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

**“MENTAL HEALTH IN HEALTH CARE REFORM”**

**Rosalynn Carter, Chairperson**

**November 18 and 19, 1992**

**THE  
CARTER CENTER  
OF EMORY UNIVERSITY**



*The Eighth 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.*

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***Acknowledgements:***

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## DINNER ADDRESS

November 18, 1992

**Elaine M. Johnson**

I'm delighted and feel very privileged to share program honors with Mrs. Rosalynn Carter. Mrs. Carter and President Carter have set a brilliant and compassionate standard for public service. We are all in their debt.

Of course, this meeting itself grows out of the personal interest and drive of our former First Lady. Because Mrs. Carter is so universally respected and admired, The Carter Center is able to assemble here this evening a company of remarkable potential ... the leaders of this nation's vigorous mental health movement. Individuals who have been tireless advocates for mentally ill adults; for children with mental disorders and for all persons and families who are disabled in some way by mental or physical impairments.

I know I am among friends here this evening. Men and women who have been fighting the good fight for many years. So this evening is, for me, a very special opportunity to do some thinking out loud about matters of concern to all of us and to do it at an important moment in our history.

Next January, a new President of the United States, Bill Clinton, will take the Oath of Office and assume the leadership of the Executive Branch. It is an intensely important moment for me and my colleagues throughout the government, and we are ready to move ahead with the new President on behalf of the people in need, whom we serve.

For the next few minutes, then, I'd like to focus on how we will approach our new tasks: who we are and what we do. And then, I'd like to spend some time suggesting a few principles that might shape our actions in the months and years ahead, when we can expect substantial reforms to be made in the way we deliver health and mental health care.

In that part of my remarks I will be speaking mostly for myself, and not necessarily for my agency, or the Department of Health and Human Services. I trust in your good grace to understand and accept that.

First, my agency. And I'll keep this brief, because I suspect nearly everyone here has a fairly good idea of who we are by now.

Public Law 102-321, the ADAMHA Reorganization Act, was signed by President Bush last July and went into effect on October 1, 1992.

The former Office for Treatment Improvement has become the new "Center for Substance Abuse Treatment," or C-SAT. It is still in the capable hands of Dr. Beny Prim.

C-SAT has a lengthy program agenda. It is, for example, funding comprehensive residential and outpatient treatment projects for pregnant and postpartum women and their children, a population

that is specifically highlighted within the Reorganization Act.

C-SAT also is responsible for "capacity expansion" grants to the states, so that they may add more substance abuse treatment slots. Other areas of interest to C-SAT involve improving systems of treatment in certain target cities and among critical populations, such as homeless persons, racial and ethnic minorities, public housing residents, and adolescents. In addition, C-SAT is concerned about improving drug treatment services for offenders held by the criminal justice system.

Let me now turn to the Center for Substance Abuse Prevention, or C-SAT. Vivian Smith is Acting Director of this Center, a position she held for its predecessor, the Office of Substance Abuse Prevention. The C-SAT staff administers several programs with which many of you are no doubt familiar:

- One is the Community Partnership Program which helps communities develop comprehensive plans for local substance abuse prevention efforts.
- Another is the High Risk Youth Demonstration Program which funds projects to help school-age youngsters who are at risk of *starting* to use--or *increasing* their use--of alcohol and other drugs. And by the way, that now includes tobacco.
- A third major C-SAT program involves grants to public and private nonprofit groups for the development of Employee Assistance Programs or EAP's. The emphasis here is on helping small businesses set up effective EAP's.

C-SAT also is charged with putting together a national data base on substance abuse prevention, something that both researchers and practitioners agree needs to be done.

That takes me to the third Center, the Center for Mental Health Services or CMHS. Dr. Frank Sullivan, who is here with us this evening, is the CMHS Acting Director.

CMHS has no predecessor from the ADAMHA days. Rather, it was created by Congress in PL 102-321. But it did inherit the service-related programs formerly administered by NIMH, including the successful Community Support Program or CSP, and the Child and Adolescent Service System Program or CASSP.

The CSP is designed to help improve the housing, treatment, and support needs of adults with severe mental illness who live in the community. Many of these individuals have a psychotic disorder such as schizophrenia, or an affective disorder that impairs their ability to carry out activities of daily living. For some 14 years now, CSP has been a significant agent for positive change at the state and community level, and we intend to maintain that program's strength and vitality.

The same is true for the CASSP, which has been a catalyst for improving state and local systems of service delivery for children and adolescents with--or at risk of developing--severe mental, behavioral, or emotional disorders.

CMHS also administers the Children's Mental Health Services Program, which is the first completely new mental health services program in 10 years. While the funding level is modest



during this first year of the program, we believe it will nevertheless be an important addition to our armamentarium of programs serving children and adolescents with severe emotional, behavioral, and mental disorders.

CASSP has also had a profound impact on the way states and localities have developed new collaborative approaches to help severely emotionally and mentally disturbed children and their families.

The Center for Mental Health Services is also the focal point for a number of programs that serve persons with severe mental illness who are also homeless. I don't want to go through these programs in any detail. I do want to emphasize the fact that we are maintaining the strength of these programs because they are so vital to the well-being of some of society's most vulnerable individuals.

Now, just a couple of words more about CMHS.

The Reorganization Act also divided up the old ADMS Block grant to the states. One piece became the \$1.5 billion block grant to states for the provision of substance abuse services administered by the Center for Substance Abuse Treatment. The other piece is a new \$278 million Community Mental Health Services Block Grant administered by the new Center for Mental Health Services.

PL 102-321 requires each state to integrate a comprehensive mental health services plan into its annual grant request. The new law also requires each state to report on how well it carried out last year's plan. And the law instructs us to place a dollar penalty on those states who do not fulfill their plans.

Margaret Thatcher once said, "No one would remember the Good Samaritan, if he'd only had good intentions. He had money too." You could pin Mrs. Thatcher's observation to the Block Grant program. In other words, we want to see more than just the plans for good intentions; we want to see money spent on those good intentions and we want to see results that benefit people.

We know that money is in short supply, and there are limits as to how much additional money can be raised for health and human services at the state and community levels. We also know that sometimes there is a real danger that the commitment to fairness can become cool, reflecting a tightening in the level of available money. We can't let that happen. We must try doubly hard to make sure that the money available to us--whether it is much or little--does not determine the scope of fairness in the delivery of vital health and mental health service.

That seems to be the heart of the matter, doesn't it? After we've reorganized and re-defined our mission, we must confront the remaining key question: Is it going to be possible in the years ahead to deliver health care to all our citizens in a manner that is both cost-effective and equitable?

And here I would like to suggest four broad principles for action:

If I had to choose a first principle, I would choose the principle of fairness in health care for all our citizens, which means that everyone has access to the best available care . . . regardless of the illness or the condition.

I'm afraid that what we have today is a very annoying contest among diseases, the advocates for each one claiming it is more important than any other and, therefore, deserves more of our scarce health dollars. Unfortunately, in this competition for dollars and attention, the public, government, and third-party payers maintain their tilt toward the more visible and tangible physical illnesses and disorders, and less of a tilt toward mental illness and chemical dependence.

Is breast cancer more or less significant than depression? Is a myocardial infarct more or less important than schizophrenia? Such questions are even offensive and foolish. And yet, a person with breast cancer does receive a great deal of subsidized or reimbursable care. Someone with a depressive disorder--may not. A person who does survive a heart attack will receive long-term support, understanding, and rehabilitation assistance. Someone with schizophrenia may not. That's not fair.

We do not choose our illnesses. Therefore, we should not be punished or placed at a disadvantage because of an illness that chooses us. We need to recognize the essential parity of and among, human illnesses and conditions.

Whether an individual has a mental disorder, a physical disability, a chemical dependency, a communicable disease, a genetic impairment--whatever the illness--that individual should have equal access to effective treatment without penalties and without sanctions.

I would propose, therefore, that our first principle, in this coming age of health care reform, be the principle of fairness--fairness across race and gender, across age and income, and fairness based upon parity across the spectrum of human illness.

My second proposed principle for the health care system of the future is that health and mental health services should be delivered along a continuum of care. Such a continuum should begin with prevention. We need to build prevention into our health delivery system once and for all. It must not be an afterthought. Afterthoughts are too late. We need to begin true health and mental health care with substance abuse education and prevention, weight control, family counseling, stress management, genetic counseling, smoking cessation and so forth.

The first step in the continuum of care for a great many illnesses and conditions must be prevention. Of course, we do not really know how to prevent serious mental illness, as we still do not conclusively know how to prevent most major physical illnesses either. Nevertheless, as part of a working principle of continuity, prevention would come first.

Diagnosis and treatment would come next, and occupy equally important status in the paradigm of our proposed second principle. In tomorrow's reformed system of health care we will have to go well beyond our old standby, the simple "medical model:" that is, find it, treat it, cure it, and move on.

We need to expand that continuum of care and make room for follow-up, for aftercare services, and for physical, mental and emotional rehabilitation services. These must also be accepted as part of the continuum of health and mental health services, whether they are delivered as home care, or on an outpatient basis, or as inpatient care or as guided self-care. Whatever is clinically appropriate and ethically possible ought to be done.

I know of no good reason for violating this principle and disrupting the continuum of care. Money, geography, social status . . . these are very poor reasons for a civilized society to decide not to provide any further health care. Rather, it should be this very principle that protects the person who moves from job to job or from city to city.

And I believe this principle of providing continuity of care can be our best weapon against the discriminatory device of "prior conditions." We need to eliminate that phrase from the vocabulary of health care and health coverage.

Americans have trouble accepting the fact that life itself is the aggregate of "prior conditions." To deny recognition to any person's "prior condition," however difficult or puzzling it may be, is to deny that person an integral piece of his or her experience, judging that person as being somehow less than whole. That's nonsense. And I have to tell you that for some of us, it's our "prior conditions" that keep us going . . . that get us up in the morning.

I believe the general public, the government, and the business community--particularly the insurance industry--will correct this situation. I believe we will yet adopt this principle of maintaining continuity of care throughout our health and mental health system, without any of the current baggage that limits care and coverage or actually discriminates among our citizens.

My suggested third principle has hovered around the edges of my discussion thus far, but let's put it out front and center right now. We fashion a system of health and mental health care that is integrated and unified, fully accessible by everyone and fully accountable to everyone.

You all know the basis for this principle. Our system of health care has developed in piecemeal fashion, and our financing systems have grown up in the same way. As a result, we are slipping more and more into becoming a society with a two-tiered system of health care:

One tier offers quality, costly care for people who are employed and privately insured--who "can afford it." The second tier offers a less costly, lower quality of care for employed or unemployed persons who depend on government health and mental health care services--who "cannot afford it."

The principle of having a single, integrated system of care is especially important for persons for whom we are the advocates: that is, addicted persons and persons with mental illness, since they tend to be disproportionately unemployed and under-employed and depend on government services for substance abuse and mental health.

I've suggested three principles that might guide us into designing a better system for delivering health and mental health care in this country:

- First, there must be fairness for all, regardless of race, color, ethnicity, age, gender--or physical or mental condition.
- Second, there must be continuity of care, from prevention through diagnosis and treatment to rehabilitation and follow-up, with no room for prohibitions against "prior conditions."

- Third, there must be a single system of care, accessible and accountable to all.

And now, let me offer my fourth and final principle. After we have committed ourselves to the foregoing three principles, I suggest we then need to keep our eyes on the cost. This may mean a more closely managed health and mental health system of care. It could mean taking a closer look at managed care.

Frankly, we don't yet know the best approach to this. The government has been trying to contain costs ever since "cost containment" became a household phrase over 20 years ago. This is not going to be an easy principle for us to pursue, because, for example, we still do not know the true size of the universe in mental health care.

The conventional wisdom says that nearly 40 million Americans have an alcohol, other drug, or mental disorder--that is, an ADM disorder--during any one month of the year. But in the aggregate, we probably have closer to 52 million persons with ADM disorders. We don't really know. For instance, we suspect that a great many persons with ADM disorders go undetected by their primary care providers or are simply misdiagnosed. I think we could also say that as the present system is structured, there is a financial dis-incentive for a primary care physician to correctly diagnose a mental disorder or a chemical dependency.

At SAMHSA, we are trying very hard to promote much greater evidence of linkage between providers of primary health care and those who provide mental health care and substance abuse prevention and treatment. I believe we're making some progress, but much more needs to be done.

A second reason we are unclear about the true size of the universe is that we still lack a few clear and generally accepted definitions upon which we could base a national patient census. The Congress also recognized this problem and, in that same ADAMHA Reorganization Act, Congress instructed the Secretary of HHS to define the two key phrases that underlie the new Block Grant for community Mental Health Services: The phrases are "children with a serious emotional disturbance" and "adults with a serious mental illness."

Our two proposed definitions were just published in the November 6 issue of the *Federal Register*. We will be receiving comments right up through the close of business, January 5th, 1993. I hope you all will find the time to add your thoughts as well.

What if that estimate of 52 million persons is increased, either through enlightened primary care or through more inclusive definitions? And what if--by some miracle of popular will--the country also adopts my first three principles and becomes committed to equitable, continuous and integrated health and mental health care? Would the U.S. Treasury survive the week? Probably not. That doesn't permit us to say, "Well then, it's back to business as usual." We honestly don't have that option anymore either. Whatever is needed--we still have to do, because this fourth principle is every bit as important as the first three: We absolutely must control the cost of care.

We should prepare for new management controls throughout the health care system. We will need to reevaluate and re-price many or even most of our services. We will need to clarify and strengthen the partnership between the public and private sectors. We might have to rearrange or

disengage some costly relationships now enjoyed by many providers. We should not rule out the possibility of opening the field to new classes of mid-level providers who would deliver less costly or alternative care to patients who need no more than that.

There is going to be a great deal of new thinking going on, to be followed by action. That's what Americans want, and I believe all of us here this evening will want to be part of the response.

I offer you these four principles this evening because, as I noted at the beginning of my remarks, we seem to be poised at a moment in history when many things are possible, when the key word in everyone's discourse has been "change." The American people seem ready to try a few new answers to several old and difficult problems. Our task, it seems to me, would be to seize this day on behalf of the people we represent, the seriously mentally ill and the chemically dependent.

We ought to do that, fully conscious of the fact that our strategies cannot be those of yesterday, but must reflect the political, ethical and fiscal requirements of today and tomorrow. The assignment sounds daunting, but I can tell you that our agency, SAMHSA, is ready and able to move forward. We intend to be part of the reform process that is already beginning to unfold.

I'll close now with one of my favorite little stories. It's about the visitor who once asked the great Mahatma Ghandi what he thought of western civilization. Ghandi said, "It's a good idea."

In a way, we're in Ghandi's position. When we're asked "What do we think about the future of ADM health services?" We might well answer, a little breathlessly maybe, "Yes, it's a good idea."

We have to do better than that. We have to come forward and spell out our "good idea" to the people of this country. And if the intellectual energy represented here this evening is any indication, I truly believe we'll do it--and do it very, very well.

Thank you.

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on Mental Health Policy*

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**MENTAL HEALTH IN HEALTH CARE REFORM**

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November 19, 1992

**PROGRAM**

- 8:30 - 9:15 a.m. Registration  
Continental Breakfast
- 9:15 - 10:00 a.m. Welcome:  
**John B. Hardman, M.D.**, Program Chair  
*Associate Executive Director, The Carter Center*
- Introduction:  
**Thomas E. Bryant, M.D.**  
*Chairman, Non-Profit Management Associates, Inc.*
- Keynote Address:  
"MENTAL HEALTH IN HEALTH CARE REFORM"  
Rosalynn Carter, Chairperson
- 10:00 - 11:15 a.m. **CITIZENS' PANEL**  
Discussion and Questions
- Moderator:  
**Julius B. Richmond, M.D.**  
*John D. MacArthur Professor of Health Policy Emeritus, Harvard University,  
Visiting Fellow, The Carter Center of Emory University Mental Health Program*
- Panel:
- Betty Bailey, Ph.D.**  
*Corporate Benefits Manager, Digital Equipment Corporation*
- Horace B. Deets**  
*Executive Director, American Association of Retired Persons*
- John Galles**  
*Executive Vice President, National Small Business United*
- Bernice Weissbourd**  
*President, Family Resource Coalition*
- 11:15 - 11:30 a.m. Break
- 11:30 - 12:45 a.m. **ELECTED OFFICIALS' PANEL**  
Discussion and Questions
- Moderator:  
**Thomas E. Bryant, M.D., J.D.**  
*Chairman, Non-Profit Management Associates, Inc.*
- Panel:
- Rep. Nancy Johnson**  
*Republican/Connecticut*
- Rep. Mike Kopetski**  
*Democrat/Oregon*
- State Rep. Jim Martin**  
*Democrat/Georgia*
- State Senator-Elect Mary Margaret Oliver**  
*Democrat/Georgia*
- 12:45 - 12:55 p.m. Concluding Remarks:  
**Jeffrey L. Houpt, M.D.**  
*Dean, Emory University School of Medicine*
- Rosalynn Carter**  
*Chairperson*

The Eighth Annual Rosalynn Carter Symposium on Mental Health Policy  
**MENTAL HEALTH IN HEALTH CARE REFORM**

Rosalynn Carter, Chairperson

November 19, 1992

**AFTERNOON PROGRAM**

2:00 - 2:15 p.m.

**Cyprus Room**

Welcome:

**Rosalynn Carter, Chairperson**

Orientation to Work Groups and Introductions:

**Leslie Scallet, J.D.\***

*Director, Mental Health Policy Resource Center*

2:15 - 3:30 p.m.

**Work Groups:**

Group Facilitators:

1. **Kathryn Cade\*** Rotunda  
*Managing Director  
Bank of Boston*
2. **Jane L. Delgado, Ph.D.\*** Cyprus Room  
*President, CEO  
The National Coalition of Hispanic and  
Human Services Organizations*
3. **Joseph T. English, M.D.** Cyprus Room  
*President  
American Psychiatric Association*
4. **Frederick Goodwin, M.D.** Cyprus Room  
*Director  
National Institute of Mental Health*
5. **Charles Nemeroff, M.D.** Zaban Room  
*Chairman  
Department of Psychiatry  
Emory University*
6. **Jerilyn Ross, M.A.** Presidential  
Conference  
Room  
*President  
Anxiety Disorders Association of America*
7. **Richard Surles, Ph.D.\*** Executive  
Director's  
Conference  
Room  
*Commissioner  
New York State Office of  
Mental Health*
8. **William S. Woodside\*** Lower  
Commons  
*Chairman  
Sky Chefs, Inc.*

3:30 - 4:15 p.m.

**Cyprus Room**

Reports from Work Groups:

**Leslie Scallet, J.D.**

Closing Remarks:

**Rosalynn Carter**

*Chairperson*

\* Carter Center Mental Health Task Force Members



# CARTER CENTER MENTAL HEALTH TASK FORCE

## Task Force Members

Rosalynn Carter, *Chairperson*

Dr. Johnnetta Cole, *President, Spelman College*

Dr. Jane Delgado, *President and Chief Executive Officer, National Coalition of Hispanic Health and Human Services Organizations*

Dr. Leon Eisenberg, *Professor, Department of Social Medicine, and Professor of Psychiatry, Harvard University*

Robert Ray, *Governor of Iowa, 1969-83; President and Chief Executive Officer, Blue Cross and Blue Shield of Iowa*

Leslie Scallet, J.D., *Executive Director, Mental Health Policy Resource Center*

Richard Surles, Ph.D., *Commissioner, New York State Office of Mental Health*

William S. Woodside, *Chairman, Sky Chefs, Inc.*

Joanne Woodward, *Actress; Director*

## Ex Officio Members

Dr. Thomas Bryant, *Chairman, President's Commission on Mental Health, 1977-78; Chairman, Non-Profit Management Associates, Inc.*

Kathryn Cade, *White House Projects Director for First Lady Rosalynn Carter; Managing Director, Public Finance, Bank of Boston*

Dr. Jeffrey Houpt, *Dean, School of Medicine, Emory University*

Dr. Antonia Novello, *Surgeon General of the United States*

## Fellows and Staff

Dr. Julius Richmond, *Surgeon General of the United States and Assistant Secretary of Health and Human Services, 1977-81; John D. MacArthur Professor of Health Policy, Emeritus, Harvard University; Visiting Fellow, Carter Center Mental Health Program*

Dr. William Foege, *Director, Centers for Disease Control, 1977-83; Executive Director and Health Policy Fellow; The Carter Center*

Dr. John Hardman, *Director, Mental Health Program, The Carter Center of Emory University; Associate Executive Director, The Carter Center*

Dr. Carol Koplan, *Assistant Director, Mental Health Program, The Carter Center of Emory University*

Dr. Maryann Roper, *Science Consultant, The Carter Center of Emory University*

Miss Margaret Cornett, *Mental Health Program Administrative Assistant*

Mrs. Ellen Wright, *Mental Health Program Temporary Assistant*

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

**Academy of Psychosomatic Medicine**

Richard C. W. Hall, M.D., *Past President*

**Advocates for Child Psychiatric Nursing, Inc.**

Charlotte M. Gilbert, Ph.D., R.N., C.S., *President*

**American Academy of Child and Adolescent Psychiatry**

David B. Pruitt, M.D., *Chairman,*  
*Work Group on Consumer Issues*

**American Association for Counseling and Development**

Lee Joyce Richmond, Ph.D., *President*

**American Association for Marriage and Family Therapy**

Mark Ginsberg, Ph.D., *Executive Director*  
Ray Bardill, Ph.D., *President*

**American Association of Pastoral Counselors**

C. Roy Woodruff, Ph.D., *Executive Director*

**American Association of Psychiatric Services for Children**

Shepard Goldberg, Ph.D., *President*

**American Association of Retired Persons**

Horace B. Deets, *Executive Director*

**American Association of Suicidology**

Patrick O'Carroll, M.D., *Representative of the President*

**American College of Neuropsychopharmacology**

Roger Meyer, M.D., *President-Elect*  
Oakley Ray, Ph.D., *Secretariat*

**American Hospital Association**

Rebecca Chickey, *Acting Director*

**American Medical Association**

Mary Ann Contogiannis, M.D., *Member, Board of Trustees*  
*President, Physicians Health Foundation*  
Marshall Rosman, Ph.D., *Director, Department of*  
*Mental Health*

**American Nurses Association**

Carla Serlin, Ph.D., *Director of Minorities*  
*Fellowship Program*

**American Psychiatric Association**

Joseph T. English, M.D., *President*  
Melvin Sabshin, M.D., *Medical Director*  
Paul J. Fink, M.D., *Past-President*

**American Psychiatric Nurses Association**

Anne Marie T. Brooks, R.N., D.N.S.c., M.B.A., *President*

**American Psychoanalytic Association**

Lawrence Inderbitzin, M.D., *Director, Emory University*  
*Psychoanalytical Institute*

**American Psychological Association**

Raymond D. Fowler, Ph.D., *Chief Executive Officer*  
Henry Tomes, Ph.D., *Executive Director*

**American Psychological Society**

Alan G. Kraut, *Executive Director*

**Anxiety Disorders of America**

Norman Klombers, D.P.M., *Executive Director*  
Jerilyn Ross, M.A., L.I.C.S.W., *President*

**Association of Mental Health Clergy**

Rev. George Doebler, *Executive Director*  
Fr. Ira Lott, *President*

**Black Psychiatrists of America**

Isaac Slaughter, M.D., *President*

**Center for Mental Health Services (of SAMHSA)**

Frank J. Sullivan, Ph.D., *Acting Director*  
Irene Levine, Ph.D., *Acting Deputy Director*

