be clinically useful in approaching the clinical condition of schizophrenia. First, the monthly meeting format has been successfully used by Chapters of the National Alliance for the Mentally Ill for many years to break down isolation and to provide group affiliation for support. Second, the provision of educational material at the outset of each meeting both supplies information useful in understanding schizophrenia and its management, and also sets a tone for the meeting of sharing knowledge, problems and solutions. Third, the group emphasizes the benefits derived from participation in a group setting with other families and patients: reduction of isolation, mutual support, information sharing and an expansion of generally constricted social networks.

Although results of this study are still in the future, clinically over 500 patients have entered the early phases at five hospitals across the United States; two in New York, one in Philadelphia, one in San Francisco and here in Atlanta at Grady

Memorial Hospital under the direction of Bill Ninan and Roz Mance. One early finding is of relevance to our discussion today--those patients whose families attended the day-long educational workshop on schizophrenia at the start of treatment had significantly better outcomes during the first six months. (See Appendix D.)

It is clear now that we have the capacity to alter the private reality of the family in its capacity to deal with schizophrenia. And it is equally clear that when exercised, this capacity provides real gains for those willing to learn about schizophrenia--clinician, family and patient as well. Psychiatric clinicians are learning to become good teachers like their counterparts in other branches of medicine with other illnesses. It will obviously take time for these concepts to become widely known and even longer for them to be widely practiced. But we do have the direction now.

Where we are less certain, however, is in altering public perceptions. No matter how successful programs of working with the family in private may be, inevitably, it is the public whose opinion will mean either acceptance or rejection for families so afflicted. Eventually we hope that all patients and families will feel accepted, because all deserve to experience lives free of disparagement and full of the knowledge that opportunities that are available to others are available to them. Jobs, housing, education must be available at the entry level into society. And society can do it. I look with a sense of pride at the progress made with other handicapping illnesses. The efforts have been made to assure access into all public buildings; to guarantee elevator access to a metro system before it could open; the enforcement of antidiscrimination laws to provide equal access to jobs. But for illnesses which handicap the functioning of the brain, we can point to only isolated successes. Progress has not provided for the mentally ill "ramps" through the complex maze of disability programs or easy access to employment. Nor have neighborhoods been accepting of housing alternatives.

It is possible to change public attitudes, but it seems that two elements are necessary before this can happen:

1. Education about the universality of illness
2. Hope.

Universality of Illness: As long as society labors under the false belief that an illness happens only to someone else, their interest and concern cannot be tapped. Data from the recently completed Epidemiologic Catchment Area Project which interviewed directly over 20,000 people in five cities (New Haven, Durham, Baltimore, St. Louis, Los Angeles) found that the prevalence for diagnosable mental illness was 20%. One in five Americans suffers from mental illness -- it is not someone else's problem.

In active collaboration with many of the national organizations represented here today, the National Institute of Mental Health has initiated two major programs to educate the public about depression and about anxiety disorders. The motivations behind such programs are multifaceted but include explaining:

- the extent of these illnesses demand public knowledge about them;
- the symptoms of depression and anxiety in their many manifestations -- for example, chronic fatigue or somatic complaints with depression; or a sense of impending doom emotional or physical with anxiety disorders;
- that these are not trivial problems -- the blues or sweaty palms; and that they are not due to personal weakness;
- the need to seek help;
- and that effective treatments are available.

With depression and anxiety, the successful education campaigns are made somewhat easier for the public to understand because depression and anxiety disorders have homologues in normal human emotional experience. It is perhaps more understandable how difficult life could become if there were no relief from these feelings or if they lasted for an extended period of time or if they intensified to a point that enjoyment of life was no longer possible. All of us recognize these feelings some of the time; persistence and severity make them treatable illnesses.

With schizophrenia, however, the experience of the illness does not have a homologue in normal emotional experience. Hallucinations and delusions, which seem very real to the person having them, are completely foreign to those who are not. The closest many of us will come to this sort of experience is in our dreams or nightmares, where rules of logic, causality and sequentiality are suspended. But we awaken from our nightmares; people with schizophrenia live with theirs. Schizophrenia is a frightening illness; but it should not frighten because of a lack of understanding or knowledge about it. All that frightens us, frightens us more when we do not understand it; try to escape it by running away; or surround it with myths. Public education may take many forms. I, like many of you, speak in a number of fora each year. The problem with this kind of education is that it reaches only those who are in attendance -- a self-defined group of people who are committed to learn more about schizophrenia -- it is as the expression goes, "singing to the choir." We need a far broader base than that. The media can and has helped-- sensitive portrayals of mental illness, as in the Hallmark production of "The Promise," or the outstanding four-part series in the **New York Times**. Spot public service announcements in the media help. These should continue and expand. We have changed the smoking habits of a nation through just such work. But do we hold the potential to go further with a systematic educational approach

to effect change. For example, introducing the concept of mental illness into school curricula at an early age--teaching much as our research program has done for families--providing knowledge and capturing interest in mental illness and other illnesses at an early age and at every age. In this regard it is interesting to note that many have begun to comment about the inadequate science knowledge in The United States--we rank last in overall science ratings in a 14 country survey, and the area of poorest performance was the life sciences. Would we be too far afield to suggest that mental illness and its treatment represents a major and growing component of the life sciences?

If we cannot do this how can we expect society in general to understand our needs for a system of community services, for parity in insurance? Illnesses that are understood gain dignity; illnesses that can be overlooked, or at best misunderstood will be ignored and disparaged.

Hope: Ultimately, the greatest help we can provide families and patients suffering mental illness is, of course, a cure. Until then, however, we must be able to offer hope for the future. The current scientific results in many illnesses convey such an enthusiasm and the impact of this is important to note. With cancer, for example, the major change in the public's perception and the family's reality came when new treatments became available through research--adding hope to patients and families and early detection and treatment as a public priority. The frustrations of the field of mental illness are legion in this regard; shared by all who have been involved, but there is also reason to feel optimistic about the future. New treatments are developing--perhaps too slowly, perhaps currently insufficient to the task--but as long as we can continue to advance the pace of research on the science of the brain, our hopes will move toward a new reality--early detection, more effective treatments and ultimately a cure.

Anyone whose life has been touched by mental illness knows that the psychological state is a primary determinant of the quality of human existence. Paul, my patient whom I mentioned earlier, a few weeks ago told me how it was for him -- he said, "I feel like I'm a caterpillar in a cocoon, and I'm never going to be a butterfly." Many illnesses have the potential to influence lives, but perhaps none so much as the major mental illnesses. In addressing anew a universal problem attended by surpassing pain--for patients with mental illness, their families, and communities throughout the world--the challenge to us all is clear: to use the beacon of science, and the light of education to improve the human condition of suffering people everywhere. Paul should be able to emerge from his cocoon and be whatever he wants to be. Thank you.

Daniel X. Freedman, M.D.

Sam, you give wings to thought, and I'm sure you will be of help to Paul. You've painted a remarkable sweep in a carefully

crafted picture of what's really happening today. What we have done is to plan a panel of respondents. Each has been thinking about this problem and will have some response.

Paul Fink is a distinguished educator, psychoanalyst, not only past president of The American Psychiatric Association, but he has chaired three departments of psychiatry. His education extends to educating people in general medicine about mental illnesses. He is currently President of the Philadelphia County Medical Society, amongst his many other activities. With Dr. Fink's tour at the American Psychiatric Association, he energized and focused the Office of Public Affairs. Those who know him, and those who will hear him, will soon understand we would not, if he could franchise it, have an energy crisis in this country.

Don Richardson, a colleague of mine in Los Angeles, is a leading educator in our public school system there; and is a past president of NAMI at a very critical time in NAMI'S history; and currently is vice president of NARSAD. In my view and an observation of many of us, that he has been a major stabilizing force as the family movements have gathered such strength through time. He has received many honors in his home state and nationally. He and his wife Peggy have three sons, two with serious mental illnesses. I know that they value the efforts that they see from this group far more than all the special honors which Don has so richly received.

Jerilyn Ross, is President of the Anxiety Disorders Association of America. She is dedicated to improving the lives of these patients. She was trained in psychology at the New School for Social Research as a therapist, and is associate director of Roundhouse Psychiatric Centers in Washington and Alexandria. But what thoroughly caps this effort of hers is that since 1987, she's had her own Sunday award-winning radio talk show. Her dedication to improving public understanding, is clear in the fact that I think we can count over 100 T.V. and radio shows in which she has participated, including Oprah, Donohue and Larry King, and I think she even had Ted Koppel listening for once. We will start with the panel response with Paul Fink.

Paul Fink, M.D.

I am very pleased to be on this panel in particular, because Sam Keith's presentation is very important. Having had a chance to read it and then hear it I think it has enormous significance. First of all I would want to say to Sam that although charisma can't be replicated, it comes in many forms and the poignancy of your presentation was extremely charismatic. We are very lucky in psychiatry to have Sam Keith.

How can anyone understand the disease who hasn't experienced it? I recently finished reading William Styron's book entitled "Darkness Visible" in which he says exactly the same thing.. "No one

can understand depression who hasn't been at the depths of their life feeling as awful and as terrible and as much despair as he felt." Similarly, Sam said, "Schizophrenia is a frightening disease." It is truly a frightening disease and perhaps that's one of the most critical explanations of why it's so hard to dislodge the negative stigmatizing feelings and attitudes that we have about this illness, words like tormented, frightened, in despair. The mind is altered; behavior is incomprehensible, and the family is changed forever.

Last week, at Einstein Medical Center where I work, we had a Mental Illness Awareness Week presentation with Lionel Aldrich talking about his life, having survived schizophrenia. During one part of the program Loretta Ferry, president of the Southeastern Pennsylvania NAMI chapter, who, for 20 minutes, held 400 people in the palm of her hand by talking about the extraordinary experience of her son's illness. This speech was peppered with one phrase, "Where is the little boy who once was in my home?" Her son, now in his late 20's, is very difficult for her and her husband to work with and understand. The other four children are fortunately successful, but they have gotten very little attention over the last 10 years, from parents whose lives are wrapped up in trying to deal with a complex and difficult illness. "Where is that little boy?"

In Dr. Keith's address, he talks about the private reality of the family, the child, the sibling, a loved one changed and lost. The question that every family has is, "Is it forever?" The self recrimination, the guilt, the shame, the misunderstanding have been mentioned already by a number of people. The importance of this paper to me is that Sam Keith brought back the idea of a biopsychosocial approach and understanding of this illness. Not just a brain disease but a disease that involves every aspect of the person's life. He talked about the emotional impact, the stressors, the affective styles, and the possibility of positively changing the course of the disease through psycho-education. Most of us don't think about that. Clearly, the graphs show that it works, and it has enormous power. What is important is that we leave this room and see to it that it is replicated all over America. Will that happen? Will we be able to take a concept that is already well on its way to being proven and make it into something that is a critical and essential part of the care of schizophrenic people?