**Compeer, Inc.**

Bernice W. Skirboll, M.S., *Executive Director, President*

**Federation of Families for Children's Mental Health**

Creasa Reed, *President*

**International Association of Psychosocial  
Rehabilitation Services**

Ruth Hughes, Ph.D., *Executive Director*  
John Woods, *President*

**Institute for Behavioral Healthcare**

Michael A. Freeman, M.D., *President*

**Mental Health Law Project**

Leonard S. Rubenstein, Esq., *Executive Director*

**Mental Health Policy Resource Center**

Leslie J. Scallet, J.D., *Executive Director*  
Jim Havel, *Associate Director*

**Missouri Institute of Mental Health**

Rebecca Defillippo, M.B.A., *Continuing Education Coordinator*

**National Alliance for the Mentally Ill**

Laurie M. Flynn, *Executive Director*

**National Alliance for Research on Schizophrenia  
and Depression**

Connie Lieber, *President*

**National Association of Private Psychiatric Hospitals**

Robert Trachtenberg, *Executive Director*  
Jack W. Bonner, III, M.D., *President*

**National Association of Protection and  
Advocacy Systems, Inc.**

Curtis Decker, *Executive Director*

**National Association of Psychiatric Treatment Centers  
for Children**

Joy Midman, *Executive Director*

**National Association of Social Workers**

Barbara W. White, Ph.D., A.C.S.W., *President*

**National Council of Community Mental Health Centers**

Charles G. Ray, *Chief Executive Officer*

**National Depressive and Manic-Depressive Association**

Helen Hintz, R.D., *President*

**National Federation of Societies for Clinical Social Work**

Nelia Rivers, L.C.S.W., *President*  
Marty Wakeland, *Past President*

**National Foundation for Depressive Illness**

Peter Ross, *Executive Director*  
Paul H. Wender, M.D., *Chairman of the Board*

**National Institute of Mental Health**

Frederick K. Goodwin, M.D., *Director*  
Alan I. Leshner, Ph.D., *Deputy Director*

**National Mental Health Association**

John Horner, *National Executive Director*

**National Mental Health Consumers' Association**

Paul Engels, *Treasurer, Past-President*

**Obsessive Compulsive Foundation**

James W. Broatch, *Executive Director*  
Patricia Perkins, *President*

**Pathways to Promise**

Jennifer Shifrin, *Executive Director*  
Jane Hall Harvey

**Project SHARE**

Joseph A. Rogers, *President*

**Society for Education and Research in  
Psychiatric Mental Health Nursing**

Jeanne Clement, Ed.D., R.N., C.S., *President*

**Substance Abuse and Mental Health Services  
Administration**

Elaine Johnson, Ph.D., *Acting Administrator*

(Center for Mental Health Services - see above)

**World Federation for Mental Health**

Eugene B. Brody, M.D., *Secretary General*  
Richard S. Hunter, *Deputy Secretary General*

## MORNING SYMPOSIUM PROGRAM

November 19, 1992

### John Hardman

Welcome to the Eighth Annual Rosalynn Carter Mental Health Symposium. I'm John Hardman, Associate Executive Director, of The Carter Center. The topic for this year's Symposium is *Mental Health and Health Care Reform*, a very timely topic considering changes we now are facing not only in the health delivery system, but in our government. The response that we've had this year has been tremendous, and this is the largest group ever attending the Rosalynn Carter Mental Health Symposium. Some of the attendees are in the auditorium of the Jimmy Carter Presidential Library where they are watching on video and will be participating in the question and answer sessions by writing their comments and sending them over. We have over 50 mental health organizations represented today. This is the largest group of individuals in mental health leadership positions to gather at any one specific time to discuss a single topic. We are pleased that all of you are here. The Symposium is possible because of the generosity of the van Ameringen Foundation and the John D. and Catherine T. MacArthur Foundation. Mr. van Ameringen is here. Please stand, Mr. van Ameringen, so we may recognize you. Also Dr. Dennis Prager and Dr. Laurie Garduque of the MacArthur Foundation are here. Please stand and be recognized.

The Mental Health Task Force at The Carter Center held its first meeting in September of 1991, with the generous support of the MacArthur Foundation. The Task Force has been working through subcommittees in the specific areas of mental health and health care reform, prevention and early childhood development and media. Additional areas that the Task Force has selected to focus on are the seriously mentally ill and research. The Task Force members have participated in every aspect of this program and the subcommittee on mental health and health care reform provided much of the background work for today's program.

I would like to introduce members of the Task Force and our Visiting Fellow in Mental Health here at The Carter Center. Our Visiting Fellow is Dr. Julius Richmond. Dr. Richmond is the John D. MacArthur Professor of Health Care Policy at Harvard University. Dr. Jane Delgado is President and CEO of the National Coalition of Hispanic Health and Human Services organizations. Leslie Scallet is the Director of the Mental Health Resource Center in Washington, D.C. Dr. Richard Surles is the Commissioner of New York State Mental Health Office. Katherine Cade is the Managing Director of Public Finance, the Bank of Boston. Dr. Jeffrey Hout is Dean of Emory University Medical School. Dr. Tom Bryant is Director and Chairman of Non-Profit Management Associates. I would also like to recognize the staff of the Mental Health Program that has worked so hard on this Symposium and with the Mental Health subcommittees: Dr. Carol Koplan the Assistant Director, Margaret Cornett the Program Assistant, and Ellen Wright, who is the Symposium coordinator.

Tom Bryant is a member of our Task Force, but Tom wears many hats. He currently serves as Chairman of Non-Profit Management Associates located in Washington. He is a graduate of Emory University Medical School and Emory University Law School. He is licensed to practice both medicine and law in the state of Georgia and Washington D.C., (District of Columbia). He holds board memberships in many organizations including the National Alliance for Research on Schizophrenia and Depression, Friends of the National Library of Medicine, and the Rosalynn Carter Institute for Human Development. Tom chaired the President's Commission on Mental Health in 1977. Most of you know Tom, and it is a great pleasure to present him to you now.

### **Tom Bryant**

Thank you, John. It is always a pleasure to be here; this is the eighth year. Some of you, no doubt, are getting tired of my face, but you are not getting tired of my words, because I have the same distinct pleasure every year, which is to introduce Rosalynn Carter. However, it provides another opportunity for us, and that is, to thank Rosalynn Carter. I think that it is no overstatement to say that Rosalynn Carter is the leading mental health advocate on behalf of mental health causes in the entire world. It's been something she's been about for more years than she probably wants to admit. She's been about it for a long, long time; since her husband was Governor, and even before. It reached a certain plateau when the Carters were in Washington, for too brief a time, and when President Carter created the President's Commission on Mental Health as one of the first things that he did after being sworn in as President of the United States and named Rosalynn as the Honorary Chairperson. Those of us who were members of that Commission and who worked with her learned first hand how devoted she was to the cause of mental health, and how determined she was to improving the lot of those who suffer from mental illnesses. She worked tirelessly then and has worked tirelessly since then. This Annual Symposium is but one example of the kinds of things to which Rosalynn devotes her attention, and I think that all of this needs to be put into context, from The Carter Center which is the site where we meet and where this work goes on, particularly this promising work of the Mental Health Task Force that John has just been telling us about. I think that it is no overstatement to say that this site, as the home and the base for the Carters, and all things associated with the Carters, has become synonymous to the world with what good volunteer efforts are all about on behalf of good causes. It is phenomenal what happens here and what happens because of her. So would you join me in thanking and in welcoming to her own home, Rosalynn Carter. Thank you.

### **Rosalynn Carter**

Thank you very much. It is wonderful to have you here this morning and to have so many organizations represented. And I want to thank the van Ameringen Foundation and the MacArthur Foundation again for making this possible for us.

When you came into The Carter Center you could not have helped seeing all of the construction and so I thought I would tell you that part of it is the road that is going to give better access to The Carter Center, and the other part, on this side of the lake across from the Library, is a new pavilion we are building. It is going to have a chapel which can also be used as an auditorium and will seat 450 people. So next year, I have my fingers crossed, we won't have to have people in the overflow room. We can have our entire meeting in the new building. I'm looking forward to that.

"Superman will die, killed by a super lunatic, an escapee from a cosmic insane asylum!" This was the headline in papers across the country in September; and just last month, here in Georgia, the news was, "Six Flags Over Georgia to open Halloween attraction: 'Asylum of Horrors'." Well, as we gather this morning for our Eighth Annual Symposium, it seems as if you and I have been fighting myths and misconceptions and stereotypes about mental illnesses for decades. And indeed, many of us have! It has been over twenty years since I began working in the mental health field, and yet, so much has changed. A quick response from mental health advocates and Superman's killer is really a cosmic criminal. And the new Halloween attraction at Six Flags is A House of Horrors.

We are learning a little about how to influence the media and about how to change public attitudes and shape public policy. Today I want to talk to you about our most important challenge of the decade: to ensure that as the debate over national health care reform proceeds we win a victory for mental health in any new plan. There is so much going on in our field that offers great hope to those who suffer from mental illnesses and to their families. And much of this has implications for the debate over including mental health care in national health care reform.

Progress in understanding the biology of the brain has been nothing short of amazing. We now know more about how messages are sent from one nerve cell to another. We can take pictures of the brain without surgery or injections. We can measure activity related to different emotions and behaviors, and we have learned much more about how medicines act in the brain. And through careful clinical trials we have used this knowledge to significantly improve treatment. New medications are helping people suffering from depression and anxiety. Special kinds of psychological therapy are also proving to be effective in treating depressed individuals. And, we have new drugs that work for some patients with schizophrenia who have not responded to earlier kinds of treatment.

I want to tell you just one success story. A 37-year old man suffering from schizophrenia for almost twenty years was in and out of psychiatric hospitals. He heard strange voices and he preached to other patients that his prayers would save the world. In 1989 he began treatment with a new drug, Clozapine, and today he is greatly improved and he is about to become a college graduate.

The new treatments reduce symptoms and restore personal effectiveness, not for all patients, but for many; not always, but often; not for good, but for long periods of time. Yet many who could benefit from treatment are not receiving it. Even those with the most severe mental illnesses could improve through treatment with the new medications and rehabilitation. Yet the hope of recovery is denied to hundreds of thousands because of the lack of access to care.

Many who could benefit remain incapacitated because they do not have any way to pay. Hundreds of thousands more, and their families, face serious economic hardship because of limited coverage under most existing insurance plans. I get many letters from distraught families describing their financial burdens and their efforts that are so frustrating, in trying to obtain care. The stark reality is that our current system of public and private insurance discriminates badly against those in need of a broad array of mental health services.

Our own Emory University is shifting insurance companies--or coverage--and the new policy provides up to one million dollars for physical illnesses and up to seventy-five thousand dollars for mental illnesses. And this is one of the better policies! This is one of the best policies.

Well, most of you know my biggest disappointment after leaving the White House was the failure to implement the Mental Health Systems Act of 1980. We lost a wonderful opportunity to create landmark change in the financing and delivery of mental health services. I am very proud though that because of the efforts of many of you in this room today and your organizations, some of its most significant principles were incorporated into new or existing programs during the 1980's.

Small but important victories were achieved in the use of SSI and Medicaid to support people with severe mental illnesses in the community, and programs like the Green Door in Washington, D.C., became possible. The Fair Housing Act and Americans with Disabilities Act now prevents discrimination against those with mental disabilities. Slowly, much too slowly, those with mental and emotional problems are being significantly included in programs designed to protect and support them.

Today we are at a crossroads. We are faced with an opportunity to bring mental health into the mainstream of our nation's health care system, and we cannot afford to miss this opportunity and we cannot afford to fail.

We have new strength in Congress: The House Working Group on Mental Health, and Congressman Kopetski are here this morning. This Working Group can serve as a focal point for marshalling our efforts. We have important new, relatively new, organizations. The National Alliance for the Mentally Ill and the Anxiety Disorders Association of America, and many others, such as the National Mental Health Association, are stronger and more effective than ever. And, we have a new Administration in Washington. Tipper Gore told me she is going to work on mental health issues. And very importantly, national mental health organizations are joining to work together to form a coalition to influence the debate over health care reform. I want to emphasize to you this morning that I fully support the message: "health care reform without equitable mental health benefits is no reform at all." Embodied in this message are three key principles that should guide all our activities.

First, we must end discrimination against those with mental disorders. Discrimination has denied those who need access to appropriate services for far too long, and it continues to limit resources available to pay for care. The stigma of mental illnesses is still all too pervasive in our society, no matter how much we have worked on it. We need more people like Patty Duke and William Styron speaking out about their mental illnesses and about their treatment and recovery.

Secondly, we must recognize that to be healthy one must be mentally healthy. Mental health is an integral part of every person's health. Awareness of mental health problems needs to permeate the health care system. Primary care physicians, nurses, physicians assistants, all must have sufficient knowledge about mental health and the interdependency between mind and body to know when intervention is necessary and who is best able to intervene.

Not many people outside the mental health field understand the nature of mental disorders or how treatable they are. Not only those in medicine, but policy makers, other health care providers and the general public, need to know more about the advances in treatment. And we, those of us in the mental health field, are the ones who are responsible for bridging that gap.

Thirdly, we must recognize the need to direct our resources in new ways. Appropriate mental health care doesn't cost too much. Lack of proper care has great emotional and financial consequences. Investing in early intervention treatment and follow-up care will prevent far more costly disability and even death. It is time for us to unite behind a common vision of our historic mission which transcends special interest in the field. The mental health community has a critical role to play in promoting a society whose individual members are healthy in mind and in body.

We must not waiver in our support of people with the most persistent disabling mental illnesses. We must ensure that these individuals have the comprehensive coordinated services they need to live in the community and the resources to obtain more intensive care in times of crisis. We cannot turn our backs on the millions of Americans--young and old, rich and poor, every race and ethnic origin--who at some point in their lives will need some kind of treatment for a mental health problem that can be reversed.

You and I know these people. They are our friends, our neighbors, our colleagues at work, they are members of our families, they are ourselves. One could be a young girl in Homestead, Florida, whose home is destroyed by Hurricane Andrew. She starts having nightmares, she can't sleep, she has stomach aches, she refuses to go to school. With the help of therapy she is able to conquer her fear about another hurricane. Her physical symptoms and nightmares gradually decrease, and she is able to go back to school.

Or one could be a 50-year old father of two children who loses his job and after three months of looking for work, he becomes despondent, withdrawn, and stops searching for employment. His family convinces him to see a physician, an enlightened physician I have to admit, because he referred him to a psychiatrist, and after treatment with medication and psycho-therapy he is able to resume his job search and become successfully employed again.

Our advocacy must embrace all those who suffer from mental health problems. We must not provide for care based only on a hierarchy of pain. We must actively lobby for fair and equitable coverage for everyone who is in need of mental health care.

For each of us this means an advocacy of inclusion. A willingness to pull together rather than pull apart. We can strengthen our ranks far beyond the sum of our individual numbers, but to do that we must speak with a clear, consistent and unified voice. And together, I believe, we can ensure that under any health care reform the following principles are embraced. Keep in mind the three principles I mentioned earlier: an end of discrimination; an awareness of mental health problems permeating the whole health care system; and the need to direct our resources in new ways. I want to carry these a step further to a list to guide us. There are seven items:

1. Mental health must be integrated into every health care reform package.
2. Any reform must ensure the availability of a broad array of mental health services to all people experiencing mental health disorders.
3. Mental health benefits should be based on the same principles and subject to no greater limitations than other health care benefits.
4. Promotion, prevention and follow-up activities are as essential as the delivery of acute care.
5. The role of the individual in determining a treatment plan must be viewed as central and never ignored.

6. Mental health services must meet the needs of the individual regardless of age, race, ethnicity, language or gender.
7. Prevention of unnecessary treatment and assurance of quality care must be monitored through careful review by competently trained professionals.

Our task is not going to be easy. It will be a struggle against ignorance, against entrenched interest, against the massive inertia of the health care system and yes, against some of the cherished traditions of our own respective organizations. We must keep in mind what the struggle is about. It is about individual human dignity. It is about the recognition of the worth of every person regardless of what disability he or she may have. About the need to see people as whole human beings; and the right of people to enjoy equal opportunity and equal treatment in all aspects of life, including physical and mental health care. It is about the importance of reducing dependency for those who are suffering from mental and emotional problems, and about the creation of new opportunities for individuals through treatment and recovery in order to become contributing members of society.

Mental health must be a part of health care reform. We can no longer afford to keep separating the body and the mind. We must unite in support of comprehensive care for the individual as a whole, rather than as isolated parts.

There is great excitement in the mental health field today. This is a time of hope and opportunity when new knowledge from research is dramatically improving care. And it is a time when the prospects for achieving equality in access to that care have never been greater. Each of us has an important role to play in the struggle. Working together, I am confident we can achieve our new vision for those we all care about. Thank you.

#### **John Hardman**

I think all of you can see that with Mrs. Carter chairing the Task Force and the Mental Health Program here at the Center, and working with all of our organizations, there is no way that we can fail. We thank her for the dedication and hard work on mental health problems over the last 25 years.

Would the Citizens' Panel please come up to take their places here at the panel table? The moderator for the panel is Dr. Julius Richmond, and he will introduce the panel members. There will be time after their presentations for questions and answers. If you will please use the microphones at each end of the room and give your name before you ask your question, so the people in the other room can hear. It would also help us in recording the proceedings of this meeting for publication.

#### **Julius Richmond**

Well, thank you very much John. On behalf of the whole group I would like to express our appreciation to Mrs. Carter again for her inspiring remarks and the leadership she is providing for all of us in the cause of improving the mental health programs and services for people not only in this country, but throughout the world.



I've been asked to serve as the moderator of this Citizens' Panel. I think it's called "citizens' panel" because the distinguished people who will be presenting to us represent organizations of quite different constituencies around the country, and we have a good deal of work before us today. This first panel precedes a second panel, just so that you can see where we are in context. The second panel will be one in which elected officials will respond to the challenge of Mrs. Carter on the issues of mental health in health care reform.

Before introducing the panelists I would like to say just a word about how opportune this Symposium is, what an opportune time we have. I think we have all recognized over the past several months that health care reform has broadly risen on the national agenda to have an extremely high priority; it and the economic issues facing the country seem to go in tandem. The press certainly talks about these almost with equivalence. It is important as we contemplate health care reform for the nation, as Mrs. Carter has indicated to us, that we make certain that the provisions for mental health services, mental health care and mental health programs are incorporated fully and equitably.

I will introduce the panelists just prior to their speaking, so I will now take the opportunity to present the first person on our panel, Dr. Betty Bailey. Dr. Bailey is the Corporate Benefits Manager for the Digital Equipment Corporation, but she is very uniquely qualified to talk to us. She has her doctorate in psychology; she has served as a faculty member in departments of psychology; she has been a practitioner and is licensed to practice clinical psychology; and, in addition, has turned her attention to organizational behavior in corporate settings and has made significant contributions to improving productivity by paying attention to the behavioral aspects of organizations. So now, I would like to call upon Dr. Betty Bailey.

### **Betty Bailey**

Thank you. I'd like to offer you first a perspective of what it's like to be a large volume purchaser. One of the metaphors that I have for being a large volume purchaser at Digital Equipment is, when dealing with mental health and health care, it is akin to doing white water rafting where there are a lot of boulders in the river. And some of the boulders that we try to guide our way around (and still end up with a good product for employees) encompass, first of all, having very good cost management. Health care costs for all of us consume a tremendous amount of our assets in large corporations. So, what we try to do is to look at cost effectiveness within health care, and be very aware of the cost impact on our product margins.

The second boulder that we try to forge our way around as large volume purchasers has to do with the quality of care, because we care very much about what all of our employees are receiving in the various health care systems. And to forge around those boulders what we are always doing in our benefits plan designs, in our interactions with other insurers, is to constantly rebalance what it is that employees need, and what it is that we can afford.

The other boulder in the river for us has to do with legislation. My company, just this last summer and fall, spent a tremendous amount of time on FAS 106 looking at our retirees' medical costs, both the health costs and mental health costs, that encompass accruing for FAS 106. Just when you think you are safe in that river, there is legislation that large employers are responding to. And with all that in mind, what we really have happening in large corporations is that benefits,

and what we're offering to employees, is becoming both an employee relations and morale concern, as well as, a survival issue because of cost.

Now, what do we do about all this? Most of us, 84% of us, are managing ourselves in some form of managed care environment, whether that be a point of service, a managed HMO approach, a managed indemnity plan, or PPO arrangement. However we're doing it, I think the watchword is experimentation. When we look at mental health as part of our overall cost, there are a lot of different approaches, even within managed care, that large volume employers are experimenting with, and indeed experimentation is the by-line.

There is no panacea, there is no one approach that employers are taking in mental health. Some employers are limiting mental health services; and some are trying to figure out how to negotiate with managed care organizations to provide optimal services, and some are carving out mental health benefits and separating it so that they think they can either contain or better understand what to do in the mental health arena.

I think that one of the challenges we face and one of the most important things that we can do in a large volume situation, and need to do more of, is to work with delivery systems to better understand the mental health needs of employees, and by having that understanding, to then justify what we need to be offering for employees. That really leads us into the realm of outcomes research and outcomes management, which I very strongly advocate and wish that more large volume employers were undertaking. I'd like to describe to you, as a mini-case study, what we're doing at Digital, just to give you more of a feel for what it's like to be a large volume purchaser. I think I can bring home to you in a little more realistic way what Digital is doing in the world of mental health, and how we're coping with all of these boulders in that white river.

First, let me describe who we are. Digital Equipment Corporation is a Fortune 500 company. It was founded in 1957, so we are a relatively young company with approximately 100,000 employees world-wide. We're one of the leading makers of computing solutions, computers, semiconductor technology, and a large seller of computing services and equipment. Here is an approach that has worked for us at Digital. If you can envision a triangle, the first leg of that triangle is integration. What we have done is to construct a vision for mental health. I was very heartened to hear you talking about vision, Mrs. Carter, because we found vision to be really a guiding light to us in terms of how we construct our mental health services and our benefits. Without a vision as a large purchaser, it's very hard to know where you're going. And one of the things we have emphasized in our vision is duality of the mind and the body. The need to take care of both the physical and the psychological needs of employees, and to do that in tandem with a lot of education and prevention that our employee assistance providers help us with in an ongoing way.

We also set high standards of quality as part of our vision, and have state-of-the-art plan design in our benefits plans. We want to support, as part of our vision, the employees throughout their life cycle. We recognize that our employees who are twenty years old have different sorts of psychological needs than those employees who are thirty, forty, fifty, sixty and so on. So the vision lets us set a leadership approach across the spectrum of mental health services that we offer as part of our benefits plans. We also integrate among the various constituencies who deal with our mental health plans and place the accountability for putting forth good benefit plan designs in mental health.

We work in tandem with our employee assistance providers, as well as with John Hancock, who are our network managers for the 90 HMO's, plus the two indemnity plans that make up our health delivery systems in Digital. And to forge that integration bond we have something that we call the "psychology task force" that meets on a regular basis to set strategy, to review what we are doing, and to manage the whole mental health portfolio. A good EAP (Employee Assistance Program) is a key intervention in companies. They not only are a bridge to longer term treatment and shorter interventions, but they also counsel employees, help them with return to work issues (should the employee have a disability), and they do a tremendous amount of training and awareness.

Going back to the prevention arm of the vision, we recently had been growing at up to 30%. So Employee Assistance helps us with training courses on managing change, managing stress in the work place, and how to deal with troubled employees. Now we have the inverse of a 30% growth rate. We're faced with downsizing as are many large corporations, so EAP helps employees and managers best deal with the trauma and difficulty of managing transition. They also are a sponsor of self-help support for employees. An example being Alcoholics Anonymous and Narcotics Anonymous. Through integration of the first leg of the triangle, a very aggressive use of EAP enables significant accomplishment towards mental health intervention on behalf of the employees.