Sam talked about the education of patients, families and societies. I want to add the education of professionals. The education of mental health professionals is critical. What I have discovered over the last 10 years is that everybody in this room in a little way, in a small way, is prejudiced against the mentally ill. I have received an enormous number of letters from people prejudiced against the mental health system. A very moving paper which will appear in a new book on stigma by Esso Leete describes

how she went to the hospital feeling terrible, mute, speechless, and despairing. She sat on the litter very quietly waiting for someone to come and talk with her. Four people sprang out to bind her limbs to the litter. She had not said one word; she had not moved; she had not indicated anything about violence.

The last decade has witnessed empowerment in a number of ways and certainly psycho-education is the essence of empowerment. The empowerment of families and the empowerment of consumers has occurred through the family movement and through the consumer movement. Last week when I introduced the speakers at the Lionel Aldrich meeting, I told a story. Three years ago at our Mental Illness Awareness Week meeting, one of the consumers in Philadelphia came up and said, "We want to be on your program." Given my not large, but reasonable prejudice against the mentally ill, and assuming that he would ruin my program, I said, "No, you can't do that. The program is fixed. We've printed the program. There are too many people, and it's too crowded." He said, "O.K., well we are going to picket your program." I said, "You wouldn't picket my program, why would you do such a thing? It's not a nice thing to do." He said, "We're going to picket your program. If you don't put me on that program, we're going to picket the program." I said, "O.K.!, We'll put you on the program!" It was not difficult to convince me. He was so magnificent. He was so important to the program. His five minute speech was the highlight of the program. It was just marvelous.

Since then, there has been a consumer on every one of our programs, and last week, when Mrs. Carter came to grace our Mental Illness Awareness Week program there were several consumers on the program and it was marvelous to know that people recover. People get well and the hope that Sam talked about is critical. And now, a treatment method using families to enhance patients into cooperative modes of behavior and which empowers both the patient and the family, I believe is the most important next step that we can take in making Sam's vision of schizophrenia come true. Thank you very much.

Daniel X. Freedman, M.D.

Don, as an advocate, consumer and leader would you please address this audience?

Don Richardson

Thank you very much. Mrs. Carter, it is a real privilege to be once more at the Presidential Center with you and these wonderful people. Being the parent of one son who has been diagnosed as having schizophrenia for over 25 years, and then five years later having our youngest son diagnosed as having schizophrenia, has forced my wife and me into a role of self-help. There is a growing awareness in these United States that has been focusing on the mentally ill and bringing about the hope that Dr. Keith mentioned so often this morning. I think I've died and gone

to heaven when I hear the encouraging comments of very distinguished professionals such as Sam. I think the portrayal of the involvement of families with the professionals as a part of the treatment team is very, very encouraging.

Mrs. Carter's support of this movement and the role that many in the audience have played in the basic changes in the professional and family's relationship over the last 10 years, makes me be very proud of being a part of the National Alliance for the Mentally Ill. This movement is just 10 years old this year. I've tried to be a leader in bringing to the public and the professionals the pain and the problems and the concerns and the priorities that families have when trying to take care of their loved ones.

Four years ago, when I was President of the National Alliance for the Mentally Ill, NAMI joined many of you in the audience in highlighting that very serious problem of the substance abusing mentally ill folks in our midst. The scourge of the drug problem in America was certainly being highlighted at that time. As I reflect over the past 5-6 years, I see a tidal wave going across the United States that's bringing to the attention of all of us that we cannot have an either/or attitude toward any individuals. A person cannot be looked at as a mentally ill person or a substance abusing person, and ignore the fact that many, many, many of our folks have both problems.

This morning, I'd like to highlight another priority that I think we need to spend a lot of time on. It's not a popular topic, but families who have mentally ill relatives, experience a never ending concern relating to the ill member's potential or actual alarming behavior. I feel the need to highlight a priority that is not currently talked about. And that is the fear or the potential of violence with the mentally ill.

Mrs. Carter mentioned how we can use the media as a beautiful example of creating stereotypes and fear. I think we need to understand that it is time in our movement to start talking seriously regarding the causes of this fear. I am very concerned regarding the lack of support, the lack of treatment, the lack of budgets that will provide these things that we need if we are going to have a successful community living among our ill relatives. I would like to suggest that we talk about the concerns and the problems of living with a severe and long-term mentally ill person who may display some potential violence or actual violence, I think we need to talk about it, and stop sweeping it under the rug as if it does not happen.

I'd like to encourage professionals to work with families as partners in finding better ways to prevent or diffuse potential violence. I support and advocate for research that would provide a better understanding of the biology of violence as well as the

biochemical dysfunctions of the brain. I have asked NAMI to take a leadership role in finding what the real world is like within the ranks of its members regarding the fear or the concern or the actual prevalence of violence.

Many of my colleagues have been concerned about the openness that my wife and I have been a part of in the whole area of needing to talk about the violence or potential violence or the fear of violence. Every survey that I have seen or that I have been a part of and Dr. Agnes Hatfield, the past President of NAMI, has also found that there is an underlying fear of what might be perceived as violence when they are asked, "What is the major cause of stress in your family?" And if we don't talk about it and come up with some statistics and some actual factual material, this underlying fear is going to be a constant basic concern with families who in turn will be afraid to talk about it because we realize that one of the most prevalent reasons for the general public to reject the mentally ill is because of the fear portrayed by the media, portrayed by the literature, and not talked about by the families themselves.

So I am taking advantage of the few minutes that I have this morning to make this point. We did well when we raised the topic of the "either/or," the syndromes of mental illness and substance abuse. We have talked about it; we have not ignored it; and I think we are beginning to come to realistic and real solutions to many of these dilemmas. If we talk about the illness, and the potential violence, I think we must be careful not to sweep everybody with the same brush. I think it's essential that we help each other to identify what causes the assaultive or the threats or the actual abuse. There are reasons, and as we identify those reasons, we can help families to live more comfortably with the fear that may be there. We can help each other to prevent, rather than have to act after something has hit the newspapers.

So I guess my main message here is that we have a lot of hope. I think basically as I review the past and my fear of what might happen with my two boys, I don't have that fear any more. I know that there is a treatment modality. I know that with the proper support, my two sons can live in the community successfully. I know with the proper awareness of the medication, they can be stabilized to the point that their usual and wonderful true selves can be displayed at all times. So I can't help but think of my own attitudes with the hope that was brought to us this morning, with the involvement that I have had the privilege of working with many of you, I can't help but think back to the fact that one time "fear knocked at my door and now faith opens that door. And you know what? There is no one there." Thank you.

Daniel X. Freedman, M.D.

Every time I'm with you Don, we learn more and it's useful. Jerilyn Ross, would you conclude this panel's presentation? I know that you are the one person in this room that professionally knows what a clock is, and I appreciate that too.

Jerilyn Ross, M.A.

It is a great honor and privilege to be here this year, Mrs. Carter, as it has been in past years. And I feel particularly honored to be part of this distinguished panel today.

While listening to Dr. Keith's excellent presentation, I was struck with how -- although we make great strides in educating consumers, their families, the public in general, and mental health professionals about recognizing and treating mental illness -- we fall way behind in educating health care professionals and gate keepers outside the mental health field. The patient with an anxiety disorder, for example sees an average of ten health professionals before getting an accurate diagnosis.

I have a weekly call-in radio show in Washington, D.C. where, even though I regularly inform my listeners that I am not an M.D., I am constantly deluged with callers with mental health problems wanting me to diagnose their conditions over the air and answer questions about the medications, neither of which, of course I will do. When I ask if they have discussed these problems and questions with their doctors, they answer they are too embarrassed or afraid to talk to them about such things or that, when they do bring them up, they are either dismissed or given an unsatisfactory response. Often these people talk about having been sent to one specialist after another to seek an explanation for their "symptoms" -- cardiologist, endocrinologist, neurologist, gynecologist, and so on -- but not to a mental health practitioner.

Even in the work place, where special employee assistance programs are set up to deal with mental health issues -- with the exception of drug and alcohol problems -- most mental illnesses are neither recognized nor adequately addressed. If the counselor hears the word "stress" -- a "safe" buzzword an employee will often use to mask a more serious problem -- he is likely to send the employee for relaxation training or suggest beginning an exercise program. But the disorders that we are talking about today: schizophrenia, major depression, anxiety disorders, are often overlooked or not recognized for what they are. And, thus, these people remain in the dark and in need. In many cases, people with serious mental disorders suffer in silence and neither reach out nor are reached out to.

I must disagree with Dr. Keith's assertion that healthy people cannot relate to the schizophrenic experience but can relate -- and therefore understand -- anxiety disorder or major depression. We all know what it is like to feel anxious and blue, but those

feelings have very little similarity to an unprovoked panic attack or suicidal ideation experienced by a panic disorder or depressed patient.

Willard Scott of NBC's Today Show, a member of the Board of Directors of my organization, has experienced terrifying panic attacks while on the air and struggles every day with the morbid fear of having another. He testified with us before a Congressional Committee several years ago. When Congressman Henry Waxman said, "Willard, I know how you feel; I too, sometimes get anxious when I'm speaking in public -- I get butterflies in my stomach," Willard quickly responded by saying, "Your Honor, comparing getting butterflies in your stomach while speaking in public to a panic attack is like the difference between someone tickling your arm with a feather and having your arm cut off with a machete. If you haven't experienced it, you cannot understand it."

ADAA's efforts in using the media to reach the public with accurate information about mental illness have proven very fruitful. It has been my personal experience that, in addition to aiming for the top media outlets or ideal story placement, using second - or third - line outlets and opportunities can be very beneficial. Opportunities that our initial instincts might tell us to reject can be turned around to become advantageous. For example, every Friday the 13th I receive at least a dozen calls from reporters wanting information about Triskaidekaphobia. After providing some historical background, I go on to relate an anecdote about a patient whose superstition of needing to touch things in a certain way so greatly interfered with his life that he became non-functional. Then I emphasize that, after appropriate treatment, he went on to live a normal life. Or I tell of a mathematician who was not able to work because he could not look at, write or say the number nine without having a panic attack. He received help and went on to become successfully employed.

At first these examples may sound trivial -- even comical -- but they are neither. And relating them to a writer provides him with the opportunity to focus on the seriousness and treatability of a given mental disorder.

When the movie **Arachnophobia** came out, my initial instinct was not to respond to the reporters' queries out of concern that they would use the opportunity to sensationalize and trivialize people with animal/insect phobias. Instead, I countered this possibility by saying to the reporter, "Wait a minute -- it's perfectly normal to be afraid of a killer spider, but millions of people are so plagued by irrational and inappropriate fears that they are unable to function without treatment," and once again I took advantage of the opportunity to let people know a phobia is a serious disorder that can be treated.

After dinner last night, I spent an hour on the telephone with a **National Enquirer** reporter who is writing a story on panic disorder. In spite of the newspaper's reputation and style, the fact remains that millions of people read it. I would rather take the time to provide such a reporter with accurate information than to allow him to write his own version. I believe we should take advantage of every opportunity to educate the public, even when it calls for turning lemons into lemonade.

We are very fortunate this year, as Dr. Keith mentioned, in that the National Institute of Mental Health is sponsoring a national education program on panic disorder. This follows on the heels of NIMH's successful public education program on depression (DART). Our hope is that these efforts will extend to public education programs on other mental disorders as well. And, I hope the work that has been done involving the families of schizophrenics in treatment and educational programs will be extended to other areas of mental illness.