The second leg of that triangle has been to work with the delivery system. We've taken a total quality management with our delivery system, again, being primarily based in managed care, and what we've done is develop with our HMO's and John Hancock, standards that serve as guiding lights. One of the things that we've done as part of our standards is to flex the mental health benefit. What that has done has had a profound effect within the HMO's, it has highlighted the importance of mental health care, and elevated the importance of mental health within the HMO environment. What we are doing is basic treatment, not on some preordained number of sessions, but rather on what it is that the individual needs to stay whole as clinically indicated, and to help them be a productive member of Digital.

Part of our benefits flex has some sub-objectives. One is a triage. We advocate and work with the HMO's to have functional assessment tools so that a good treatment plan can be worked out for an employee. What we don't want to have is a blanket approach for treatment. A metaphor might be, if you have a hammer, the world looks like a nail. We don't want to have that sort of approach for our employees, but rather, we want people who need group therapy, should they have a substance abuse problem for example, be allowed to have group therapy. Those who need individual counseling to have a treatment plan that allows their needs to be met, etc. And we want to be offering good case management, so that there's coordination of care, and the primary care physician can understand and coordinate services across the array of all health services.

And then lastly, one of our standards for mental health is outcome data. We truly want to know what works best for employees in mental health areas. Outcome data can provide some answers that we may mainstream and transfer that knowledge to other large providers.

The third leg of the proverbial triangle is to work with external organizations. The Washington Business Group on Health, the Carter Foundation, and others, are a vital part of staying on top of what is state-of-the-art technology in mental health as well as it offers an arena in which to participate in various projects, some of which are in the outcomes research vein. One example of such a project that we are working on now is a depression outcome study that we're partnering

with three of our HMO's and the Washington Business Group on Health. We're hoping to have some preliminary data in just a few weeks from this depression outcome study that we may share with others and which will also give us some advice and direction in how best to deal with depression across all of our 90 HMO's.

In closing, I think having an integrated approach internally working with others, externally working with the delivery system to best understand what the needs of employees are, lets us offer a comprehensive spectrum of care. I would hope that the government and large business, and other interests that are represented here, partner in whatever we undertake. And I would hope that we also take an activist approach for mental health. I believe that all of us need to work in concert as activists to have the best possible outcome for health care reform, and certainly for mental health as an important component. I would hope that there is a spectrum of care, because people need different sorts of services depending on where they are in life, and depending on what their problems are.

### **Julius Richmond**

Well thank you very much, Betty. I would again remind all of you to keep your questions in mind so that when each of the panelists has presented we can then have a question and answer period. For those who are in the museum library, be sure to be writing your questions so that we can have them over here for responses. The next participant in our panel is a person who is the Executive Director of one of the largest, if not the largest, membership organization in America, the American Association of Retired Persons (AARP). When one gets to the stage in life that I've arrived at, one looks very closely at what the AARP does, and I must say, after looking closely over these many years, I really like what I see in terms of its leadership. It is quite remarkable, since Horace Deets has taken over the leadership in the AARP, he really has moved into a kind of statesman-like position of leadership that has become very important to all of us in the nation. I could say many things about Horace Deets, but I think what I want to say most is that he represents what a keenly honed social conscience, combined with leadership skills, can bring to policy development for a very significant segment of our population. He has led the organization into drafting a health care plan which was published in the last issue of the AARP Bulletin. The plan is *Health Care America*.

More than that, as evidence of his statesmanship, he has a column on each issue of the bulletin and here on page 3 his column *As We See It*, is a column that's titled: *It's in our Interest to Aid the World's Children*. And that's what I mean by statesmanship, that he's carried the organization beyond the parochial view of interests exclusively for the elderly to a broader approach on behalf of our society. It brings us to an appreciation that the elderly in our society also need to devote some attention to the care of the young. And so it is with a great deal of pleasure that I introduce the distinguished Director of the AARP, Horace Deets.

### **Horace Deets, American Association for Retired Persons**

Thank you very much for those very kind words. I'd love to take a copy of that to share with my staff. They've given me a banner which says, "Happiness is Waking Up in the Morning and Finding Your Boss' Picture on a Milk Carton."

At AARP we basically divide the world into two, members and potential members. And with 33 million members and growing, it seems that we are half way there. In fact, it does constitute one half of America's population age 50 and over, which is the eligible group. It has its drawbacks too, because there are a lot of perceptions of what that means and what we do. Last night when I met with President Carter, he said, "Oh yes, you are the group that's running the country." And I said, "Don't I wish." He said, "Well you are, I'm a member, I know." And I said, "President Carter, if I had one-half the power attributed to me, we would have health care reform in place today." This has been an issue for us for many years.

This morning Mrs. Carter has put forth a very comprehensive blueprint of what true health care would be with its inclusion of mental health benefits. And she's given us a sense of urgency and I think a sense of direction. For me this seems something like the words of that eminent American philosopher, Yogi Berra, "This is déjà vu all over again." Because, in 1972 I was working with the Washington Hospital Center in Washington, D.C., as part of a model alcoholism treatment program that National Institute on Alcoholism and Alcohol Abuse (NIAAA) had funded, based on a concept that we should treat people where they are, since 95% of the alcoholics are not skid row bums. And there was nothing on an out-patient basis. So we had an out-patient psychotherapy counseling center and we stressed family counseling, trying to get to causes as well as symptoms. And some of the same problems that we are hearing today we heard then. That is, the insurance companies, at that point, considered alcoholism a self-induced illness and therefore not covered. It's not much different today, although we do see some hopeful signs.

I'm also pleased to be here as part of AARP because for the elderly this is doubly difficult. Older people as a group have to swallow a double dose of misinformation about mental health. First of all, today's older Americans grew up in a time when emotional problems were considered a sign of character weakness. You didn't discuss these, you didn't share them with others. The stigma was very pronounced, and those stigmas die very hard. Secondly, they're coping with the fact that physicians and mental health professionals only lately have come to grasp the special mental health needs of older people. The 1991 Consensus Conference on Depression and Aging noted that many doctors lack an understanding of depression, believing that depression in later life is inevitable. They still haven't distinguished between normal aging (which by the way, I think is a synonym for living) and illness. In great part this is because, if the doctor received any training in geriatric medicine, the odds are the only elderly they saw were those who were infirm, those who were ill. If these doctors could spend a week with me and the vital upbeat volunteers that I work with, they'd know a lot better.

Bob Butler, who's head of the Mt. Sinai Medical School, has a unique program for geriatric training and one component is that all medical students must take geriatric training. Part of the geriatric training is to go down to the 92nd Street "Y" and get their clocks cleaned by some elderly people in checkers and chess, and to recognize what healthy aging looks like so they don't start assuming that to be old is to be sick.

Four or five years ago, Mrs. Carter invited me to be on one of these panels, and unfortunately I had a conflict. When I asked if I could send someone from AARP who is a better speaker, better qualified than I, she readily agreed. Some of you may remember, it was Dr. Kermit Phelps who is the past-chair of our Board of Directors. Kermit was about 80 at the time, a clinical psychologist. He wrote all of his own speeches and was still going strong. And he must have

done well, because the following year I didn't get invited. Kermit got invited again. That's the kind of image of healthy aging we need to have.

Depression is not inevitable among older persons. It's not a character defect, it's a disorder, and like diabetes and measles, it can be treated. We support increased research into the normal aging process and its impact on mental wellness. We believe it's important to balance the knowledge of mental pathology with an increased understanding of mental health maintenance in older persons. The problem, as I said, is that a resident typically devotes less than 4% of his or her training to geriatric mental health. And this is particularly unfortunate for older persons limited by inclination and circumstances. They normally depend on general practitioners and internists for their health care management. And these health care professionals often lack adequate training in areas of mental health and in geriatrics. So chances are that an older person's depression will be misunderstood or undiscovered by the one physician who knows him or her best. In fact--and this I found shocking when I read it--sixty per cent of all older people who commit suicide had been examined by a primary care physician within the previous month! Tragically, about 6,000 older people commit suicide every year. Common problems among older persons, for example, loneliness, anxiety, and depression, often go ignored and untreated because the symptoms are overlooked or assumed to be normal aging. In some cases, a sympathetic ear during an extended visit may be all that's needed. In other cases, timely and tactful referral to a mental health care professional may be best.

Considering the pain and consequences, on the one hand, and the effectiveness of early diagnosis and treatment on the other, it's obvious that mental health is a critical component of health care. Therefore, as our country comes to grips with our health crisis, we cannot overlook mental health.

And since our start in 1958, health care has been at our very core. When our founder, Dr. Anders, created the AARP, there was no Medicare. The elderly could not get health care insurance and this is one of the driving forces that helped launch us into the size that we have today. In 1976, we supported national health care insurance. It went nowhere. Our members didn't strongly support it. In 1991 and 1992 we developed a plan called "Health Care America," which represents our current best thinking of what we've heard from our members and others. We're taking it around the country to local forums. We have 1,300 volunteers, each holding local forums, and we've asked them to hold five to ten and get reactions. And the article in the paper that Dr. Richmond referred to indicates that those who understand it like what they hear, including their accepting the funding mechanisms, because we're not denying that it is a very expensive proposal. The trouble is, many of our members are not aware of the plan. And that is the sad part. It is going to be hard to get a consensus that people don't understand. So this is going to be the stress we continue to put on health care reform.

As with mental health, you cannot afford to continue a cure-now-pay-later health care approach, postponing necessary public health treatment and economic deficits to burden our children and their children. And yet, this is what we're doing as we are in the economy, the environment, and so many other things. And certainly we cannot afford to countenance a false dichotomy between psyche and soma. In our approach to health care reform we have to see them as united in a person.

Modern medicine has shown us repeatedly that mental illnesses spawn physical symptoms and that physical causes underlie many mental disorders, and yet we continue to treat them as separate.

Of the hundred or more proposals now before Congress--and I'm sure you've been through quite a few, Mike--very few contain anything about mental health. And that's unfortunate, especially for older Americans. Clearly, "health care reform that ignores these patients is no reform at all," to quote someone who made that statement this morning, and I think that should be repeated far and wide. It would be the public equivalent of abandoning older people with mental health problems on an ice floe to drift alone without hope waiting for death. This is why in our plan we have provided a full range of mental health coverages. Unfortunately, as I look at the list, I realize it too is deficient, and that is sad, but we'll have to go back to the drawing board. We do provide for a limited in-patient psychiatric care, initial diagnostic evaluations, medical management of psychotropic drugs, treatment of Alzheimer's disease, and outpatient therapy of up to 50 days per year, and these have 10% co-insurance. It's that last one with the cap that concerns me and we have to look at that. Unfortunately, we are not getting a lot of response saying "you are not covering enough mental health," because I wonder sometimes if the real need is identified by people, and if they realize how much of a need there is. Health care reform, true and comprehensive reform, means addressing the acute, long-term and mental health needs for everyone at a fair price. We cannot let old and irrelevant stigmas continue to be associated with either mental health, mental illness or with aging. And we cannot leave anything or anyone out on an ice floe of neglect.

At AARP our mission is not improving the quality of life of older people, our mission is improving the quality of lives of people as they get older, and the sooner we start, the better. And that is what I try to explain to people who don't understand the inter-generational linkage. You can't plan for your retirement at age 65 by beginning at 64. You really can't plan for the rest of your life beginning late. If you neglect a child in health care, education, support, you're going to lower the ceiling on the work life which is going to correspondingly lower the ceiling on life in retirement. We recently ran an ad of a baby in diapers (full-page ad) in Newsweek, that said, "We're planning for her retirement now." And it's not that I'm trying to get more members in a hurry. My Membership Director told me to wake him in 1996, when the baby boomers start turning 50. What we're trying to recognize is that if we really want to improve the quality of life for people as they get older, the sooner they start, the better. And as a nation we have the means of taking care of each other, and to offer everyone the way to a sound mind and sound body. It's not that we lack the means. We have to galvanize the will to do something. Thank you.

### **Julius Richmond**

Well, thank you very much, Horace. I couldn't help but reflect as you mentioned trying to gain understanding on the part of your membership on the draft plan on health care. You have kept your focus on the importance of it being simple and lucid. I think it's not only that simplicity makes it easier to understand and to gain acceptance, but as a sometime administrator of large scale programs, I would like to suggest that if we can't keep it simple in understanding, it isn't likely that we're going to be able to manage it very effectively.

Well, we clearly are getting backgrounds of organizations of varied experience and now I'd like to turn to the small business community. John Paul Galles, who is with us, is the Executive Vice President of National Small Business United (NSBU). He's had very extensive experience in the leadership of small business organizations, and as a mid-westerner, I'm pleased that a lot of that experience was in the mid-west, particularly in the state of Michigan.

I think it is appropriate to indicate that in the debate on health care reform, clearly the role of small business has assumed very major proportions. Indeed as individual states, like my own of Massachusetts, have tried to tackle health care reform, they have tended to flounder on the issue of how to involve small business and the employees of small business. So I think it's very important that we have John Galles on our program today. I'm pleased also to indicate that he and I have one thing in common, we both hold degrees from Indiana University, but there is one difference: he got his degree in the old fashioned way, he earned it!

And so John, I'm very pleased to have you with us.

### **John Galles, National Small Business United**

I had the occasion this summer to travel on the Colorado River through the Grand Canyon on a white water rafting trip and I can join the analogy that Betty introduced to our discussion. Small businesses may have been on board the raft on the river of change for a part of the trip, but they got flipped out in the rapids, and they are now fighting those rapids, hopefully with a life jacket on, and trying to dodge the rocks as well.

Small businesses want health care reform badly. Small businesses are suffering under the escalating costs of health care. The costs for their employees is dramatically higher than the cost per employee for large businesses and for those who are funded through government programs. The cost shifting that occurs dramatically affects small businesses. We are engaged in health care reform dialogue, with an attempt at addressing cost containment, in order that more of our business owners can provide health care to their employees, and compete for the available talents within the work force for their businesses.

There are a number of principles that Mrs. Carter identified at our dinner last evening. Universal care, fairness, equitable care, equitable distribution and non-discriminatory delivery of benefits. Let me suggest that we not try to develop a standard that applies to everyone, but that we need to focus on individual needs. National Small Business United will be opposed to any mandated employer-provided coverage. Mandating employer-provided coverage is a cop-out. It's not a way of getting to the real heart of the problem. The fact is that individuals go without health care, not businesses. Our system has avoided addressing individuals or engaging individuals in the health care process. Individuals are outside of that process. They are users without being payers in a direct way, and we need to encourage their personal responsibility. Personal responsibility in the direction of lifestyle, personal responsibility in discussions with providers of health care, and personal choices about the kinds of health care they select.

All corporate entities in business are trying to obtain a competitive edge. They are looking for ways or niches that will allow them to succeed or to cut costs. Certainly the advantages that large businesses have over small businesses allows them to negotiate fees for service in a local delivery market that are lower than others may pay. Small businesses don't have that clout. They are essentially disenfranchised from the system, and they are trapped by mandated benefits that apply to commercial insurance carriers who generally provide coverage to smaller businesses.

Small businesses have fought for the elimination of mandated benefits by states. Twenty-two states actually have responded by eliminating some of those mandated benefits and have allowed a lower-cost, reduced-benefit health care program to be delivered. Such packages may be known as "bare



bones" packages. Those packages have been unsuccessful within those states where those offerings have been created. These programs are not available to those businesses currently covering their employees. These programs have been poorly marketed and are only available to businesses which are not providing health care.

The Robert Wood Johnson Foundation has studied the issue of health care for the uninsured for a number of years. They have managed a dozen projects in a dozen states and found that many small businesses simply do not offer employee health benefits, primarily because of the high cost of health insurance premiums. But small employers that they've surveyed were very sensitive to premium prices and wanted fairly comprehensive benefits.

One of their most successful projects has been around the city of Denver, a program called SCOPE, which actually delivers certain first dollar coverages but establishes a co-pay of 50% of the cost up to a level of about \$3,000. SCOPE encourages people to obtain service when they need it, but also engages them in the process of making real choices. We can't afford consumers who simply take services for granted and pass costs along to their employers and the insurance company. I think we've got to be well aware of the fact that our business community is incredibly diverse and that it's very segmented.

When we passed our Employee Retirement and Income Security Act, the ERISA Act, we allowed businesses to opt out of the state regulated health care system and to create their own systems for covering health care. A lot of reformers are pointing to Hawaii and their mandated coverages as a way to change, but they forget that Hawaii's system was created before the ERISA Act and that large employers are combined with small employers in that state. We certainly could support some of those changes, but we ought to make changes that make sense and will work.

Talk about fairness. Corporate entities are entitled to deduct one hundred per cent of their premiums for health care, although if you happen to be a partnership or a sole proprietorship, until this year, you can deduct only 25%. Unfortunately, President Bush vetoed the most recent extension of that deduction and those entities will not be able to deduct any of those premiums. If we really want to turn our system around, we should make health care premiums deductible for anyone who purchases health care, whether they are an employer or an individual.

While we stand opposed to employer provided health care, we stand four square in support of an individual mandate, one that engages individuals in the process, encourages personal responsibility, and one that supports individuals who can't afford their own health care. We believe that individuals should choose to participate and pay for their coverage when they can afford to, or they should negotiate with their employer for coverage; or if they cannot afford coverage, they should enroll in some kind of system that provides a certain amount of public support. We think that providing subsidies to businesses is counter-competitive.

I shared the scenario with a couple of you that there may be shoe stores in your small towns, or in your big towns around the country, which have earned you respect. You continue to go back to them because of the confidence you have in them to provide you with good shoes and good service. And so they can charge enough to not only pay for the shoes, but to pay their employees and provide them with health care. If another shoe store opens down the street and chooses to price their product differently and they are not providing health care, should we support that small business and those salaries to the disadvantage of that other business that was in place before? We

believe that subsidies ought to support individuals. Most of the uninsured in this country are those individuals who are temporarily employed, part-time employed, seasonally employed, or simply unemployed. And we need to get a real handle on how to help those individuals more successfully than we have in the past.

Our market has become incredibly segmented. Of the \$940 billion dollars we're spending as a nation, nearly 40% of our total spending is being paid for by our federal and our state governments, through Medicare and Medicaid. Public share of health care spending will grow as our population ages and we'd better come to grips with that fact. Remember also that self-insured, larger entities, another 30%, have some ability to negotiate fees for service, or work with HMO's and develop certain organized delivery systems that engage providers with payers in a way that ensures care for their individuals at a lower cost. Smaller businesses haven't had that clout and only occupy the remaining 20% of the market with individuals at 10%.

Health insurance networks are being discussed. Health insurance partnerships within a community are ideas that are still ideas. We don't know how to establish them nationwide. We aren't sure how we're going to get businesses to sign up within those networks. We're not sure how they're going to engage the system and negotiate fees for service or lump-sum payments in organized delivery systems. Believe me, small businesses will be effectively engaged in that discussion and anxious to find some opportunities for their businesses and for their employees.

What compassion exists within our tax system when health care premiums are deductible but we don't deduct health care expenses until they've absorbed 7-1/2% of our income? If we really want to be a compassionate society, maybe we'd better think about reorganizing our tax system and making health care expenses deductible at a first dollar expense. We don't have to be paranoid about how the system will change. We just have to engage the system of change and make sure that we distribute those dollars in the most effective ways that we can.

Congress is still frightened about how to make health care reforms after passing the Catastrophic Reform Act, and then repealing it one year later. They also passed a law called Section 89, which attempted to eliminate discrimination in the delivery of benefits through businesses to employees. That too was repealed, largely because of its impact on small businesses.

Small businesses try to provide benefits to individuals in a way that suits their need. They hire elderly people, they hire young people. Generally, small businesses hire people for their first jobs in this world. They do a lot of job training. They help prepare people for their next jobs in life. Small businesses are an incredibly huge portion of our economy. Nearly 96% percent of all businesses in the United States have fewer than 100 employees. Nearly 84% of all businesses in the United States have fewer than 20 employees. Small businesses employ just over half of our private work force. It's an important community to confront with health care reform and they are anxious for health care reform. I think a lot of people--a lot of small business owners, to the surprise of many democrats--voted for President-elect Clinton in the hopes that he actually would contain health care costs and change the system.

Premiums for small businesses are growing at 25% or more per year. That can't be sustained. The average cost of an annual employee premium for health care has grown from \$890 in 1980 to nearly \$4,500 in 1992.

No wonder our economy isn't recovering. It isn't recovering because employers are not hiring workers like they once were. They can't afford to grow by adding more workers. The cost of hiring one more worker is not only \$4,500 for that premium, but it also includes the increased payroll taxes that have grown since 1980 for Social Security taxes. We've got to confront these costs in a broad-based effort through a lot of testing and learning within the states. We also have to confront it on a local level if we are to be successful.

Local discussions between employers, big businesses and small businesses, individuals using the health care system and local providers is an important dialogue that must get started quickly. Any kind of national effort to contain cost will only be effective when local communities get together and understand how they are going to cut costs and where they are going to spend money in the process. What new technology, what new medicines will they afford, how will they cut back on the over-specialization, the duplication, the number of beds and the kinds of doctors they have in their communities, are all important questions to raise.

We need more general practitioners; we need fewer specialists. We're going to have to reorient this economy and this health care market. It won't be done today, it probably won't even be done for a generation, because the doctors that will be trained today, are still being trained with the expectation that we need a large supply of specialists.

We've got to find funnels for small businesses, so that they can achieve the proper care. A headache may require an MRI, or it may require two aspirins. We've got to help people learn about the choices available and help them make wise choices with their dollars, the limited dollars they have.

Small businesses will be engaged in this process and you can count on NSBU to be part of this discussion. We want change; we want health care reform as soon as possible. We want cost containment, but we want fairness as well. We want to provide coverage that people need and want. The contractor who's building a new building, and wants to hire people, generally will hire younger people. But if those younger people want a new car rather than health care coverage, it's easier for that contractor to provide them with more money instead of health care. If those individuals are charged with the responsibility of enrolling in the health care system they may negotiate with that employer to provide that health care coverage.

Small businesses are important to all of our communities. Many of your own health care programs operate as if they were small businesses. They have to pay overwhelmingly large costs for their own employees. We stand ready to be part of this battle. We would like mental health care benefits to be part of any package, but we've got to do it in a way which helps individuals make better decisions, which makes them more than simple patients, but actually consumers of health care, knowledgeable, and wise about the choices available to them and learning that mental health is as essential as physical health. Thank you.

### **Julius Richmond**

Thank you very much. We now come to our last panelist, and it's a great personal pleasure to have this opportunity to introduce an old friend.

We both started out in Chicago, but she has remained there in the heartland of America and she's done a number of very remarkable things. We've been associated in many efforts on behalf of children and their families. She's on the faculty of the School of Social Services Administration at the University of Chicago. She's a contributor to *Parents Magazine*, she, however, is the kind of person, and this is what I would like to emphasize, who when she sees problems, rather than pondering about them indefinitely, she decides to do something. So Bernice invents new programs, new institutional forms. It was in the mid-70's that she founded Family Focus, a comprehensive program to help the parents of young children learn how to deal with child rearing issues more effectively, but in the process, also, to provide some respite care for those parents. And then she and her colleagues invented a national extension of the program. She's the kind of leader whose leadership extends all the way from the grassroots to the national level. She founded an organization called The Family Resources Coalition. And she keeps all of us involved in consciousness-raising across the country on behalf of children and parents. It is therefore, with a great deal of pleasure that I introduce to you, Bernice Weissbourd.

### **Bernice Weissbourd**

Thank you very much, Julie. It remains an honor for me to be introduced by you. I can't help but start off by saying that as I sit here and see the magnificent view from the window in back, the beauty, the stateliness, the purposefulness of it makes me think of what we're about today. And it also seems like the most appropriate representation of Rosalynn Carter.

I was asked to talk to you, obviously, from the point of view of children and families. And the phrase "children in crisis" is common today. The National Commission starkly delineates the deep trouble our children are in and this is an audience that doesn't need to hear the statistics. I'm sure you're all familiar with them.