I want to conclude by saying that this is certainly a very exciting time in the mental health field. During the past decade we have learned a great deal about how to effectively treat many of the mental illnesses which previously went undiagnosed and untreated. When we talk to the media, we should now begin to focus not only on how terrible these disorders are but on the fact that effective treatments are available. It is important for us to generate this kind of optimism so people will be more encouraged and inspired to get the help they need and deserve. Thank you.

Daniel X. Freedman, M.D.

Sam, thanks very much for what you have done, and to this distinguished panel for the thoughts you have planted. I think discussions should take place in the hallways now with a brief coffee break. We will resume at 11:00. Thank you.

We now move into the next phase of the program, "Family and Mental Illness: the News Coverage Connection." We have as our moderator of this distinguished panel Everette Dennis, who is the executive director of the Gannett Center for Media Studies at Columbia University. It is a pioneering venture, kind of a think tank for the media. He has been an educator in journalism for a lifetime and a distinguished one. He has taught in major universities in the midwest and was Dean of the School of Journalism at the University of Oregon. He has spawned some 11 books and three more are in press and I am going, to turn the program promptly over to you, so that this panel and the audience can have the kind of interaction you planned on the topic of "Families and Mental Illnesses: the News Coverage Connection."

Everette Dennis, Ph.D.

Dr. Freedman, thank you very much. What we are talking about here this morning connects with Rosalynn Carter's earlier remarks

about stigma. Stigma has been a theme throughout these symposia over several years. It is something we can probably never say too much about, however this morning I think there is something of a new wrinkle.

Some of you may think that to talk about families and mental illness on the one hand and news coverage thereof on the other is something of a mutually exclusive concern. You might say, "Well, mental illness within families is something that is pervasive throughout this country and something that everyone has experienced in one way or another." And yet we don't hear about it or read about it very much in the news media. At first glance, that may seem to be true. But in fact we do hear about it. We hear about it sometimes in coverage of family mental health services and activities, relatively little of that, but we do see some kind of coverage. We also hear about it in the coverage of news, such as when mental illness and the role of the family is connected with an untoward incident of some kind, such as a murder or other violent crime. Such a bizarre incident occurs and people say, "What was that person like?, What was their family like?" And you know those stories only too well.

Today on this panel we have some very distinguished and knowledgeable people -- people who know what they are talking about. Some panel members are going to address you as news sources who happen to be mental health professionals, while others are news people who have covered mental health as a news story. So we have a variety of news sources here talking about our subject, "Family Mental Illness: the News Coverage Connection."

Let me introduce the members of the panel and then move into a discussion of a number of questions I hope will start a conversation up here at the table that will extend into the audience very quickly. Please feel free to interrupt if you'd like to ask a question. Or you can hold your question until the panelists have made some brief remarks. Don't be hesitant at all about asking questions; you don't need to feel this is a closed seminar up here. A good many experts are also in the audience and we would like to hear from you.

To my immediate right is Dr. Carrell Dammann who, as many of you know, is a clinical psychologist and a leader in the field of family therapy and family therapy systems for some 20 years. She was a founder and director of the Atlanta Institute for Family Studies from 1977 to 1989 and in May of 1989 she started Open House, a place for family healing, a program very well received here in Atlanta, and elsewhere in the nation. She brings to us her background as a clinician, a clinical psychologist, and someone who knows this subject very well.

Monica Kaufman is known to all of you as the anchor at WSB Television, where she does the 5 p.m., 6 p.m. and the 11 p.m.

Action News. She has been on the staff at Channel 2 since August of 1975. Before that she worked for four years on the Louisville Times, and worked for WHAS TV in Louisville as a reporter and as an anchor. She is a much honored member of her profession, having won several Emmys and other awards.

John S., "Jack" Langford is the Senior Judge of the Superior Courts of Georgia. He is, as another of our speakers this morning is, a graduate of Emory, not of the medical school but of the law school. He has been a full time trial judge for 24 years, including five years as a judge of the juvenile court. He has been -- and I think this is a very significant datum you might want to remember -- a trial judge and a decision-maker in approximately 18,000 family law cases. That's a lot of cases, and a lot of knowledge. He is very well-connected, involved in the National Judicial college, the American Academy of Judicial Education, and several other important organizations.

Steve Smith is a broadcast news executive with Gannett Inc. here in Atlanta. Prior to that assignment he was, for several years, the vice president and news director of WXIA TV in Atlanta. He has been an assignment editor for ABC News, and worked with WXIA prior to that time. He has worked with WSB radio in Atlanta, in Fort Meyers and Naples, Florida. He is also a winner of several Emmys and a person who has not only covered the news as a reporter but given the assignments. He decided what was news in everything from Hurricane Hugo to the Mandela visit, to the business of the child murder cases in Atlanta.

Rona Schpeiser is a social worker, who until recently was the assistant executive director of the Jewish Family Services here in Atlanta. She has been in private practice for many years, and had worked in the mental health field in several states, including New York and Massachusetts. She brings the view of a distinguished, psychiatric social worker.

So we have a panel of knowledgeable experts who are going to have something to say to you in just a moment. I want to share with you, since you should be in on the whole conversation, the memo I wrote to them, which was a kind of a test. I guess I thought I was a teacher again and I would test them on a few questions. So here are the questions I asked. You be the judge as to whether they are answering them appropriately and responsively and then we might just give them grades at the end.

To begin with, I asked them "To what extent if at all, are the problems of families coping with mental illness reflected in the news media? Are we getting coverage at all, and what is it like?" I also asked, "Is the portrayal accurate and representative, or is it misleading, biased and otherwise skewed? Is there a particular example from their own experience some of us here might have known about or read about that provides a very good or bad example of coverage of this problem? Further, in the case of an

incident involving a mentally ill person, should the psychological state of the family be an issue in the news coverage? Who are the best and most appropriate sources of news and information about mentally ill individuals and their families? Are these the family members themselves, their neighbors, therapists, law enforcement officials or other persons? To what extent are the best sources of information accessible and cooperative with the news media? How many of these people representing the mental health field or the legal profession are cooperative as sources of news?" This is something we might want to ask Steve and Monica.

I also asked them, "What barriers do mental health professionals present to the media, barriers such as confidentiality of material? What in your estimation constitutes ideal coverage of families coping with mental illness and how would you diagnose the present state of media coverage in the print press and broadcast media?" While it is going to be difficult to cover all these questions in a brief period of time, you be the judge of how responsive the members of our panel are here this morning. I am going to begin by asking Carrell Dammann to comment.

Carrell Dammann, Ph.D.

Well I would like to take an opportunity to say how truly appreciative I am to Rosalynn Carter and others for the focus on the family of the mentally ill this time. I have been to this conference for several years and I am very gratified to see that as our subject of focus. One of the things that I would like to comment on, because I think it is quite relevant to what happens in terms of the media, is that any time there are problems or difficulties of any kind, one of the most human responses is to try and assign blame. And unfortunately in that process, there is a process that takes place in interpersonal networks where the blame begins to create splitting. This splitting can occur within families, between family members, and between family members and the treatment community. What feels very hopeful to me today about the issues that we are talking about is the coming together of the community to combat that splitting process. I think that the media certainly has an important function and role in this process, in helping us to come to this as a community.

In the early days of family therapy, I was just reflecting on this as I was listening this morning because it seemed very relevant to me that one of the earliest kind of innovative, experimental ideas was initiated with families of schizophrenics in Philadelphia by Ross Speck and Carolyn Attneave who is an anthropologist and had worked with tribal studies for many years. What they did was to bring together not only the family but they developed something called network therapy. Where they would involve not only the family but the community. They would do things like bring in the milkman and the postman, people who had frequent contact with the family and with the problem, to try and build a support network.

Unfortunately, very often when attention is drawn to a mentally ill person in our society, it is at a time of crisis, the breaking of a news event that is sensational or is frightening, which calls in the focus on that issue. That of course is the most untimely way for us to try and provide full information and to respond and do something in an educated way. I think the fact that we are focusing on this and talking with each other about it will enable us to perhaps cooperate more fully to recognize some of the problems and to learn some ways to anticipate them. But because that often happens in a sensationalized way, it very frequently initiates splitting and blaming and looking to lay blame or cause. And I think that one of the things that is most important for the media is to try and get information from as many sources as possible. Unfortunately, the focus that gets the information out is usually going to be at a time when the least information is known and there is not access to that information. So that the information that comes out is often very incomplete and by the time there is a fuller understanding of the incident or what is happening the news media has moved on to other events and we lose our chance to educate.

I have been very much aware today that many of the families who are here who have mentally ill members were talking about "My husband or my wife and I have struggled with our children." One of the factors that I did want to comment on today, because I think it hasn't been commented on, is that one of the images that I think often emerges very quickly is a false one. The reality of the "normal family" in our society today is no longer an intact family. Only 16% of our families are intact families with both parents and the children living in the same home. The majority of our families are now single parent families. And often one of the images that we see emerge very quickly when there is an incident, is that of a mentally ill person who is from a broken home. And the reason I wanted to come and focus on that is that we then automatically attribute it to a problem in the family and blame it on the family. When we talk about blaming families, let's be very clear what that most often means is not blaming families; it's blaming mothers. For the most part, the theories that emerged were schizophrenogenic mother, not the schizophrenogenic family. We minimized the fact that we give to the women in our society most of the caretaking functions in the family and that means when something goes wrong, they are often the ones who are considered at fault.

Let's look at another statistic which is that one of the highest divorce rates in all of our statistics is in any family which has an exceptional child of any kind. The fact that there is a child with an exceptional kind of problem or disability imposes severe strains on families. All families struggle with a variety of issues and certainly with parenting issues. The extra strains placed on a family by having a child with some kind of developmental disability increases the pressure, increases the

tension. And very often, our helping systems feed into that problem. Again, it was mentioned this morning that we must not take this mandate to work with families as partners as an opportunity or an excuse to put the care of significant problems back on the family. But that often happens, and more often than not, that care is given to the mother which places demands, and puts strains on the marriage. So I hope that we can be mindful of the ecology of the impact on the entire family system and the care giving network, and that issue may get looked at in the media as well as some of the others.

Monica Kaufman

The problem with giving television reporters any amount of time is that we usually deal with one minute and 30 second stories. And, we are seldom allowed to give our opinion. So, when Dr. Dennis said "You have five minutes to expound," I think I got carried away at my typewriter. But, I hope I have some information that you can use.

Shots rang out in crowded Perimeter Mall here in Metro Atlanta. People dived for cover, but five were felled by bullets, one dies. The gunman is caught, slowly leaving the mall. He actually surrenders. It is later we learn, that the gunman is a recently released mental patient. The story was the shooting the first day, and then the story was the shooter. His story was told through his court hearings, and subsequent reports on why had he been released from a hospital, particularly when he had said he wanted to kill someone, voices told him to. But also, the story was told through his family, who spoke freely of the problems they had had getting him the help that he needed, keeping him hospitalized, keeping him on his medication. They also questioned "How had he been able to buy a gun with his history of mental illness?"

Far too often, this is the way that we in media examine mental illness -- when it is part of a crime. But seldom is the family involved as this family was. Usually, we just show you the family sitting huddled in the courtroom stressed and in tears. But we at Channel 2 have decided we need to look at mental illness in other ways too. A three-part series by our health reporter Diana Davis won some major awards. She looked at schizophrenia through the eyes of the patients, their families, the communities in which they lived. The reports put a face on the illness. It showed families coping. It told why sometimes they must let others care for their loved ones - not out of a feeling of "I don't want to deal with this anymore," but out of a realization they aren't really trained to deal with it. There was a look at independent living for patients. There was a look at shared living, and there was an attempt to get rid of the guilt and embarrassment many families feel because their child, their mother, their father - a family member is "crazy."

Next month, Diana receives another award, a national award for her three-part series on depression that ran just a couple of months ago. The report showed the debilitating effects of depression, that can occur at any age. Sufferers talked about how paralyzing the illness could be. The subject was a woman, middle class, that any viewer could relate to. But it's also important to talk about the homeless person, and that's a little later. But anyway, the woman profiled about how depression can paralyze a family, particularly children. The reports told people not only how to recognize the blues in its severest forms but also how it is treated, sometimes with medicine. The report also detailed what to do when it hits in its milder forms. It also gave phone numbers and addresses of who to call when you need help.

Many years ago, when I got into this business, I remember trying to talk a news director into doing a report on depression. His reaction was, "We can't do a story on depression; it's too depressing!" The audiences reaction to a series on depression was a real concern. Well, today's news director believes in "news you can use." So, he or she is aware that people are interested not only in their physical health these days (working out), but their mental health.

Even before the depression series, for the last six years, Channel 2's Public Affairs Director, Jocelyn Dorsey, in cooperation with the Center for Mental Health has co-sponsored what's called "The Depression Hotline." It opens every December eighteenth, goes through December twenty-sixth, and is open from the hours of 6 p.m. to 9 p.m.. It's an opportunity for people, who are just not enjoying the holidays because the holidays get them down. The hotline provides someone for them to call, someone to talk to. It's a phone call away, help. All of this is heavily supported through well-produced public service announcements, so people get the word.

When we examined Alzheimer's Disease in a series in the 6 p.m. news, an hour long special in prime time and a half hour telephone show at 11:30 after the news, we also put together a hot line. We put together pamphlets. We also brought together resources that got a day care center for Alzheimer's patients. This place gives patients a break from the home, some fun therapy. But more importantly, it gives a respite to those family members who were dealing with this 24 hours a day. Families told their stories. They let viewers see what it's like to live with an Alzheimer's patient. Our camera people, and our reporter lived with the family so that you could learn what it was like. But there is more in the works. Jocelyn, on her **People to People** public affairs show will feature Compeer/Atlanta. It pairs professional volunteers with mentally ill patients. These volunteers become friends. Call it a new form of the Big Brother/Big Sister program. We got into all these mental health issues because of a health reporter who keeps her ear to the ground; because of a public affairs director who

listens when viewers call because of those viewers who called and suggested ideas and complained when they felt that a news story had not appropriately addressed an issue -- and then, because of the cooperation of mental health professionals, we educated a lot of people about Alzheimer's and got help for others.

There are times when in criminal cases, information cannot be divulged, particularly patient information, because it is confidential. But we've oftentimes found that families who are comfortable with the situation will provide us that information because they don't want the story to be sensationalized. They want to put a human side on the story, to say, "This too, could happen to you." It also helps that each year during Mental Illness Awareness Week a list is sent to the media. On that list are the names of the eleven psychiatric hospitals and their administrators and marketing directors as well as the names of six mental health organizations and associations. These people make available to the media, family health care professionals and patients who are willing to talk about various aspects of mental illness, so as to de-mystify it.

Again, stories are best told through people who are affected, not just those who work with the mentally ill. That's why for better coverage, families need to be able to remove "the veil," be willing to open up. When the legislature considers, for instance, cutting funds for the Central State Hospital in Milledgeville, families should be the ones along with the administration of Central State to talk about what happens if the staff is cut. What happens to the people who are there? What kind of burdens would be put on the family? And, how much harm would it do to the client, the patient?

When homelessness is looked at, we should remember that the homeless are not just the working poor, but sometimes they are the de-institutionalized mentally ill. That should spark a discussion, not only on the air, but in editorials, in letters to the editor, in just plain discussion about homes, group homes, what they accomplish, what it means to the patient and to the family. But then we have to deal with the "bugaboo" that nobody wants a group home in their neighborhood. But maybe they would, if they saw one. Maybe they would if they experienced one. You don't have to give the home address, you can just show tight shots of the house, the interiors and sometimes you don't have to show the exterior if you don't want the neighborhood to get upset. But I am a firm believer in the best way to show it, is up close and personal. Pull out neighbors, talk to them about what it's like, if they have even known the difference. We did that and surprisingly, some neighborhoods said "We didn't know it was there." The point is, if people get to see it, and talk to the people who live around it, it's not scary. We fear those things we don't understand. We fear those things we don't know.

There is another way the media provides a voice for the families and health care professionals who work with the mentally ill; there is editorial opportunity in what we call "free speech messages." Now sure it's only 30 seconds to 40 seconds, but it's better than nothing. You'd be surprised how many people don't take advantage of those, and they don't just run at 2 a.m. They run during good news segment times too. Also there is something at our station called "Here's to you" where volunteers, ordinary people doing extraordinary things, are profiled. It is time for mental health professionals and families who have a volunteer who works with them to send in those names. Again it's getting praise for the person who does the work, but it is also educating viewers about mental illness. There are radio talk shows; you know, all-news radio, all-talk that needs to fill time. But again, the mental health care professional should be paired with a recovered or coping person and a family member. More fodder for discussion.

The treatment of mental illness as it relates to the family on daytime talk shows, far too often, concerns subjects that could be classified under a very broad definition of mental illness. Examples are bulimia, anorexia nervosa, fear of flying, stress, battering, pedophilia, suicide, kleptomania, paranoia. Sometimes, because these are titillating topics, they become titillating topics rather than illuminating topics. But that is another discussion for another day.

The bottom line to all my remarks is this: We in television news do our jobs well when we tell the viewer how they are being affected by the story. When we tell them the story through the people who live with the problem daily and cope with the problem daily and survive it daily. We tell the story best when media, the families and mental health people work in concert, remembering the rights of the patient and the public's right to know. Remembering, if it's told well, in the end we all benefit.

Judge John S. Langford

I work in the court system. The court system is not on the cutting edge, essentially, of mental health issues but is the place where such issues eventually wind up for adjudication or sometimes hoped for resolution or interpretation or whatever else a relief might be sought.

Nearly one-half of the cases handled by state trial courts is essentially intra-family litigation - either dissolution of the marriage relationship, litigation over status or assets, custody disputes, juvenile delinquency or neglect issues, or intra-family violence issues. Family failure and family dysfunction are major problems presented to courts. Unfortunately, such court matters are almost universally handled in mass production style, without casework services, through an adversary process. There is considerable support for the position that the adversary process may not be the appropriate method for adjudication of family

failure/dysfunction disputes.

The legal system is not on the cutting edge of progress in the field of mental health nor any other field. Matters generally only make it to the courts some months or some years after developments or taking of positions or studies or factual situations. However, issues in the process of developing are quite likely to eventually wind up before courts for some form of adjudication - the trial courts trying the factual disputes and the appellate courts providing evolution of the law and changes in the societal rules. Problems of the "rich and famous" (and also infamous) disproportionately are likely to wind up in the courts and thereby in the media, it being the general attitude that anything in court is public property, subject to open hearings, open records, and unrestricted media comment. In many situations, the personal devastation experienced by parties may be compounded in the process of litigation. The stress, the publicity, the disclosure of matters, generally regarded as being private, may cause and frequently do cause a heightened degree of anxiety, depression, etc.

Within the legal system, there is some inherent conflict of various well-established rights. For instance, an individual's right of privacy comes in direct conflict with freedom of the press or the right of the media access to whatever matters wind up in the courts. Once a dispute goes to public trial, the right of privacy virtually disappears. Further, in some situations, media publicity prior to trial may interfere with the ability or likelihood of fair adjudication of issues presented.

While there are some matters which are generally regarded as "confidential", such as communications between psychiatrist and patient or between husband and wife, these confidential protections generally erode or evaporate once the matter is in litigation. In many instances, the claiming of confidentiality simply whets curiosity of the media seeking to know the information.

The legal "system" (or more accurately perhaps "non system") functions primarily to regulate conduct. The mental health "system" functions to understand conduct. Both deal with human conduct, but each approaches that conduct from differing points of concern and inquiry.

Overall, in a free society, we are more likely to agree on what is "unjust" than what is "just." Similarly, I suggest that, overall, in a free society, we are more likely to agree on what is mentally unhealthy than is what is mentally healthy.

Strangely enough in our society, once we express the feeling that something is "confidential", that not only arouses curiosity, but also seems to impose "stigma." Conversely, something that our society seems to impose or tolerate a "stigma" upon seems to

generate more jealously guarded "confidentiality." It might be, therefore, that to eliminate or reduce stigma, one of the things we need to do is to make all matters more open, construing nothing to be shameful or embarrassing or sensitive. This, however, would be a major departure from the way civilization and human relations have evolved up to this point.

Steve Smith

Monica and I did not plan this, we didn't even discuss that we were going to be here together but my theme is pretty much the same as her theme. It is to remove the stigma of mental illness in whatever form it happens to be, whether it's drug abuse, psychosis, schizophrenia or whatever. It takes people who are willing to openly discuss it, and openly discuss it in forums as open as television news, out there for the whole world to see. It's one thing to do it in a closed room and I know that personally, both as a father and a husband and a son of someone who is distressed by this. It's a very difficult thing to talk about; it was something that I probably would not have talked about to anybody, much less on the 6:00 news. My job is to try to get people to talk about all sorts of outrageous things, or personal things on the news media, and that has changed over the years and I think that my feeling about that has changed in a positive way.

The willingness of people who are afflicted by such diseases and their willingness to talk about this very publicly removes the stigma. There was a time when people wouldn't talk about certain other forms of disease, whether it would be cancer or heart disease, or whatever, and that has been overcome. I have seen that overcome in folks who have children; and some close personal friends have a child who has Down's Syndrome which, I guess is not classified as mental illness, per say, but at least it's a very difficult thing for a family to deal with. Yet they have been very open in talking about that both on our news, and I think in fact on Channel 2 news, as have many other people. And it has begun to remove the stigma of that.

I think discussion, open discussion, helps to make people more comfortable. And it also makes people realize when these folks talked about their problem others realized that, "Hey, I'm not alone." You may live alone with whatever it is. You may think about it constantly and it may be a very serious personal situation. But once you begin to talk about it a little bit, other people talk about it and you realize that, "My gosh, this affects more people than I ever thought." And again, as Judge Langford said, it does tend to change the definitions, just a little bit, of who has it, and what it is, and what it really means.