I hope you're also familiar with George Bernard Shaw's comment that "the measure of a man's intelligence is how deeply he can be moved by statistics." I will give you only one. Today we have more children living in poverty than at any time in our history: one in four children and one in two minority children. And poverty, as you know, is a breeding ground for mental health problems. Today we find that 12 to 14 percent of our kids have emotional problems and there is an increasingly high rate of depression among children. What is available for these children? Let me give you just a few vignettes. School resources, as you know, are limited to begin with, and budget cuts make them even more limited. One of the first places a budget is cut is the item covering mental health resources. They're likely to be eliminated, so children's mental health problems in the school years, rather than being alleviated are exacerbated. A child, for example, who has difficulty learning and gets no help, gradually becomes despairing, loses self-esteem and can develop dysfunctional behavior that lasts throughout his life. When he can't learn he develops secondary disabilities, and although school may have labeled him correctly, it does not provide the intervention and therapy that he needs. Furthermore, insurance does not cover developmental delays. The result is that early intervention programs are short of both the funding and staff resources they require to serve all the children who need them. In some areas, there is as much as a year to a year and a half wait to receive what we call "early intervention services."

When a child is eligible for mental health treatment that is covered by an insurance policy, companies push for short-term care and have a 5,000 dollar ceiling, regardless of need and regardless of whether the person needing care is an adult or a child. That's difficult enough for

an adult, but for a child it's senseless. You can't start treating a child and then stop at some arbitrary time unrelated to the child's progress. The result is often devastating. Those families with HMO coverage are finding that although they have better access to care, they often have no choice as to which individual delivers that care. This is a betrayal of one of the most basic premises of treatment, the importance of making the right match between the therapist and the client, a particularly important aspect of children's treatment.

I see people out there nodding their heads. Families who receive public assistance find that the private care sector does not take green cards, so they resort to taking their children to clinics. The end result is that very often the least-experienced people, often students, are treating the most severely disturbed children.

There are kids in two-parent working families who spend every afternoon home alone watching television. We see them becoming dull and withdrawn, and inaccessible. These children are deprived of a community of people who care about them and who give them a sense of belonging. We see children become the emotionally distraught victims of, say, a sudden casualty in the family, and that family has no insurance, so the adults are overwhelmed and stressed and the child suffers.

We have a new term for children called post-traumatic syndrome--a term which previously defined war victims, now describing children living in neighborhoods where violence is constant. When random violence suddenly occurs in an affluent suburb, as it did in the case of Laurie Dan in Winnetka, social workers, psychologists, and psychiatrists all collaborated and organized to meet and discuss with the children and families the issues that would alleviate their anguish, their fear, and their rage. Nothing is being done for the shell-shocked children in ghetto neighborhoods. We have senseless vandalism, sky-rocketing rates of delinquency reflecting children who are angry and restless and who form gangs which substitute for the families they do not have.

These are just a few examples of what's happening to many of our children today. And yet we know what children need to grow up to be healthy. And I'm going to list what I believe are three essentials. One is strong families, another is supportive communities, and the third is a society that cares.

First of all, children need families who can provide nurturing stimulation, guidance and "irrational" love. I really love to say that because I think it's so true, and I think we are very aware of the importance--somebody just told me on the bus today that she works with severely disturbed children and some of them end up honor students, and some of them end up committing suicide. I asked her if she had any sort of "gut notion" of what the difference was and she said, "Yes, how involved the families are." And I really believe that to be true.

Secondly, families exist as part of an ecological system. In other words, children cannot be viewed as separate from their families, nor families as separate from their communities, or from the greater society. Decisions made on behalf of children must integrate and acknowledge this inter-connectiveness of relationships and community.

A supportive community assures the mental health of children by being involved with its families from birth. Mother visitor services could be provided to every new-born baby's family. When my first child was born, which was 43 years ago, I was visited by a Mother Visitor from the health department, as was everybody else in the city of Chicago. This is no longer true. In the state of

Hawaii this service has now become available, and they have found that a full 15% of all newborns are in need of support, extra support, either because they're born with conditions that require care or because they're born into families that need help. These children and their families then receive the appropriate follow-up services to assure their optimum development. Home visiting for every new mother is the first step in a supportive community. Then there must exist a basic floor of integrated services available through a family resource and support center--offering parent education, peer support, job-skills training, social and recreational activities, parent-child progress--with the potential of identifying and addressing the needs of families for mental health, social support or child care services.

The Family Resource Program would also operate a referral system to assure that the identified needs of children and their families would be addressed promptly and effectively. It would be the base for coordinated comprehensive services, so no child goes, as some do today, to 18 different agencies to solve a problem.

The next tier of services would consist of intervention services for children of all ages with mental health and developmental problems, and for their families. This would include appropriate, adequately financed therapy in the least restrictive setting possible. Psycho-social and therapeutic support and intervention for highly stressed families would be accessible through an integrated and coordinated system which meets the multiple needs of families.

The next tier after that would be crisis care, and finally, residential care for those children who are unable to live with their families. I'm talking about this as a model for what we believe every community ought to have. Through these initiatives in the community we could provide coordinated support to families on a continuum from prevention to early intervention, from short term crisis management to long term intervention for troubled families.

I want to say that it's not only the existence of coordinated services that matter, it's the manner in which they are delivered. We use the term "family friendly," to describe programs and systems in which relationships of trust and mutual respect between staff and parent replace bureaucratic relationships based on attitudes of superiority of the helper toward the "helpee."

I hope I have a minute to tell the story that Barry Brazelton tells when he is in a situation where he is giving immunization shots to families who otherwise would not get them. If a mother hands him a crying baby and he just gives that baby a shot and the mother moves on, that's one thing. If the mother hands him a crying baby and he spends some time looking at the baby and cooing at the baby and telling the mother what a wonderful baby she has, as only Barry can do, then gives the baby a shot, and then hands the baby gently back to the mother and tells her the baby is going to be fine, and so on and so forth, then that mother comes back for the next shot and the first mother doesn't.

Thirdly, we know children need a society that cares about them. Today we can change our mindset from struggling against our *status quo*--and I feel I wake up every morning now, and I say, "Gee, I don't have to be against ..."--to making opportunities work for us. We can build policies for children on the basis of what we know and I would like to emphasize that we've learned a great deal. There has been an explosion of knowledge on the importance of the years from birth to three, based on the fact that it is in these years the foundation is laid for the child to trust his environment or not, to have self-confidence or not, to become a learner or not.

Furthermore, we know that services provided early on are enormously cost effective. The Perry Pre-school Project and Headstart research both indicate that every dollar invested in quality comprehensive early childhood programs saves \$4.75 in reduced expenditures for unemployment, welfare, delinquency, and high school dropouts. Comprehensive prenatal care for mothers helps prevent low birthweight babies and costs an average of \$600 per month, while neonatal intensive hospital care for premature babies averages more than \$1,000 per day, not to mention the longer term cost of disability. It has been estimated that the economic cost to society of one child who fails to become a productive member, is three hundred thousand dollars over the course of a lifetime. I'm always a little reluctant to concentrate on cost effectiveness, because it's only second to human values that are inherent in what we're talking about.

We also know programs that work: programs that are flexible and responsive to the needs of children and their families and programs for adolescents that delineate clear directions, provide stability, caring, skill-training and counseling. Good prevention programs can reintegrate kids into their society. They use people from varied fields--social work, psychology, education, people from the community--and they are the cheapest form of mental health care.

There were some good federal programs mentioned last night, and the planning grants tied to Public Law 99.457 which will provide prevention and early intervention services to very young children at risk is an important step forward. It can make an important difference in the lives of children, but not until Congress also delegates funding to implement this legislation and move it from the planning process. Margaret Mead once said that a civilization can be measured by the way it treats its children. We have the possibility to act now and we must, because our children can't wait. Thank you.

### **Julius Richmond**

Thank you very much Bernice. I couldn't help but think, as you quoted George Bernard Shaw on statistics, of Victor Seidel's comment that "statistics are people with the tears washed off." And I think it's important that we always remember that when we concentrate only on numbers. I think what Bernice teaches us is clearly that we have the knowledge base to really improve the lives of children and families, and particularly those who are in greater need in this country. What we seem to have lacked, and I don't mean this in a partisan sense, is really the political will to build upon that knowledge and to develop the kinds of programs that can prevent many of the problems that Bernice was talking about.

Now we come to the time at which you and the audience can engage in the discussion. As was indicated earlier, we would appreciate your going to the microphones, identifying yourself and your organization, and if you want to direct your question to a specific member of the panel, please do so. Otherwise we'll try to make a judgment as to which member of the panel can most appropriately respond, and if we could have some of the questions from the Museum Library audience brought over, we'll try to weave those into the question and response period as well.

### **Jim Smith**

For Dr. Bailey, my name is Jim Smith. Can you share any information as to what your company does for employees and for their sons and daughters who have developed schizophrenia in terms of on-going health care for the employees themselves? You've talked about depression and other

psychiatric conditions, but no one on the panel, as yet, has addressed the issues related to health care for people with long-term mental illnesses, as it's called today.

**Betty Bailey**

Of course our benefit plans do cover family members as well. Our two most prevalent diagnostic categories are anxiety and depression. However, it's not unheard of to have some sort of psychotic diagnosis such as schizophrenia as well, and we do cover that, both on our indemnity side, as well as through our managed care benefit flex side. And once again, should somebody be in managed care and 60% of our employees are, what we do is work with that family member and ensure that the benefits are flexible, so that they have the right kind of assessment, coordination of care, and length of care that they need, as well as the follow up to ensure that their health care needs are taken care of.

Let me mention just one more thing, though. On the indemnity side, where people don't have the access to the managed care, we have a program that I'm really pleased about, called Family Education. It essentially readies the environment for a person (a family member or an employee who has been hospitalized or has some sort of extensive out-patient care) so that the environment in the family system itself is essentially readied or conducive to that person entering the home, as opposed to a situation that all of us run into, especially with adolescents, where there has been so much disruption in the family system that often there needs to be some healing in order for the person to come back and have a smooth re-entry to the family life.

**Debbie Honorov, National Foundation for Depressive Illness**

My question is directed also to Ms. Bailey. We're also very concerned about the way corporations treat our mental health issues, and you have an exemplary program, but I'd say it's very rare to have that type of program in a corporation. Obviously you have the support of top management for something like this to be able to integrate these different functions. What did you do to get that support, and what can we, in the mental health community, do to educate top management about the need for better mental health coverage?

**Betty Bailey**

We thought that the benefits design was an organizational intervention and it was treated as an organizational intervention and that started with our board of directors, as well as our executive committee, and then on down to the group managers, as well as the employees. And there was a constancy of purpose in terms of the communication at all of those levels to engage and involve, and we're still diligent about communication. So what we did to make this work is not treat it as a one-time event. It's an on-going and vigilant piece of work. I want to say, too, I gave Digital as a case example, but I don't think it's totally unusual or unusual even in terms of large-volume employers. I think that large-volume employers have the kinds of programs that I'm describing, that work.

To make them really "stick," to make them last, which is what I'm getting at, you really need to involve all levels and especially, communicate, communicate, communicate! Train your human resources people so that they can work with employees at large. We also go back periodically to give updates to both our board of directors and our executive committees and our group managers,



to let them know the return on investment of the various programs' thrusts. So you really have to do all of those things. I can't give you a real short one-shot answer, because, you have to do many things, and really treat the work as a total systemic intervention for it to be lasting.

**Jay Centifanti, Pennsylvania and Protection Advocacy Group**

We in Pennsylvania hear that more and more large U.S. corporations are moving into self-insurance in combination with managed care, particularly for mental health care coverage. Is your company doing self-insurance or contemplating doing it and why is this trend emerging?

**Betty Bailey**

Yes, we self-insure all of our health programs and have for quite a few years. I think it's easier for employers--I can't answer for every employer. For us, self-insurance is an easier approach; it takes away a lot of middle cost and has been the most efficient and effective way. We self-insure our disability program as well as our health programs. So the answer is yes, I do think that it is a trend, and I think that it's efficient and effective and those are the major reasons why.

**Melvin Sabshin, American Psychiatric Association**

I think you were giving us a friendly warning about the response to the AARP draft benefits and I wonder if you might make some comments on how we could help you in getting a stronger response to improve the benefits, or at the very least, to maintain what you've done so far. This might be an occasion for a group of us to think through with you about what can be done to get a stronger AARP member response in the face of many of your members denying the possibility of mental illness in themselves or their families. How can we help?

**Horace Deets, American Association of Retired Persons**

I think that the degree that any organization can use its communications vehicles to share with your membership and to get into the general media a sense of the urgency of the problem and cut through some of the clutter, which unfortunately a political campaign will have, where 90% of discussion of the issue is on trashing the opponent's plans and exaggerating its weaknesses, also pointing out that with all the concern about the economy and the cost of fixing the system, the most expensive alternative is the *status quo*. People don't want to think about that, but it is. Doing nothing is the most expensive thing we can do.

So I think if you can get the information out to your groups (also I would welcome any critiques) we would be happy to share with any group copies of our draft proposal. I would welcome your critiques, your suggestions of how it could be strengthened, and what could be done to improve it. We have publications going to every member's house. *Modern Maturity* goes out six times a year and our Bulletin eleven times, and even though we run repeated articles and special supplements, we can't say we have communicated simply because we've put it in print. If the message doesn't get through, we haven't done it, and we have found and we learned through Catastrophic Reform Act that the message doesn't get through simply because we put it in print. Wherever we can have local discussions and get a group talking with them and answering questions and concerns is most effective. Maybe in addition to the media outlets, whenever you have meetings make it part of the agenda, and that would be very helpful.

**Shepard Goldberg, The American Association of Psychiatric Services for Children**

The last remarks pick up on the concerns of what's happening to children, including Mrs. Carter's remarks regarding the victims of Hurricane Andrew. These are youngsters who are having problems that are not related to a medical diagnosis. They are not seriously emotionally disturbed and as long as we continue to fund services through health care and health insurance, a mental illness diagnosis becomes the ticket of admission to get services. How, in terms of corporate America, or in terms of any plans that may be developed, can we break that strict medical model? Some of the elderly are just treated for depression with anti-depressants when there are a whole other range of services they require that do not fit a mental illness diagnostic model. Why do we have to come up with post-traumatic stress or some other mental illness diagnosis, or create a symptom, if we're going to provide help for the people who require services?

**Julius Richmond**

Anyone want to make a comment?

**John Galles, National Small Business United**

I'll try to respond to it from my limited perspective, and that is that I think you should stop using the health insurance system. You ought to engage the free-enterprise economy. Start to market your services. Tell your story and take the mystery out of it. Help people come to you. Make it easier for them. Help them understand what the costs are up front. Help them understand that there are ways to support those costs. There is a real need for you to confront small employers and help them with their problems because they're unaware of how to engage the system. You've got to become marketers, just like the retail store down the street. I know that sounds awful, and it's something you probably don't want to do. But you could probably save yourself a hell of a lot of money and time waiting for reimbursement from some third party administrator, if you went directly to some of those businesses and worked out some deals. Help them serve their employees and their families more directly. I think that's an important step that will save a lot of money in the system and serve more people sooner.

**Julius Richmond**

Bernice, would you like to comment?

**Bernice Weissbourd**

I'd like to comment, because I'd like to give you the exact opposite point of view.

I think we need to do exactly the opposite. I think we need to become very strong advocates for a national health policy that covers all children from birth to eighteen. And the ways that can be done are also delineated in the National Commission on Children's Report, in their health care section which I would like to refer all of you too. It's not ideal, but it does really recommend a policy that ensures from birth through eighteen total coverage for all kids. I don't think, from my experience and also from history, that if we don't do this on a federal level that we will ever see a time when kids are covered.

I'd like to say one other thing about this. When we talk about this, it's not that we're blazing new trails. Every Western democracy has this kind of coverage for children. We talk about it as if it's way out or revolutionary or unattainable. None of that is true. We really have to recognize that we are just basically very far behind and we need to catch up.

**Julius Richmond**

Horace...

**Horace Deets, American Association of Retired Persons**

There is no question a new paradigm is needed, but I would concur more with what Bernice said. Now I would like to point out something. I was given material for speeches for a couple of years on the fact that we spend more and we have greater gaps in our health care system than anything else. And two of the indicators I got are longevity, life expectancy in this country, and the infant mortality rate. And I would submit that those are not so much failings of our medical system as they are societal problems of breakdowns in family support and community development. And I think if we don't have an integrated plan that looks beyond isolated segments and sees that connectedness, we're not going to have much success.

**Julius Richmond**

I can't help but just add a comment or two. There are certain things that need to be done through community organization and public health. Just to build on the comments that have been made, what the questioner was referring to are services that are preventive. In the United States, out of the over 800 billions of dollars that we are expending for health, only four or five per cent of that, believe it or not, goes to health promotion and disease prevention--all too little. We can't really deal with the kinds of issues we are talking about unless we engage in some redistribution of resources.

We are very handicapped from our social-cultural tradition in this country of tying the financing of these kind of services historically to a fee for service kind of arrangement. These are the kinds of services that are best done in organized settings. This is part of what I was alluding to when I said we need to exercise the political will to really reinvent a lot of things that we used to do at the community level in years gone by, like the home visiting that Bernice alluded to in her comments.

Well, we should move to a question from the Museum Library. This one is directed to John Galles:

**Deborah Reed, Clinical Nurse Specialist from Emory University, Department of Psychiatry**

With the recent Supreme Court decision allowing self-insured employers to reduce benefits when faced with a serious illness, such as schizophrenia, what would you advocate small businesses do regarding this issue in the face of serious and persistent mental illness?

**John Galles, National Small Business United**

Are you all aware of the Supreme Court decision? Yes. O.K. The basic drive for any small employer is cost. The driver has to be dealt with. When we learn to confront cost and control it from escalating as rapidly as it is, more employers will provide more coverage for more employees. Simply mandating that they provide coverage, whether it's for schizophrenia, or for AIDS, or whatever it might be, is not going to solve the problem, because more people will be out of work or go without coverage as premiums escalate. More people will be left out of the system, and we'll have to find ways to cover them through unemployment insurance or publicly provided insurance.

We've got to find ways to engage the system which are less expensive. Which means avoiding some of those administrative costs that insurance companies impose, changing the way that products and services are priced whether it's through organized delivery systems, or fee for service systems, making sure that they are level costs, instead of costs that continually get higher and higher as they are shifted onto small businesses and small employers.

I'd like to be compassionate and say that every small business is willing to pay for all infirmities, at whatever the price, but that's not the case. They can't do that and open their doors, keep people employed and support the family systems that are in place around the country. We've got to come to grips with that and be honest with ourselves. If we had unlimited resources, we could do that, but our resources are limited and we've got to find a way to redistribute them on a broad basis so more people can participate.

**Julius Richmond**

Well, I have great compassion for those of you who have sent questions from the Museum Auditorium and those of you who are still wanting to ask questions, but in the interests of the physical and mental health of the group, I think it's appropriate that we abide by the schedule and declare our coffee break. I want to thank the members of the panel and all of you.

**John Hardman**

As you know we are very fortunate to have Dr. Julius Richmond as our Visiting Fellow for Mental Health here at The Carter Center this year. Most of you know that Dr. Richmond was the Assistant Secretary of Health and Human Services in the Carter Administration, from 1977 to 1981. He was also the Surgeon General of the United States during that period of time. In addition, Dr. Richmond worked with Dr. Betty Caldwell on development issues in young children in poverty areas and was appointed the first Director of the Headstart Program during the Johnson Administration. Dr. Richmond brings a vast amount of experience and knowledge to the Task Force.

There are copies of *Health Affairs* and the *Proceedings* from last year's Symposium on the table and you're welcome to take a copy. Tom Bryant will introduce the elected officials participating on our next panel.

## **Tom Bryant**

Let me just welcome our panel members. I'm going to do what Julie did by introducing them individually before they speak, but let me say something about them collectively.

We've heard, I think I've heard it mentioned four or five times this morning, the term "political will." The political will to do, the political will to reform, the political will to whatever. Well, when we as citizens of the [United] States collectively get the political will, one of the things that we do is elect people like these here today. Each of these individuals on this panel, whether they are in the Federal Congress, or in this instance, in the Legislature, in the Senate, and in the House of Representatives in the state of Georgia, these are the individuals who have the responsibility for drafting those laws and those changes in laws and for setting the kinds of conditions for reform.

We are very fortunate today to have a group of individuals who have been active, not only in the mental health field as each of them individually has, but who have been active across the spectrum of various human concerns they have experienced. Fortunately both of the members of the Congress that we have were earlier members of their respective state legislatures and so they have dealt with those kind of problems, from that point of view.

First, I'd like to introduce Congressman Michael Kopetski, who is from Oregon.

Let me tell you a bit about him. His district in Oregon includes Salem. We have all heard of Salem, Oregon. He's the Congressman from the Fifth District in Oregon, and he was elected to the Congress in 1990, and was reelected, so he was an incumbent who did not get "dis-elected." He has been a very active member since he came to Congress. I told you that prior to coming to the Congress of the United States, he was a State Representative in Oregon from 1985 to 1989. One of the little things that stands out in his resume that I like particularly, and I think Rosalynn will like also, is that he was a delegate to the Democratic Convention in 1976, which was kind of a very important convention for a lot of us in this room. I haven't asked him how he voted, and I won't do that now, but I assume he voted correctly at that time.

Another interesting thing from his resume is that he was on the staff of the Senate Watergate Committee back in 1973 and 1974. Those of you who remember that committee will remember various individuals and various questions that were asked, such as what do you know and when did you know it? Congressman Kopetski has made a point since he's been in Congress of having a particular interest in mental health. He's one of the founders and one of the Co-chairmen of the House Representatives Working Group on Mental Health. So, would you please join me in welcoming Congressman Kopetski from Oregon.

## **Congressman Michael Kopetski**

Thank you very much. I want to thank Mrs. Carter for the invitation to join all of you today at this Symposium. This is a great honor for me, a new member of the Congress, to be here and to be with you, the advocates who want to move the mental health agenda forward in this country.

I also want to recognize the great work that Mrs. Carter has done for over twenty years in this field: from her work with the President's Commission on Mental Health to her work with the National Mental Health Association and the National Alliance for the Mentally Ill, to her

sponsorship of these Annual Symposia. Those concerned about the state of mental health care in this country owe her an increasing debt of gratitude that will only continue to grow. The word "Carter" in this world has become synonymous with compassion, and Mrs. Carter has earned this distinction.

One issue that Mrs. Carter talked about was discrimination. It is a fact of life that those with mental illnesses are discriminated against by our society in all sorts of ways--through insurance coverage, both public and private, through job opportunities denied, through the stigma society attaches to mental health disorders, and by the media as well. We must remember that those with mental illnesses are also victims; they are victims of physical abuse. We did a study just a few years ago in Salem, Oregon, the capital city of Oregon, and found that 25% of the responses that our local police department was making in terms of assaults were to those who probably have a mental illness, particularly a chronic mental illness; and that these are the victims of violence in our society and not the perpetrators.

There's a very real chance that if we don't work hard enough those with mental illnesses may be discriminated against even more in America, especially by the omission of mental health illnesses and mental health provisions in national health care reform legislation. To quote Mrs. Carter from her testimony today and last year before the Congress on legislation authorizing fundamental health care she said, "What is at stake here is fundamental human dignity."

In the 1950's and the 1960's there was a battle going on, an effort to fight a different kind of discrimination and that had to do with racial discrimination, of course. Congress and the Administration responded by enacting the Civil Rights Act which provided much needed leadership and law in our society. Well, the federal government is in an excellent position today to make similar progress on behalf of those with mental disorders. But the federal government must act.

History will judge us not by whether we win these battles against discrimination at whichever level it occurs, but whether we make the fight and we make the progress. It takes leadership, of course, to overcome discrimination and to move forward as a society. By ending discrimination we truly help each individual in our society.

At the important juncture we have now, we must have strong, active leadership by mental health advocates as health care reform is high on the national agenda. With single party control of the White House, the House and the Senate, there's no excuse for the Democrats not to lead and not to accomplish. Quite frankly, we do have to have the leadership. The national will is there, I believe. We need the leadership. We need new ideas and the fresh energy to realize the potential that we have in the current political environment for progress in the mental health care field.

Before I talk about today's opportunities, let me just take a moment to go back to 1980 when the Mental Health Services Act was passed. This Act was timely, the need was great. Unfortunately, more than a decade later, we still have not fulfilled our responsibility as a society for making mental health care accessible as was outlined in this Act. I'm talking about our failure to fund adequately the provisions of that Act. In fiscal year 1980 federal support for community mental health centers totalled 324 million dollars. In 1991 that level of support is 245 million dollars, or a 27% reduction unadjusted for inflation. Although that number has gone up, we are still working hard just to catch up with 1980.

In short, the federal government must put more money into mental health care for Americans, *more money*. We shouldn't be afraid to say that, we shouldn't be afraid to ask for it. We need to spend more of the tax payers dollars on mental health care. In dissenting views, however, on the conference report on the legislation, six Congressional Committee members called the idea of mental health prevention programs "frightening from both a philosophical and a fiscal point of view. The very best thing the federal government can do to help prevent mental illness in the population is to keep a very low profile". President and Mrs. Carter provided exceptional leadership that day in guiding this bill to enactment in the face of this ignorance by members of Congress. The time today is ripe for a similar kind of leadership as we write history in enacting health care reform legislation. There is still, obviously, a significant amount of stigma, of misunderstanding, and of plain ignorance, about mental health issues which each of us must fight in our own way today.

Funding issues for human services are even more at risk given the recession, the federal deficit, and the problems state and local governments face with their own fiscal needs. Advocacy from the community must be active. Success won't happen without a strong effort by advocacy in the community and in Washington. As it's name implies, the House of Representatives is truly a representative body. Members will respond to the calls from their constituents, so constituents must inform the members of their commitment to this issue. That's your job. Think about it. The issues that see the most action are the ones that are the focus of the most attention, both by the media and by the public. While legislators have an obligation and an opportunity to educate and lead, it's got to come from the ground up as well. If we are to include mental health care in our universal health care legislation, people have got to let their representatives know of the need for that. In an advocacy effort we must work together; as important as the volume of the message is the message itself.

It's important now more than ever that the mental health community come together and realize that unless we paddle at the same time and in the same direction around those obstinate boulders we aren't going to get around those rocks and those boulders as was alluded to this morning. Health care reform and expansion of coverage is on the verge of happening in this country. If all of the separate fiefdoms of mental health care advocates-- if all we do is keep pushing our own separate agenda--the opportunity to establish mental health care as an equitable part of universal health care coverage will slip through our fingers. If everyone in this community is saying something different, legislators aren't going to hear. The noise will muffle the call.

It's also important that the message given to legislators by advocates can't be just, "we need more attention, we need more money." True as it is that mental health care isn't equitably supported financially, members of Congress hear that "we need more money" message from just about every human services group in this nation. What will help the mental health community is to go a step beyond and show how the mental health field can help in solving other related problems. Whether it's a homeless situation, police activity, as I related earlier, employee absenteeism, employee productivity.

Another point to make is that research is increasingly showing that mental disorders do have a biological basis. In a recently released report on the subject, Dr. Laura Hall of the Office of Technology Assessment wrote that, "the majority of experts and interested parties in the OTA recognize that the research data increasingly show that biological factors play an important role in these disorders."

The same report mentions the recent court case involving a father who sued the Arkansas Blue Cross and Blue Shield for increased coverage for the care of his daughter who was hospitalized for a bipolar disorder. The result was that, as many of you know, this was termed a "physical disorder," and did, therefore become included under the provisions of the policy. While we must gain support for the adequate treatment of all mental disorders, not just those with a known or suspected strong biological basis, the point still should be made. We have to do more than ask for the dollar.

In closing, I'd like to touch upon something Mrs. Carter pointed out. Not everyone needs catastrophic care. There is a wide spectrum of mental health care needs that we must address. I think it would be a mistake to focus only on the severe mental illnesses at the expense of other issues, such as outpatient care, rehabilitation services, and partial residential treatment.

One of the major shifts that has been happening in the health care field overall is an increased emphasis on alternative means of care instead of primary focus on acute care in the hospital. Alternative and preventative care is less expensive and is cost effective. Very frequently it is also better for the patient. This is as true for mental health as it is in other fields. And we should not ignore the fact in working to improve the mental health care system.

I just came from Oregon, my home. I left on Tuesday night on the "red-eye" as we lovingly refer to it, and back in Oregon it's the time that thousands of geese migrate from Canada to that state south of us. You can learn a lot about leadership and what's going on in our society if you watch those migrations of geese closely. I've spent a lot of time thinking and looking at the geese as they fly up the Willamette River.

The first thing that I notice is that they appear more organized than they really are, especially if you look inside the organization. Inside, it seems like there's a lot of chaos. Different individual geese take turns being in front. They're continuously changing and they're ready to accept change in the world that's right in front of them.

I also notice that they make a lot of noise. They talk to each other, they encourage each other, they criticize each other. When they finish their turn, they congratulate that person for taking the lead role. Sometimes they'll have constructive criticism on the route they took or that they didn't stop soon enough for a little rest, but they're clearly not afraid to speak their own mind and talk to the world and make a lot of noise doing that. Finally, and what I really like about them, they reach their goal.

I want to thank you for this opportunity to speak today. It's a great honor for me as a new member of Congress to be here. I look forward to working with each and every one of you in moving this agenda forward.

**Tom Bryant**

Thank you very much, Congressman Kopetski.

Our next speaker is Congresswoman Nancy Johnson, who is from the Sixth District of Connecticut which is the New Britain area of Connecticut. Congresswoman Johnson has, as I said as she was coming in, served three terms in her State Senate. Prior to that she was, what can only in our



modern terms be called, a community activist of enormous magnitude. She is now in Congress. She has been there since 1983, and has one of the most coveted committee assignments in the Congress of the United States. She is a member of the House Ways and Means Committee, which is, as you know, a powerful committee, which makes her a very powerful Congresswoman. She has been there since 1983. She has acquired that wonderful ingredient called seniority, and as young and attractive as she is, I don't want to misuse that term, but one of the good things about it is that one of her causes is national health care reform. She is a known national leader in that; and Nancy is a wonderful leader in the Congress. After the election there is a new term that is coming in vogue called the "loyal opposition." Well, Congresswoman Johnson may fall in that group, but one thing that all of us who are involved in mental health issues should be aware of, and we probably are, she's been loyal to us all along and whatever role she does fit in, we are very pleased to welcome you to Atlanta and to this conference. We will now turn it over to you.

### **Congresswoman Nancy Johnson**

Thank you very much. I'm very pleased and proud to be a member of Congress at a time when I believe we will finally act on an extraordinarily important issue in America, namely, health care. A proud, strong, and humane nation ought to be able to find affordable and universal access to health care for all its citizens.

I come to this issue with rather broad experience. I chaired the board of my local child guidance clinic for a number of years and was either treasurer or chair for twelve years, and in the State Senate in Connecticut I helped to rewrite our hospital cost commission legislation three times. Needless to say, we had difficulty in making it work. But I come to this issue of how is Washington going to make your health care system work with a good deal of experience.

A year and a half ago, I introduced the first comprehensive health care reform bill in Congress. I tell you that because as one who has actually written insurance reform regulation (I represent one of the big insurance capitals of the nation), throughout the course of this process, half of my companies hated me and half loved me. Having to translate things into law and trying to see how you are going to make the system change and how you are going to achieve the goals that we talk about is, in the end, what really matters.

So I'm going to generalize first, and then be quite specific about the challenges that I think you, the mental health community, need to face squarely and tough-mindedly if you're going to have an impact on the debate in the next six months and, hopefully, on the outcome.

I do hope that we will pass health care reform legislation by August. I'm not optimistic that we can do it in 100 days; I think that would be unwise. We've got a lot of new members and it's an extraordinarily complex system. We're talking about almost 15% of our GNP; nobody ought to go in and change the way 15% of the economy works without a lot of study and thought.

To lay that kind of foundation, I founded the Republican Health Care Task Force, and at the same time the Democrats in the House founded a task force. There's been a lot more education of members than meets the public eye. There is a solid foundation of knowledge, a lot of consensus in Congress. So in talking about my vision for the future, I'm going to just sketch what I think, what I at least am trying to head for. I think it's fair to say that all of the major initiatives, from President Bush's initiatives to the House Republicans' very well developed initiatives, (which didn't

get a lot of publicity), to the Conservative Democratic Forum proposal, (which was also very well developed), though you may recognize it by the title "Managed Competition," deserve scrutiny. The latter seems to be the proposal that President Clinton is most interested in right now, although he combines it with global budgets and they officially don't have global budgets in there. I'll talk about that a little bit later. The vision that I'm sketching can be drawn from all of those plans.

So, while I am going to tell you my personal vision, nonetheless, I think you'll see a lot of agreement. This is at least the direction we'll go. There is a difference between my vision and others, and it's different in some important ways.

The direction that we're going is toward a nation whose health care is organized into coordinated systems of care. Coordinated systems of care is a phrase that President Bush invented, and I like it because nobody knows what it means. And the truth is, nobody knows where we're going to be in five years. Those who are talking about managed competition are talking about much better coordinated care. There isn't a human service program that we're passing in Congress that won't require case management, such as in foster care. So, coordinated care is in mind. It is going to be a very important component in the reorganization of our health care system. That may mean that we won't have individuals' physicians out there (my husband is a physician, I should have mentioned that), practicing all by themselves in their own practices. It may mean that, but we do have to move towards a system that provides a coordinated system of care.

Only if you get a well-coordinated system of care can you take a far more holistic approach to health. Not only can you have a system that is able to deliver preventive knowledge and outcomes research results, but also a system that is able to do some of the things that we know desperately we need to do now, but our system doesn't enable us to do. We've got to eliminate duplication of testing. A system like ours can't do that. If you get a referral from another doctor, you don't know what his equipment is like, you have got to do the tests. The hospital is liable, so they're going to redo the test. The system doesn't allow elimination of an enormous amount of duplication. Look at the way we administer our system.

Now, in other industries, and I represent a big manufacturing industry, I spend a lot of time on factory floors. You know that guy at the machine. When he works now, everything that he does goes right into inventory, right off to billing, right off to reordering of materials. We are going to be moving in many areas when we talk about administrative reform; don't think only about billing. It is true that we can't do the record-keeping in the way we've been doing it. When I talk about administrative reform, and remember this is my vision, what I'm telling you is that in five to ten years, the physician will chart his visit with you. He will press a button, and it will go to your pharmacy of choice with a prescription printed out. It will go to his billing section without any further handling. You will never, no matter where in the United States or abroad you get sick, will ever write your name down again or your insurance information down again, because that will all be handled by a smart card. Anything that you have done to you nationwide will go back to your integrated chart. Your physician will know exactly what the symptoms were when you got ill in Colorado, but you live in Connecticut, and what drugs you were given, and what treatments, and so on and so forth. And so when I talk about improved administration of health care, I mean an improvement of a lot of things about billing and management, inventory of medications, and management of prescriptions and things like that.

I also mean a new level of management of medical information that will allow us, for example, to get national feedback on the consequences of the use of a new drug or a new diagnostic technology. I mean, isn't it bizarre in today's world, that if we use a new drug or we invent a new surgical procedure, or a new diagnostic procedure in New England, people are not aware of it in other parts of the country? And then somebody begins to trace what happened when you used it, and finally when you get enough information, you publish it in the *New England Journal of Medicine*, and maybe the physician has time to read it, and if he does, maybe he uses it. Now that is stupid! We cannot function that way if we're going to afford high quality health care for all Americans. We cannot do that. We don't have the right to be that negligent of how we manage knowledge.

In a really sophisticated technological medical system, a physician's charting would be charted in such a way that at the end of the course of treatment, a particularly uncertain new drug or, whatever the government was tracing, would automatically be dumped into the information bank and part of the outcomes research that allows the information to be fed back into coordinated systems of care which would say, this doesn't work or this does work. It would radically shorten the amount of time and reduce the amount of resources we put into some things that we use in situations that, in the end, will make no difference and in some situations will make an enormous difference. We cannot afford the luxury of not using the knowledge that we have and not developing the knowledge that we need.

I stress outcomes research and the knowledge it can bring, especially a system in which everyone participates, a coordinated system of care. Because only if we're able to differentiate between necessary and unnecessary care, and I understand all of the pitfalls behind those simple words, can we do that. We have the resources to provide quality care to everyone; and if we create that capability, we can provide better care because those same coordinated systems of care can use outcomes research, the kind of research that has been developed right in my own district.

The University of Connecticut Medical Center has tracked what happens when physicians bring up drinking to their patients, that indeed they think there's some reason to be concerned about the amount of alcohol they're using. The only difference is between those cases in which that was brought up and those cases in which that wasn't brought up. Now that's easy information. But it turns out to have a powerful impact on the course of health in a coordinated system of care, particularly when it is paid on a *per-capita* basis. That's a good reason for using that information and making sure at their monthly meetings that they've covered that and whatever else was new. The next step after having fed this information back in, because they'd have an incentive to make sure that they minimize high cost care and maximized low cost care, is preventive care. That's early intervention care.

So the combination of a bit more coordinated system of care, of better outcomes of research, of better preventive knowledge, and radical reform of the way we administer health care can give us the kinds of cost reductions that we need and also expand access and create the universality and holistic approach that we need.

Now the question is how do we get from here to there? I'm going to just name off quickly the five things I think have to be done to get from here to there. I want you to note that my goal is to change the structure and motivation of our system and of the participants, both of providers and recipients, patients and doctors, nurses and home care providers and everybody else.

We have to radically reform the way we administer, we must change the way the insurance industry functions. Now, the literature is fond of describing insurance reform as small group reform. There's no small group reform. You can't reform small group without reforming large group. Nobody any more is talking about small group reform. We are talking about restructuring the insurance industry, in the same way government in America is good at restructuring markets when we don't like the way they're performing. And we will restructure the insurance industry so radically that it will no longer be able to make money by assessing risk. Now, if you're an insurer, you've got to find some other way to make money. If you can't make money on assessing risk, there is only one way to make money: make sure that you are the very best at early intervention, prevention, early diagnosis and using what works. So you see, reforming insurance is absolutely essential to creating coordinated systems of care that are motivated to do prevention, to do outcomes research, motivated to look holistically at their people. So with administrative reform, and insurance reform, you have to form a malpractice liability system. You just absolutely have to do that. With that you also have to reform some of our medical education.

Here is a wonderful story from an endocrinologist in my district, who graduated from Yale, and was trained at Yale. He goes back to his rounds and is appalled about what the attending physician is teaching the students; he knows that nobody will pay for all those tests, and furthermore, it's going to make no difference in the treatment of the goiter that we happened to be talking about. So, he went back on his rounds and said, "Don't do all those tests; your treatment isn't going to change. The knowledge you're going to gain isn't very useful and nobody is going to pay. Save that money to inoculate kids in America." So, when we talk about reforming malpractice, let's acknowledge that our current malpractice system has driven a very deep-seated and fairly destructive change in medical education and those things will go hand in hand. We have to reform our tax law, so that it too encourages coordinated care, and we have to reform the way we do Medicaid and Medicare, so that all of those folks will be motivated to move into coordinated systems of care.

All of this means that there are three issues that you really have to concentrate on, and I'll just talk briefly about them because I know you'll have wonderful questions and I want to get to those. There are three issues that you're going to have to deal with: one is the issue of global budgets and I particularly want you to note that in my approach to reform, at no time do I talk about money. For instance, in changing the tax code in my bill, I want to change the tax code so that you can't get the right to reduce premiums unless your people are in a plan that is correctly structured. That's different than those who want to reform the tax code so that you only can write off premiums to a certain dollar amount of care. The danger in the dollar caps is that regional costs are very different, and you will get great disparities in access to care if you look at dollar cap. Even if you do the basic benefit plan and then you articulate that into a dollar cap, you are in trouble. I think our first step ought to be to look at the system of care and have our tax code favor and force participation in the right kind of system of care.

I believe cost control will follow--that we'll be able to control costs as a consequence of how we structure care. But this issue of global budgeting has to do with that tax issue of--do we cap the dollar amount of care that we're going to subsidize for you? More importantly, is there going to be a global budget behind health care reform? The Managed Competition Proposal of some of my colleagues in the House is extremely thoughtful.

Clinton has combined that with a global budget proposal. I'm unalterably opposed to global budget. You can see very clearly the danger in a global budget from our experience in Medicaid. Medicaid is a globally-budgeted program. The VA system is a globally-budgeted program. Medicare is a globally-budgeted program. Do you remember our big reform of the Resource Based Relative Value Scale (RBRVS) system? When we passed that, we passed it with a global budget. Therefore, if there's an increase in volume, there's a decrease in reimbursements. Our reform (and this is very relevant to mental health people) of the RBRVS system was supposed to increase reimbursements for internists and reduce reimbursements (and I'm on the subcommittee that did this, I was there, we tried to do it right) for surgeons and people like that. It's outcome in Connecticut was a twenty per cent cut in reimbursements for internists, so they are now reimbursed less than under Medicaid, and an increase for surgeons. So, global budgets are very difficult because of their volume adjustors. What happens if you have a global budget and you have an increase in AIDS cases? Everybody gets a reduction in reimbursements, because they treated more AIDS cases. Global budgets are very arbitrary; they are very difficult. They are very popular politically because they result in a far higher estimate of savings.

A newspaper ran a column one time during the campaign about what Bush's plan would save, and what Clinton's plan would save. One was one hundred sixty-eight billion or something like that and the other was seven hundred and fifty four billion or something like that. It was entirely this global budget issue. So we can get back to that. I am adamantly opposed to global budget. It would particularly hurt folks like you.

The second issue you have to look at is outcomes research. How can you be part of that? Mental health is more difficult. I don't know how much outcomes research you have done in mental health, but I do know that stress is costing industry \$300 billion a year and we ought to be able to document that. Columbia Medical Plan did a study that showed that people who received early mental health treatment had a much lower medical cost and people who didn't had higher medical cost. But you're going to have to talk that language. You're going to have to be part of that game. It's absolutely essential that you understand that, because in the long run we have to be able to compete for mental health dollars because they work, because they make people well, because they reduce their health costs in other areas, but you have to and are obligated for your own self respect, to be able to turn that into studies and statistics, and you probably have done it. I'm just not aware, but I need it. So outcomes research and the kind of central role that it will play in this debate, and lastly, the issue of basic benefit plans are important. Some ought to have one basic benefit plan that might help you; maybe you'd rather have only one battle. If you lose, you may be sorry.

Other proposals, both mine and former Senator Bentsen's, let the market create a variety of basic benefit plans, because we define a basic benefit plan as one that doesn't exclude for pre-existing conditions, any plan that accepts everybody, and so on and so forth. We look at the structure of the health care rather than at exactly what that benefit plan attracts. I hope you will devote some of your resources to helping me on those issues of basic benefit plan and global budgets and outcomes research. Thank you very much.

**Tom Bryant**

Thank you, Nancy. Let's hear next from State Representative Jim Martin, who is in the State House of Representatives here in Georgia. He's been there for nine years. He's the Chairman of

the Human Services Subcommittee of the House Appropriations Committee in Georgia. In 1989, (this will be of interest to this group), he received the Mental Health Association of Georgia Legislator of the Year award. When he's not legislating, he's in the practice of law. He's a graduate of the University of Georgia, undergraduate and law school, and he has his MBA from Georgia State University. He's from the Morningside area of Atlanta. Jim.

### **Representative Jim Martin**

Thank you, Tom. If an expert is someone from out of town, Mary Margaret and I have a distinct disadvantage due to the fact that we live within about three miles of The Carter Center. We certainly are not experts. I would be remiss if I didn't say to Mrs. Carter how much we, as Georgians, appreciate the things that you and your husband have done for this state and this nation. Obviously, in the area of mental health your contributions have been wonderful for us in this state and for the people in this nation. As we have a new president going into office, I hope he will be as successful as President Carter was in avoiding conflicts that bring American soldiers in jeopardy. We appreciate all that you and your husband have done.

The state usually is at the end of the list and probably should be. Today is no exception. I'll make a couple of comments and let Mary Margaret correct me, and then we can answer questions.

First, social benefits in this country, in large part, are paid by private employers. In the discussions we had this morning, and as Representative Johnson's remarks indicated, we cannot forget how important the deductibility of fringe benefits is, and we cannot lose sight of that in this debate over health care policy. The tax law requirements for the deductibility for health care costs by private employers need to be looked at, and certainly this examination can play a significant role in social policy in health care.

Secondly, the federal government, through its direct support of mental health and mental retardation and substance abuse programs, makes a significant contribution. Indirectly, through its Medicare program, it makes an additional contribution and participates at the state level, where Mary Margaret and I are. Medicaid is the joint state/federal partnership which assists in the efforts of the state governments to deal with mental health, mental retardation and substance abuse.

In Georgia, in 1991, the figures are instructive. Of about 600 million dollars the state spent for mental health, mental retardation and substance abuse, 400 million dollars of that went into institutional care, and 200 million dollars went to community care. We know that's got to change. All those amounts, the most significant portion of which is hospital care for which the state pays about 296 million dollars of the 418 million dollars, came from the state budget. In the community setting, a significant portion of the 189 million dollar community budget was paid for from the state general appropriations. I think states have to be involved in the issue of national health care reform in the area of mental health, mental retardation and substance abuse because the fact of the matter is that financially, the states are very much involved in that effort.

I had the pleasure of serving with a commission that's reviewing all of the state programs in mental health, mental retardation, and substance abuse over the past several months, and I have a couple of comments to make based on the report that they generated. Let me preface my remarks by saying, would all of the members of that commission who participated stand up so you can take part of the blame for this? Stan is over there. Stan Jones was the chair of that commission and

began his work in health care and in the mental health areas under Governor Carter many years ago and still continues his work.

That group, when it began its investigation into what was wrong and what needed to be changed in the state of mental health programs, mental health, mental retardation, and substance abuse here in Georgia, identified certain issues that they called an "Agenda for Change." Those included empowering consumers and families to make choices, and second, insuring a comprehensive and integrated system of services and supports with a single point of entry. A lot lies in what Mrs. Carter was saying this morning in terms of integrated system: injecting more competition to increase use of private providers; strengthening local community decision making; establishing a single point of accountability for hospital and community services; improving the governance of the service delivery system; separating service planning and service delivery and finally, developing a client-centered delivery system. So you see, with that agenda at the state level, and looking at that in terms of the current system, we had a big job before us. I was amazed, frankly, not so much by the commission, although they were extraordinary, not so much by the political figures who were involved, although their contribution was significant, but by the fact that all of the advocacy groups were able to come together with that agenda and develop meaningful proposals for change here in Georgia.

From that basic agenda, the commission identified certain organizing principles, and I'm not going to give you all of them, but they're very instructive, about how we go about reorganizing mental health, mental retardation, and substance abuse services at the state level. They must be consistent with whatever plans are developed at the national level in terms of health care reform, including mental health. Consumer choice is important--that is the ability of the consumer to choose the treatment as opposed to the providers determining what it is that the consumer needs. Interestingly enough when that issue came up at the Board of Human Resources meeting, one of the more conservative members of the board said, "Well, does that mean that we're going to let the patients drive the bus?" The response by the chairman was, "No, it just means that they'll have the right to decide where they're going." And that's a very important part. Secondly, the single point of accountability is important, so that we can hold some persons accountable to the public for where the dollars go, both in terms of hospitalization and community care. Thirdly, we need a comprehensive system that includes a whole range of services. Fourth, privatization should be considered. Fifth, local planning should be encouraged.