As a journalist, I know that we do cover things that are sensational. The Perimeter Mall shooting of course is one of the most sensational things that we have had to cover recently. I think it helps both the audience and it helps us as journalists to

perform our responsibilities more effectively if in the continuing process, it becomes a little bit more commonplace to discuss these things. Then it doesn't seem quite so sensational, so outrageous, and maybe it is a little bit easier to understand. Even though, it's not right, it's extremely troublesome and detrimental, but I think it makes it just a little bit easier for all of us to understand. So I would encourage you, and I also would be interested in the opinions of those of you who disagree and feel it inappropriate to talk about that.

From our perspective, I would encourage both those of you who are practitioners, and those of you who face the problems yourselves, to discuss it more openly as you become comfortable. I think that makes it better for all of us in the long run. That would be what I really think is the most beneficial thing relating to the media as we cover this story.

Everette Dennis, Ph.D.

Steve, thank you very much. Rona Schpeiser, please.

Rona Schpeiser, M.S.W.

It's difficult to be the last person on a panel that has covered the topic exceptionally well, but I want to thank Rosalynn Carter and the people in charge of this program for inviting me, a long time social worker and advocate, to participate. I think that social workers need to be advocates as well as therapists. I think that we were, although some of us forgot for a while, and now some of us are coming back. And that way, we can be more supportive of the media in reporting on the things we know so well.

I've seen heads nodding as people talked about confidentiality. It is very important not to give out names and identifying information about people, but we can sure talk about the problems we know about very well without hiding behind a cloak of confidentiality. I think that is part of our job as advocates, and maybe the job of everybody in this room who has had the opportunity to hear what we have heard so far in this conference.

I think if I had only one thing to say, it would be that my concern is about divisiveness on issues. I get concerned when people say, "What programs are we going to give money to, the elderly or youth?" I've read a lot of columns about that recently. Do we really expect families to choose? If I have an elderly, depressed parent it is going to impact my whole family, my children, my husband, and me. If I have a depressed child, it's going to impact the whole family, my husband, the grandparents, uncles and aunts. So, I think it's unrealistic to be asked to choose and yet I think part of this comes out of the cutbacks in mental health in the last ten years. And the focus on the "L" word, if you are a liberal you are a bleeding heart and you want to help everybody, and everybody knows there is no money for that and so everybody incorporated that message. It began to be, "We'll

only fund one thing, schizophrenia, homelessness, drug programs; we have to choose." I have real concerns about the priorities of society. It says to families and to its citizens that it is O.K. to choose, and it's O.K. that you are going to leave some people neglected because you have chosen to help the homeless.

You know the homeless are not a single phenomena. It's very interesting because we get on band wagons. The press gets on band wagons, the funding sources get on band wagons and we all want to help the homeless. I certainly participate in wanting to help the homeless, and do... but what leads to homelessness and what funding do we need to prevent homelessness? Funding for housing, and funding for the mentally ill, and funding for education and funding for research and jobs. What are we doing?

So you see it's troublesome if we try to be divisive, rather than coming together. One of the things that we say all the time is, "No one wants to help people who are different than they are. It isn't my problem." In the last 10 years we have really focused on the survival of the fittest. "People need to be strong, take care of themselves, and they are not my problem," although there is stress on the need for volunteers. You tell me, who wants to volunteer when what's communicated is..."These are worthless people who aren't helping themselves?" So you see, there is really a dichotomy. The volunteers I know, for example in the Compeer program, tell me they get as much as they give. I see the difference it makes in people's lives. So yes, volunteers are critical. However, you need funding for volunteer programs; they don't just operate by themselves.

We need a society that cares and wants to fund programs for the myriad problems, which, by the way are increasing as resources are drying up. Several of us talked last night about the mental health centers that are closing all over the country. Just as we are talking about going into a recession, the increase in stresses in society, we are closing up the people who are supposed to help. It's absurd.

You know, I started in social work, working at the Greenwich House, in New York, a settlement house. That was a total community support system. What concerns me today is that we don't have adequate community support systems. People who undergo stress, such as you do if you have a mentally ill person in your family, feel so isolated. The depression becomes so contagious. And what a loss to society. That's what needs to be communicated. We not only lose a potentially productive member of society in the mentally ill person, but in their families as well. Depression makes it very hard to function. Many families don't have the resources to both cope with their mentally ill person and communicate and contribute anything to the society around them. If they were given support and respite, think of what it would mean to the rest of us and to the quality of our life. We need to think

about that, in terms of what funds we are going to give for education, for research, for mental health services, and for child care... resources so that families can cope with societal stresses, especially when there is mental illness or other special needs in the family.

Deinstitutionalization was to me a very exciting word when it first appeared. I chair a task force that focuses on serving those at risk of being institutionalized. The only trouble is, that the promise was for increased services in the community. The reality is that this has not happened, and so we call it a failure. Some of these issues need to be stressed in programs, in the newspapers, and on television. Some of it is. We have heard examples of some excellent programs. But we need even more of that. We need to get away from the "choosing" between the homeless and the mentally ill, and think more in terms of the whole society needing to deal with its problems and choosing that as our community priority.

Everette Dennis, Ph.D.

Rona, thank you very much. I think we've had a very constructive discussion here, and a veritable textbook on some of the questions and I think all of my questions are answered satisfactorily so I've given everyone an "A." I'm sure you have questions, however and we'd like to have some time for any of you who would like to raise questions for the panel or make suggestions or comments as well.

Audience Participant

Regarding the Perimeter incident, I was very pleasantly surprised at the responsibility of the news. The print media did very well. There were six news reporters, seven columnists and one editor who wrote articles or spoke about the Perimeter incident within that first week, and each and every one of them was very responsible. We did write them letters and tell them we appreciate it. I think it's because of the relationship that they have with the Georgia Alliance for the Mentally Ill. I'm sorry we didn't get to say "thanks" to the television news media because I think that they also were responsible. I go all around the country, and that isn't what's happening everywhere; so I think Atlanta should be proud that this is happening. We also have a very good public service announcement that we just produced for Mental Health Awareness Week. I understand the lead in time for the Atlanta television stations is two months or so, we will be visiting you with that P.S.A. soon. My son, who is a recovered person, is bringing that to you. It's excellent, and I hope you'll show it.

The last thing we do is to have a big news report on the care of the seriously mentally ill, jointly issued by Public Citizens and the National Alliance for the Mentally Ill. I think that has received some coverage. It certainly speaks for the lack of services in the country and Georgia is half way there, thanks to John Gate's leadership I think.

I'd like to say, one last thing on stigma and professionals and that may be part of the response to the previous panel. I think we still have a long way to go with the professionals who work with families. Not all think as Sam Keith does. So I'd like us to re-think some of our concepts in family assistance theory too.

Everette Dennis, Ph.D.

Thank you very much. Is there another comment?

Audience Participant

I appreciate the fact that Atlanta is not as bad as other areas for sensationalizing the mental illness; but what I would like to know is "Why is it news when we are being abused in hospitals, but it isn't news when local consumer groups ban together and show what a recovering individual can still do?" Dr. Keith talked briefly about the percent of recovered people, I'd really like to hear more from the rest of these folks who are showing that a mental illness is not necessarily a lifelong occurrence.

Monica Kaufman

That's easily done by getting in touch with the people who do the story.

Audience Participant

How? They do not want to talk to our recovered, functioning people who are running a protection and advocacy office here.

Monica Kaufman

Well I think that in that instance, say if you have problems at our station, and you sent it to the health reporter, or you sent it to the assignment editor and nothing was done, that's when you follow through, and you look for other conduits. You send a letter to the news director with a copy to the vice president and general manager of the station, and say, "This would fall under such certain categories." It could be a special assignment report during Mental Illness Awareness Week; it could be a special feature for Jocelyn's "People to People" program; you might consider this during what we call our "slow periods." We will cover anything at Christmas; we'll cover anything during the summertime because nothing's happening during those slow periods of time. Tell them, here are the people who are affected, here are the people who are willing to talk. Then you ask for (most stations don't tell you about this; but all of us have to do it) ascertainment luncheons. That is, where you come in and sit down with the leadership in both radio and television at our shop. And you talk about coverage and issues. It usually ends up, the person is carried into radio and put on during a radio broadcast or plans are made to do something with the public affairs director later on. So just because two or

three avenues tell you no, you must be persistent. Because it's the "squeaky wheel that gets oil." There are a lot of people trying to get on television, radio and in the newspaper. There are a lot of people who want coverage, and never say "publicity" because even though we know that's what it is, we in the news business do not do "publicity." Watch your language. So don't give up and don't stop sending things in.

The other thing I'd like to say is that you've got to be an advocate in the media. You've got to push. Every time you hear, (and it's amazing to me that no one calls so this is my personal band wagon today), every time you hear in a crime story that so and so is a Viet Nam Veteran, you should get on the phone and you should write. Because it is then assumed that every person who was in Viet Nam is a "nutcase." Just as I get upset and you get upset every time every bank robber is described as a 6 foot 5 inch black male. Or the rapist is a 5 foot 2 inch black male. You should only use race, you should only use Viet Nam vet when it applicable to the story. If you don't call and "raise Hell" at your particular radio station, television station, or to the newspaper, then that will continue. You have to raise the sensitivity. And the way you raise the sensitivity is to complain in writing because it goes into the Federal Communications file. We have to have licenses to operate. It also informs the vice president and general manager and pretty soon, there is a memo dealing with the issue of "Do not use black or white unless it is applicable to the story." We will have that same thing used in terms of mental illness. So, if you want it, you gotta fight for it.

Everette Dennis, Ph.D.
Mrs. Carter...

Rosalynn Carter

I think that's one of the values of Media Watches which has been so successful and I would suggest that you just send that incident or the name of that person to all of your friends; send it to me; we'll all write to them.

Everette Dennis, Ph.D.

Thank you. I think maybe Monica's comment is a good benediction for us here, and that is, a number of you I'm sure feel that there ought to be more continuity of coverage of these subjects you care about. I think she's saying that to get continuity of coverage, you have to have some continuity in the way you work with the news media. I think now in the words of Howard Cosell, "Over to you Dr. Freedman."

Daniel X. Freedman, M.D.

Thank you Dennis, thanks to the panel. Monica Kaufman's slogan is, "We will fight for time," and that's what I now must do. Thank you all for your interesting comments.

Before we move to the summary of comments for this morning's program with Dr. Houpt and Mrs. Carter, I'd like to call on Joseph Rogers, President of SHARE, Mental Health Consumers Self-Help Clearinghouse; and I understand you promised me a two minute set of comments.

Joseph A. Rogers

Yes, I just wanted to comment briefly on the previous two panels. One of the things I observed as a consumer myself and a patient of services is that what we really begin to be aware of in ourselves is our use of language. I know that it becomes difficult when you are living in a short-cut society that it's easier to use short-cuts in language. But I noticed on both of our panels that we tend sometimes to use the short-cut language, which is in itself stigmatizing. There basically is a movement among disability groups all over the country, and it's called "The People First Movement." In the description and discussion of people who have a disability, you don't label them with the disability, you name them as people, and then if it is relevant to the talk, you talk about their problem. So it's people who have been diagnosed mentally ill, not "schizophrenics," not the "mentally ill" and God forbid, not "CMI's."