The list goes on with emphasis on consumer choice in this system, as the system provides opportunities for treatment of people with mental disorders, mental retardation, and substance abuse. Consumer choice is needed in two levels: one is in terms of planning of what those services shall be and secondly, in terms of individual treatment plans that will address the needs of the individuals. Other issues were identified through the process of this exercise in public input, and finally, a proposal was made. Mrs. Carter will appreciate the difficulty we will have in getting this through the legislature, but it's easy to come up with a proposal. I think it has real merit. It may be instructive in terms of what states need to be doing in terms of participating in this national debate. Our studies suggest a regional, not state level, service planning agency with a majority of consumers and family members making decisions for that community about what part of the 600 million dollar pie they spend for what service. We recommend a service delivery agency which contracts with public and private providers with a majority of consumers that makes determinations as to how those services are delivered. Frankly, when I started out on this commission, I didn't think that would work. I am now convinced that in mental health, mental

retardation, and substance abuse that that's where we need to be going in terms of more consumer orientation, rather than provider orientation.

What does all that have to do with the remarkable comments by Mrs. Carter this morning? I have two observations. One is that in terms of involving mental health in any national health care plan, we need to make certain that the states don't get off the hook in terms of the financial support that they provide to mental health now; that the states don't use it as an excuse--and I'm a state legislator--to reduce the state financial commitment in the area of mental health, mental retardation, and substance abuse. And secondly, that what we're learning as we talk to consumers and advocates and providers, and as was mentioned in Mrs. Carter's address this morning, the importance of redirecting resources to the people and the importance of individual choice in this system. I am hopeful that the state leaders who will participate with our national leaders on this issue will come up with a meaningful health care program, and will recognize that we cannot have a meaningful health care program if it does not include mental health, mental retardation, and substance abuse services. Thank you.

#### **Tom Bryant**

Thank you, Jim. Our last speaker of the panel is Senator-elect Mary Margaret Oliver. Ms. Oliver is a graduate of Vanderbilt University and Emory Law School. She practiced law for about 15 years and then was elected in 1987 to the House of Representatives in the State of Georgia. She was just elected to the Senate from the 42nd State Senate District. Mary Margaret, you get the last word.

#### **Senator-elect Mary Margaret Oliver**

My last word will be brief. I generally feel very lucky and exceptional in my opportunities, but the opportunity of the job that I have right now to try to conclude this exceptional panel, I don't feel very lucky. This is a unique opportunity that you have had and I have had to listen to some real national and state leaders to talk about these important issues. I will try to do so very briefly, because I think it's important as advocates and voters to have some discussion about what is the precise political mood right now. What is our job in understanding, as legislators and politicians what people are saying to us as we come out of this very important election.

One of the unique experiences I have had in politics is to observe the phenomena of growth and emergence of The Atlanta Project in Atlanta. And one evening this spring, I had the opportunity to participate in a cluster meeting that President Carter was leading in Decatur. And he said something that struck me as very important. This was a comment he made, again, in the earlier part of this election season. He said that the obstacle for real change for people who were in poverty was their hopelessness, that was too often matched by the hopelessness of elected officials. As an elected official on that night when I was probably a little bit fatigued myself, it had a real meaning to me. And as I watched President-elect Clinton campaign this summer and fall, talking about the man from Hope and about hope for the voters, it continually reinforced to me what we as politicians who are newly elected, whether we served before or not, must address--the real issue of hope in a community of voters who will accept no excuses. Another way of examining the no-excuses mentality is to examine the phenomena of research and outcome results.



The issue is accountability and many of the things that I've done in my legal career and political career have led me in different directions to understand accountability. The only case I ever observed argued before the United States Supreme Court (and I flew from Boston to watch this argument, where I was teaching at the time) was the JL-JR vs. Parham, a case involving children in Georgia's state psychiatric hospitals and their rights. In the last six years I have been involved on the periphery of the contempt actions and continued federal court actions trying to enforce the rights of the JL-JR population of children in state hospitals and I have directly, as lead counsel, been involved for six years in a case of Todd D. vs. Andrews, which involves the rights of psychiatrically-impaired special education students.

In this 15-year observation of one issue of children with psychiatric impairments, I have seen, I'm afraid to say to you, very little accountability and very little progress. What we have seen is a perpetuation of what I have called a competition not to serve among our education, our community-based, our hospital professionals, and most importantly, our politicians.

The mood, the political mood right now, is accountability. And how do I become more accountable? How do I become more effective? How do I become more energetic and hopeful for change? And that is, I say to you, by your participation in these issues. If I live to be 80 I want the JL-JR and Todd D. population issues to be resolved. That is one of my central responsibilities--to talk about that issue everywhere I go in the mental health community and to use it as an example. That is one example of a system that is failing the mentally ill population.

There are many other things that these important people have talked to you about: the importance of state leadership in maintaining the state's role in mental health issues and the necessity for us to work together. The working together part is something that the commission (that Stan Jones and Jim [Martin] have worked on) has been enormously effective and enormously productive in their report. I think that the success of that commission which is redesigning Georgia's delivery of mental health services is going to depend in the next few months on the 1993 General Assembly session, on your advocacy to your personal representative.

I say frequently to groups like this that the most important piece of information that anyone ever gives to me is their street address. There is a psychopathology of politicians about who votes for me. The first year I was in the General Assembly, the most letters I ever received on any one subject dealt with mandatory kindergarten testing for five-year olds. It was a groundswell of interest from individual voters and the number of letters was five in number. I say to you that if you do not know the name of your state representative, you do not know the name of your state senator then please today find out who that person is who has been newly elected to represent you. And please contact that person before January 11th and express your personal commitment to helping that person with mental health care reform.

Thank you very much.

**Tom Bryant**

Thank you to all and I know that we want to have questions, but I know that Congresswoman Johnson is going to miss her plane, so, Nancy, is there anything you need to say right at the last minute, here?

**Congresswoman Nancy Johnson**

I just want to say that I appreciate the comments that have just been made, and if you don't know your Congressman, it's your job to sit down in their office, both in the District and in Washington, and really establish a relationship with them and educate them. Because this, as important as it is, is only one of the many issues a member of Congress will deal with, and without your help and support and direction, they could deal with it wrong.

I also want to say that I very much appreciated the comments of both of your distinguished state legislators and the kind of planning that you're doing here. This kind of study and analysis is exactly what needs to go on. As we move toward a national solution, we must make sure that it allows you to define what that coordinated system of care is, so that it will be inclusive and well coordinated. That's going to be one of the most difficult aspects of solving these problems, because when Washington decides to act, sometimes we are so involved in street addresses. Thank you very much. I'm sorry I have to leave.

**Tom Bryant**

Thank you, and I assure you that all the national organizations represented here will soon be calling on you.

Now, we've got time for a few questions for this panel and I've got some from the other room.

**(Read by Tom Bryant) From Crawford Harris, Tennessee Mental Health Consumers Association and Rushmore Group**

Since it is impossible for an American-trained physician to have not done something from public monies, would you support required *pro-bono* services for psychiatrists, perhaps in the arena of one hour a week? Who'll take that?

**Senator-elect Mary Margaret Oliver**

I want to say to our Emory Medical School community that I have had, twice in the last week, people (credibly impressive to me) tell me that part of the health care reform is the reform of medical health school education. That's made an impression on me this week. And in that context, we in the legal community have struggled with mandatory *pro-bono* work forever, and we have always had it in one form or another as part of our profession. I think that Emory Law School is now going back to mandating public *pro-bono* work as part of legal education and I think that the medical schools are going to have to begin and implement that discussion that carries a mandatory *pro bono* contribution beyond medical education.

**(Read by Tom Bryant) Dana Santafanti, student at Georgia Southern University, directed to Representative Jim Martin.**

Is Georgia currently down-sizing its state hospitals, or are state hospital dollars following the consumers into the community?

**Representative Jim Martin**

I guess (because this question's from a Georgia Southern person, although I went to the University of Georgia, I must recognize Georgia Southern as a wonderful school) that's the whole point of this commission. It will never happen, as long as the providers are driving the budget. When the local planning agency looks at their share of 600 million dollars and determines how much of that has to go to the hospitals and how much is left to go to communities, I believe there will be dramatic changes in the use of those resources and it will enable not only the community programs, but also the state hospitals to begin thinking about providing community services. I think that's wonderful. So the answer is yes, the Commissions' recommendations will help to downsize hospitals.

**(Read by Tom Bryant) Maureen Abate, Child Psychiatric Clinical Health Nurse Specialist in Grady Memorial Hospital**

As you know, children are one of the most underserved populations with regard to mental health services. The question is, do you see in this state, Georgia, the potential to incorporate the mental health boards proposed by consumers citizen advisory groups into the structure of the recently formed Division of Youth and Family Services, and will the Department of Family and Children Services play a role in this vision?

**Senator-elect Mary Margaret Oliver**

I was the author of the bill that created the new Children and Youth Services Agency and we did that with a little bit of risk (as you frequently do) and with a concept that we were going to take the first step of providing a separate agency for juvenile justice and community based treatment programs for that population. It was obvious to us that we would re-evaluate, to the extent to which children's mental health services and foster care services and child abuse services would be brought into the new Children and Youth Agency over the next few years. I think that is an issue that we need to evaluate and I'd like your input on that.

Specifically, I'd also like to point out on that particular issue that we have to find a way to make our school system responsive to all health care issues for children and most importantly, issues of emotional and mental health for children. The Family Connections Project which promotes inter-agency cooperation as a facilitator is, I think, a good example of the way school systems and school superintendents and physical health directors are beginning to coordinate their programs with a school focused approach.

**(Read by Tom Bryant) Saul Sherr**

What is the role of family in the new system of things to come?

**Representative Jim Martin**

Well, that's critical. The actual boards will be appointed by the county commissions. So advocacy will happen at that level in terms of the appointments to fill the consumer and family slots, but we all recognize that there is a need to hear both voices. The mix between consumers and family

members would be left to the local County Commission in making their appointments within the requirements of the composition of the planning council and the service delivery agency.

### **Henry Quay - Member of The National Alliance for the Mentally Ill**

I have been through mental illness with a son. He had an auto accident and was misdiagnosed as manic depressive because his illness was evaluated using his symptoms only. I call this method of diagnosis "symptomology." We were dragged through the mental illness system for about four years before we finally got a correct diagnosis. He had a neurological condition. He was able to get back on his feet. When we looked for rehabilitation for him, there was nothing available. The state rehabilitation consisted of sitting him before a television camera and attempting to train him to interview for a job. He had a college degree but with no rehabilitation available, how was he to seek meaningful employment? He decided to go back to college and seek a masters degree in rehabilitation counseling. He is now employed as a professional. His correct diagnosis cost me about \$2,000 because I had to make two flights out of state with him to get the diagnosis. Today this technology is available in the state. I was once told by a doctor "these tests are expensive." My reply was that the cost of three days in the hospital (as of today, two days in the hospital) would have paid for the proper diagnosis. At the time of his diagnosis, our son had been hospitalized approximately 150 days. I think all our systems need better methods and procedures for proper diagnosis.

I have several things I would like to say regarding the proposed reorganization. Someone said a while ago, you've got just so much money to spend. What happens is that you have child advocacy on this side, you have mental illness on that side, child abuse here and mental retardation there, all seeking these limited funds. I say we should all get together. I look on this list and there are about 50 organizations that are represented here. The Senator or Representative from Oregon was talking about the ducks flying. I recently read an article regarding ducks flying in formation. They draft each other similar to the draft the NASCAR drivers use. The lead duck is working the hardest and that is the reason they keep changing the leader. Any of you that are leaders of organizations know that, but if all of our organizations were formed to be like the ducks and work together as a team and work with our legislators to have one community health center rather than five or six community health services, this would get rid of some of the bureaucracy. That way, if I go to a center with a child that has a problem, they could say, "Well Dad, you go around the corner and get help in the same building." I don't have to go twenty miles away. I want to say something to you Jim. We have one gentleman up there I can't vote for. His name is Tom Murphy and he blocks everything I may request my representative to introduce if he does not like it. I would like for you to help get rid of him so we have equal representation.

### **Representative Jim Martin**

See, he directed that directly to me! I'll answer by saying I voted for Speaker Murphy, and I did it without any reservation at all, because of the contribution he's made in this area. But you and I may disagree about that. Let me also respond to what you're saying by saying this: when the Commission looked like it was going to make a decision, all the providers-- all the advocacy groups like your own or other organizations, got together and said, "Look, we can't let these fools make these decisions. We've got to come up with a plan we all agree to." And they did it here in Georgia. The same thing is necessary regarding the topic of what Mrs. Carter is talking about. All the advocacy groups have to agree about what it means for mental health to be part of the

national health care reform package and then present that to the decision makers, because, frankly, the issues are too complicated for legislators like myself and Mary Margaret to handle.

**Tom Bryant**

We are about to cut off, but I want to give Congressman Kopetski a chance to say what he wishes to say.

**Congressman Mike Kopetski**

I believe there are a couple of issues that were touched upon. One of the problems that I saw as a State Legislator serving on our Appropriations Committee and now in the Congress, is that we recall in the seventies when we had the Civil Rights Movement for the mentally ill in our society. We de-institutionalized them and the states promised that those dollars that used to go for institutionalizing individuals would go to community-based programs. That didn't happen and we know the results. These are the homeless in our society; these are the victims in our society in so many ways. So when we talk about getting back to where we were, we really are talking about getting back to the seventies and the days of the Carter Administration when we had a commitment to this population. We lost that commitment in the eighties for a different reason, mainly because we shifted dramatically to spending on the military in this society. We, as a society, increased the military portion of the budget from about 21% of the federal budget to 30% of the federal budget. We made this conscious choice in this society that we were going to take money away from people, put these people out on the street, and put the money instead into the military-industrial complex. We have the opportunity today, now that the budget walls are coming down this year, to shift some of those monies back to people.

I believe that it's also important to note that what we do at the federal level must allow for states to have flexibility, so that we're not designing a national program, but we're allowing for the local experimentation and local community needs, that may be different in Georgia, Oregon or New York City. I know that's important to do.

Also, I'd like to come back to the need to fly together on this. We need successes, no doubt about it, or else policy makers or appropriators won't give you more money. If you can't come in and say, this works, please give me more money, they're not going to give you more money. So, we have to spend money on the easy cases, so we get the success and it does help those people. We also have to spend the money on the tough cases as well, even if it's a seriously mentally ill person. The only board of directors on which I serve is a non-profit group in my state for chronically mentally ill people who are deaf and who have a history of violence. This is a tough group of people to serve. Until we identify that need in society, come up with a program that works for them, we're not going to fix the overall problem. We cannot fix the overall problem, I'll conclude, unless we're all flying in the same formation in this area.

**Tom Bryant**

We're going to have to move on. I would like to thank the members of the panel. I think we've got the metaphor for the morning as flying in a "V" shape together, the leaders are going to change, but some leaders are going to pick up right now, and the next leader I'm going to call on is Jeffrey Houpt, who is the Dean of the School of Medicine at Emory University. Jeffrey and I

co-chaired the first Rosalynn Carter Symposium eight years ago. He was then merely the Chairman of the Department of Psychiatry. He's moved on to far greater responsibilities now--running the medical school, and who knows, may take on the world tomorrow! Jeffrey.

### **Jeffrey Houpt**

Thank you very much Tom. Mrs. Carter, thank you again for your interest and your leadership. And thank you very much elected officials and also the citizens who were on the panel earlier. It's late in the day but I do want to take the opportunity to make a few comments.

The problems that we face are very significant. There really is no "simple fix" to all health care issues in terms of where we are at this point. I want to sound a cautionary note for the mental health community. I think that we face a difficult task at this point in time, and I don't think that for a minute we should assume that things are going to go our way--that, in fact, health reform is going to help mental health services a lot unless we are very, very active. Also I want to kind of sound a wake-up call today, if that's necessary, and to point out some of the reasons why I think that's the case.

The reasons I see are these: there is a national voice at the current time which says that health care costs too much, that we have a problem with the uninsured, and that we have some poor health indices. These are usually directed toward infants and children. Many of the root causes are outside the health care system, but I believe that these are the factors that are driving the changes that occur at this point. We need to ask ourselves whether or not mental health is really a part of the national voice when it comes to that reform or not.

The elderly as a group voted more in favor of health care reform than any other group and yet we heard this morning that mental health is not high up on their agenda. The point that I would like to make is that we are going to have health reform--the system is going to change. What happens to mental health is going to happen as an epi-phenomenon to what happens to health care reform. I don't think we are going to drive the system. So, I think we ought to try to anticipate what's going to happen in health care reform and utilize that knowledge as a way to organize our energies so that we might "fly together" as the metaphor has been.

To me, the central concept in health care reform is the concept of managed competition. I disagree to some degree with Representative Johnson on that particular issue. I believe that there is a great need for improved administration of health care. That technology is available to us and will be useful. I don't think, however, that necessarily is tied to managed competition. Managed competition is a device to control costs of health care by determining who gets health care and what health care they get. That's what managed competition is about from my point of view.

Now what does managed competition mean? What it means, basically, is that the control shifts from the provider, where it has been for decades now, to the payer. The payer is going to decide what services people get and at what prices they are going to get these. And payers are going to put together mechanisms by which to control these costs. These mechanisms are well known to us. Algorithms and gate keepers: somebody in a room sits down in front of a computer, and an algorithm goes up, and they decide whether or not they are going to pay for a certain service and the use of primary care physicians as gatekeepers. These are the mechanisms for cost control.

The consumer affects the system only to the degree that he can affect the payer. And I laud the new Georgia system which, since the Government is the payer in this case, takes the consumer and puts him in the position to affect what happens.

In the private world, the consumer can only affect the system inasmuch as he or she affects the payer. Now, how many employees are going to go to their employer and say, "Look, I need to have money to see my psychiatrist to get my depression treated; I want money to pay for my Tofranil, or my Haldol." I think it's unlikely. People sneak off to get their mental health care in this society. They don't sit down at a table and start screaming and yelling about it having to be covered. How are we going to affect the payer? It's going to be very difficult.

Now, managed competition is going to come in a very decentralized way. We are not going to be able to lobby in one place the way it is being set up at the current time. If Atlanta goes the way of San Diego, for example (you always talk about the future because you know what the present is) if it goes the way of San Diego, there will be three or four health care systems in Atlanta in a few years. I hope Emory is one of them. The question is--are you going to be included in the care that is provided in three or four years, and if you are, how are you going to influence it? Well, the point is we are going to have to advocate in every hamlet in the country. It's not going to happen the way it's happening now, by national mandate. The money is going to be divided up locally. The employer is going to decide who gets what and whether or not they get it. So it's going to dilute our advocacy, and I think we need to be very much concerned about that.

The other concern I have about managed competition is that it's an ideal system for things to kind of fall out of the bottom. That is, it's an ideal system for skimming off things and letting other things fall to what we now call the public sector. I am very concerned about that. I spent an interesting meeting last week with a group of capital venturists in Atlanta. They are just salivating over the thought of managed competition. I mean, they see this as a great way to make money. Are they going to make money? They are going to make a lot of money. How are they going to do it? First, they are going to run the system. Administration comes off first, then you do services. And they're going to pick profitable things: free-standing cardiology centers; free-standing oncology centers with home infusion. I listened very carefully and I didn't hear mental health coming up in those discussions very much. This has to be of some concern to us. Because the way this system works now, if it is left to a decentralized system, it will fall through into the public sector and we will need to worry about it at that particular level.

The second reason why managed care is so popular is not just because it controls cost, but because it helps us as a nation to avoid the basic issue--that is defining what basic health care coverage is. This is a surrogate for that discussion. This decentralizes the discussion and lets the payer decide what basic health care coverage is; that's who determines it under the managed care system. There is no debate over what basic health care is under this system. So my suggestion is several things based on this.

Let me say that managed competition has some positive points. You have asked me to talk about mental health issues and so that is what I am talking about today. Competition is motivating, that's positive. Managed competition offers us the possibility in the future of molding public and private systems--something we have not been able to do. It's the opportunity that we ought to take a look at and it might control costs. So I am not speaking against managed care, I am just talking about what our problem is going to be with managed care.

I believe if managed competition is invoked, that there needs to be a combination of decentralized managed competition with national mandates. There needs to be some kind of creative tension between the two in order to define the safety net. I would prefer that it would be an up-front discussion about what basic health care ought to be in this country, and let's price it, and let's ask people if that's what they want to pay for or not. Why don't we do it that way--take it from the start--what's the budget; what are you going to get for it? I'm the dean of this school, people are in my office every day saying, "You need to help me do this." My first question is "How much does it cost?" Then we will decide whether we can do it or not. We need to have that kind of debate with our health care system. I believe the more you move to that kind of discussion, the closer you move to a German system. I would offer to the congresspeople another option for the way we are going which is the way we legislate laws as a way of mandate, and wonder if in the area of health care it really wouldn't be wise to set aside politics from health care, and to have an agency that cannot be fired, that cannot be affected politically (an analogy to the Supreme Court or the Federal Reserve Board), that would determine what basic health care is. You also can do it with single-termers. You put professionals and consumers on it, and there would be some debate, and there would be some idea of budget and priorities that would be set by this, hopefully, non-partisan commission. And they wouldn't be under the pressure that they are under to respond to constituencies. Because some of these decisions are going to be hard decisions and unpopular decisions.

Well, what can we do? I think we need to work with alliances. There is going to be a great deal of interest in children because of the new administration and we can certainly support that. And it's an opportunity for us to look at our agenda again with regard to children--an opportunity to cast schizophrenia as something that robs children of their future and include it in children's kinds of activities. I think that we ought to be working with the elderly; I think what we learn today about the elderly and their perceptions about mental illness offers us a great opportunity to insist the Association of Retired Persons accomplish their agenda so that it helps us as well.

I think, as a profession, we clearly have to get into the area of outcome research. I'd much prefer to go to a congressperson and say I have a program that I can prove to you that works, and it's going to cost this much, and is going to save this much money. I think that would go straight through. We just don't have the data to do that at this point in time. I think we need to accept as a group that we are not going to get everything that we wish.

Thank you very much for the opportunity to make those comments.

### **Rosalynn Carter**

Thanks, Jeff. You are reminding us of the pitfalls, but seriously, it's very important for us to think about these things. It's getting late, as Jeff said, and I know we're all hungry, but I want to take time to thank everybody, because I think we've had a really wonderful morning.

I want to thank the participants. I think both of the panels have been good. You've given us a lot to think about. And the organizations that are represented, the people that are here, we have our work cut out for us. It is very important that we work together and very important to "fly in formation," to be sure that we get mental health care in national health care reform. We'll talk a lot about this later. There's another group here that I want to briefly mention and that is the board members of the Rosalynn Carter Institute at Georgia Southwestern College in Americus, my



alma mater. We are doing something there that really does affect those of us who care about people suffering from mental illnesses. We are working with caregivers. We are working on a program to try to help make life easier for those people who give care, and in turn, make life easier for those people who receive care, not just for the mentally ill, but for the physically ill, for those people who are tied down, possibly with an elderly person in their home--across-the-spectrum of care giving--and we're setting up a model in a sixteen county area in Southwest Georgia.

We've brought together professional caregivers, lay caregivers, the heads of all the different government agencies that deal with those who have problems, the religious community. We've formed what we've called a Care-Net and we've just finished a needs assessment in our area. We used the students at Georgia Southwestern College. The students, working with the professional caregivers, called on family caregivers and filled out a questionnaire that we had developed, and then the students with the family caregivers interviewed the professional caregivers. We just completed that (with some really interesting information) and we're going to base the actions now of Care-net on what we have found in our needs assessment. I think that you might like to hear more about this program. Maybe next year we can report to you on it. It's really fascinating and I think it's going to be a model for the country. We're now developing a book for caregivers too; that's really exciting to me.