I want to also point out that basically this concept of consumer education and family education is really a two way thing. It's not something that has grown out of a benevolent professional movement. I think Dr. Fink alluded to that strongly that families and consumers have fought to have the professionals begin to participate in a co-participant manner. It's not something that grew out of five NIMH studies, I'm sorry to say, as much as I like to support research at NIMH. It grew out of a strong consumer and family movement, demanding that this kind of program be developed. The best kinds of these programs I feel are the ones that are empowering in their peer support and their group programs. If you're running a hospital or running a clinic, and you want to involve consumers in education, you have to be open to them educating you. Sometimes I see the educational programs as an excuse not to change a hospital-run educational program. They say, "Well, you are just sort of ignorant about the problem, and if you have more knowledge about the problem, you won't be bothering us about the fact that there is not phone accessibility on the wards." The hospital has to realize, if they are going to have an effective family education program, they have to be open and willing to listen to the patients and the family members when they demand change, and they have to be willing to change. If they don't change, when demands are reasonable and legitimate, family members are going to see, and consumers are definitely going to see you as phonies and are not going to deal with your educational program very usefully.

I want to point out, too, that I think it would be really good

if we could hear in this kind of program more from direct consumers about what they feel the role of families is in terms of the whole treatment or recovery program. I think there are a lot of emotions involved in that, not because of the family psychodynamics but because of the illness. Many times there is unresolved anger that separates the family and the consumer, (person with mental illness), from his or her family. I think we need to really address that issue. As Don was saying, on the issue of violence, I think there are issues of anger and feelings no matter what the illness, when you look at alcohol and drug recovery, the issue of anger is a very important concern (even though you are not blaming the family for the illness).

Finally, I just want to say that recently we are speaking for ourselves more and more in the media. As consumers and family members we are responding to situations like the mall shooting. Unfortunately they happen. In Philadelphia, we had an incident, which was a mall shooting situation. We went out aggressively to the media. We didn't wait until the media came to us and demanded that they hear from people who are not involved in shootings but involved in putting their lives together. We actually ended up using an opportunity. We are doing this legislatively, and we need to find ways to change that fear.

Just a quick story...When I first went on Oprah Winfrey's Show, I was concerned and afraid what the reaction was going to be, particularly from my in-laws who knew I had a mental illness but didn't know the depth of my mental illness. I went on the Oprah Winfrey Show and I didn't tell them I was going to be on the show, maybe hoping they wouldn't see the show. Of course they watch every single Oprah Winfrey episode, and they saw the episode. The rest of my extended family on my wife's side saw the episode. (very nice, Jewish, conservative, middle class people) and basically I went to the Bar Mitzvah for my nephew with apprehension. I wondered, "Are they going to treat me differently now? Are they not going to treat me the same?" Well they did treat me differently. I became a celebrity, and people really liked to talk to me, so don't be afraid.

Daniel X. Freedman, M.D.

Well, you are a celebrity, Mr. Rogers, and thank you for sharing it with us. Jeffrey Houpt is going to summarize this morning's thoughts as he sees them. There's several reasons I like to come to Atlanta. One is that I can see Jeff Houpt and I am reminded of the long fight of us educators in psychiatry. Psychiatry now has a fit place within the medical school which was not necessarily a given when I was trained. It was leadership such as Jeff Houpt's, (no wonder Emory has chosen him to be the Dean of the Medical School), and this is a new shift, in the more discerning schools throughout the country that the kind of leadership that psychiatric researchers and teachers such as Jeff can give is rare, and needed for American medicine, its patients

and its students.

Jeff is a Philadelphian too, born there. He got his B.A. at Wheaton College in Illinois, and I must say that along the way in his training he was fortunate enough to be at Yale for his psychiatric residency. So, as chair of Emory department since 1983 he has begun to get it moving. He's turned it over to Dr. Manning at the moment because he's got larger things, as Dean to take care of, Jeff, take care of us at this point with a summary.

Jeffrey L. Houpt, M.D.

Thank you Danny. It is a pleasure to be here. I had nothing to do with planning this program. I was able to come and watch as many of you have. In previous years, I sat with some anxiety hoping everything went O.K. but I passed that responsibility on, and I don't have any of those worries. So it's wonderful to be able just to kind of reflect on the meeting and to make some comments. I found the meeting very stimulating; I found myself furiously writing notes for a second, third, fourth, and fifth version. And probably I will wish, after I say what I'm going to say, that I had a chance to do the sixth version, but you will have to hear my thoughts as they are now.

I will say this (based on this mornings' discussion) that the first step in de-stigmatizing schizophrenia or an illness, is to make it a medical illness. And when I say that, I am not talking about making it a narrow, biological illness. I am talking about taking it out of the realm of the spiritual and the social and the trivial. I think the family advocacy movement has demonstrated that for us in the last ten years or so. I think Dr. Keith's statements provide the right model for us. That is, Dr. Keith was careful to talk about the biology, but also to talk about the psychosocial aspects of the illness. I think we need to keep that in mind. In fact, as he talked, I decided I would write down what I meant by a medical illness. And I simply mean a disorder of biology that unfolds in a social setting which has intense psychological meaning. I think that's what schizophrenia is, and I think that's also what leprosy is, what AIDS is, what cancer is and what heart disease is. And as I listened to Sam talk, I began to try to think how schizophrenia is homologous, if you will, to those particular illnesses.

Sam mentioned two very important parameters in understanding a medical illness: universality and hope. I would add two more to those, particularly when you think about the issue of stigma. The third I would add would be contagion. The fourth I would add is whether it would be counterintuitive or not. And I thought I might just make a few comments about leprosy, AIDS, cancer, schizophrenia and heart disease in that framework.

I believe that the problem with leprosy was not that it wasn't viewed as a biological illness, but that it was contagious. That's

what created the fear and the stigma around leprosy. I think the issue with AIDs has to do with the lack of hope, as Sam mentioned. It's bolstered somewhat by the notion that it's not entirely universal. With regard to contagious, great efforts are required by the Centers for Disease Control to counter notions of contagions and so forth with AIDs, and to talk about the need for safe sex, for bleaching needles and so forth. Cancer has come a long way. It wasn't long ago, that it was viewed as a dirty illness and something that could be caught. I think that if you see enough cancer patients and their families as a psychiatrist, you'll find that that is still embedded in much of their thinking at this time, although they know rationally that that is not the case. Cancer, of course, does offer hope in some cases, and less hope in others. Cancer and AIDS, however, are intuitive. AIDS being caused by a virus and cancer by some oncogene that's turned off or turned on at the wrong time to allow cells to proliferate is an intuitive kind of process. Its a biological process and I think the public can view it as kind of intuitive.

How does schizophrenia stack up in this regard? Well first of all, as Sam points out, it is universal, having comparable incidence to multiple sclerosis and diabetes. But I submit to you that the public views it as not universal at all, even though it's more universal than many mental illnesses. What about hope? Well I submit that it's viewed as hopeless, even though we know that there are 25% who make nearly complete recovery, and another 50% that, with proper treatment and support can manage O.K. What about contagion? Well I think this is a issue and I'm not talking about the viral theory of schizophrenia when it comes to contagion. But I think the contagion is in violence. And I want to echo some of the things that Don Richardson said. I think the major problem that we face, or one of the major problems with regard to stigma or schizophrenia is the fear of being attacked like people were in Perimeter Mall. And I think as professionals we have not faced up to that. Our defense has been largely statistical and accurate, but has not spoken to the emotion in the argument. Our defense has been that the numbers are less. But, in point of fact, to the people who are being shot and so forth, the numbers don't really matter. I think as a profession and as an advocacy group we need to take a more serious look at this and I support Don in the idea of discussing it openly.

I had wondered, for example, Dr. Keith, if included in your study might be a post hoc analysis of violent events with those people who received a psychoeducational program. Because I would wonder if the immediate hope for violent events would be in the psychosocial matrix in which the violence occurs. Perhaps the answer is ultimately in the biology, but in the immediate near future it's most likely in the psychosocial network. And I would call on NIMH to look at it in that context and to fund some research about this very important issue.

Finally, I think, schizophrenia suffers because I think it's counterintuitive. We can't understand it. We can't understand the experience. In the case that occurred in Georgia in the mall, we just had to read the newspaper article and just wonder about it. The man involved said he shot the people because there was something implanted in his stomach that told him to go ahead and do it. That puts fear in people when they hear that. It's not something that they can immediately relate to.

So I think using a medical model for the illness is the first step to destigmatizing. It can also provide a framework around which we could develop a program to help destigmatize this illness further by looking at the parameters by which the public views these illnesses.

Now the panel I found very very interesting, and I think the one thing that I learned for sure is that Monica Kaufman should have five minutes, and not 90 seconds to do her stories. Mrs. Carter mentioned her efforts with the media to promote an accurate portrayal of mental health professionals, neither evil, always bearded or God like. A proper rendering of mental health facilities and an accurate portrayal of families is needed. And I think those are three very important themes. Monica Kaufman suggests daytime soaps, which I think is important, as an outlet and a force which directs attitudes in this particular country. I think also the idea of pairing patients and professionals in interview situations would also be a very interesting one. At this point, we usually make a call for more mental health professionals to get involved in the media. I would suggest not that more get involved, but the right ones. Not everybody is an anchor on T.V., and not everyone in our profession should be on television, not everyone carries themselves well on television.

I grew up with two goals in my professional life, both of which I've now given up and gotten beyond. One was to avoid lawyers at all costs, the other one was to avoid the media at all costs. And I did pretty good as a psychiatry chairman, but not real well. You can't be a dean and not have any concerns about either of those. I've gotten more comfortable. I went to a program that we call "the dean school" which is a 3-day training program on how to be a dean. (It always interests me that it takes at least six months to learn how to fit a pipe if you are a plumber, but three days to be a dean). Part of our training was dealing with the media, dealing with this issue of thirty seconds and so forth. I found it very helpful if for no other reason to kind of de-condition me to the anxiety of it, and to get clear in my mind what I wanted to say, and to say it and to say it about six more times, so that hopefully, when the thing came on the news at night, that thing I said six times was there. And in our activities at Emory, I have gotten to practice that a great deal, particularly around animal rights activists and protests and so forth. I do think we need to get some of the right people there.

I think we need to understand the constraints of the legal system and the media. They were outlined this morning; they are not our adversaries. They have constraints just as we have constraints and they need to work within those constraints just as we do.

Where do we go from here in terms of this symposium? Well it's my sincere hope that this symposium will take on a form, in the best sense of the term of becoming more institutionalized. In addition to sponsoring these annual meetings, I would like to see us develop a clearinghouse for information with regard to what would be in the public good in the area of mental health, and as an advocate for important and pertinent programs to improve mental health services across the country. Plans are underway at this time to move in that direction so that the symposium becomes a major and perhaps the leading clearinghouse and place of policy-making for mental health policy in this country. It could serve no one better, and it could not be led by anyone better than Mrs. Carter. Thank you.

Daniel X. Freedman, M.D.

Mrs. Carter, I echo exactly what Jeff prescribed. This group should become institutionalized. All of us in some way or another are going to try and make that happen because it can happen here; it has happened. The follow up from the President's Commission has been tangible and succinct. Mrs. Carter, you're the Chairperson of this morning's meeting, would you like to summarize before we close? Rosalynn Carter..

Rosalynn Carter

Well I do have some things to say. I don't think I'm going to let you see all of my notes.

I thank the panel for speaking about the news press. There are some really good things happening, but as Everette Dennis said, we have a lot to do to educate the media about mental illnesses. Just to give you an example, there is a story this morning in the Atlanta paper by Beth Kurylo who was very understanding about the issue. Unfortunately (and I'm embarrassed to read this) but whoever does the titles under the picture says, "Rosalynn Carter, who is lobbying Hollywood to more accurately portray mentally ill characters!" It's up to us; we have a long way to go. There is also an article today in USA Today. I hope people will look at this and think about mental illness and know that somebody is working on it. But don't believe that I said, "Those with mental illness can live normal lives just with medication." I didn't say that. So, no matter how hard we try sometimes, we can be misrepresented. That does not mean we don't need to try, we need to keep trying, and keep trying and keep trying until we educate not only the media but until we educate the people in our country about mental illnesses.

I want to thank all of you for coming this morning, and I want

to thank those who took part in our program. I especially want to express my appreciation again to the van Ameringen Foundation, Patricia Kind is here, and we are so pleased, Patricia, that you were able to join us today. Denis Prager is here from The MacArthur Foundation. I want to thank those two, because as I've said before, the symposium would not have happened without them.

I want to thank the participants on the program, especially Dr. Keith, for his presentation. We are really pleased that you could be with us, and we wish you good luck, and much success as a new Director of the National Institute of Mental Health is being selected. We have somebody in mind that we can think of right now. All of us!

I would also like to thank Danny Freedman and Everette Dennis for leading the panels, the participants, Tom Bryant and Don Manning who were my co-chairs, and then the people who helped plan the meeting. Dr. John Hardman who is a Carter Center person, couldn't be here with us today, because he is in Geneva. He has gone to Geneva to represent the Carter Center, working with the World Health Organization to educate developing countries about the dangers of cigarettes and smoking. We are happy about that. Jeff Houpt helped with the planning of the meeting. We thank you for that. Also, Dr. Roz Mance from the Department of Psychiatry at Emory, Dr. Denny Jewett from the Department of Psychiatry. And finally, I think we all should give a big round of applause to Geri Scheller-Gilkey.

I think we have all been moved by the presentations this morning. We have a lot to think about, to take home with us. How can we help families, how can we increase understanding? Talking about the issues is important, as we've done today, and taking home what you have learned to your organizations is important. We are working on institutionalization of the Rosalynn Carter Symposium on Mental Health. I hope that will come about. I want you to think about how important it is for us to work together. I think if we do that, we can go a long way toward helping people who suffer from mental illnesses, which helps all of us. Thank you so much for being with us this year, and we look forward to next year. Thank you too, Dr. Roy Menninger for your presentation last night. Thank you for being with us. Thank you all for being with us.

Tom Bryant, M.D., J.D.

With that, we will conclude our Symposium program this morning. Thank you all for joining us.

The Sixth Annual Rosalynn Carter Symposium on Mental Health Policy

**FAMILIES COPING WITH MENTAL ILLNESSES:
IMPROVING PUBLIC UNDERSTANDING**

Rosalynn Carter, Chairperson

October 18, 1990

AFTERNOON PROGRAM

Afternoon Session closed to general audience; open to symposium speakers, representatives from national organizations and special guests

12:30 - 1:30 p.m. Luncheon in Rotunda B

1:30 - 2:30 p.m. FUTURE COLLABORATION BETWEEN THE ENTERTAINMENT MEDIA
AND THE MENTAL HEALTH COMMUNITY

Thomas E. Backer, Ph.D.

President, Human Interaction Research Institute

Brian Dyak

President, Entertainment Industries Council, Inc.

2:30 - 4:00 p.m. A WORKING SESSION: MENTAL HEALTH PRIORITIES IN THE 1990'S

Facilitator

Leslie Scallet, J.D.

Director, Mental Health Policy Resource Center

4:00 - 4:30 p.m. Closing Remarks

Steven S. Sharfstein, M.D.

*Executive Vice President and Medical Director,
Sheppard and Enoch Pratt Hospital*

Rosalynn Carter

Chairperson

* * * * *

Wine and Cheese Reception will follow

The Sixth Annual Rosalynn Carter Symposium on Mental Health Policy was made possible by funding from the van Ameringen Foundation, New York, New York, and the John D. and Catherine T. MacArthur Foundation, Chicago, Illinois.

The afternoon session of the Sixth Annual Rosalynn Carter Symposium was a closed work session. The first segment of the afternoon session was facilitated by Thomas E. Backer, Ph.D., President of the Human Interaction Research Institute and Brian Dyak, President of Entertainment Industries Council, Inc. They presented the following depiction suggestions for the entertainment creative community and facilitated a discussion of future plans and possibilities for activities between the mental health community and the entertainment industry.

The following points regarding portrayal of mental health professionals, treatment facilities and services, and families of people with mental illnesses were developed as a resource for the film and television industry. They are not meant to limit the creative process.

DEPICTING PROFESSIONALS WHO WORK WITH MENTALLY ILL PEOPLE

- Try to show therapists as human beings -- neither "infallible gods" nor "malevolent manipulators" -- most do their jobs skillfully, and lead ordinary family and personal lives as well.
- Limit the "Freudian stereotype" -- male therapist with a beard, a German accent, a pipe and a detached manner -- to uses that are appropriate to the historical era of a story.
- Show working with severely mentally ill people as a specialty -- most psychologists, psychiatrists, and other psychotherapists in the community don't regularly treat severe mental illnesses like schizophrenia or manic-depressive illness.
- Include mental health professionals as supporting characters in stories having nothing to do with mental illnesses.

DEPICTING TREATMENT FACILITIES AND SERVICES FOR MENTAL ILLNESSES

- Include depictions of effective treatments for mental illnesses other than psychotherapy, e.g., medications which can effectively treat depression and schizophrenia.
- When appropriate, show community facilities (halfway houses, day treatment centers) as alternatives to traditional "mental hospitals" for treating people with mental illnesses.
- Show that some facilities now use teams of professionals who carefully coordinate their work with a given patient.
- Have characters make statements about the benefits of treatment -- for instance "I got treatment, and it helped."

DEPICTING FAMILIES OF PEOPLE WITH MENTAL ILLNESSES

- Emphasize that blaming families for a child's mental illness is incorrect; current scientific evidence confirms that family interactions are not the cause of mental illnesses.
- Include in stories the painful, often devastating impact of mental illnesses on family members.
- Have characters mention community and self-help services that are available for families to help them cope with this impact.
- Include positive, loving relationships between family members and people with mental illnesses as part of some stories, and show that there is real hope for families to heal and recover.

These suggestions were generated at a meeting held in June 1990 between Rosalynn Carter and several creative people in the Entertainment Media community. Formulation of the depiction suggestions was facilitated by the following advisory group:

Thomas E. Backer, Ph.D., Human Interaction Research Institute
(co-chair)
Brian L. Dyak, Entertainment Industries Council, (co-chair)
Loreen Arbus, producer
Larry Stewart, writer-director
David Moody, Integrate Communications
Doug Dulstman, Warner Brothers Television
Henri Bollinger, Entertainment Industries Council
Rosalind Jarrett, ABC Television Network
Dan Weisburd, producer
Jill Bowman, CBS Entertainment
Gil Steele, CBS Entertainment
Shelly List, List/Estrin Productions
John Bancroft, MDR Inc.
Bruce McKay, producer

The second segment of the afternoon program was facilitated by Leslie Scallet, J.D., Director of the Mental Health Policy Resource Center. She facilitated work groups focused on Mental Health Priorities in the 1990's. The following is a report of the outcome of those workgroup discussions:

1. What are your shared goals and aspirations for the mental health of individual Americans by the year 2000?

A decent life for all people with mental illness/mental health problems

Normalize the need for care

Reduce stigma

End trivialization of mental illness

Increase acceptance of mental illness

Political and social will to end tolerance for ill health, homelessness

Reduce/eliminate mental diseases/illnesses/disorders

Find causes

Eliminate disease

Reduce incidence of mental disorders

Access to needed services

Apply what we know

Ensure parity, equal access

Promote universal health insurance

Remove ethnic barriers

Expand family involvement

Recognize need for support services

Address cost and profit issues

Perspective of wholeness:

Continuum of mental health and illness

Diversity of mental status

All segments of the population

Mental illness and health of the whole person

Mental status as one element of the person

Collaboration among all parts of the MH system

Refine roles, functions, levels of care

Prevention as an important theme

Clarify "Mental Health" and "Mental Illness"

Distinguish mental illness from life stresses

Use language of the beneficiary of treatment

Focus and target who and what we are talking about

Examine need for new nomenclature

Define MH and MI

2. What are the most important changes needed for progress toward your shared goals?

National shift in attitudes

Compassion, fairness, quality of life

Shared responsibility
Education/sensitization: continuing process, various sectors:
public officials
communities
professional education/training
law schools regarding mental illness
media: entertainment, news
Policy change resulting from attitude change
active political involvement by consumers, professionals, advocates

System changes
rational reimbursement system
restructuring of funding streams
identify underserved populations
client-centered system
role of patients and families
proper distribution of professionals
more resources for children
comprehensive system, universal health care

Better answers
more research
research more "cure" oriented
research applied to new treatments/practice, relationship to clinical realities
outcome and cost/effectiveness studies
analysis of all policies as to their impact on mental health

Consensus
on what we know
what are the problems
priorities and resource allocation
reduce fragmentation/turfdom within the field
bipartisan
professional and consumer advocacy
coalition groups: Leadership Forum, Carter Symposium

3. What are we asking of whom when we ask for these changes?

Personal sacrifice
from those who care
taxes
co-funding
private sector contribution

Change beliefs and established practices
government programs become flexible, delegate to provider
positions/sides gain flexibility
media provide realistic portrayals
public suspend disbelief and fear
everyone change attitudes: public, governments,

insurance companies, professionals, media

Professional changes

associations: compromise and conciliation
not fight publicly
improve public service side, training
not overtreat (even with insurance)

4. What do we have to offer in return?

Political clout

votes
PACs, support
consumer, family movements
recognition, awards

Knowledge

professional information
experience of consumers, families
research

Social benefits

productivity in workplace
healthy children
increasing self-respect, sense of justice
more taxpaying citizens

5. What are the most important opportunities and trends that we can utilize?

public priorities/crises
health/costs debate
current congressional action: Pepper Commission,
Kennedy-Waxman Year 2000 report
prison costs
homelessness concerns
drug abuse
children
aging of the population, fragmented caregiving

Backlash to reductions in social services

deinstitutionalization, reductions in CMHCs
concern about availability of an adequate workforce
EAP movement
increase in corporate sensitivity and responsibility
emerging scientific knowledge
media interest and power
increased access to media
telecommunications technology

Recurrent volunteerism and altruism

consumer movement and grassroots activism

6. What sources of strength and leadership can we call upon?

Mrs. Carter
grassroots
advocacy organizations
consumers, family groups, self-help
coalitions of any or all of these with professional
groups
media access
supportive public officials
public/private/voluntary collaboration
private funding

Closing Remarks:

Tom Bryant, M.D., J.D.