Well, let me thank all of you. The last people I want to thank are the Task Force members for all your help with this program, and The Carter Center Mental Health Program staff, Carol Koplan, Margaret Cornett and Ellen Wright. Thank you so much for putting together this program that I think has been so wonderful. That concludes the morning session. Thank you.

## AFTERNOON SESSION

### Editor's Note:

Participants in the afternoon work groups were given instructions (Appendix A) from The Carter Center staff about discussion of three topics related to the inclusion of mental health in health care reform. In addition, they were given a working paper in draft form entitled "*Principles for Including Mental Health in Health Care Reform*" distributed by a coalition of mental health organizations (Appendix B) which also could serve as a basis for discussion. A "*Summary of Results of Afternoon Working Session*" compiled after the Symposium can be found in Appendix C.

### **Leslie Scallet, Moderator**

We will have results from each of the groups, and then there will be a report back here. In addition to that, once the Symposium is over, all of the materials and what's on the flip charts will be sent to the Task Force. The Task Force members will synthesize the entire body of knowledge that we generate this afternoon, and then there will be a written report back to all the attendees, so you'll see more than what came out from each individual group. We'll try to do some kind of analytical synthesis. We'll have to see what we come up with, but we want to capture, not only any things that are raised in four of the eight groups, but we also want to capture that special good idea that may have only come up in one group.

After this Symposium, we are going to have to get together again and ask, what is it that the Task Force finds most useful to take this process the next step further? What can we most usefully do to be helpful? And we'll be looking to the wisdom that comes out of these groups as one source of ideas for us.

Each group this afternoon will be talking about three basic areas, and I think you've all gotten this on a sheet of paper. The first one is, "What steps are groups and coalitions you are involved with (not only mental health coalitions, but others) now taking to have an impact on the health care reform debate?" And then, "What are some of the things that need to be done next?" The more specific we can be about types of strategies for reaching Congress, or types of things that need to be done to reach the new Administration, or to reach out to other constituencies that we haven't been talking to, or whatever--the more specific you can be, the better.

The second area is the question whether a specific plan for building mental health into health care reform proposals should be developed, and if so, how specific should it be and what are the elements that are still needed to produce it? One of the things that you have all been given is a draft working paper that has been developed by some of the mental health organizations and has been circulated for sign-on and still continues to be circulated for sign-on. Some people regard that as a sufficient basis for going forward. Others regard any set of principles--that or any other--as not being sufficiently specific as a basis to go forward. So we need to have some discussion about that. The purpose of that discussion is not to endorse or not endorse any particular set of principles, but rather to get some discussion going.

And then the third area we'd like to talk about, if there is time, and there may not be, we would very much like some input on what you think the likely impact would be on mental health care in general of some of the proposed reform directions that are abroad in the land. There, I'm most interested in the issue that Jeff Houpt raised at the end of his remarks this morning -- the impact on public systems if mental health is not well included within the national health care reform proposal that is eventually adopted. And what is the likely interplay between public mental health and the private systems.

We're going to divide into groups. There are four groups that will be meeting in this room in different corners. Group Number One, with Kathy Cade, will be following one of these staff members over here. Group Number 2 will be in that corner with Jane Delgado. If you're in Jane Delgado's group, that's where you need to be. Group Number 3, Joe English was unable to facilitate this afternoon, so Henry Tomes will be leading that group, and that group will be back there, in the back of this room. Group Number 4 will be in this room, led by Fred Goodwin, and that will be over in this corner. Group Number 5, led by Charles Nemeroff, will be going to the Zaban Room. Group Number 6 will be led by Jerilyn Ross, and will go to the Presidential Conference Room. Group Number 7 will be led by Richard Surles in the Executive Director's Conference Room. The last group, Group Number 8, will be led by Jeff Houpt rather than Bill Woodside, and you will be taken to the Lower Commons Room. See you all at 3:30.

### **Leslie Scallet**

I'd like to go through the groups and each of the facilitators will report very briefly, as I said, for three to five minutes, as to what happened in their session.

We're going to start with Richard Surles.

### **Richard Surles**

I had a lot of fun in my group in that it was not a rowdy crowd, but it was a very thoughtful group.

The group generated six major points. First, this is not a time for concessions on anything. While the group found the priority setting and the attempts to describe the benefits interesting, the scope of the benefits is probably too inclusionary and unrealistic. However, at this time in the development of a health care plan, a broad scope approach should be continued. The judgment favored The Carter Center and the Task Force to continue to be "on board" in terms of the national debate on health care reform. The mental health field must not be left out of the health care planning process, but be a player and find the points of entry so that we are in the discussions from the start.

Second, there were specific suggestions about getting on board and four influence groups were identified to be aggressively pursued. One group, the American Medical Association, will clearly play a role in health care reform. The American Labor Movement and some of the larger unions will clearly be players, as will the American Manufacturing Association, as we heard this morning from the small business side. Those three entities are definitely going to be institutional players in the reform effort, and efforts to influence their planning should be considered.

Third, there was an endorsement in our group of the need for a national media strategy. A critical concern was expressed that issues be publicized regarding the debate about the need to include mental health in reform efforts. Mrs. Carter's speech this morning was a very good opening description of what that debate is.

Fourth, as the planning for national reform emerges, we should anticipate an expectation for compromise and that some rationing will occur. A traditional health care plan will not include all that the mental health community will believe is necessary, and we should be very prepared to describe shortcomings and create an expectation that if a benefit is not going to be included in health care, then an alternative plan will be required.

Fifth, state government, in the past twelve years, has increased non-traditional health care benefits through the federal/state Medicaid program (*i.e.*, case management, rehabilitation). Some of the benefits currently offered by states could be eliminated in the reform effort. For services not included in reform, attention will need to be given to who will pay for supported housing, for vocational rehabilitation, for the opportunity to return to work after recovery.

Sixth, the group feels that mental health representation should be included at every level in the issue of reform and governance. If we move to a highly decentralized regional system with 1500 regions in the country, mandatory inclusion of mental health leaders in the government structure, at whatever national, state and regional level, should exist in any system of oversight and quality review. Therefore, a major commitment should continue to be sought for the right of inclusion and the right of participation in the allocation of resources and the oversight of mental health treatment.

## **Leslie Scallet**

Richard, that was a model of conciseness and clarity and I hope that all the rest of our facilitators will follow that example.

Fred Goodwin is next.

## **Fred Goodwin**

We don't have a consensus to report, but we do have a lot of stimulating ideas that were shared, if not completely agreed upon. One that we all shared is that there are a lot of models out there, including the Canadian model, right next door, which most of us didn't know much about, and we got right down to it. We need a mechanism for informing the advocates about what really is the truth about the Canadian system, rather than the various mythologies which have been put forward on both sides of it.

One point about models, by the way, is that some of the models which different groups are putting forward contain at least rudimentary efforts to put cost estimates on them, while others do not. And what was clear from those who have interacted with Congress is that the legislators all want to know, "what does it cost?" So, we want to build from the knowledge base that we have regarding cost data. Fortunately, the mental health field recently has developed some good cost data based on diagnosis, disability, and duration. I think everyone agreed that you need all three of these elements; a diagnosis, a disability estimate, and a duration estimate to be credible.

Of course, integral to our discussion was the one issue that's behind this whole meeting, which is--what is the spectrum of coverage? We got into an interesting discussion about other areas of public policy formulation that might help us think through the differences between our goals, which I think we all share, and tactics, where I think people differ. There are many experiences to draw on. Somebody brought up the Fair Housing law, where starting modestly and expanding gradually worked well. We also talked about the Americans with Disabilities Act, where starting more broadly seems to be working; and health insurance itself, starting narrowly in surgery and expanding into everything else. So, we have to look outside of the mental health arena for other examples, including many for which the policy implications have not been developed fully. That was the consensus of the group.

One of the more interesting ideas was that with more and more consumers benefitting from the evolution of treatment, we ought to think of ways to bring the consumers, or patients, into this process in a more visible and effective way. Also, it was pointed out--and this was interesting to many of us--that the Americans with Disabilities Act, since it includes mental disabilities, is now providing an incentive to people to self-identify as mentally disabled and mentally ill. That's an army of people who could be part of the education process. The dilemma we face is how soon do we have to have a position? Much of what we talked about pointed to gaps in knowledge that would help inform our position. If we are talking seriously about doing something by August, then we may not be able to fill some of the knowledge gaps in the time available before we have to take a position.

A point that one of our members mentioned that relates to this is how do you get the elite in the country--who often are in decision-making positions, and who may be more likely to be well-

covered, or at least relatively well-covered--to really care about this issue? How do you get them to really own it? This is where we agreed on the active involvement of the consumers themselves, as opposed to the family movement which, of course, is involved.

The issue of services research came up several times, and the question, "what knowledge base do we have?" I think that we can reassure everybody that the Advisory Council to the National Institute of Mental Health will have prepared, by mid-December, reports on the actual incidence of each of the major mental disorders in the Diagnostic and Statistical Manual (DSM) system and, related to that, cost data. How many of those people now are seeking treatment? In any given year, it comes out to about 18 million people nationwide in mental health treatment, an average of 14 visits per year, and we are costing out what the system is now costing. We will be able to give hard estimates of that using data from the new Dorothy Rice study. We will address the "iceberg" issue that scares insurance people--that is, that roughly half of the people with a mental disorder diagnosis are in treatment. We also will be able to show that appropriate mental health treatment will yield significant decreases in the inappropriate and ineffective use of general medical services by people with severe mental disorders; that is, we have an offset effect. The question came up over and over again, how do we, in fact, disseminate this kind of information more effectively? We identified one problem--that there are lots of estimates of costs by different groups. There is the official NIMH Epidemiologic Catchment Area, or ECA, data base of the federal government, and lots of advocacy groups are putting out their own numbers. The question is could we get some kind of a clearinghouse so that all the groups would at least be able to know what the other groups are putting out, and be able to share that? That is, I think, one of the better ideas--along with getting the consumers (or patients) more actively involved in this process, and more allied with the professional groups--that came out of our session.

We closed on a somewhat pessimistic note, however--the point that Jeffrey Houpt and Tom Bryant warned us of--that the train is already moving out of the station, and is moving out with managed competition and managed care. And decisions are being made relatively quickly, so that we may have to move forward, even in the absence of filling out the data in all cases.

The final point was, of course, the emphasis that the bulk of mental health care delivery is now going on in the primary health care system, and any proposals that don't give emphasis to the primary care system are going to be off target.

#### **Leslie Scallet**

OK. Just for Richard's and Fred's benefit; any notes that you have, any flip charts, or anything from your group, if you can please make sure that you leave them here for us to work from in putting together the overall synthesis.

Now we'll go back to the order on the page, and I'd like to call on Kathy Cade.

#### **Kathryn Cade**

Our group came from a slightly different perspective than the first two who have just reported. We had a number of representatives from smaller organizations across the country. While these organizations have a keen interest in the inclusion of mental health in health care reform, are very concerned about the issue and want to be involved, they don't have the resources to play at the

same level as some of the larger organizations who are well represented in Washington. They don't feel that they, as individuals, have the ability to play a direct role in this debate, nor do they feel that they know how to get more involved. There seemed to be consensus among the group, however, that if we're going to be successful in including mental health in any kind of health care reform, there must be some fairly significant changes in society's attitudes and values about mental health and about the appropriate way to include it. And, the smaller organizations felt strongly that their on-going efforts in education and advocacy could contribute effectively to the necessary attitudinal change. Given their frustration about playing a more participatory role, it seems to me that the next steps for the Task Force should include looking at ways to expand the coalition. Specifically, we should identify strategies to incorporate the very large number of people represented in smaller organizations who don't have the ability, on an individual basis, to influence the debate.

We also spent a fair amount of time talking about the role of data in the debate. What kind of data is out there? What kind of messages are we trying to send by using data? What have we got? What do we need? How should we be using the data more effectively? Therefore, a second challenge for the Task Force going forward is to define how to become a more effective participant in the debate by positioning ourselves so we speak the language people in Washington are accustomed to hearing. Critical to our future success, for example, is our ability to respond to the question, "What are the costs and what are the benefits?"

A third area of discussion focused on interesting strategies that small organizations are using now which don't necessarily influence the national debate but present opportunities over the long term to make care more accessible. One of the organizations has its individual members lobby directly those drug companies who are producing medicines their members use on a regular basis. The message they send is the following, "You are making a great deal of money off of the drugs that we use. In fact, it is too much and we want to know how can we change this?" And it appears they are meeting with some success in changing policies at these companies. This is an interesting example of an issue the gentleman from the Small Business Association raised this morning, *i.e.*, the need for individuals to play a more central and active role in this whole debate.

A fourth issue that was raised and also was touched upon earlier this morning, which is worth repeating, is the role of the large corporation. Since many self-insure, they function to a certain degree outside the regulatory system. As the national health care debate unfolds, it may or may not include those who opt to self-insure. Yet these corporations are major providers of health and mental health coverage, so it's important to figure out strategies to incorporate them as well.

The remainder of our time was spent reviewing key issues that have been debated for the last six months, *e.g.*, what is the role of the medical model in shaping the debate? How do we get around the medical model? How do we talk about the continuum of care?

At the end of the session I was asked, as someone who is now outside the mental health field, about my personal observations regarding the mental health community's efforts to influence the debate. During the past six months based upon regular reports from Leslie [Scallet], I became quite optimistic about the progress that has been made in building consensus among the mental health constituencies around the inclusion of mental health in health care reform. Yet, after listening to the discussion this afternoon among individuals and organizations who have not been involved in that process, I am struck by how fragmented the field remains and how deep the

divisions are. The individual interests of specific constituencies still represent very powerful forces in the discussion.

I would close then with the thought that to the extent we continue to remain fragmented, we jeopardize our collective abilities to influence the debate; and, we run the risk that mental health coverage will not be incorporated in the way that we would want in any kind of health care reform.

### **Leslie Scallet**

That is a great definition of the glass half full and the glass half empty. I've always been a glass half full person and I do see a tremendous amount of progress that we've made even though I also see the continuing problem of fragmentation. That's what we're all here about. Next is Jane Delgado.

### **Jane L. Delgado**

First of all, I want to thank the very productive group which I had the pleasure of facilitating. Our discussion focused on three key issues:

1. Steps groups and coalitions are now taking to impact on the health care debate.
2. Specific plans and/or elements for building mental health into health care reform.
3. Impact of proposed directions of health care reform on mental health services and systems.

The group was very task oriented as we addressed each of these areas.

1. Steps groups and coalitions are now taking to impact on the health care debate.

Most of the participants indicated that they were active in several existing groups, *e.g.*, Mental Health Liaison Group, Mental Health Leadership Forum, Families U.S.A., National Health Care Campaign, CUMI (Council for Understanding Mental Illness), and SAMHSA.

Given the breadth of existing groups, no new group needs to be formed. Instead there needs to be better coordination among the groups represented at this conference as well as better coordination with groups which are not part of this conference.

In the latter situation, we mentioned the National Health Council, which is an umbrella group for all health agencies; the National Assembly, which is for social service agencies, and United way. These are organizations that we need to target with our message of including mental health in health care reform. We also talked about networking more with the disabilities community, not only in the sense of what we typically do, but in discussions about health care reform. Because a substantial number of the people who receive disability benefits have a mental health related determination, they should have a say on how benefits are established. We also talked about reaching out to other people, like the AMA's Health Access America project.

The reason we're reaching out to others is to benefit from their strength so that mental health is represented by a broader range of groups. We must also flaunt our numbers so that decision makers recognize the mental health community as a sizable portion of voters and constituents. Moreover, the ability of individuals to relate to mental health as an issue must be made more personal. People must be made aware of how close mental illnesses are to them and their families.

There was some discussion on the biological origins of mental health problems but the group decided that such an important and complex discussion was beyond the current task.

2. Specific plans and/or elements for building mental health into health care reform.

The group acknowledged that there would be some form of rationing. Given the likelihood of rationing several questions were raised: Do we define who is most in need? How do we determine need? Do we look at cost? Do we look at the situation? After much deliberation the group decided not to buy into a forced situation based on "most-in-need."

Participants expressed concerns about the lifetime limit on mental health services, *e.g.*, limit is too low and people end up in the public sector. Any new system must look at how people should be served based on their psychological and medical needs. Additionally, early intervention must be built into the program.

The statement of principles was used as a starting point. Already thirteen groups have signed on in three days; we have to see what else we can do in the future. The statement of principles can guide us in some general way while at the same time on a parallel track we work to make mental health part of health care reform. This would include public education and professional education, outreach and inreach.

In public education we wanted to make people aware that there is a gap in mental health and physical health coverage. We also want to present accurate numbers for relative risk so people understand how mental health impacts their lives. Part of these activities would involve more information about stigma.

If we want to make mental health part of health care reform we need to educate our legislators, and we need to start talking about a grass roots letter writing campaign. We also talked about how we have to target the media more to change what they do.

3. Impact of proposed directions of health care reform on mental health services and systems.

We're very concerned about what happens to Medicaid. We are also unsure of what will happen to long term care. We were very pleased about any proposal where pre-existing conditions are eliminated. At the same time we support a federally defined benefits plan only if it includes mental health. The issue in any federally mandated minimum benefits package would be to define which illnesses would be covered. The consensus was that at this point the most important thing was to have a health care reform plan that includes mental health and is flexible.

Thank you.



### **Leslie Scallet**

I'm really very impressed with how concise this is. We actually have a chance of finishing on time. Next, will be Henry Tomes.

### **Henry Tomes**

Thanks Leslie. The group that I was in, Group Three, went along very well. We had a very intense and a very participatory group. Had lots and lots of ideas. In fact, we were generating ideas at such a rate that we thought it would be a good idea for Bernie Arons, who was our recorder, to come up and give our presentation. I just want to say that we did, in fact, cover all the things that we intended to get into, and it was across a very wide range. We had a lot of people in our group who really wanted some kind of action. Someone said earlier that they had the impression that the train had left the station, or was leaving the station, and we might not be on it. I think that was also the sense in our group--that if we took much more time to try to get our act together there may not be an audience to appreciate it, and Bernie is going to tell you the details on this.

### **Bernie Arons**

I should be able to keep within our time limit because some of the groups have covered areas which were discussed in our group. We started with the first question, "What are the groups doing and what's next?". We went through a number of items that people are doing, some of the emphases that they are making, and we came up with, basically, three important things.

The first thing is that there needs to be a simple and direct core message, but that the present simple and direct core message is a little too simple and maybe not direct enough. There needs to be some work done to expand the core message at this point, get something that is reliable, that all groups feel means the same thing to them, and then be able to present that specifically. That was number one--the message.

The message had three parts: first, develop what the mental health community wants; and secondly, be able to package that in a way so that the general consumers could understand. A good public relations message about mental health that goes out, using the media, using various public relations techniques, op-ed pieces and so forth, would spread that message to others. Second, publicize in all ways possible. Using various methods, what was called "lobbying", or "foyering" techniques, develop the grass roots and also try to spread your influence as much as possible. Develop the message both for the mental health community and then for the general consumer and the general public. Thirdly, publicize your message and then develop your advocacy. Those seem to be the primary issues that came up in the first part.

We then went on to talk about should there be a specific plan and what would be the elements necessary to develop such a plan? To summarize our discussion, the conclusion was that it was not the time for a benefit package just yet. There did not seem sufficient agreement, but there could be some steps that would get to that point. Those steps would be to identify the principles, the criteria which could be used to judge all bills, all proposals that are made. These principles and criteria had to be developed further. Some of the proposals for what principles to rely on would be the organization statement that was distributed in Mrs. Carter's remarks. That could

lead, when possible, to a benefit package. Meanwhile, one should develop the legislative strategy to be able to move, no matter what proposals are given. So we should work with constituencies, develop background, develop logical arguments, develop business context and have a readiness to respond to whatever proposals are put forth. The issue was raised that it's important to know what the playing field is. If the playing field is going to be managed competition, we need to know more about that and how mental health should play a part in that. There was a feeling that to take no action at this time means to live with what is likely to be a very minimal mental health benefit.

We then tried to go on to number three. "What is the likely impact of reform going to be on the present system?" We didn't get too far. There seemed to be a fear that if there are some major changes in health reform it's likely to destroy some of the public safety net, through Medicaid or through the public system that has been built up for mental health care. We need to pay attention to whatever reform is put in place that does not further accentuate an unequal two systems of care for individuals with mental illness, and that we maintain some form of safety net for those left out of the system.

### **Leslie Scallet**

Two of you for just about the same amount of time as one, that's great. Charles Nemeroff.

### **Charles Nemeroff**

Group Five had a very productive session. We came to many of the same conclusions as the other groups. We had a spirited debate. We were somewhat amazed to find that the representatives of many of the professional organizations all had, at various stages, developed plans and had lobbied with Congress, as well as with the Clinton Transition team. We are concerned about splintering of the advocacy and professional groups. There was a universal concern about the issue of the gatekeeper, whomever that person or persons will be.

There was a consensus in our group that we've been notoriously poor at communicating the issue of outcome, and the fact is, for example, that we're very good at treating depression. In fact, we're better at treating depression than cardiology is at treating coronary artery disease. Thus, the treatment of depression is more successful, as Dr. Keith reminded me, than angioplasty for coronary disease, yet we never make that point--at least not well enough. Moreover, we don't talk about the impact of no treatment, although we know that it's devastating. Because of all of these issues and more, and because of a lot of confusion among the Clinton Transition Team and others in Congress being lobbied by different "guilds" if you will, we recommend a learned respected advocate (or advocates) who have no guild allegiance, but who can support a unified mental health and substance abuse program. We came up with the First and Second Ladies, past and present. Hillary Clinton, Tipper Gore and Rosalynn Carter all have an interest in this area, and they are as learned and respected advocates as we can ever come up with. We were very taken with the idea of a "supreme court" of health care, and we thought that it could function in a fashion similar to the Federal Reserve. Everybody thinks highly of the Federal Reserve, particularly its impartiality.

We had a lot of concern about what would happen if Medicaid is dropped. This ranged from questions such as: is managed care going to swoop down and negotiate with state facilities, community health centers and the like, as to whether Medicaid and Medicare would somehow be

combined into National Health Insurance? Virtually none of us knew that there are 160 current health care bills before Congress (and we didn't think very many of our patients knew that, and certainly hardly any of our colleagues), and that there certainly is no venue for us to keep up with all of this. It's a real communication problem.

Then lastly, getting back to the basics of medicine, the very real unsolved problem is that technology has outstripped our budget and we don't seem to get that yet. The simple fact is that all of us would want our child, if they were suddenly psychotic, to have an MRI scan, which costs as much as \$1,200, or a PET scan, which might cost \$2,000, because maybe there is something wrong with their brain that can be treated; yet how are we going to make that available to everybody in America? In a sense, the National Institute of Mental Health has done too well and has conducted and supported research intramurally and externally that has resulted in advances that we now cannot afford. It's something we don't like to talk about. We're frightened by the fact that we can't afford the very best care that can be provided. And somehow that's very anti-American. Thanks.

**Leslie Scallet**

Jerilyn Ross.

**Jerilyn Ross**

In spite of the diversity of individual organizations represented in this afternoon's breakout groups, most of the issues brought up in our group have already been discussed during this summary session. However, we do have some additional points to make.

In our efforts to work together and find common ground, several coalitions of mental health organizations have been formed. There is concern that there may be a good deal of overlap, which could be counterproductive to achieving our goals. It was suggested that we find a way to coordinate the various coalitions and their activities. Several of the organizations said they are waiting for more guidance and direction from other groups before they move forward in developing their own health care agenda.