Many of you know Steve Sharfstein, his grand title is going to get grander. He's Executive Vice President and Medical Director of the Sheppard-Pratt Hospital in Towson, Maryland, which is a very large suburb of Baltimore. When Rosalynn and I first encountered Steve, he was at the NIMH. He came to help us with the President's Commission that led to the 1978 report that Beverly referred to. And there are a lot of great stories about that and I'm not going to bore you with any of them other than to say that Steve was extraordinarily invaluable because I think at that time and now, Steve has as comprehensive in-depth view on what Americas' mental health system is all about, what it's been about, what it is now and where it might go. Steve is an extraordinarily capable psychiatrist and extraordinarily capable researcher in psychiatry and extraordinarily capable administrator of a very large institution. He is a public servant, or has certainly been a public servant in it's best sense of the word. He has been here with us since it began. He's just an all around terrific fellow. So why don't you come up here.

Steven Sharfstein, M.D.

This has been a great day. It's about families and I immediately associate to my own family. Two items come to mind. One is the story that I often tell before I give my talk on the financing of mental health services, which was that in my family when I was small, the subject of sex and sexuality was a completely open subject. But the subject of money was always a big mystery. One could never ask about the price of things or how much Daddy made because that wasn't polite. So I became very curious about that. So I think families matter in terms of one's growth and development.

Why did I go into psychiatry? Well, I think the principle reason was that I came from a family with a very heavy loading of bipolar illness. My father's brother and his sister both had severe manic depressive illness and I have four first cousins who are on lithium. In fact, there is a psychiatrist in New York who

I call once a year who I have dubbed my family physician because he manages all my first cousins and we always keep up to date in relation to that. At one point, I took the family tree to Eliot Gershon at the NIMH and he was fascinated and gave me a set of color blindness cards to take to the next Bar Mitzvah or wedding, which I did, and proceeded to sit there (it's a little bit like Joe Roger's story) and they test everybody in terms of color blindness. I certainly was impressed with the genetics of the situation from my own family, and feel that the recent findings and the approaches have been most appropriate.

Then my clinical experiences. I immediately thought of some of those experiences relating to families. When I was a resident in Boston and began to work in a community mental health center, one of the things I did routinely was that when one of my patients was discharged from the community mental health center, I went home with the patient. Literally went home. I was discharged too. In other words, the first outpatient visit was a home visit that I made to the patient and got to know (I knew the family already but got to know) the family in the home environment. I think that we do too little of that.

In my days at the NIMH, for 8 years, I ran a group of long term patients. Patients who had a long term experience with the mental health service system. Every Tuesday night we met. There was one of my patients who still calls me every month or every other month just to chat. I stopped the group in 1983 but he would call me every Tuesday morning. He would say "Is the group meeting tonight?" Now, the group met every single Tuesday night for 8 years. Even 8 years later, that was the issue for him. I used to say things like "Did the sun rise this morning?" you know, and other kinds of items but that was his issue. Well he did real well in a group that was very family oriented. We were a family. There were 12 that started with the group in 1974 and by 1982 there were still 8 of the original 12 in the group. I worked with the group so that when people developed problems that could lead to a relapse and a re-hospitalization that they would call each other first before they would call me. And we worked together. In 1978 in Maryland, there was a Proposition 13 initiative on the agenda. A tax cutting initiative. Many services were scheduled to potentially be closed including the services which funded those Tuesday night groups. This patient, with the support and help of the group and with my support decided to become politically active in trying to get this particular tax initiative defeated. He made sure that every patient in the group was registered. That was one thing that he did. Then he actually worked for the group that was against this resolution which was mostly government employees. He went in there and helped lick envelopes and then with some discussion ahead of time, decided he would work the polls on Tuesday, it was Tuesday night and he did that. He came in that Tuesday night acutely agitated, very upset because of course when you work the polls and you have the brochures, people don't take

your brochure when you go in. They're not interested. He felt very rejected by the whole experience, upset by it. No matter what the group did, no matter what I would say, he was getting more and more upset cause he was convinced that he had failed, that the "Trim" resolution was going to pass. But lo and behold, in Montgomery County Maryland, the Trim resolution failed. There was no task cutting. I was concerned, I was thinking that maybe I was going to have to re-hospitalize him and he hadn't been hospitalized in four or five years and I was feeling kind of badly about it, maybe I shouldn't have let him do this. The next day, after Trim had failed, he called me and took total credit for it; (laughter) which I gave to him, that was fine with me.

And then at Sheppard-Pratt recently I had a family experience. About a year ago, an extremely distressed family came to see me about the care of their daughter who had been in and out of the hospital for about 8 or 9 years with very severe bipolar illness. One of my clinicians had definitely dropped the ball with this patient. They were very upset with Sheppard, I met with the family on several occasions, got them re-connected to the system and then had forgot about it. In the mean time became very interested in possibly developing a life care case management program in the private sector. The kind of case management program that at the NIMH with Judy Turner who is in the audience we had thought through in 1976 and 1977. What we did though, was send out a questionnaire to a hundred families who had a long term experience with Sheppard-Pratt. We also sent out the same questionnaire to 50 NAMI families in Maryland asking them what kinds of services do they think important in the life care continuum, and how would they feel about a case management service in the private sector. There was a cover letter from me in that mailing, in that piece of research. The father of this patient called me and said "I got your letter." First, for a minute, I couldn't think which letter he talked about, and then I realized that he was on the list of 100 families. He said "This is such a good idea, I want to give you a million dollars for it." (I had no idea that he was that rich. Absolutely no idea you know, when I had met with the family.) I said "Oh my God!" that was my reaction. I said "You're the first one who responded." He said "You mean I'm the only one that answered your questionnaire?" I said "No you are the only one who said he would give me a million dollars for the idea." In any event, he actually ended up giving me 1.3 million to endow the program. So we are getting it off the ground, we are going to develop this program; very much family oriented. We have a family advisory group. And a group that will focus on the life care continuum. The continuum of services outside the hospital using case management as the central point and hopefully, that will be successful. Would not be successful except for interaction with concerned families.

Despite this, I do want to emphasize the fact that Leslie brought up earlier which is the need for government. The need for government to develop opportunities for the entire system to be

responsive to the needs of individuals with mental illness. The need for the government to provide the incentives for the public and the private sectors to work together are on the whole range of treatment opportunities and support opportunities. Direct support for families, that can come from government. Whether its vouchers or chits for respite care, or whether its just the whole question of social security disability and providing the kinds of funds that are necessary to sustain the individual over the long term within families. I think that that's absolutely essential.

This is the 10th anniversary of the signing of the Mental Health Systems Act. Suddenly it occurred to me that that was the case. It was in October of 1980 that the Mental Health Systems Act was signed. It is also the 10th anniversary of the development of the National Plan for the Chronically Mentally Ill which was directly out of the President's commission report and the Systems Act. As you know, the Act was repealed, there was a loss of political will and I think that was a tragedy at the time. Yet, despite the set back, as evidenced by this meeting and the previous meetings the family stayed together. The family that I'm talking about is this family and various portions of the act were reenacted during the last 10 years by the way. If one talks about the homeless demonstrations or the child and youth program or the protection advocacy program, piecemeal various aspects of the Mental Health Systems Act was reenacted over the 10 year period.

The six conferences - and I think that we are getting better every single year, so next year what I am really looking forward to is a follow through of that. I think there really has been some continuity Bev, through this process. If you've been through all six as you have you know there is sort of a timelessness quality. I was sitting here today, and I thought "Gee, I was here yesterday, and the day before yesterday." There is just something about the continuity. I think we have a great deal of thanks to give the Carters- especially Rosalynn Carter for being part of her family, for allowing us in that much and for her to stay with us, and to hold us together over this time period. I actually had the opportunity 10 years ago, (I think this may be the 10th anniversary) anniversary phenomena of being invited into the family quarters of the White House for a celebration of the signing of the Mental Health Systems Act. There was even a cake that we gave to Mrs. Carter on that occasion. It was a very joyous occasion. The picture of that actually hangs in my family room in my house. So it has been really quite important, I'm very happy to be part of this new family as I strongly believe and has been emphasized today over and over again, is sustaining relationships which make us mentally healthy. And it's sustaining relationships which help recovery from severe mental illness. That's what's important. Thank you.

Rosalynn Carter

I'd like to thank Steve for reminding us of some of those good days. I had not even thought about this being the 10th anniversary of the Mental Health Systems Act.

Are Dr. Capitan and Jack not in this room? This is the same group that was at dinner last night, and several people there asked me what the Rosalynn Carter Institute is. So just very briefly, I want to introduce Jack Nottingham to you. He is at Georgia Southwestern College, our local college in Americus, which has started the Rosalynn Carter Institute for Human Development. Our focus there is on caregiving. Jack is the Executive Director of the Institute, Dr. Capitan is the President of Georgia Southwestern. Dr. Capitan was here earlier, but I'm not sure he still is; he was at the dinner last night, however.) We are trying to develop at the Institute model in our area of the state to help care for care givers -- get them together, let them work out their frustrations and problems, and see what we can do to help them. We hope the model we develop can be replicated across the country. I've talked to the heads of many organizations, and there is not a lot being done across the spectrum of human service caregiving. The National Alliance for the Mentally Ill, for instance, does take care of its families, and other organizations have some programs for their particular group; however, our program will be for all caregivers. We had one meeting in Americus just to see what happened. We invited caregivers, professionals, advocates, family members, consumers, the religious community, and people who had someone in their home they had to care for all the time -- all these people -- and it was quite emotional, particularly for those who don't see others very often. To get together so many people who have the same kinds of problems and live daily with somebody who is unhappy and sick and handicapped, and see them share their experiences and their frustrations was really wonderful, so we formed a national coalition to get ideas from the different organizations about what we can do in our caregivers program. We will be meeting tomorrow, and some of you here will be attending.

Well, you will be hearing from Leslie (Scallet) on priorities. I look forward to her report. You'll be hearing from Tom (Bryant) and Brian (Dyak) on ideas for the media initiative. And I want to hear from you. If you have any ideas about either one of these things -- priorities for the 90's or the media initiative -- send them to Tom or Brian or Leslie, or to me and I will send them on. I'll be looking forward to hearing from you and seeing you again soon. Thank you.

Appendix A

The Role of the Family in Schizophrenia

- **65% of patients discharged from hospitals return to their families of origin**
- **Families are a natural support system**
- **Families can have a positive impact on outcome**

Appendix B

Considering the Family's Needs in Schizophrenia

- Family Burden
- Transitional Requirement
- Disguised "finger pointing"

Appendix C

Psychoeducational Workshop

Presentation Goals

- Provide factual information about schizophrenia
- Principles of communication
- Problem solving and stress reduction skills
- Group affiliation
- Enlist the family as a therapeutic aid

Appendix D

Psychoed Workshop – Participation Stabilized at Six Months