It was suggested that since there is currently a good deal of "turf battling" between some of our organizations, we may want to look at other disease-related groups and see if there are successful models that we can learn from. The Americans with Disabilities Act was brought up as an example of a positive outcome of groups working well together towards a common goal.

We talked about paying special attention to plans and programs that are already in existence, such as the one developed by the Progressive Policy Institute (which President Clinton is using as a road map), and see if and how we can integrate our needs into that plan rather than try to create something new.

Our group was concerned about making sure that mental health care is not isolated and that it becomes part of an integrated health care system. We agreed that our first order of business should be to set priorities and develop a set of principles that everybody can agree to. There was no agreement in this group on the principles that have been developed thus far.

It was suggested that we can become more effective and efficient in our educational and lobbying efforts if we pool our resources, perhaps by establishing a clearinghouse of key legislative contacts, and keeping each other informed of legislative initiatives and activities.

Much to our surprise, a member of one of the consumer groups said that his constituents were not really concerned with the issues surrounding mental health care reform. He said the chronically mentally ill are currently getting Medicaid and Medicare, and are more concerned with what might be taken away from them than with what they might get. A statement was made reflecting the sense of hopelessness many of these people feel; "We are already terrible abusers, and we feel powerless, so what's the point?" This needs to be addressed. Paul, perhaps since you represent a very important patient group, rather than my speaking for you, it would be helpful for us to hear your comments directly.

**Paul Engels**

I can be really brief about it too. I was really quiet in the discussion, and people wondered why I was so quiet, and I said, "Well, we don't really--we who are the consumer group with persistence in mental illness--don't feel like we're really a part of this, because we already, in a sense, have universal health care. We have Medicaid; we have Medicare. The one thing we actually do have is health insurance. There are vital things we don't have. We don't have income. And we don't have vocational rehabilitation services, and we don't have housing. If we are content to live on SSI at \$5,000 a year, then the one thing we can do is use a lot of health care services. We can use our Medicare card, and we can use our Medicaid card. We can soak up lots of doctors visits, we can soak up lots of intensive community mental health services, but that is only if we are content to live with \$5,000 a year. We face the trade-off between buying 100 dollars' worth of medication and eating that month. So, that is our world.

We all are sort of walking around on the streets. We have got our Medicaid card; we're on the streets; we are going to the food shelf for food. We may or may not have a house to live in, but street life is our condition. The one thing that we do have is the Medicaid and the Medicare card. The one thing we might fear is the managed care, because in the managed care system, if we're going to triage, we're the people who are not going to get the health care, which is the one thing we have actually got now. So, that's what life is about for us.

[Inaudible question from audience]

**Paul Engels**

Users. I would say we are heavy users. We live in doctors' offices; we use a lot of community Medicaid-funded services.

**Leslie Scallet**

Thanks to both of you. I just wanted to say that you could be very easily defined as abusers in the larger debate--when we get into the larger debate. You'll likely be called heavy abusers as opposed to heavy users, so we have to be careful about that, too. O.K. A final word, as always, goes to Jeff Houpt.

## Jeffrey Houpt

How many of you have enjoyed seeing Tom Bryant act like Vanna White? We won't take that any further, I think.

We had a small group and a loud group. We were so loud that all the rooms around us were closing their doors. We weren't very disciplined at all, but we believe that out of chaos comes creativity; so we came up with a few ideas.

We ought to lead it off by the fact that we were deeply honest with each other in our group, because when we got to discussing what our strengths were, we decided that our greatest strength was that we fight hard to protect our own turf.

We had agreement on the big things. We want children who are safe, and we want mental health treatment that is adequate in any health care plan. We have really no agreement on the smaller things, the details that become part of the legislation. Our group felt that it is time to move beyond this. It is time to categorize what the differences are, to sit down together and make some compromises, so that we can proceed with some uniform voice.

We talked a lot about managed care and how to work in a managed-care market. We concluded that it would take a multi-pronged strategy, but one of them (at the local level) is, we just are going to have to organize and compete with the existing companies. Now, we have a bit of trouble. The Travelers can come in and they can organize people and set up a system that doctors and offices are not allowed to do, like fee-splitting and so forth, and we need some help with the Federal Trade Commission. We feel that managed care is here to stay and what we ought to be doing at local levels is organizing physicians and other providers into teams that can compete for these dollars and provide decent care to our patients.

The group didn't like the idea of the "supreme court." That was a wrong analogy. Apparently, people aren't happy with who's on the Supreme Court these days. (Leslie says it's getting better.) The model suggested was the Federal Reserve Board as with that group, or Utilities Commission. And we basically felt that out of a number of strategies, that might come down the pike as part of a national health plan. We ought to be able to jump on board. And if there is such a thing that comes down, we ought to grab it and ride with it and see if we won't do better with that kind of a voice to mediate the effects of primary care in the periphery.

Now, to be a little controversial, we feel unanimously that we need to take the profit out of medicine. One of the biggest problems with medicine in the last twenty years was the movement toward the proprietary sector and skimming profitable patients off the top, leaving a bigger and bigger carcass to be carried in the public sector and in social welfare roles, or whatever. And if there were anything that came along that would force profits from medicine back into the system, that would be something that would benefit our patients and would benefit mental health treatments. So if anything like that comes down, we think we ought to jump on board that thing.

We think if there's any legislation that comes along that would mandate the public sector having benefits similar to the private sector, that we probably ought to hop on board that as well. Anything that comes along that would blend the public and the private sector might be to our advantage, and we probably ought to give some thought to hopping on board those as well. We

reiterated again (which many people have today) that there is a need for outcome studies, so that we can argue our case more effectively.

And finally, as a measure of our pessimism and so forth, we noted that if we can just get people to use a single insurance form we could probably save 10 billion dollars. We have not been able to do that yet. That's about it. Thank you.

### **Leslie Scallet**

I'm very proud of everybody. That was terrific. We have the flip charts here. Does each of them show which group it was? If not, could the group leader make sure that somewhere on one of those pages we know what group we're dealing with; and anybody who has any notes that they make sure that they get included in the overall summary.

I'm not going to try to integrate all of this right now, although I think all of us heard quite a few common themes and even some similar ideas, which really pleases me; because if we can find what those things are, we are likely to have the elements of our next steps that need to get taken.

I'd also like to encourage those of you, both who support the current set of draft principles that are going around and those who have questions or concerns about them, to sit down together and see if you can move that process a little farther forward. I don't know who that would be. I guess Joe Manes of the Mental Health Law Project has been the scribe of that effort. So anyone who would like to get involved in that process talk to either him or to any of the organizations that you're comfortable with who's already signed on. We would very much like to encourage the development of some kind of position, and at this point, that is a vehicle that may be able to do that.

I would also like to encourage anybody who is here who comes up with any thoughts or ideas coming out of this meeting that you didn't get on the table, please communicate with us. We are here. You can either communicate with The Carter Center Task Force, write to Carol Koplan, here at The Carter Center, or you can write to me in Washington. I guess my address is over here, somewhere. Please feel free to continue communicating. I think one of the things that I heard in this whole meeting is the need for all of us to have better communication with each other on an on-going basis, to know what each of us are doing, consolidating activities, and working together. And one way to do that is to keep in touch. With that, I'd like to .... Oh, Jim, one more?

**[Inaudible from the audience]**

### **Leslie Scallet**

The Kopetski Resolution, which I think has been distributed to most of these groups, calls for the inclusion of mental health in any form of national health care reform, and I think that's something about which we are all in agreement. Thank you very much, and I'd like to turn it over to Mrs. Carter.

**Rosalynn Carter**

Well, I'm very proud of you, too. You did a lot of work in a very short period of time, and the Task Force now has a lot of information to work with. I think today has been so important. I think it's so important for us to get together, and work together, and stay in touch; and as Leslie said, if you do have any thoughts that were not expressed today, or any new ideas, or if you meet with groups that you think we should include in our next meeting, would you please let us know? We'll be in touch with you, because when we get all of this assimilated, and hopefully come up with the common threads that run through, (and Leslie has a way of putting it all together so that it is so understandable), then we can decide on the next steps.

Please stay in touch with us, and I look forward to seeing you again soon. We're not going to wait until next year. There's too much to do and too short a time to do it in now, so we're going to have to all work together in a kind of concentrated way in the next few months. Thank you all for being here. It's been a great day.

■ ■ ■

To: Symposium Participants  
From: Carter Center Staff  
Date: November 18, 1992  
Re: Afternoon Session

This evening and tomorrow morning Symposium participants will hear a variety of viewpoints about mental health in the health care reform debate. Tomorrow afternoon invited participants will divide into eight work groups to discuss these issues and what needs to be done.

You will be assigned to a group led by a facilitator. Each group will be asked to identify and discuss the following:

1. What steps are groups and coalitions now taking to have an impact on the debate, and what needs to be done next?
2. Should a specific plan for building mental health into health care reform proposals be developed, and if so, what are the elements still needed to produce it? (*i.e.*, How far should the mental health community go in advocating limits for mental health care?)
3. What are the likely impacts of some proposed reform directions on current mental health services and systems (*i.e.*, what happens to mental health care if Medicaid is eliminated and incorporated into a national health care plan?)

The goal for each group will be to suggest practical ideas, ranked in order of importance, for how to work toward including mental health in health care reform. The group leader will report back to the assembled participants on his/her group's ideas during the closing forty-five minutes of the Symposium.

After the Symposium, the Task Force will synthesize the results of the meeting and send them to all attendees. The Task Force will also utilize the results in thinking about possible activities to build on the Symposium.

A group of national mental health organizations have developed the attached set of principles as a working document as a possible focus for evolving agreement. These principles can service as a resource for discussion.



MEMORANDUM

*Appendix "B"*

To: Participants in Carter Center Symposium  
From: See organization list below  
Date: November 16, 1992  
Subject: Principles for Mental Health Care in Health Care Reform

The national organizations listed below or their Washington-based staff representatives have endorsed the attached working paper entitled: *Principles for Mental Health Care in Health Care Reform*.

The paper contains a statement of guidelines that the signers plan to send to the Clinton Administration transition team and to members of Congress to assist them in designing the mental health portion of health care reform legislation. The document could also be used by mental health organizations in evaluating specific legislative proposals for health care reform.

We urge additional organizations to endorse the principles to demonstrate to policy makers that the mental health community stands united in approaching health care reform issues.

American Association for Marriage and Family Therapy  
American Association of Pastoral Counselors  
American Psychiatric Association  
American Psychological Association  
International Association of Psychosocial Rehabilitation Services  
Federation of Families for Children's Mental Health  
Mental Health Law Project  
National Association for Partial Hospitalization  
National Association of Protection and Advocacy Systems  
National Association of Social Workers  
National Association of State Mental Health Program Directors  
National Council of Community Mental Health Centers  
National Mental Health Association

## **PRINCIPLES FOR MENTAL HEALTH CARE IN HEALTH CARE REFORM**

Mental health care must be viewed as an integral part of a national system of health care. The following principles emphasize the needs of individuals for mental health services based on a particular payment system, although they assume that private health insurance will remain as an important form of securing benefits. The six principles are:

1. **NON-DISCRIMINATION** - People of all ages who have mental health needs and their families participate fully in the nation's health care system. Non-discrimination in the provision of health care means:

- Current health status is not a factor in determining coverage for medical and health related services. The health care system prohibits coverage exclusion or limitations based on pre-existing conditions.
- Cost of coverage is based on the concept of broadly shared risk. That is, individual/family coverage costs are determined by community-wide usage rather than claims experience by small groups that exaggerate the impact of high service users.
- Health care coverage is portable and continuous. It is not dependent on a particular employment arrangement.
- Mental health services are available on the same terms and conditions as other medical and health related service, i.e. services are voluntarily sought and accepted.

2. **COMPREHENSIVENESS** - People who need mental health care, regardless of age, have coverage for a broad array of mental health and rehabilitation services delivered in culturally sensitive settings. These include:

- Preventive services - e.g. developmental and mental health screening and counseling to avoid and/or ameliorate illness.
- Emergency services including crisis intervention and crisis residential services.
- Case management services.
- Inpatient services.

- Outpatient services, including:
  - partial hospitalization
  - psychotherapy and counseling
  - medication management visits
  - psychiatric rehabilitation
  - day treatment for children and adolescents
  - family support services
- Prescription drugs.

3. CHOICE - The range of comprehensive services is based on individual need and informed choice. While recognizing the need to control unnecessary services, a consumer sensitive health care system will provide for consumer participation in treatment planning, decisions, including selection of services, setting and providers.

#### 4. EQUITY

a. SERVICE EQUITY - The provision of mental health services is not limited by artificial and arbitrary numbers of visits, days or procedures. Service equity means that the health care system:

- Determines amount, duration and scope of services based on medical and psychological necessity in accordance with professional standards of reasonable care.
- Ensures that services are delivered in the least restrictive environment able to meet the needs of the individual with minimal disruption to normal life style.
- Ensures the availability of appropriately trained personnel and services.

b. COST EQUITY - Individuals who have mental health care needs and their families do not spend a disproportionate share of their income and resources to obtain services. Families do not have to select less than optimum services because of cost considerations. Cost equity means the health care system:

- Limits expenses for participants through reasonable cost sharing requirements and overall limits on out-of-pocket costs.
- Ensures adequate reimbursement for service providers.
- Does not discriminate in reimbursement rates between private and public providers.

5. EFFICIENCY - Health care financing policies contain incentives and reviews so that services are delivered in the lowest cost settings consistent with appropriate care (see Managed Care below). An efficient health care system is one that:

- Allocates resources in a reasoned way among preventative services, acute care, and rehabilitation services.
- Undertakes reviews and evaluation to ensure that services are both cost efficient and effective.
- Reduces administrative complexity.

6. MANAGED CARE - The health care system employs managed care techniques to control unnecessary utilization through review of treatment and service plans while protecting the patient's right to quality care. The health care system also employs managed care devices such as: utilization review; prospective and capitated payments; preferred provider; and, negotiated performance-based contracting systems. An appropriate managed care organization:

- Ensures an adequate range of high quality, individualized services appropriate to the needs of the patient.
- Uses reviewers who are licensed or certified in the area of health care they are reviewing.
- Publishes in an accessible place and manner the review standards and criteria used in evaluating care plans.
- Establishes arbitration or similar hearing arrangements to resolve appeals to the organization's decisions.
- Ensures the confidentiality of patient-provider information.
- Makes decisions quickly.

- Maximizes patient choice.

The population described in this paper are individuals who meet the diagnostic criteria for mental, emotional or behavioral disorders contained in the current edition of the Diagnostic and Statistical Manual published by the American Psychiatric

## **PRINCIPLES FOR MENTAL HEALTH CARE IN HEALTH CARE REFORM**

As of March 31, 1993, the following national organizations have endorsed the PRINCIPLES:

Academy of Psychosomatic Medicine  
American Academy of Child and Adolescent Psychiatry  
American Association for Marriage and Family Therapy  
American Association for Partial Hospitalization  
American Association of Children's Residential Centers  
American Association of Pastoral Counselors  
American Association of Psychiatric Services for Children  
American Association of Private Practice Psychiatrists  
American Counseling Association  
American Nurses Association  
American Occupational Therapy Association  
American Orthopsychiatric Association  
American Psychiatric Nurses Association  
American Psychoanalytic Association  
American Psychological Association  
American Society for Adolescent Psychiatry  
Anxiety Disorders Association of America  
Bazelon Center for Mental Health Law  
Child Welfare League of America  
Family Service America, Inc.  
Federation of Families for Children's Mental Health  
Federation of Behavioral, Psychological and Cognitive Sciences  
International Association of Psychosocial Rehabilitation Services  
National Association of Counties  
National Association of Protection and Advocacy Systems  
National Association of Psychiatric Treatment Centers for Children  
National Association of Social Workers  
National Association of State Mental Health Program Directors  
National Council of Community Mental Health Centers  
National Depressive and Manic-Depressive Association  
National Federation of Societies for Clinical Social Work  
National Mental Health Association  
Society for Education and Research in Psychiatric Nursing

## RECOMMENDATIONS FOR MENTAL HEALTH SERVICES IN HEALTH CARE REFORM

Endorsed by the Following Organizations

American Academy of Child and Adolescent Psychiatry  
American Academy of Pediatrics  
American Association for Marriage and Family Therapy  
American Association for Partial Hospitalization  
American Association of Children's Residential Centers  
American Association of Pastoral Counselors  
American Association of Psychiatric Services for Children  
American Association of Private Practice Psychiatrists  
American Counseling Association  
American Mental Health Counselors Association  
American Nurses Association  
American Occupational Therapy Association  
American Orthopsychiatric Association  
American Psychiatric Nurses Association  
American Psychological Association  
American Society for Adolescent Psychiatry  
Anxiety Disorders Association of America  
Bazelon Center for Mental Health Law  
Center for Victims of Torture  
Child Welfare League of America  
Family Service America, Inc.  
Federation of Families for Children's Mental Health  
International Association of Psychosocial Rehabilitation Services  
National Association of Counties  
National Association of Developmental Disabilities Councils  
National Association of Protection and Advocacy Systems  
National Association of Psychiatric Health Systems  
National Association of Psychiatric Treatment Centers for Children  
National Association of State Mental Health Program Directors  
National Council of Community Mental Health Centers  
National Depressive and Manic-Depressive Association  
National Federation of Societies for Clinical Social Work  
National Foundation for Depressive Illness  
National Mental Health Association  
Zero To Three

Rosalynn Carter Symposium  
November 19, 1993  
*Summary of Results of Afternoon Working Session*

Leslie J. Scallet  
Member, Carter Center Task Force on Mental Health

For the afternoon session of the Annual Rosalynn Carter Symposium, participants from nearly 50 national mental health and related organizations were divided into eight working groups. Each included varying types of organizations roles (chief executives, presidents, government relations, public relations). Each group had a facilitator/reporter, who was charged to lead the group in discussing three topics:

1. What steps are groups and coalitions now taking to have an impact on the health care reform debate, and what needs to be done next?
2. Should a specific plan for building mental health into health care reform proposals be developed, and if so, what are the elements still needed to produce it?
3. What are the likely impacts of some proposed reform directions on current mental health services and systems?

The participants then reconvened to hear the reports.

The afternoon provided a rare opportunity for individuals representing a broad cross-section of opinion and perspectives to meet face to face and discuss common issues. No attempt was made to force a consensus in the limited time available. Rather, the session was a chance for participants to exchange views, with the hope that some themes and ideas for future action might emerge.

This summary synthesizes the results of the individual discussions and identifies some common themes.

#### OVERARCHING THEME

Throughout, the discussions underlined the seriousness with which mental health organizations view the coming national health care reform. There is substantial fear that mental health will be poorly served - either left out entirely, severely limited, or included in such a way that current services and systems will lose focus and resources. **The overwhelming response was that the field must find a way to define and communicate fundamental concerns and positions in a common voice so that decision-makers will have to listen. And the field must reach out to find allies representing broader interests.**

#### STEPS NOW BEING TAKEN

This part of the discussion was designed to identify activities already underway so that additional organizations might participate or pursue similar activities on their own.



Many professional organizations have begun to develop plans and approach both Congress and the Transition Team. Some concern was expressed about the splintering effect this produces. At the same time, others were concerned about setting up any particular group as a "gatekeeper".

There was general recognition that individual organizations or interests will pursue individual agendas, and that each may seek support from like-minded groups. However, there were also several broader efforts identified that could provide umbrellas under which a variety of concerns could fit - either as the primary vehicle for advocacy on this issue, or in addition to, an individual or mental health field effort:

Mental Health Liaison Group/Mental Health Leadership Forum Principles Initiative  
Council for Understanding Mental Illness (CUMI)  
Congressional Resolution (Kopetski/Shelby)  
Interreligious Health Care Access Campaign  
Aging Coalition  
Health Access America  
Washington Business Group on Health  
Coalition for Citizens with Disabilities  
Substance Abuse Coalition  
General medical groups, *e.g.* AMA, primary care physicians

### **NEXT STEPS NEEDED**

This part of the discussion was the major focus for most groups. Several areas emerged as needing concerted attention:

#### **1. Data/Information**

There were two concerns here - **gaps in available knowledge**, and the need to **digest, synthesize** and **package** information that is available. Areas in need of attention included:

- Costs of treatments, and of no-treatment
- Treatment benefits and effectiveness
- Linkages of health and mental health
- Outcomes
- Experience in other nations
- Critiques of studies/proposals that purport to evaluate mental health care or coverage
- Epidemiological data on disorders -- who needs and doesn't need some form of care
- Utilization (appropriate and inappropriate) and unmet demand
- Gap between mental and physical health coverage now, and implications
- Experience/implications of managed care for mental health/mental illness

There was recognition that a variety of projects are now underway through NIMH, SAMHSA, OTA, or other organizations to develop this type of information. However, it will be very important for all those advocating on this issue to have access to the same numbers and studies.

## 2. Communications/Public Relations

The primary need seen here was development of a simple, strong and clear message to flesh out the idea that "mental illness is real". Among the elements to be incorporated:

- Mental health/mental illness is tangible, though difficult to measure
- Mental health/mental illness affects people in all walks of life and at all ages
- There is a range of severity of mental health/mental illness problems, just as in physical health
- Many mental health/mental illness problems, just as many physical health problems, are chronic
- Effective treatments exist for many mental health/mental illness conditions
- We are still searching for "cures"
- Many individuals who have or have had a mental health/mental illness diagnosis live productive lives
- Non-discrimination

## 3. Strategies/Tactics

The common theme here were the need to work collaboratively and to broaden the base of support for mental health/mental illness within health care reform. A variety of suggestions surfaced for how to go about this":

- Enlarge coalitions to include broad-based organizations, *e.g.* medical, labor, education low income advocates, League of Women voters, AARP, small business, children's advocacy groups
- Use experience from other policy issues, *e.g.* the coalition that successfully pushed the ADA, gradual acceptance of Fair Housing, other "disease groups."
- Tie mental health/mental illness to broadly popular issues, *e.g.* education, ADA, children
- Assure that we at least get "a nose under the tent."
- Better coordination/coalition to avoid duplication of effort
- Clarify issues of setting priorities: levels of impairment, diagnosis v. functioning
- Focus on concerns of employers (*e.g.* less regulation, early intervention, output data)
- Identify "learned and respected" advocates without "guild" allegiances, (*e.g.* Mrs. Carter, Mrs. Gore, Mrs. Clinton)
- Promote the idea of a "supreme court" or "public health utility commission" to address questions of quality care, resource allocation, care for health v. care for illness
- Publicize message in all ways possible
- Grassroots lobbying campaign
- Strategic legislative process: constituents, background, arguments, business contacts
- Delay specifying a benefits package until "pushed"

## NEED FOR A MORE SPECIFIC PLAN FOR MENTAL HEALTH IN HEALTH CARE REFORM

Discussion in this area was limited. However, most groups identified the need for both **big picture** and more **targeted** approaches. Some suggestions:

- Look at models of care for full range of needs
- Apply international or other models as appropriate, based on developing needed information about each
- Include such concerns as rise of HIV/AIDS and crack babies
- Public system, and differences with other elements of health services
- Danger of creating/perpetuating two classes of care
- Incorporate "diagnosis x, disability x, duration x" - the way the medical/insurance world works
- Focus on "managed competition" as the likely approach
- Principles/criteria to judge proposals or bills
- Place of self-help mechanisms, and ways for recovered/treated consumers to work within the system
- In essentials, unity; in non-essentials, diversity; in all matters, charity

### **LIKELY IMPACT OF REFORM PROPOSALS ON MENTAL HEALTH SERVICES**

Few groups had sufficient time to address the question in depth. However, there was a high degree of consensus on several **areas of concern**:

- Danger of losing services now covered through Medicaid
- Danger of "dumping" excluded mental health/mental illness problems to public sector
- Perpetuation of two classes of care
- Danger for mental health within a managed care environment